

**Forming a kinship with loss:
Navigating form and non-form in the narratives and
practices of care at the end-of-life for people affected by
dementia**

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PhD in Medical Humanities

I, Joseph Michael Sawyer confirm that the work presented in my thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

This thesis provides an empirically based reflexive account of the social space occupied by people with dementia facing the end-of-life. It addresses how knowledge in the field is constructed to create visions of success, meaning and value that become established as orientating ideals.

Quantitative and qualitative data was collected between October 2021 to March 2023. Social network analysis was used to contextualise informal caregiving across nine different networks of care. This was followed by interviews and long-term participant observation with five people with dementia, their friends, family and carers. From this data, it was clear that what is commonly perceived as absence was crucial in the responses given. This absence constituted a space where dementia distorted cognitive and social norms, creating a world beyond what is empirically recognisable. Working with research participants it was possible to create an embodied representation of absence which recognised the suffering as well as the healing that results from engaging with end-of-life care in advancing dementia.

The thesis focusses on a dialectic between experience and theory which challenges notions of progress that become paradoxical at the frontiers of human existence. Throughout the study I describe a shift in focus from the production of a programme theory that would determine *what works*, towards an analysis that focussed on the emergence of two worlds, which I have described as ‘form’ and ‘non-form’. The ethnography describes these worlds, offering a reflexive account of the possibilities in working with and within them. In doing so, I argue that progress, meaning and value are not ends in themselves but exist as ephemeral yet transformative moments that arise through a deep articulation of our greatest vulnerabilities. The PhD proposes that recalibrating the narratives and practices of care to accommodate all that is non-form is critical to how the end-of-life is experienced.

Impact statement

How people affected by dementia are supported at the end-of-life constitutes a national and global priority. My thesis represents one of the first attempts to characterise the losses associated with dementia while examining their role and function in relation to the provision of care.

I provide insights into how the ideal of good care is created and through this, how we come to establish what might be of value. My work acknowledges that dementia represents the progressive transition towards the end of a personal and social world; a world that has been intricately developed yet will also unravel to reveal its own unique geography. It is within the solitude of this unravelling that paradoxical moments of value may emerge. And it is here, through relationships shaped through acts of caregiving and receiving that we might build acceptance towards all that is imperfect.

Such insights are crucial in understanding how we orientate the day-to-day practices of care at the juncture between living and dying, offering direct practical benefits. Beyond this, my work presents a series of organising concepts that address a dialectic between theory and experience. Their function is best understood in viewing how service led interventions are calibrated against them, helping to provide a sense of direction when considering what constitutes success. As such my findings have relevance to clinicians, academics, advocates, evaluators and policy makers in their pursuit of new knowledge and the progress with which it is associated.

At a systems level my theoretical insights provide a reference point upon which to orientate complex and profound change that is necessary to re-imagine a future where quality, access and equity of care is improved. This is of particular relevance to the field of public health palliative care, offering guidance on how existing concepts might accommodate the challenges posed by dementia.

Analytically my thesis brings an emerging voice that helps understand a series of sensibilities beyond which our institutional, intuitive and corporal senses might define. This is part of a unique contribution that I hope to be of significant utility to scholars in the field of clinical medicine, medical humanities, medical anthropology, medical sociology and their related disciplines.

My work has already led to two peer review publications, two book chapters, an international conference presentation and several international workshops and webinars. I have connected

with international scholars to form a network that has a global reach and might act as a platform for the dissemination of publications that are still to come. My work also provides the empirical and theoretical foundations that will have incremental impact. Much of the potential here resides in addressing long standing and poorly acknowledged tensions that underpin what is considered success or failure in the field of dementia care. Whilst my work has particular relevance for palliative and end-of-life care, I argue the implications extend into how death, dying and loss might be considered a foundational point on which to define a more integrative approach to care, not just for people with dementia, but beyond.

Preface

Fifteen years ago, as an undergraduate medical student working towards an intercalated BSc, I was asked to write an essay on ‘the molecular actions that underlie different treatment options in osteoporosis’. I discussed how the recognition and manipulation of increasingly intricate cellular pathways might pathologize the ageing process and muddy the waters between treatment and iatrogenesis. I concluded by questioning the nature of the point we might be aspiring to reach.

The opportunities brought by increasing knowledge and technological advancements continue to narrow the borderlands between life and death. Yet within this narrow terrain, mystery, moral quandary and uncertainty persevere, compacted but undiminished in their presence, whilst appearing almost impenetrable to repeated attempts to seek meaning and define value.

There appears to be a relentless and forever expanding drive to generate a body of work that turns the needle on the dial closer towards certainty and its associated successes. Yet I argue this might also conspire to conceal, rather than reveal, what is necessary to understand about suffering, loss and the persistent and impenetrable darkness that surrounds matters of dementia and the fourth age. My thesis is concerned with this juncture. As such it does not seek to offer protection from the extreme darkness of life, but rather to reside within these borderlands between living and dying, where our perception of all that is familiar, ordered and structured becomes bent, warped and alien.

This preface therefore serves as an advance warning as to the nature of what is to come in the following chapters. I invite the reader to consider that the protection afforded by a structured response provides only momentary relief from the disorientating depths of human loss. Beyond this, within the depths of absence, there might also be a presence which characterises both the value and meaning that also reside here. I encourage people to look unflinchingly in the face of what is often profound sadness and suffering. To tread the path that exists at the margins between theory, culture and spirituality. To reflect on how participants experiences might awaken something within us, how we might accommodate moments of beauty and grace that rise to meet us from within the unending, and often monotonous depths of sadness and suffering brought by loss.

In describing many of the issues I raise, and the experiences of people that I have met, it has not always been possible to conform to a structure and style of language that might be considered as ordered, coherent and succinct. Indeed, there are many instances where the language of academic orthodoxy conspires to conceal meaning, as much as it endeavours to do the opposite.

The language and style of this thesis can at times reflect and embrace the messiness of the subject it is addressing, accepting that sometimes, it can be no other way. This, I would argue is the language of what I term 'non-form', it is rich in metaphor and imagery and might be considered to border on the poetic. This is in recognition that scientific rational and expression, like all things, has an outermost point of usefulness. This is aptly observed by the Sufi Master and poet Hafiz:

The
Great Religions are the
Ships
Poets the life
Boats.
Every sane person I know has jumped
Overboard....

Navigating the borderlands between life and death necessitates an ability to dwell with the suffering, darkness that cohabits these same places. It is perhaps natural that in occupying these spaces, all that is familiar, all that has shaped and guided life's endeavours to this point may feel of limited use. It is therefore possible that much of my writing might feel threatening or be seen to challenge a set of values to which we are closely adhered to. My intention is not to devalue or dismiss these structures, but instead to acknowledge them for exactly what they, imperfect approximations, that like all things, will ultimately disintegrate in use and form when at the outermost limitations their useful existence. Where I identify a potential fault in the current response to dementia it doesn't not necessarily mean that the entire structural response is at fault, more that our ideals to which we strive for must accommodate and be hospitable towards failure and fall-back. Sometimes in identifying a fault I am simply trying to break thorough the falsity of images and expectations that may have blinded us to a wider, more illuminating field of view that encompasses hidden wisdom and within it, the beauty of the flaw.

This thesis does not claim to provide a resolution to the multiple and profound challenges that arise from dementia, old age, frailty and death. Largely I argue that any such pursuit provides only momentary relief before realising that defining and separating out success in the face of loss is a futile endeavour that might arrest the appearance of all that might be found within the absence. It is through a greater engagement and hospitality towards the imperfection of a 'true ideal' that we might see things differently, to view care of the dying as an opportunity to form an intimate connection with that part of our being that is forever broken and vulnerable, accepting with humility, forgiveness and compassion the gifts this may impart.

Glossary

Below are a set of terms that I use throughout the thesis. Whilst they have a clearly associated meaning, this may not be obvious in the context that I am using them. For example, discussing ‘value’ in death or a ‘presence’ within all that is empirically absent. In situations such as this I am restricted to a set of words that can never fully encapsulate the totality of the human experience. Whilst this glossary is designed to bring greater clarity to my writing, the meaning of terms is perhaps best understood in conjunction the wider context and the unique response their use invokes within the reader.

Advanced dementia: There are various attempts at defining the different stages of dementia in academic literature. I am using the term ‘advanced’ to suggest a state that is characterised by profound dependency, where people are reliant on others for basic tasks of living such as eating, cleaning and dressing. I also use the term to suggest a close proximity to the end-of-life. Whilst I am wary not to define a time scale, it might be considered a state of being which is adjacent to death.

Absence and emptiness: I frequently use this term in the context of advanced dementia. In earlier chapters I often mean it in the literal translation of word, highlighting to the reader what is commonly observed and understood as memory fades and dependencies become more pronounced. As my theory develops, I use the term to characterise what might exist at the periphery of our focussed gaze. Here, as these spaces are recognised as bringing their own influence, whilst containing moments of presence and value, it becomes almost an oxymoron. By absence I am often referring to what is not empirically observable, whilst also suggesting that this in itself is ‘something’.

Beauty: I take inspiration from the work of John O’Donohue in my use of this word. In his book ‘divine beauty’ he characterises beauty as something beyond that which is simply beautiful to look at. Rather he discusses it as an experience, something that is almost other-worldly that brings a sense of deep satisfaction and ‘homecoming’. Something that greets us beyond our empirical senses, invoking a sense of combined awakening and surrender that instils a sureness to our being.

Value: I have struggled with this word. I recognise that it implies a certain ‘goodness’. For something to have value, it must be important and held in high regard. Yet I am using the word

beyond these connotations alone. For me, the word value also implies a vulnerability, a preciousness that is fragile to loss, misrepresentation or abuse. Whilst we might seek to uphold what is of value, our values might also challenge, disrupt or even upset.

White shadow: The white shadow is a metaphor that allows for the discussion of seemingly polar entities that can combine to exert influence and create moments of profound transformation. An example might be the recognition of beauty in death, or the presence and intimacy that appears during moments of near complete emptiness. It is a way of introducing the reader to what might appear to be polar entities that can combine and work together in such a way that characterises peoples experience of mystery, enigma or paradox.

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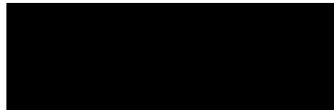
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Chapter One

**From living well with dementia to dying well with
dementia: Paradoxes and problems in current approaches
to end-of- life care**

Contents One

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Introduction

The evolving approach to dementia care has brought greater recognition of how people can and do live well with dementia. Elements of the supporting academic discourse have been used to shape public health resources prioritised to meet the needs of an increasing number of people dying with the condition (WHO 2012). Living in an active and successful way can however be paradoxical when considered in the context of advanced dementia and the end-of-life. Here, death's emerging shadow blurs the parameters of success, leaving people, and entire health systems, lost in their understanding of what it means to be dying with dementia.

In this chapter I address the apparent need to define and orientate an approach to end-of-life care that enables people, communities and health systems to transition from living well, to dying well with dementia. I will evaluate current end-of-life care strategies in dementia by drawing on an analysis of Western society's changing relationship with death and its evolution in thinking in terms of a 'good death' with palliative care. Juxtaposing this alongside the specific challenges dementia poses for end-of-life care I aim to highlight disparities that arise when concepts such as personhood and citizenship are used as a vehicle in pursuit of a good death.

In chapter two I will introduce, define and critically assess the components of informal, community-based care as part of the emerging notion of a 'new public health approaches to palliative care' (Abel and Kellehear 2022; Kellehear 2007, 2013a; Kellehear and O'Connor 2008). New public health approaches to palliative care have been positioned as a more sustainable and equitable model of end-of-life care (Kellehear 2013b), yet inherent tensions in the theoretical foundations remain (Whitelaw and Clark 2019) whilst their relevance and application to people with dementia is yet to be meaningfully considered.

These first two chapters will map what at times feels like fragmented and disparate terrain. In doing so I aim to demonstrate how individuals, communities and health systems are often left unsupported in their attempts to navigate the inherently disorientating void of decline, dependency and death. I end by addressing the apparent need to define and orientate an approach to end-of-life care that enables people, communities and health systems to transition from living well, to dying well with dementia. Here, death, dying and the dependency this brings might be imagined beyond something that is expected and normal, but instead something of intrinsic and transformational value.

Chapters five and six offer empirical data to support the description of a heuristic designed to fill this void. Rather than seeking to understand what might work for such people, it is an attempt to demonstrate what is already known, and how this might better inform the broader approach to death, dying and loss. The thesis addresses the central question of how we understand loss, absence and the suffering associated with the darker elements of life in such a way that reveals moments of transformational meaning and value. In doing so, I am ever conscious my work should not deny the reality of profound sadness and suffering that dementia might bring. Instead, I explore how people navigate and accommodate loss within their lives and how they might come to heal through such processes. Ultimately I do not claim to offer a resolution to the multiple and profound challenges posed by dementia. Rather the aim is re-imagine an approach to such problems that captures a set of values that exist beyond those associated with the challenges in overcoming them.

The need for end-of-life care in dementia and the complexity in delivering it

In 2020 there were over fifty million people worldwide with dementia, numbers are expected to double every twenty years to reach over one hundred and fifty million by 2050 (Collaborators 2022; Guerchet and Prince 2020). This is reflected in record rates of ageing across the world (UN 2019). Increasing rates of dementia are already causing major challenges to the provision of end-of-life care and have led to calls for the urgent examination of novel approaches (Etkind et al. 2017).

Challenges in delivering care are deepened by dementia's uniquely complex effects. Although the dementias are progressive and terminal, the trajectory is highly variable and unpredictable (Murray et al. 2005) meaning the end-of-life is difficult to recognise (Browne et al. 2021). At the very end, uncertainty and loss of control are compounded by a disturbance in biographical continuity and the prospect of 'loss' of self (Haeusermann 2019). At the same time, the social relationships fundamental to how dementia is experienced, are irreversibly altered (Sawyer et al. 2019; Macdonald 2018a). Further complications are found through dementia's association with old age, frailty and multimorbidity (Welsh 2019) where human physiology is unpredictable and decision making subject to the quandary of knowing when, where and how to intervene (Kaufman 2015d).

At the precipice of such challenges, a diverse literature concerned with intersection between ageing, personhood, citizenship, and dementia has evolved (Kitwood and Bredin 1992; Bartlett and O'Connor 2010a; Higgs and Gilleard 2016e). Here complexity is considered through an array of philosophical, ethical, and values-based frameworks. These frameworks are often used within Western social, political and academic discourse in a manner disproportionately orientated towards early dementia, and a culture of living in an active, productive and successful way (Higgs and Gilleard 2016e; Tolhurst et al. 2019). This approach has conflicting values at the end-of-life where progressive decline and dependency dominate. How such theory is used in the transition from *living well* with dementia to *dying well* with dementia is important in understanding the meaning and expectation of a 'good death' and 'good care'.

Such complexity transcends the priorities and capabilities of health and social care services, suggesting solutions are not to be found exclusively in the realms of increased service provision. Informally organised care, conducted within and delivered by networks of lay people already represents a significant portion of the human resource used in providing end-of-life care (Langa et al. 2001; Wimo et al. 2023). Understanding this as part of the solution, but with its own limitations, is a priority in meeting the stated need and complexity.

Advancing the idea of a 'good death' and its relevance to dementia

Human views on death have evolved over time, giving rise to the objective of a 'good death' (Smith 2000; Meier et al. 2016; Collier and Chapman 2023). To understand the value of this in dementia, it is necessary to appreciate the historical context on which the concept is founded. In Illich's *limits to medicine*, he traces the history of death's relationship with culture and medicine (Illich 1975a). He points to the evolution of assumptions from late antiquity and the European renaissance, where death was seen as the influence of a supernatural outside force, to early modernity where it became a 'natural event' within the human life course. One unintended consequence of this was to reduce the sacred status of the human corpse to that of an object. Deprived of spiritual or legal standing, the corpse became a site of education and medical ritualisation (Walker 1990). For Illich, this, alongside a preponderance for more exact measurement and a fascination with serial time, led to the idea of death being an interruption to a sequence of linear events, as opposed to the completeness of an individual's life. It also depicted the end-of-life as an event, as opposed to a transitional process at the reaching of life's aim. Beyond the focus on time, there was also a growing sense of individuality that necessitated a mastery and control over death (Sorabji 2006). Once the great social leveller, death was

increasingly viewed as untimely, especially for those not of good health and in old age. The deferment of death therefore became the ambition for an evolving social class who sought the expertise of physicians in their endeavours (Giglioni 2017). Illich argues this represents a return to more primitive ideas of death as a failure of human defence against external forces. Instead of a supernatural force, he describes it as a “social force”, where every premature or “clinically unnecessary” death is the result of a delay in medical intervention. In this way, the idea of a ‘good death’ creates a search that keeps people occupied as consumers, consumers of the tools necessary to afford control over death so that it may occur on human terms and in line with individual choice (Illich 1975a).

In Kaufmann’s *‘Ordinary Medicine’*, she expands upon Illich’s work to evaluate the unique role of Western medicine in shaping our understanding of the dying process (Kaufman 2015d). Here modern medical practice is described as existing within a chain of other healthcare drivers to create an industry that is primarily evaluated against longevity and cure (Kaufman 2015d). Kaufmann argues the success of treatments, and their increasing availability, mean they become normalised to the point they are less a choice and more an ethical necessity. For Kaufmann, the ‘ordinary’ nature of medicine creates an environment where the body is understood as ‘fixable’ and life ‘extendable’ yet without defining an outer limit to these parameters. The idea of dying as part of the life course, and the values this holds for humanity, are therefore replaced by a state of perpetual chronic disease management. Here progress is paradoxical in that increased knowledge, surveillance and modification of human physiology is designed to reduce risk, yet increases it, through a hyperawareness of the body’s naturally deteriorating biology. This leaves physicians, families and patients rooted in a quandary of decision making as to where the line between living and dying is drawn, whilst concealing death as having any valuable meaning.

The role of palliative care in shaping and sequestering a ‘good death’

Within this context, the specialty of palliative medicine has emerged. Based on Cicely Saunders’ philosophy of ‘total care of the dying’ (Saunders 1996a), palliative medicine has promoted greater attention to psychological, social and spiritual care, bringing care of the dying into sharper focus for healthcare internationally (Stjernswärd, Foley, and Ferris 2007). In 1987 palliative medicine was recognised as a subspecialty of medicine in the UK by the Royal College of Physicians (Hillier 1988). Within this role palliative care has been instrumental in developing and publicising the idea of a ‘good death’ whilst working towards a culture that normalises death as a topic of public conversation (Mannix 2021, 2017; Clarke 2020). The concept of a ‘good death’ includes;

the ability to “retain control of what happens, to have control over pain relief, to have choice and control over where death occurs, to be able to issue advance directives which ensure wishes are respected” (Smith 2000: 129; Henwood and Neuberger 1999; Meier et al. 2016). Whilst such a discourse has afforded a platform for the discussion of dying, it has done so under strict parameters set by the broader healthcare industry within which it lies. Here, the “truth making” chain of industry, research and evidence normalise an approach where the co-morbidities and symptoms associated with dying can be fixed, prevented or alleviated (Kaufman 2015b). Where this does not happen, it risks being interpreted as a failure of care and, more specifically, a failure of palliative care (Collier and Chapman 2023).

The emphasis on a ‘good death’, is therefore reminiscent of Illich’s “unending search” that keeps people occupied as “consumers forever” (Illich 1975a). The extension of palliative care services into old age, frailty, chronic illness and dementia can be seen in this light (Lind Alliance 2017). Framed within a need for increased access and equity of care (Wasson and George 2001), the ideal of a good death with palliative care, is now systematically implemented across health and social care policy (WHO 2018). The procedural components of a good death have become ritualised by professional structures that rely heavily on autonomy and individual choice, reinforcing the idea of death as disruption to a linear sequence of events. The ‘good death’ therefore is a death that is allowed only where clinically necessary, namely when the person is old and in good health, or when all available medical treatments have been exhausted. This is in opposition to death being something beyond control, something that is woven into the nature of our human bodies and their inherent vulnerability to decline, illness and injury.

Analysing where palliative medicine fits within Kaufmann’s quandary of ‘ordinary medicine’ offers a different perspective that is representative of the specialty’s long term struggle for identity (Kearney 1992; Sawyer 2018). Kaufmann argues that the evolution of medical technologies and the introduction of “strangers at the bedside” such as lawyers, bioethicists and regulatory bodies has resulted in medicines changing means and ends. Available technological innovations have defined medicine as a stream of progress orientated breakthroughs that objectify longevity over social good (Relman 1980). The success of such innovations in adding wanted years to life, is evidenced through clinical trials which create a technological imperative to intervene (Kaufman 2015a). However, palliative medicine sits somewhat outside this framework.

In the UK, palliative care is funded mainly by charities and has a relatively small evidence base, especially where randomised control trials are concerned (Visser, Hadley, and Wee 2015). This

means decisions are often made according to a values-based framework, allowing interventions to be contextualised within the relevant phase of life whilst allowing the value death holds for human life to be considered and understood.

Palliative medicine therefore sits within the increasingly narrow borderlands between life and death where moral quandary and uncertainty reside. Often dominant in their presence at the end-of-life, these forces are nonetheless hidden, unceremoniously ushered towards the periphery of conscious thought by a system designed to remove them from contention. Whilst there is an understanding from within the specialty that the tools of 'ordinary medicine' are unhelpful here (Sawyer 2018), there is a constant pressure from the chain of healthcare drivers to conform to a technical and systems based language of care; to treat symptoms that will inevitably take hold, to standardise and reduce multifaceted complex problems, such as death, into what might be understood as success or failure, good or bad. People often arrive at these borderlands well versed in the language of ordinary medicine and therefore poorly equipped to navigate the paradoxical circumstance of not wanting to die yet, but also not wanting to be kept alive in a state of prolonged decline and dependency.

The enigma of death's presence

Philosophers and theologians across the world have long recognised the importance and necessity of humanities impermanence (Holloway 2004b; Rinpoche, Gaffney, and Harvey 1992; O'Donohue 2003c). Yet the darker side of human finitude, the uncertainty of the unknown without the potential for knowing, the prospect of suffering, decline, dependency, indignity, and loss, coupled with the reality that all of us, at any time, are old enough to die, will always leave people beset by fear and grief. At the centre of humanity's prolonged discomfort with suffering and death, is the eternal human search for meaning. That in a single, unpredictable heartbeat, we lose all that has been so intricately grown seems completely out of rhythm. The discord compels people to seek answers, whilst the reality of their answerability only makes such questions more compelling. The human eye seeks to rest on some final focal point as a tonic to the meaningless emptiness over which life seems to be stretched. Yet to search for such a point within the infinite and inescapable void of death is inherently disorientating because of its absoluteness and its incomprehensibility. Instead, the temptation is to examine such a void through the lens of how best to avoid it. This represents an enduring tension in how we conceptualise death. To trust in the suffering and unknown presented by death within a world that strives to vanquish

such entities is an almost absurd remit, yet this is often all that remains at the reaching of life's aim.

The evolution and role of the good death

I have examined how the imaginary of death has evolved in response to various social institutions and latterly modern medicine and palliative care. These institutions, and those around them, shape our experiences and organise our judgments with regards to death and dying in a way that they become normalised and given moral imperative (Kaufman 2015d). This can be seen through the creation of the accepted standard of a 'good death'. I have argued that such an ideal does not accommodate the darker side of dying, the inherent suffering and moral quandaries that exist at the juncture between life and death. How, for example, we understand a 'good death' in the context of sudden death, suicide, or death in dementia where individual choice and comfort is paramount, but not necessarily achievable or practical, is rarely discussed. I have described how the medical specialty of palliative medicine has challenged thinking around death and dying, yet it has done so from a constrained position within a chain of healthcare drivers that normalise the decision to pursue measures of longevity and control. This has created both a subjective and objective inability to define our outermost limits and provide value to the work of caring for people at the end-of-life.

The current state of end-of-life care in dementia

With a limited conceptual understanding of the dying process provided by social and medical institutions, it is hard to define an approach, with a corresponding set of values, that embraces the unique and individually complex experiences associated with dementia.

Towards the end-of-life in dementia there is typically a profound dependency on others to meet basic needs (Thuné-Boyle et al. 2010). This stems from progressive immobility, behavioural changes, dysphagia, incontinence, and a limited ability to express ones needs that infers significant disadvantage. This is demonstrated in practical terms by the fact people with dementia are less likely to receive palliative care (Birch and Draper 2008; Sampson 2010) and are less likely to receive analgesia, even when prescribed (La Frenais et al. 2021). People with dementia may also experience delirium that is often undetected or managed inappropriately, leading to increased morbidity and mortality (Bauernfreund et al. 2018; Jackson et al. 2017). Other physical issues include progressive dysphagia that is poorly anticipated, leaving families and caregivers

struggling to accept and support difficulties with eating and drinking at the end-of-life (Barrado-Martín et al. 2021).

Such complexity is often met by a discordant and underserved professional response (Sampson 2010). Palliative care staff report limited capacity to provide care for people with dementia (Ryan et al. 2012). This is compounded by the fact that health professionals and families do not clearly recognise when someone with dementia is dying (Faes, Cohen, and Annemans 2018; Browne et al. 2021). This can mean the locus of professional responsibility often swings between emergency services, general practice, palliative care, psychiatry and medicine for older people (geriatrics). This is reflected by work that suggests professionals often feel unsure how best to meet the needs of people in advanced dementia (Lee et al. 2017; Davies, Maio, Vedavanam, et al. 2014; Ryan et al. 2012) whilst families and other informal caregivers are confused as to which service to contact for support (Davies, Maio, Rait, et al. 2014; Davies, Maio, Vedavanam, et al. 2014). Whilst advance care planning may help with some of these issues, its implementation is not straightforward in dementia, with effects on cognition meaning it differs from other illness groups (Denning, Jones, and Sampson 2011; Sampson and Burns 2013; Harrison Denning, Sampson, and De Vries 2019).

Beyond the person with dementia, the end-of-life also impacts entire social networks. Complex decision making relating to medical treatments and transitions in the caregiving environment, can cause uncertainty and moral distress for all those involved (Shepherd et al. 2019; Sawyer et al. 2019). Along with physical, emotional and time commitments necessary to meet practical care needs, families as well as close contacts, on whom the tasks of caregiving most commonly fall, may become overwhelmed (Abreu et al. 2020; Cuijpers 2005; Wilks et al. 2011).

Despite interventions designed to address these issues (Downs et al. 2021; Davies et al. 2021; Walsh et al. 2021), better end-of-life care for people with dementia continues to be challenged by the relational processes through which care is delivered and experienced (Sawyer et al. 2019). At the same time, a disproportionate focus on the virtues associated with independent choice and control can leave the uncertainty that defines the juncture between life and death as something to work against, rather than something with inherent individual and collective value.

Whilst dementia is now acknowledged as the leading cause of death in the UK (ONS 2023), the process of dying, and the complexities this brings are often left concealed within institutional structures and their associated practices (ONS 2020). To develop a more nuanced understanding of human capacity to support people with dementia at the end-of-life I will now systematically

map the major existing theoretical frameworks for thinking about dementia, exploring how they influence our understanding and experience of the dying process.

Deficit and loss in advanced dementia

Originally understood as part of the ageing process, an awareness of the underlying biological processes led dementia to be categorised as a distinct pathology. With this came enhanced diagnostics, new therapies and improved access to services and support (Bartlett and O'Connor 2010b). However, an unequivocal focus on the disease also brought a neglect of the underlying person. This, alongside the therapeutic nihilism associated with the disease, contributed to an understanding of dementia as a 'living death' (Lefever 2011; Macdonald 2018a). Where dementia's effects on social relationships are portrayed through a lens of loss and incapacity (Wilks et al. 2011), people may experience social exclusion long before the dying phase (Walsh, Scharf, and Keating 2017). This contributes to their systematic marginalisation in economic, cultural and social terms (Butler 1969; Benbow and Jolley 2012). Given the chronicity of dementia, such processes can become engrained, contributing to the 'shrinking world' of people with dementia (Duggan et al. 2008).

As a person's capacity to partake in society declines due to the nature of the disease, and the restrictions and prejudices placed upon them, families and caregivers may begin to anticipate death well in advance of its event (Sweeting and Gilhooly 1990). "Anticipatory grief" as first described by Sweeting and Gilhooly, suggests that as people adjust to the potential loss of a person, they may emotionally or physically withdraw themselves. In extreme cases, the person may be categorised as already having died, with close contacts unable to recognise any form of the person they once knew (Sweeting and Gilhooly 1997; Cohen and Eisdorfer 2001). This in itself makes it very hard to ascribe meaning or value to the provision of care for such people, thus reinforcing the described social stigma, whilst leaving those in caregiving roles concealed from view (Bauman 1992). The social exclusion that follows is before other marginalising factors such as race, gender and social class are considered.

Where a narrative of deficit and loss prevails within a society that considers such issues as incompatible with meaning nor value, there are two options. Either resource to counter the notion of deficit and loss arise, or we are accepting of this insurmountable suffering and consider euthanasia on compassionate grounds (Hertogh et al. 2007). Understanding the discourse surrounding euthanasia and assisted dying is beyond the scope of this thesis, however I will

discuss some of the common counter measures to deficit and loss and how they have come to shape people's experience and understanding of death in dementia.

Personhood, citizenship and the moral standing of people dying from advanced dementia

Adapted from the works of Kitwood (Kitwood and Bredin 1992), ideas on personhood are now frequently used within the academic and clinical literature relating to dementia whilst it is often utilised as the basis for 'person centred care' in institutional settings (NICE 2006). In a series of works, Kitwood described what he saw as a fundamental denial of personhood for people with dementia (Kitwood 1993; Kitwood and Bredin 1992; Kitwood 1997b). He argued individualism had reduced the notion of personhood to two criteria, autonomy and rationality (Kitwood 1997a). The reduction of personhood to 'cognitive competence' has profound implications for the moral recognition of people with dementia. Kitwood's intervention was to conceptualise personhood as relational, thus shifting the focus from the disease process towards the interpersonal environment (Kitwood 1997c). It has since been adopted as a core component of 'good care' and a vehicle for achieving a 'good death' (Read and MacBride-Stewart 2018).

Models of personhood such as this have helped focus attention on the value people with dementia hold and how this might relate to the communities to which they belong. For Kitwood, what is of value when considering personhood is not defined by a person's own set of capacities or characteristics, instead personhood is relational. This means personhood is a gift that is bestowed upon one another and arises as a product of being incorporated into a community that values and cares for people with dementia (Swinton 2021). The difficulty here is that personhood becomes dependent on others seeing value in people throughout dementia's progressive effects. Where this value is unseen or ignored then people will inevitably lose their personhood and the struggle to preserve it becomes lost to inevitable failure. This issue becomes even more problematic when there is no inherent mechanism within the model that commits or obliges people to offer the 'gift of value' that might define personhood. In a culture that does not naturally gravitate towards the vulnerable, this raises questions as to whether or not we trust that communities do indeed value people with dementia in such a way that defines a relational approach to personhood.

Kitwood's ideas on personhood, and other person centred initiatives, have also been critically examined from their wider philosophical context (Higgs and Gilleard 2016e). Kitwood it is

argued, amongst others, has ‘sidestepped’ the metaphysical components of personhood, namely agency, identity, reflexivity and will, confounding these with components of personhood from moral philosophy (Higgs and Gilleard 2016e). In doing so, there is little room to manoeuvre around the reality that, whilst their moral standing as persons should be upheld, an advanced state of dementia is unavoidably characterised by profound dependency. This would suggest that many people with dementia *do* indeed lose the components and capabilities of personhood. This is important, as when the expectation of good care demands that personhood is upheld through the dying phase, the responsibility for this is unavoidably placed on other people (Higgs and Gilleard 2016e). Where agency, identity, reflexivity and will are now the responsibility of another person, this can lead to a narrative of stabilisation intrinsically linked to prevention, prevention of what is an inevitable deterioration of one’s personhood to the point of death. Rather than providing mediation and support for this decline, the struggle to maintain personhood can lead to distress of a moral nature whilst decision making becomes rooted within the Kaufmann’s quandary of ‘where to draw the line’ (Kaufman 2015d). Debating the role of personhood has led some to question whether or not it is anything more than a ‘placeholder’ for claiming rights (Higgs and Gilleard 2016a). Here, Higgs and Gilleard argue that an individual’s personhood can only be preserved through the dependency, cognitive decline and disrupted identity associated with advanced dementia when it is understood as a proxy or placeholder for moral status (Higgs and Gilleard 2016a).

Academics and activists have suggested the limitations of Kitwood’s personhood can, in part, be overcome by thinking about models of citizenship (Swinton 2021; Bartlett and O’Connor 2007). Bartlett and O’Connor have advanced a model of social citizenship that broadens the locus of responsibility by placing greater emphasis on organisational practices, social location, culture, ethnicity and gender in understanding not just *the* dementia experience but the plurality of dementia *experiences* (Bartlett and O’Connor 2010a). Crucially, where Kitwood’s approach to personhood is presented more as a moral choice, a citizenship-based approach defines the person with dementia as an active agent who interacts with society to bring about individual and shared societal goals (Bartlett and O’Connor 2007). That people with dementia stand as active citizens means their rights would be backed up by laws and obligatory duties that demand shared and mutual responsibility for one another. Whilst such an approach addresses some of the limitations of Kitwood’s approach, it remains problematic for many people with dementia. For example, whilst it may counter injustice and oppression via legislation it cannot force people to love and value one another meaning the interactions with people with dementia will remain

difficult for some, especially in a cultural context that is heavily influenced by the metaphysical components of what might define personhood (Swinton 2021). That dementia is a degenerative condition and follows a trajectory that moves away from autonomy, agency and self-representation that citizenship-based models value creates inherent tensions when thinking about the end-of-life and care for people in advanced states of dependency.

Measures that counter the narrative of deficit and loss in dementia have given a platform to the fact that people can and do live well with dementia (de Boer et al. 2007), yet they do not offer a framework for understanding value or meaning in the suffering associated with dependency, deficit and loss that is many peoples reality. The risk is they therefore contribute to the wider philosophy of death as absence, devoid of meaning or value. Whilst a moral duty to care remains, the absence of an appropriate philosophical framework to support this work means that marginalised communities affected by dementia are labelled as ‘hard to reach’ (Field et al. 2019; Bartlett, Milne, and Croucher 2019). Services founded from this perspective have not addressed the reality that deficit, loss, and suffering are indeed a fundamental component of dying, especially in dementia. Here, it is not the community that is ‘hard to reach’, but rather the service that is inaccessible and of limited use in the first instance.

Whether or not person centred initiatives are useful concepts around which to focus improvements in end-of-life care is therefore an area of debate (Farah and Heberlein 2007). What is clearer, however, is that the narrative around it persists as a powerful presence in society, as well as clinical care and legal systems. As Higgs and Gilleard conclude, its purpose may be in questioning “not personhood, but that which it serves – namely, the idea of possessing moral identity” (Higgs and Gilleard 2016b: Page 22).

Dying from advanced dementia, the added context of old age, frailty and multi-morbidity

Death in dementia is most common in old age, a fact that brings its own unique challenges. The development of a ‘hyper-cognitive society’ (Post 1995), along with its structural individualism, has made the body a key site to display identity and societal value, with some arguing the ‘corporeal capital’ gained through owning a healthy body as a critical resource used to engage with the notion of successful ageing (Higgs 2012; Davis 2020a). Within such a discourse, ‘normal ageing’, where infirmities, indignities and dependence prevail, is understood as failure (Davis 2020a). At the same time, the absence of any meaningful understanding of the shortening of time

can mean the dying phase is missed, or worse, devalued to the point of ambivalence. Such an eventuality is synonymous with the notion that dying in old age is both ‘natural’ and ‘appropriate’ with the assumption that it effortlessly happens at some point meaning those occupying caregiving roles are concealed through a lack of legitimacy (Bauman 1992).

The primacy afforded to independence and autonomy results in the challenges of physical deterioration in old age being met by technological and social interventions that seek to prevent, fix or stabilise. This is evident in the response to the ‘syndrome’ of physical frailty which is cast as a co-morbidity to the ageing process necessitating a clinical response to stave off an eventuality that is incompatible with ‘a good death’ (Jeste, Lee, and Cacioppo 2020; Marzetti et al. 2017). Such interventions breed complexity and uncertainty meaning the medical care of very old people becomes increasingly challenging (Wise 2013; Morin et al. 2017; Wastesson et al. 2018).

In a similar vein, the social isolation of older people is often described as an ‘epidemic of loneliness’ (Jeste, Lee, and Cacioppo 2020). Where social isolation is seen as a threat to human capacity to partake in society in a productive way, interventions follow that responsabilise people and institutions for the maintenance of a naturally depreciating resource. This can reinforce the notion of ‘old age as failure’ (Poscia et al. 2018; Dickens et al. 2011) whilst further contributing to the negativity around issues of decline and loss. An alternate approach appreciates the contraction of time around failing bodies as means to building a deeper connection with the immediate environment. This connection is constantly reinvented as people rebuild their worlds, fostering new relationships and engaging in opportunistic sociability that maintains a social ecology relevant to the roles and identities of very old age and dementia (Ward et al. 2022).

Conclusion: The orientating narratives to dependency, death and dementia

Juxtaposing the theoretical and philosophical underpinnings of the existing approach to end-of-life care in dementia, alongside the reality of the problems faced in providing it, highlights the absence of any meaning or value in how the dying process is understood. Where death is viewed through the lens of how best to avoid it, there is little room to move beyond notions of control in defining a good death. This is problematic in all deaths, but especially so in dementia where progressive decline and dependency can exist for years. The absence of attention to humanity’s inherent vulnerability, and the values of caring for people in a state of near total dependency,

creates a vacuum filled by notions of stabilisation and prevention that take their reference points from the ‘truth making’ industry of modern medicine and the corresponding values of autonomy and independence (Kaufman 2015b). In dementia, a focus on modifiable risk factors, active social participation or the preservation of personhood is united in essence through the desire to control. Where there is a possibility of control, there comes a responsibility for delivering it. Where control is illusionary, the responsibility will inevitably result in failure and its associated distress. The absence of control may instigate deep fear yet within it, or indeed in the effects that surround it, we might find reference points better suited to the roles and identity of the dependent dying.

Such an approach is echoed by Gilleard and Higgs’ social imaginary of the ‘fourth age’ (Gilleard and Higgs 2010b). Here they tend to focus on the darker side of old age by grouping the experiences of abjection, shame and limited agency into an imaginary likened to a cosmological black hole. They argue such a black hole may be “understood by examining not the experience itself, but its impact on the discourse that surround and orientate themselves to it” (Gilleard and Higgs 2010b: Page 1). It is here, in the ‘event horizon’ that we might begin to understand more about care where people dying of dementia are concerned. As with the event horizon, it is not necessarily its existence that needs explanation but more its “nature, meanings and the relationships through which it is realised” (Higgs and Gilleard 2016c: Page 91). Through this we may begin to understand the moral imperative of care as a means of realising dependency and decline as a social presence in the lives of everyone.

Chapter Two

New public health approaches to palliative care, a brave new horizon or an impractical ideal? An integrative literature review with thematic synthesis

Contents Two

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Introduction

In chapter one, I illustrate how dementia, old age and frailty pose fundamental questions as to how we understand death, whilst demonstrating the complexity of its effects are poorly catered for by the dominant philosophical and ethical frameworks employed by medicine and palliative care.

Such challenges are set against a backdrop of broader questions relating to access, equity and what is perceived as the ‘professionalisation’ of end-of-life care. How this notion is understood alongside the ever-changing weight and value attributed to ideas of neighbourhood, community, work, culture and family tradition is a source of tension. Increasingly, people are searching for and using frameworks from outside of the biomedical domain in order to work through such tensions and improve end-of-life care (Gott et al. 2018). One such framework exists under an amalgamation of seemingly interchangeable terms including a ‘new public health approach to palliative care’ (Sallnow 2016), ‘health promoting palliative care; (Kellehear 1999) and ‘Compassionate Communities’ (Kellehear 2013a).

The close association between public health, health promotion and palliative care is not immediately obvious. Traditional public health measures of disease prevention and control have been adopted by palliative care since the 1990s helping to improve access to analgesia and integrate services into the mainstream (Stjernswärd 2007). While these remain important concerns, a *new* public health approach focusses on health promotion and empowerment as a means to increasing our own personal resources for life and living. The Ottawa Charter was central to this shift and for the first time placed emphasis on reorienting health services to strengthen community action, develop personal skills and create supportive environments (WHO 1986). Engaging communities in health projects has subsequently been shown to improve health behaviours and consequences (O’Mara-Eves et al. 2013) leading Kellehear to outline his ‘health promoting’ or ‘new public health’ approach to palliative care (Kellehear 1999).

This method recognises that it is often not health professionals, but rather friends, family and close social networks that provide the majority of care when someone is dying or grieving (Kellehear 2013a). The support that these people require to carry out such tasks is built up through additional networks of people that link together to create what have been termed ‘Compassionate Communities’ (Kellehear 2013a). Such communities can be developed to act as a repository of knowledge, experience and human resource that can be accessed and utilised when

someone is dying (Abel, Kellehear, and Karapliagou 2018b). Interest in this idea has accelerated at a rate outstripping any form of sustained change or impact (Collins et al. 2020). Some have alluded to the relationship between public health and palliative care being “largely symbolic and tactical in nature” arguing the need for “greater theoretical, practical and critical engagement” (Whitelaw and Clark 2019). In this chapter, which is an expanded version my published literature review (Sawyer et al. 2021), I will argue that tensions extend further than this and are, as yet poorly acknowledged and accounted for.

The numerous people involved when someone is dying represent an array of differing ontological, philosophical and indeed existential perspectives on death. Attempting to conceptualise death in a way that unifies and mobilises entire communities is therefore fraught with complications. The lack of such a consistent approach has implications for how we then delineate responsibility. This is of particular importance when delving into the relationship between professional and lay caregiving services. Such ontological and existential factors have to match the processes and outcomes and therefore necessitate considered formulation. This is especially so when considering performing an intervention, such as those associated with Compassionate Communities. Here, issues relating to the often universally accepted notions for positive change, such as empowerment, compassion, social capital and community can cut both ways when considered at the level of the individual. Such theoretical inconsistencies can permeate through at an operational level and into the wider structures and frameworks at play.

Managing this complexity necessitates good leadership. This in itself is a complex area that brings with it the slippery subject of power, its use and indeed misuse, and how this then comes to bear on the ontological and philosophical foundations of a new public health approach to palliative care. Taking these factors into account I will also challenge the inherent tensions in using traditional academic and medical structures to evaluate the ‘impact’ of such work. I examine the concept of ‘experience’ and how this may be defined and utilised in the process of evaluation. I hope this may prevent the finer complexities of a new public health approach being reduced to overly simplified policy that satisfies the pursuit of immediately viable and effective solutions to proxy measures of what may constitute ‘good care’ or a ‘good death’.

Ultimately, I argue that by embracing unresolved tensions and contradictions, we have the potential to overcome or accommodate them in order to provide a level of transparency that is essential to building the collective moral responsibility that the movement adheres itself so strongly to. To this extent, the aim of the chapter is to identify studies explicitly affiliated to

Kellehear's ideas on new public health approaches to palliative care and systematically map the theoretical underpinnings and assumptions upon which they are based. In doing so I hope to identify and examine some of the inherent tensions with the hope of providing a theoretically sound platform for the development of future work in this field.

Methods

From this point forward I use 'new public health approaches to palliative care' as an umbrella term to encompass concepts including health promotion, Compassionate Communities, Compassionate Cities and any other measure relating to community engagement and asset-based interventions. In many cases, new public health approaches were found to breach the boundaries of what might be considered a systematic scientific approach. Rather they take the form of a social 'movement', suggestive of a much broader socio-political agenda. I therefore refer to new public health approaches as a 'movement' throughout the thesis. I summarise the empirical and theoretical literature, integrating theory from a range of disciplines to provide a more comprehensive understanding of new public health approaches to palliative care. I followed the overall framework put forward by Whitemore and Knafl for rigorous integrative literature reviews (Whitemore and Knafl 2005), for data analysis I used Braun and Clarke's flexible and reflexive method for thematic analysis (Braun and Clarke 2020).

Problem identification stage

I sought a theoretical framework that would allow me to depart from a solely descriptive process and allow me to review the literature through a more analytic lens. This was crucial in addressing the overall research question of what might be considered the constituent components of new public health approach to palliative care, where and what are the underling tensions, and how do such tensions impact on the development of the movement.

Through general reading that followed a brief scoping search of the literature, I understood new public health approaches, and Compassionate Communities in particular, to be socially constructed, complex and unpredictable entities. I decided there was a need to understand these concepts in relation to human behaviour in a more interpretivist approach. With the intention of embracing the naturally inherent complexity within such concepts I also drew on critical realist philosophy when analysing data. Although not explicitly a 'realist review' this framework enabled

me to think what might be working and why, but also for whom and in what context, thus helping to refine my theoretical arguments.

Literature search stage

I designed and carried out a search strategy in March 2020, this was updated in 2021 to capture newly published material. The databases Cinhal, Embase and Medline were searched using the following terms: Health promotion, public health, social change, new public health, palliative care, end-of-life care, terminal care, incurable, hospice, palliative medicine, community, community engagement, community resource, social networks, caring networks, social capital, asset-based approach, Compassionate Communities/cities, community development, social support, community participation, and community support.

The search included empirical and theoretical studies written in English and explicitly acknowledged as sitting within the framework new public health approaches or health promoting palliative care as defined by Dempers et al (Dempers and Gott 2016). Studies describing initiatives or theory relating to salutogenic notions such as promoting community engagement, nurturing Compassionate Communities and adopting asset-based interventions to palliative care were also included. Details of the selection process are outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) chart (Moher et al. 2009) (Fig. 1). Details of the individual studies are in table 1.

| Author | Aim | Participant/sample | Design/Method | Key finding | Country |
|-------------------------|---|---|----------------------------|---|-------------|
| Allen '12 | Examine EOLC pathways in context of health promotion | NA | Theoretical | Biomedicine predominates, ACP as a means of health promotion | UK |
| Aoun 18 | To determine who provides bereavement support in the community | Bereaved people | Cross-sectional survey | Strengthen Compassionate Communities to support bereaved people | Australia |
| Buckley 02 | Understand an educational strategy to encourage health promotion | NA | Theoretical | Holism as a framework for teaching the practice of health promoting palliative care | UK |
| Byock 01 | Conceptual framework is presented that describes pertinent whole-community characteristics, structures, processes, and outcomes. | NA | Theoretical | The framework offers a map for whole-community research, intervention, and evaluation with the goal of changing the community culture related to life's end and thereby improving the quality of life for dying people and their families. | USA |
| Abel 13 | Propose a new model of palliative care | NA | Theoretical | The person with illness is the centre of a network that includes inner, outer networks with communities and service delivery organisations | UK |
| Abel 18 | Stress the importance of networks of people | NA | Theoretical | Communities can offer possibilities for support | UK |
| Abel 18 | To propose a practice model on a public health approach to palliative care | NA | Theoretical | Inadequacy of a solely clinical model of care | UK |
| Abel 18 | To evaluate a population health complex intervention of an enhanced model of primary care and Compassionate Communities on population health improvement and reduction of emergency admissions to hospital. | People with emergency hospital admissions | Cohort retrospective study | Intervention was associated with reduction in unplanned hospital admissions with an associated reduction in healthcare costs for the area | UK |
| Conway 08 | Examines an emerging shift to public health approaches in the 'developing world' and the 'developed world' | NA | Theoretical | Community based approaches can contribute to a much broader agenda and potential for palliative care | UK |
| Correa 18 | Describe an existing model of care in primary care setting | Case study | Case study | Approach can provide more equitable care | Brazil |
| De Lima 16 | To propose a role for the integration of public health into the community setting | NA | Theoretical | Implementation must be prioritized and planned by the health administrators as a priority public health issue, not only to improve the global efficiency and appropriate use of resources in the system but also to improve the quality of care for patients with life-limiting illnesses and to relieve suffering. | USA |
| Dempers 17 | Explore understandings, uptake and nature of public health approach in NZ hospices | hospice leaders | Mixed methods | Public health approach is a priority, however there is poor understanding of the principles | New Zealand |
| Fook 10 | Explore the use of critical reflection in supporting health promoting palliative care | NA | Case study | Different assumptions exist depending on the stakeholder, critical reflection as a way of resolving this. | UK |
| Gomez-Batiste 18 | Describe the aims, activities and phases of a Compassionate Community project | Volunteers | Mixed methods | joint leadership with clear aims and targets is important to success | Spain |
| Gott 20 | To highlight gender inequalities regarding end-of-life caregiving and palliative care and show how these intersect with other social determinants of health | NA | Review | To argue for a paradigm shift in palliative care research, practice and policy to incorporate a focus on gender especially in communities | New Zealand |
| Gott 18 | Explore the role of community at the end-of-life for people in advanced age. | Patients and relatives | Qualitative interviews | providing community-based care for people of old age is fraught with tensions and needs to be flexible and responsive to the unique needs of those in advanced age | New Zealand |
| Green 15 | Critical description of the relationship between | NA | Theoretical | Community brings both positives and negatives and should not be | UK |

| | | | | | |
|-----------------------|--|--|------------------------|--|----------------------|
| | communities and the public health profession | | | romanticised. The context in which such programmes are implemented is crucial and a 'one model solution' is unlikely to be of use. | |
| Hartley 16 | To situate hospices within the broader community and describe methods of engagement | Vignettes | Theoretical | Hospices as part of a community and a necessary change in attitude from within mainstream healthcare professionals | UK |
| Hazelwood 18 | Describe an established public health and palliative care alliance | NA | Theoretical | Enthusiasm exists for the topic, local ownership is crucial for success, there are established barriers, evidence is a complicated issue | UK (Scotland) |
| Horsfall 12 | Illuminate the quality and effect of informal caring networks at the end-of-life | Patients and relatives | Qualitative | Carers successfully mobilised to provide care at the end-of-life. This contributed to social capital and towards the concept of a Compassionate Community. | Australia |
| Horsfall 13 | To develop an understanding of how formal and informal carers work together when care is being provided in a dying person's home | Professional and voluntary care givers | Qualitative | Combinations of formal and informal caring networks are essential to support people and their primary carers. Formal service providers do little to establish, support, or maintain the informal network | Australia |
| Horsfall 18 | To understand if and how network centred care supports carers of the dying while developing a whole of community approach. | Caregivers, service providers, community members | Qualitative interviews | Service systems need re-orienting to place caring networks as central to the caregiving process. | Australia |
| Huang 18 | Describe the five basic principles of the Taipei declaration on health promoting palliative care | NA | Theoretical | Integrate palliative care into public health policy, create supportive environments, strengthen community actions, develop personal skills, reorient health services | Taiwan |
| Johansson S 10 | To describe how caregiving can contribute to social capital as opposed to draining it | Community members | Case studies | There must be attention to the way that caring is organised, supported and recognised, which can make the difference between a positive and a negative experience | Sweden and Australia |
| Kellehear 07 | Critical analysis of health promotion from within the specialities of palliative and bereavement care | NA | Theoretical | Death as a social experience that requires active community-based support and development | UK |
| Kellehear 08 | To summarize the main rationale and concepts of health-promoting palliative care, lists some of the key policy and academic writing on the subject, and provides one example of its practice | NA | Theoretical | Strengthen a community's capacity to support in order to help the individual | Australia |
| Kellehear 09 | Critical commentary on policy approach to death and dying in dementia | NA | Theoretical | Current policy is overtly clinical and has disproportionate attention to physical and psychological domains | UK |
| Kellehear 10 | Outline of key approaches for health promoting palliative care | NA | Theoretical | Techniques for building community capacity for the activities of caregiving | UK |
| Kellehear 13 | Examines a health promoting policy, its conceptual origins and importance to current practice | NA | Theoretical | Health as a shared responsibility | UK |
| Kellehear 16 | To provide an academic and professional context to the ideas of health promotion and palliative care | NA | Theoretical | Understand how an emphasis on public health with affect efforts to provide clinical support at the end-of-life | UK |
| Kellehear 19 | An argument to act on the social determinants of health in the context of palliative care | NA | Theoretical | A social model of health for palliative care, promote civic engagement and partnership, build and normalise cultural literacy, | UK |
| Kelley 07 | To conceptualise a rural communities process of developing palliative care | Health care providers | Qualitative | Theoretical model whereby palliative care is developed in sequential phases. | Canada |

| | | | | | |
|---------------------------|--|------------------------------------|------------------------------|---|--------------------|
| Kelley 18 | Integrate palliative care services into an indigenous community | Primary carers | Qualitative | Evidence for the implementation of a public health approach to palliative care in an indigenous context | Canada |
| Kumar 07 | Discuss the evolution and functioning of the neighbourhood network in palliative care in Kerala, India | NA | Case study | key successes and learning points from a practical example | India |
| Kumar 13 | Discuss the state of palliative care in India | NA | Mixed methods | Potential for a public health approach to improve access to palliative care | India |
| Leonard 15 | To analyse the caring networks of people with a terminal illness who are being cared for at home and identifies changes in these caring networks that occurred over the period of caring | Informal caregivers | Mixed methods | Networks increase in size through caregiving, there is importance in the relationship between core and peripheral network members | Australia |
| Lewis 13 | To summarize the literature on social capital, well-being, and quality of life for key outcomes to inform a model of social capital in palliative care | NA | Literature review | social capital can provide structure for understanding how care is provided at the end-of-life | Australia |
| Librada Flores 18 | Describe a method for developing Compassionate Communities | NA | Theoretical | a framework for the development of Compassionate Communities | Spain |
| McLoughlin 16 | reflection on the adaption of the world café movement in the context of end-of-life | NA | Theoretical | preparation, presentation and pilot evaluation of Compassionate Communities café conversation | Ireland |
| Mills 15 | To identify and examine community-based activities around death, dying and end-of-life care which might reflect a health-promoting palliative care philosophy. | Local community groups | Qualitative | potential to enhance health service provision whilst restoring community agency | Australia |
| Mills 16 | To discuss future directions for community engagement as a public health approach to palliative care. | NA | Theoretical | The use of the arts, social media and appreciative enquiry in contributing to asset based public health approach | Australia |
| Mills 19 | To discuss the contribution of palliative nursing to health promoting palliative care | NA | Theoretical | Valuing compassion expressed within social networks of crucial importance | Australia |
| Murray 12 | Highlight the need to provide palliative care in the East Mediterranean | NA | Review | Building capacity to benefit access can be done through a public health approach | East Mediterranean |
| Murray 10 | Highlight the challenges to palliative care | NA | Theoretical | Addresses 5 key challenges to providing palliative care on a global scale | UK (Scotland) |
| Murray 08 | To discuss the importance of primary care in providing community-based palliative care | NA | Theoretical | Relationship between primary care and specialist palliative care and also the wider community is important, can't neglect the role of primary care physicians | UK (Scotland) |
| Murray 16 | To describe a renewed vision and shared purpose with respect to end-of-life care | NA | Theoretical | clinicians have the potential to support communities to play a role in end-of-life care | UK (Scotland) |
| Murray 15 | Document barriers and facilitators for palliative care in the community and to provide a resource toolkit for use by professionals to develop services | Professionals | Systematic review and survey | Toolkit can help community-based palliative care services develop | UK (Scotland) |
| Noonan 16 | To explore the concept of death literacy | Relatives and healthcare providers | Mixed methods | Describes a conceptual framework for understanding the outcomes for a public health approach to palliative care | Australia |
| Abel 18 curriculum | To critically evaluate the UK palliative medicine syllabus in relation to contemporary palliative care policy | NA | Theoretical | Current syllabus not accommodating of current policy | UK |
| Patterson 14 | Scottish perspective on health promoting palliative care | NA | Theoretical | The amount and the diverse nature of health-promoting palliative care activity currently taking place in Scotland indicate that many | UK (Scotland) |

| | | | | | |
|-----------------------|--|---|---------------|---|---|
| | | | | | organisations perceive the importance of this issue and are taking action to address it |
| Paul 16 | Explore the role of hospices in working with schools to promote education and support end-of-life and bereavement | Hospice staff, children and parents and schools | Mixed methods | Innovations identified to help hospices engage with communities | UK (Scotland) |
| Pereira 18 | implement an education programme and investigate its impact | teenagers | Mixed methods | Programmes contributed to creating an awareness of palliative care | Portugal |
| Pesut 14 | An exploration of rural palliative care with a focus on responsibilities that support good care | Community members | Qualitative | The complexity of responsibility and how this is negotiated | Canada |
| Prince-Paul 08 | To advance understanding of the social well-being domain, a dimension of quality of life, from the perspective of dying individuals | People with cancer | Qualitative | The importance of close relationships at the end-of-life | USA |
| Rosenberg 10 | Critical review of the literature relevant to the conceptual foundations of health promoting palliative care | NA | Review | Health promotion is amenable to the core concerns of palliative care, research needed on impact | Australia |
| Rosenberg 11 | Critical discussion on the role of responsibility and privacy at the end-of-life | NA | Theoretical | Demonstrates the complex and dynamic nature of the transaction between the dying person, their family, and the palliative care service providers. | Australia |
| Rosenberg 16 | Evaluate progression in palliative care | NA | Theoretical | Evidence is required for funding bodies and policymakers, without it, putting the 'public' into public health may remain an array of short-term, project based activities at the edges of clinical care. | Australia |
| Rosenberg 18 | This study examines the ways health systems, services, and individual health care professionals influence care at home at the end-of-life. | Informal carers | Qualitative | To upscale and maintain the successful efforts of people to care for someone at home at the end-of-life, formal service providers must integrate into caring networks, positioning themselves as integral members of caring network | Australia |
| Ross 18 | Understand how nursing community may engage with Compassionate Communities | NA | Theoretical | Compassionate Communities must work alongside services and not replace them | UK |
| Rumbold 14 | Understand how bereavement care fits into the model of health promoting palliative care | NA | Theoretical | Care around grief should be of equal importance to the care of the dying person | Australia |
| Sallnow 15 | To present a definition and a conceptual model of community engagement for end-of-life care services and the communities they serve | NA | Theoretical | Community engagement is a spectrum of activity | UK |
| Sallnow 16 | To review the evidence relating to the impact of a new public health approach to end-of-life care | NA | Review | Evidence exists and the approach can influence complex issues such as community capacity, wellbeing and social isolation. | UK |
| Sallnow 16 | To consider the research challenges related to examining new public health approaches to end-of-life care and how learning from more traditional or classic public health research can influence a future research agenda. | NA | Theoretical | By bringing together strong traditional methods such as analysis of longitudinal population-level data with participatory approaches that draw on communities' experience and aspirations for care, the authors suggest that new and improved opportunities exist to evaluate the impact of participatory approaches. | UK/Belgium |
| Sallnow 17 | To understand the impact a new public health approach to end-of-life care project can have when initiated through a hospice | Caregivers, palliative care professionals, patients | Mixed methods | Collective social capital can be used to understand the role of reciprocity and interdependency between the lay and professional worlds. | UK |
| Sawyer 18 | To describe the informal resources and networks available to persons affected | Patients and relatives | Qualitative | Community based approaches may extend human resource and supportive networks | India |

| | | | | | |
|------------------------|--|-------------------|-----------------|--|-----------|
| | by Multidrug-Resistant Tuberculosis, how they are accessed and how they are integrated into everyday lives | | | | |
| Sawyer 19 | To understand how social capital is used in EOLC in dementia | NA | Review | Complex systems such as communities and social capital do not offer uniformly positive outcomes | UK |
| Sinclair 14 | To explore perceptions of Noongar community members towards advance care planning (ACP), while developing culturally appropriate information resources for use in community and hospital settings. | Community members | Qualitative | Culturally appropriate methods of engaging Aboriginal people in ACP discussions should include Aboriginal health workers and take a whole of community approach to awareness raising. | Australia |
| Sirianni 19 | To explore why health promoting approach has not been adopted in the Canadian context | NA | Theoretical | Compassionate Communities as a potential solution to palliative care policy issues | Canada |
| Stajduhar 10 | A critical analysis of health promotion and 'empowerment' in the context of palliative family caregiving | Family caregivers | Theoretical | In particular, there is a risk that empowerment may be operationalized as transferring technical and medical-care tasks to family caregivers at home | Sweden |
| Stjernswärd 07 | To explore public health strategy in palliative care | NA | Theoretical | Framework for integrating palliative care into a country | USA |
| Stjernswärd 07 | Describe principles of public health national palliative care programmes | NA | Theoretical | Four foundation measures to help establish palliative care | USA |
| Lindqvist | To share ideas, experiences, and reflections from the early stages of a research program looking to develop health promoting palliative care | Community members | Action research | Including publics in public health research, means also including ourselves and making public many of the reflections, the mistakes, and the experiences we all have, to foster collective learning. | Sweden |
| Tompkins 18 | To present the historical development of the public health approach to end-of-life care in Canada, including its successes and hardships | NA | Theoretical | The evolution of the movement has not been difficult. Some confusion within core concepts has led to some downfalls. More work needed and support for key stakeholders is key. | Canada |
| Vander Ploeg 01 | Understand health promotion in the context of occupational therapy | NA | Theoretical | Health promotion and palliative care have a lot in common with respect to an occupational perspective | Australia |
| Williams | To examine how Canada's Compassionate Care Benefit operates as a public health response in sustaining informal caregivers providing P/EOL care | Caregivers | Qualitative | Financial benefit has potential to relieve some of the burden caregivers experience when trying to balance employment and other roles while caring for a patient at the end-of-life. As such, it marks a step in developing a public policy that addresses the public health issue of caregiver burden | Canada |

Table 1: Literature chart of included articles

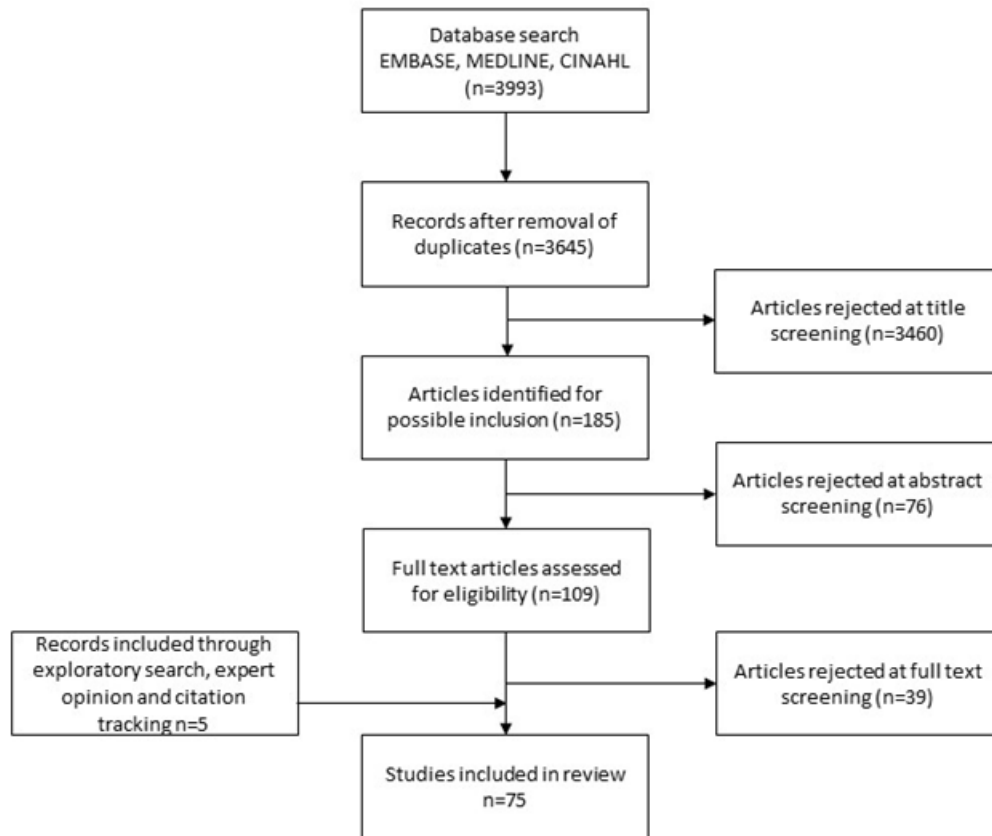


Figure 1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)

Data evaluation

Due to the challenge of applying uniform quality criteria to a diverse range of research designs, integrative literature reviews do not lend themselves to evaluating the quality of data, (Whittemore and Knafl 2005). Furthermore, this review focussed on the conceptual frameworks adopted and the underlying theoretical assumptions as opposed to the outcome of research findings per se. As such quality was less relevant compared to a traditional systematic review looking at more homogenous data. The studies in this review have therefore not been subject to formal quality assessment.

Data Analysis

The analysis of the data was based on the flexible and reflexive method for thematic analysis proposed and refined by Braun and Clarke (Braun and Clarke 2020, 2006). I understood meaning and knowledge to be situated and contextual whilst researcher subjectivity was conceptualised as a resource for knowledge production as opposed to a source of bias. I used reflexive thematic

analysis in a predominantly deductive way, using existing research and theory from the field of sociology and social gerontology relating to communities, social capital, age, ageism and stigma as well as drawing on critical arguments relating to the relationship between lay communities and the state. I then juxtaposed this theory alongside ideas inductively developed from the examined literature. To add ontological depth, and better understand causation, I used abductive reasoning as a final step in the generation of themes and the writing of the chapter.

Data analysis was conducted using QSR International's NVivo 12 software. First, to aid data familiarization I reviewed seminal papers and textbooks on the topic in an effort to become grounded in the literature and develop a broad base of terms through which key theoretical components could be understood. The data set was then organised into codes. These were based on the key components of the health promoting palliative care, typically containing at least one observation or facet. I use the term 'code' as defined by Braun and Clarke (Braun and Clarke 2020) who conceptualise this as 'an analytic unit or tool, used by researcher to develop (initial) themes'. Rival theories were highlighted and discussed in memos that were then linked to relevant codes.

Codes and memos were analysed for patterns, content and meaning in relation to the overall research question. Evolving ideas and tensions were discussed in weekly seminars that sought to identify existing pan-disciplinary theoretical frameworks that would corroborate or refute emerging theory. Patterns were then grouped together into sub-themes and then subsequently themes. The idea being to reach a nuanced analysis that provides overarching, multidimensional and 'meaning rich' themes. Themes were further refined during the writing process.

Data analysis was heavily disrupted by the COVID-19 pandemic when I was redeployed back into full time clinical work in the National Health Service (NHS). In this role, I worked as a community-based palliative care physician. The experiences in working as a palliative care physician through the pandemic and the influence this had on data analysis was discussed with my supervisors following a return to academic work. There is no doubt this role has influenced analysis of data, being open to this and embracing it as a resource for knowledge production is noted as a key component to the methodology. I decided that actively challenging personal experiences through the systematic evaluation of existing empirical and theoretical data, including actively seeking out opposing or 'rival' theories to my lived experience, would add integrity and strength to the methods and subsequent findings.

Results

Of the seventy-five articles identified, thirty-seven were theoretical and thirty-eight were empirical studies. Articles originated from the UK, Ireland, Australia, India, New Zealand, Spain, Portugal, Belgium, the USA, Canada, Taiwan, Sweden, Brazil and the East Mediterranean. Themes are divided into four sections; philosophical perspectives; processes; structures and finally experiences. The philosophical underpinnings of the movement are evaluated first in order to understand how death is constructed as an idea, thus providing a lens through which the following sections can be interpreted.

Philosophical perspectives

Historically, the way we conceptualise death directly corresponds to the resources developed to support it. For example, the power of religious social imagery concerning death developed a corresponding social role for those people experiencing it (Kellehear 2007). Similarly where death is characterised by the mere absence of life, the roles of those experiencing death are hidden and lack legitimacy (Bauman 1992). Understanding death from the perspective of its physical processes is recognised as reinforcing the notion of death as a final end point simultaneously shifting the balance in power from the dying person to the doctor (Ariès 1974). The articulation of palliative care, public health and health promotion in closer terms has resulted in a new, more expansive understanding of death and the experiences it brings. The key components, as distilled from the literature, are outlined below.

The whole as greater than the sum of its parts: Death, grief, caregiving and bereavement as one totality

Death is conceptualised as a process that both shares and requires an interdependence and social connection with processes of grief, caregiving and bereavement (Horsfall et al. 2013; Huang, Huang, et al. 2019; Kellehear 2007; Kelley et al. 2018; Rumbold and Aoun 2014). New public health approaches reject the notion of palliative care and bereavement as separate entities and construct a paradigm that embraces the totality of end-of-life experiences placing them together as shared social experiences (Rumbold and Aoun 2014; Kelley et al. 2018; Huang, Kuo, et al. 2019; Horsfall et al. 2013; Kellehear 2007). This is reflected in the development of Compassionate Communities that provide a social framework of support for problems that exist in the social world (Kellehear 2013a). In doing so, the movement subtly acknowledges the notion

that there are unseen and unquantified mechanisms at play that become lost when the whole is unpacked into its constituent components.

A shared breath, a shared life and a shared death

A dominant theme from within the literature was that of death as a shared social *process* (Aoun et al. 2018; Bunce 2018; Abel et al. 2013b; Conway 2008; Dempers and Gott 2017; Horsfall et al. 2013; Horsfall 2018; Kellehear 2007, 2016; Kellehear 2019; Kelley et al. 2018; Abel 2018; Noonan et al. 2016; Rosenberg 2011; Rumbold and Aoun 2014; Sallnow, Richardson, et al. 2016b; Sallnow, Tishelman, et al. 2016). Authors draw upon the idea of the universality of death, grief and loss and a shared impermanence held between all living things (Kellehear 2007; Mills, Rosenberg, and McInerney 2015). Death therefore is not characterised simply by the absence of life, beyond which there is social vacuum. Rather, it is argued that death can be ‘full of life’ through the interpersonal experiences that the process of dying, caring and bereavement brings (Kellehear 2007).

Consequently, death is understood as having its own life course where the associated transitions and transformations unfold over time to generate social change. In this way, death as a process has its own legacy which can ‘increase compassion, empathy and social sensitivity’ whilst the dead play important roles for the living as role models and motivators of change (Kellehear 2007). Such a notion is encapsulated in the sharing of breath; that the breath we take was someone else’s moments ago and will become part of someone else soon after we let it go. It continues to exist through others long after it has passed through us.

Framing death in such a fashion raises important questions relating to responsibility, duty and motivations in relation to end-of-life care. The multiple stakeholders involved in providing end-of-life care; families, communities, workplaces, professional services and the state, do not share a unified philosophical approach to death, thus creating a discordant and fragmented response.

Dancing your own dance: Negotiated Responsibility and the moral landscape

Morality has been described as being born out of shared understandings of ‘assigning, accepting and deflecting responsibility’ (Walker 2007). Where responsibilities are not clearly understood or felt, fragmented care, power struggles, service gaps and moral distress can prevail (Pesut, Robinson, and Bottorff 2014). It follows that for the human interdependencies to be realised as actual connections rather than theoretically constructed ideals, there is a necessary negotiation of

responsibility that follows. The literature talks of compassion as a ‘moral imperative’ upon which the movement is built (Kellehear 2007). There is also mention of how ‘shared responsibility’ is a ‘hallmark’ of Compassionate Communities (Mills and Mills 2016; Conway 2008; Dempers and Gott 2017; Aoun et al. 2018). However, there is less clarity on the negotiation of responsibility and how this then creates a compassionate moral landscape.

In the context of care, such negotiations, and their related outcomes, depend significantly on the cultural context and a society’s position on the spectrum between collectivism and individualism (Triandis 1993). Central to individualism is the autonomous individual who exists in a largely heterogeneous and competitive society. The breadth of variety promotes a tolerance of difference yet breeds dependence on services. The solidarity or interdependence here is rational, for example I choose which service to use and how much to pay for it, but recognise I am also interdependent on its function. Collectivism is founded on the interdependent self (Markus and Kitayama 1991) and exists largely in homogeneous cultures. The norms, roles, rules and values of society are well established and promote a degree of duty yet are difficult to break free from (Triandis 1993). In reality any given culture incorporates a mixture of both, for example families tend to adhere to collectivist principles whilst the market is inextricably linked to individualist social relationships (Triandis 1993).

At a surface level, new public health approaches would seem to endorse a reconstructive collectivisation, i.e. the redesigning of our individual lives in an attempt to collectively confront death through our own autonomous individual lives. In this way responsibility is governed by a form of duty and maintained through social norms. It follows that such a model risks ostracising those who disagree or are unable to partake in such activities. Where such people are free to leave without repercussion the collective culture is at risk of a gradual erosion.

At a deeper, more abstract level, the idea of a shared responsibility is suggestive of an innate connection held between all living things that breeds a fluency to the roles we play in life and death. Here responsibility is less of a cognitive process and more something we *feel* which compels us to move and act in a way that is unique to us as individuals. This notion gave rise to the theme of ‘dancing your own dance’ which evolved in response to the dilemma of negotiating responsibilities.

To understand this notion better, we must combine knowledge relating to collectivist and individualist philosophies with more creative ideas on how responsibility is given the space and

time to evolve and be felt within us. Part of this process involves understanding where professional services sit within the paradigm of death as a ‘shared social process’.

Creating, holding and nurturing space: The intersection between public, professional and lay services and the implications on responsibility and duty of care

New public health approaches to palliative care incorporate ideas on health promotion as a means of disease prevention and harm reduction. Such principles demand greater public responsibility, yet they also create bureaucratised systems that demand compliance rather than nurture shared responsibility. In this section I discuss these tensions in the hope of finding a clearer path forward.

The literature describes the idea of a Compassionate City (Abel 2018; Kellehear 2019). At one level, a Compassionate City is understood to hold some degree of responsibility for end-of-life care. This is clearly not at an individual level, but perhaps more in creating an accepted space for citizens to perform some of the ‘work’ of caring (Horsfall 2018). Organisations are then able to respond to local needs rather than vice versa leading in theory, to more equitable care (Kellehear 2005).

Within this concept, and interdependent upon it, is nestled the idea of a Compassionate Community. Such communities are described as having an ‘outer network’ of communal support that lies in relation to an ‘inner network’ of private domestic relationships (Abel, Kellehear, and Karapliagou 2018b; Gott et al. 2018; Horsfall et al. 2013). In its broadest sense a Compassionate Community is conceptualised as sharing some responsibility for end-of-life care, yet the specifics of what it is responsible for and how this is held between networks, are unclear.

At the level of the family or an inner circle of care, the culturally embedded norms of kinship present duty as a concept that is distinct from responsibility and more in line with some form of obligation (Finch and Mason 2008). Parent – child relations are in some cases founded on norms of obligation, how these norms operate and are created within a Compassionate Community is relatively unexplored yet crucially important. Whilst there are perhaps clear principles which can be referred to when considering the ‘proper’ thing to do, there is no consensus regarding what is reasonable to expect.

At the level of the patient and the professional there is a more defined, although not binary locus of responsibility. The difficulty arises when responsibility is viewed at a population level. Firstly,

professional services do not have the capacity to manage such responsibility and secondly they are considered by some to hold a benign, yet enduring paternalism that is a philosophical and structural barrier to the paradigmatic shift of conceptualising death as a shared social process (Rosenberg 2011). Framing the problem in public health terms is a logical step to fostering the human resource communities' offer and building political capital, but conceptually the locus of responsibility remains rooted in the professional domain. This represents an enduring tension across the literature and a significant barrier to the progression of the movement.

Interdependent on any form of responsibility lies the question as to what motivates a person or group of people to act or assume accountability, both in the first instance and then in a sustained fashion. If Compassionate Communities are motivated purely by altruism, driven by ideas of interdependence and compassion as a moral imperative, they will be subject to the previously described limitations of a collective culture. Furthermore, it cannot be assumed that all people in all communities are altruistic. Whilst altruism can be fostered via the responsibilities held at a civic or organisational level, the reality is that whilst communities bring companionship, practical support and comfort they also bring ignorance, rejection, and patronisation (Rosenberg 2011). Furthermore, altruism is difficult to implement systematically and can quickly lead to bias (Oakley 2013).

If motivation is modelled on social exchange theory (Dowd 1975) and reciprocity, i.e. that a compassionate act is exchanged for another or some other form of 'capital', there are still inherent tensions. For example, many people at the end-of-life are unable to reciprocate acts of care thus giving rise to the need for professional services. In such an approach, care may be 'commodified' and subject to market rules. This is in contradiction to understanding death as a *'shared social process'*. There is some evidence that under the paradigm of shared social responsibility, reciprocity is not defined in terms of simple dyadic transactions (Sallnow 2017; Sallnow et al. 2018). For example, where an act of care or compassion is unreciprocated due to ill health of the recipient, then the benefactor will seek reward elsewhere in the community (Sawyer et al. 2019). Where these pathways are cultivated this can, in theory, lead to the building of community capacity. There is therefore a fluidity to the idea of responsibility and the sharing of roles may need to be more commonplace. Traditionally described in the biomedical literature as a source of burden and distress (Stajduhar, Funk, Jakobsson, and Ohlen 2010), the sharing of roles can also be perceived as a fulfilling and rewarding process (Horsfall, Noonan, and Leonard 2014).

The fluidity regarding responsibility and motivation described within the literature gave rise to the overall theme of '*Creating, holding and nurturing space*'. Under this paradigm Compassionate Communities unify professional, public and lay services by forging a space that permits a fluidity to responsibility that then allows people to find their own personal way at the outset, whilst giving room for others to move in and support them at times of difficulty.

Processes over outcomes, lenses as opposed to interventions

The idea that *how* the end-of-life unfolds is of greater importance than any single measurable outcome is central to new public health approaches (Conway 2008; Hazelwood and Patterson 2018; Kellehear and O'Connor 2008; Kelley 2007; Mills, Rosenberg, and McInerney 2015; Noonan et al. 2016). Using the example of responsibility and duty; whilst a lay person may accept a caring responsibility, it does not necessarily mean that the experience is perceived in net positive terms and will contribute to community capacity. It is the process through which responsibility is negotiated and the moral landscape that is constructed that ultimately decides this.

That said there is a tendency in the literature to use a new public health approach to demonstrate effect on well-established outcomes such as preferred place of death and avoiding hospital admission (Abel et al. 2018). This is reflective of the more biomedical palliative care literature that speaks in terms of outcomes that may be interpreted as 'positive' or 'negative'. For example, a home death may be perceived as 'good' or a transition in care from home to hospital or care home perceived as 'bad'. This infers a more traditional public health perspective and reveals the tension between defining death as a shared social process with varied outcomes as compared to a clinical process with defined endpoints amenable to focused intervention.

It follows that new public health approaches have somewhat of a fraught relationship with professionally instigated interventions. On the one hand, interventions to aid community development is a central facet to the movement (Kellehear 2013a; Kellehear 2019; Kellehear 2005). Whilst such initiatives are developed in response to the needs as identified by members of the community (Abel, Kellehear, and Karapliagou 2018b; Kellehear 2013a, 2005) and seek solutions via collective community resource rather than upscaling private or government based professional services (Kellehear 2005), they nonetheless have the potential to demand conformity and narrow the locus of responsibility.

On the other hand, if death is viewed as a shared social process, new knowledge, skill and experiences evolve naturally as a direct response to the challenges of caregiving through the dying process. What is important is how these grow organically and ‘ripple out’ into the world, contributing to a greater body of collective resource. Initiatives are therefore not required to *make* the ripple, but instead to give it the momentum it needs to aid community development. Without an appreciation of such processes, interventions have the potential to wield a power that generate entrenched social norms and demand conformity. Viewed in such terms it is less an *intervention* that is required but more a platform or stage that affords the space for networks to generate and multiply. Where a change is required, it may be as subtle as creating a lens which offers a different perspective and set of solutions (Pesut, Robinson, and Bottorff 2014).

Permitting both joy and grey hollows: the meaning of suffering in relation to the idea of a ‘good death’

Ultimately the fundamental purpose of new public health approaches is to enhance feelings of support and security at a time of immense sadness and vulnerability. To achieve this, there needs to be some form of understanding as to how we view human suffering and what should be done in response to it.

As I have already discussed in detail, the specialty of palliative medicine, and the medical world in general, has been influential in promoting the idea of a “good death” (Meier et al. 2016). Whilst individuals and their families may differ in their preferences as well as their normative beliefs regarding what constitutes ‘good’ or ‘bad’, the public message is clear; that there are co-morbidities and symptoms to dying that can be fixed, prevented or alleviated, and where this does not happen it somehow translates to a failure in care. The idea of anything other than a ‘good death’ has come to represent something of a failure for palliative medicine. This only serves to distance the speciality from the social roots of death and dying and edge it more closely towards a biomedical model.

A more social approach to suffering is perhaps grounded in the idea that death, much like the life lived until that point, is a ‘mishmash’ of joy and grey hollows (Kellehear 2019; Horsfall, Noonan, and Leonard 2014; Noonan et al. 2016; Rosenberg 2011; Pesut, Robinson, and Bottorff 2014). Easing the pain as a loved one dies is an insurmountable task. Nor is it necessarily a virtuous one when creating an environment of complete emotional sterility would be the only such way of achieving it. Whilst the pain, fear and terrible sadness is there for all to see, there is

also companionship, courage, strength, love and compassion in such an example. Caring at the end-of-life must therefore accept, and then accommodate, both the joy and grey hollows it brings.

Rather than something that can simply be alleviated or eliminated, the literature is suggestive of suffering as something with meaning and importance that can be instrumental in creating new social legacies, building social relationships and building a source of new knowledge and hope (Kellehear 2019). New public health approaches to end-of-life care therefore embrace and work with the suffering that comes with death. By encouraging people to hold it and work with it so it can be experienced in a healthy way that allows people and communities to transition through and develop from the experience it brings (Horsfall, Noonan, and Leonard 2014; Kellehear 2019). Conceptualising suffering in this way is vital to incorporating the full spectrum of community resource into the response to death and dying.

Processes

I now aim to evaluate the processes at play within new public health approaches to palliative care, using the core philosophical underpinnings as a lens through which to understand them. I encourage the reader to regularly reflect back on the underlying philosophies described so as to make sense of the forthcoming themes.

Invoking and awakening the idea of community as an independent agent of care

This theme is an attempt to bring some consensus to the medley of processes mentioned across the literature. Within it I describe some of the commonly encountered ideas including empowerment, network building and social capital, and how they align with the philosophical principles described. I identify and discuss some of the inherent tensions by drawing on existing literature from other disciplines before describing my ideas on ‘invoking and awakening community’ as an overall theme.

Empowerment

Empowerment is an established concept in new public health promoting strategies (Labonté and Laverack 2008) and is often used as a way of describing shared responsibility (Buckley 2002; Sallnow and Paul 2014; Dempers and Gott 2017; Green 2015; Hazelwood and Patterson 2018; Horsfall et al. 2013; Kumar 2007). The idea stems from the notion that humans have a specific

set of resources that allow us to adapt to illness and live with the anguish this may bring (Illich 1975b).

There are various levels of empowerment mentioned in the literature (Sallnow and Paul 2014). At the level of the dying person, it can be seen as a tool to making a healthy adaptation in the face of one's own mortality, this helps to maintain a sense of control and agency for the person. At the level of community, empowerment is taken to mean the pooling of a community's collective resource to take action and generate solutions to common problems (Horsfall et al. 2013; Kumar 2007). At the level of policy and public infrastructure it is about building a facilitative, non-prescriptive structures that foster such processes (Conway 2008).

That empowerment tends to be universally accepted as a force for good within the field of community-based care has implications for family and caregivers, especially at the end-of-life. For example where people are 'empowered' to die at home, family members may be forced to relinquish traditional family roles (Stajduhar, Funk, Jakobsson, and Ohlen 2010) whilst the highly gendered dimensions of caregiving are accentuated (Gott, Morgan, and Williams 2020; Williams et al. 2011). Furthermore, empowering people to work in a more holistic and supportive manner neglects the fact that not all people have the same thresholds to provide such care. People unwilling or unable to work in this way may then be subject to discrimination (Williams et al. 2011).

These are examples as to how tensions can arise depending on the level at which empowerment is interpreted. In many ways empowerment therefore is not something that is bestowed or gifted upon a community but something that is invoked within it. This way the power is allowed to be built collectively so it is less easily stolen, displaced or corrupted.

Network building

Network building is one of the predominant processes in engaging with and empowering communities (Horsfall, Noonan, and Leonard 2014), however a range of techniques are described. Authors describe using activism and 'disruptive innovation' as a means to achieving the scale and momentum necessary to bring change (Kumar 2013; Murray and Mason 2010). Although not formally evaluated in academic terms, the development of such initiatives has the potential to exert significant pressure on the relationships and actions of local and national governing bodies. This influence is important in instigating a cultural shift that brings lasting change. However, the influence of state developed interventions can risk 'crowding out'

organically developed interventions, thus jeopardising solidarity within the community (Kumar 2013). I could not find empirical evidence for this phenomena in the context of Compassionate Communities, however the topic has been discussed at length in the field of sociology and social gerontology in relation to the welfare state (Van Oorschot and Arts 2005). Opposing this argument is the idea that state interventions draw people into action (Künemund and Rein 1999). This positively links the growth of community support to the level of giving and receiving (Künemund and Rein 1999).

Community based interventions can also be founded on existing networks and social assets. Such networks may not develop in a uniform or predictable pattern (Horsfall 2018) as they respond to the complex interplay between love, intimacy, trust and duty. The fields of academia and biomedicine are fundamentally restricted in their abilities to understand how networks move and re-organise at the end-of-life. To help overcome this, there is a need to embrace the capacity held by the arts to provide a creative medium that dynamically engages communities to awaken the spirit within human relationships (Mills and Mills 2016). Only then can we truly foster the full potential within such complexity.

Another approach is to target the structures that impose a blockade on organically developed social networks. This allows for the 'rippling out' of knowledge and experience thus allowing the caring capacity of a community to develop naturally. Advocates of such an approach theorise that lay networks of people want to be involved but lack capacity due to other responsibilities or structures that impede them (Horsfall 2018; Horsfall, Noonan, and Leonard 2014). At best, professional services and the stream of bureaucratic interventions designed to help do fill the void, at worst they are further structures that obstruct peoples desires to partake in the caregiving process (Horsfall, Noonan, and Leonard 2014).

Social capital

Regardless of the approach to network building, new public health approaches are inextricably linked to the multifaceted concept of social capital. Generally social capital is understood in three levels; bonding, describing strong homogenous relationships that foster trust and maintain resource; bridging, between people across difference that generates access to resource; and linking, across explicit power differentials allowing for the generation of increased resource (Woolcock and Narayan 2000). The effects however are not universally positive (Daly and Silver 2008; Portes 1998). At the level of individually bonded ties, there may be damaging close

relationships, caring roles may be subject to gender, cultural and economic bias whilst the strength of individual ties may bar outsiders thus limiting development. At a community level, disparate pathways to bridged social capital on the basis of social class, race, education and gender can create negative group norms and cause social exclusion (Portes 1998). Macro level influences through linked social capital can also lead to the possibility of corruption and nepotism.

Framing the concept in palliative care terms, caregiving at the end-of-life is thought to have potential in contributing to social capital through the social interactions it brings (Horsfall, Noonan, and Leonard 2014). Caregiving can also help build trust, reciprocity and adherence to a new set of social norms that facilitate social agency (Johansson, Leonard, and Noonan 2012). This is in opposition to the isolation and burden more commonly attributed to caregiving at the end-of-life, especially where old age and dementia are concerned.

However, framing caregiving in such terms neglects the described, more dispassionate, body of work on social capital. Such work would suggest the shaded support of someone far removed from the business of family politics, who can provide a comfort and confidence that is unique in a community that knows everyone's business, can in itself be a sanctuary (Pesut, Robinson, and Bottorff 2014). Attention must also be paid to the levels at which social capital operates. For example, where informal carers are recruited to provide bridged and bonded capital, they may be subject to the all-consuming nature of care (Williams et al. 2011) and subsequent economic hardship (Williams et al. 2011) if they are not supported by linked capital that affords them the space to fulfil such duties.

That enhanced social capital is desirable on the part of the dying person is another source of tension. Whilst death may well be universally and routinely experienced it remains a highly intimate and private matter (Rosenberg 2011). Balancing both the personal and social nature of dying is not straightforward. This is illustrated by work showing people in advanced age can actively withdraw from or resist community support (Gott et al. 2018; Hauge and Kirkevold 2012).

The capacity of social capital to be operationalised by new public health approaches is therefore very much dependent on a greater theoretical understanding of the tensions at hand. Additional processes and supportive structures are necessary to develop a robust understanding and subsequent plan for integrating informal networks into caregiving. Regardless of the specific approach taken, a consistent undercurrent to the processes involved is to frame death as shared

social process by giving precedence to a metaphorical web of ‘betweenness’. Consistently across all studies, death and dying directly breeds new social relationships and experiences, in many ways therefore, community is not something that is produced but rather invoked and awakened. In this idea of community, identities of awakened and realised individuals challenge and complement each other allowing individuality and originality to enrich both the self and others.

Embracing that which emerges from the space: The construction, interpretation and use of knowledge

Complimentary to a thoughtful approach to social capital is an understanding of the process by which knowledge is constructed, interpreted and used in the context of end-of-life care. Just as medical professionals have expertise and knowledge relating to disease and clinical assessment, communities hold knowledge relating to customs, values and practices (Fook and Kellehear 2010) whilst families and close networks hold knowledge relating to a dying person’s identity (Sawyer et al. 2019). New public health approaches would view all this as knowledge that is relevant to the end-of-life process. This is representative of a paradigm shift from traditional approaches that are based on a hierarchy of knowledge. Where knowledge and expertise are seen to emerge more broadly, people will seek it from the widest range of possible sources. For professionals to actively partake in the exchange of relevant knowledge they must first recognise the importance of socially and culturally constructed knowledge relating to the dying person (Sawyer et al. 2019). Removing pre-conceived ideas regarding the importance of professional knowledge can then allow for mutual experiential learning that fosters a cultural literacy drawn from experience (Kellehear 2019).

Communication flow via ripple effect

“Social networks lay the foundation for social interaction, which in turn brings about trust, expectations of norms emphasising reciprocity, and cooperation” (Kääriäinen and Lehtonen 2006). In order for this to happen and for knowledge to be disseminated and learned from, communication flow is of vital importance (Horsfall, Noonan, and Leonard 2014). Conversation allows for the social diffusion of insights and experience that have developed in response to the act of dying (Kääriäinen and Lehtonen 2006). This generates access to knowledge and a repository within which it can be stored and accessed again. Such processes also give rise to a universal language that endorses death and dying as a shared social process. This is described

within the literature as the concept of ‘death literacy’ (Noonan et al. 2016; Huang, Huang, et al. 2019; Horsfall, Noonan, and Leonard 2014).

The dissemination of knowledge and experience in this way helps produce structural and communal change that embed the work of caring within the community and maintain new public health approaches in line with its philosophical underpinnings (Sallnow, Tishelman, et al. 2016). In these situations, knowledge is conveyed in the form of narrative as opposed to didactic educational techniques employed by professional services. Story telling is thought to create very broad and inclusive opportunities for participation and reflection (Hazelwood and Patterson 2018). It also reinforces the notion of experiential learning, one of the processes central to the functioning of a Compassionate Community.

A ripple effect was a term used in the literature and is apt due to the fragility it implies. Taken outside of the social context, this form of knowledge is rarely endorsed and where it is, it is perceived as unquantified and unvalidated. Professional services may also be seen to obstruct the ripples that create such knowledge capacity, this was acknowledged, although not necessarily explicitly, across the reviewed literature (Horsfall 2018; Lewis et al. 2013; Pesut, Robinson, and Botorff 2014; Rosenberg, Mills, and Rumbold 2016; Rumbold and Aoun 2014).

Dynamic modelling

Crucial to the processes mentioned thus far is the ability of the movement to continually adapt to changing environments, both physical, social and cultural (Bunce 2018). Processes must recognise and accommodate both slow burning cultural change but also mirror significant shifts in cultural practice that follow major public events. This is a notable distinction from the ‘cultural syndrome’ of collectivism outlined previously (Triandis 1993). A health promoting approach to palliative care requires an adaptive culture that has the ability to transcend challenges and create new patterns of behaviour yet is not limited by professional boundaries (vanderPloeg 2001; Kellehear 2013a; Sallnow, Richardson, et al. 2016b). Effective partnerships at the individual, community and service levels are required with ongoing consultations with members of the public described as a defining feature (Bunce 2018). Without such measures any cultural change runs the risk of replacing one rigid cultural norm with another. The constant swaying between cultural norms is more akin to some kind of temporary policy fashion rather than a progressive extension of the idea of death being a fundamental part of our human fabric.

Structures

Leadership, development and the spectrum of power

Both Compassionate Cities and Compassionate Communities require leadership to socially market the concept and enlist the co-operation and creativity of the wider community and potential institutional participants. Leadership must also deliver sustained growth and development of the movement that allows for dynamic modelling. Leadership does not have to come from within the field of health and social care. Indeed, leadership from outside this field would help ground the movement within the philosophy of death as a shared social process. Given the range of enthusiasm for the movement from a variety of sources this feels like a realistic possibility (Hazelwood and Patterson 2018). The danger however is that communities become ‘responsibilised’ for circumstances that are not of their own making and are beyond their means to effectively address (Conway 2008). There is mention of a locus of leadership being assumed at the hands of the dying person (Gott et al. 2018; Horsfall, Noonan, and Leonard 2014) although this concept is complicated by the nature of disease e.g. dementia and the restrictions experienced during very old age. In contrast, professional services hold significant power in addition to their expertise and are uniquely placed to hold such a leadership role. The irony being that the very services possessing the expertise to lead this shift in control are the same services that would be required to yield that control (Rosenberg 2011). There is also a concern that the curriculum for UK health professionals involved in providing such care is of a narrow focus and fails to accurately articulate the foundations of health promotion at the end-of-life (Abel and Kellehear 2018). Given this there is ample opportunity for the corruption of such power (Kellehear 2016). Leadership must recognise that a social approach to death cannot be ‘delivered’ but requires careful cultivation and awakening through collaborative engagement. Perhaps most importantly, there is a requirement for leadership to utilise the power and control afforded by the role whilst simultaneously ceding such power allowing for organic community development to flourish.

Spaces

A social model of death is a settings based approach (Kellehear 2019). Space is used as a platform for social connectedness that affords room for people to gather and their stories to be shared. Much of the literature is devoted to the idea of home-based care and a home death (Kumar 2013; Kumar 2007; Noonan et al. 2016; Rosenberg 2011; Sallnow 2016). The home

provides a degree of independence, control and autonomy from professional structures (Noonan et al. 2016; Rosenberg 2011; Kumar 2007) whilst providing the opportunity for the coming together of intergenerational networks (Noonan et al. 2016; Horsfall, Noonan, and Leonard 2014). However, for others the home can be a place of abuse, exclusion and isolation (Horsfall 2018). The involvement of professionals at the end-of-life and the ‘paraphernalia of care’ creates somewhat of a hybrid space where there is encroachment of professionalised norms on the traditional culture of the home. A compassionate space offers necessary protection and support yet is reflexive to the identity and agency of the individual at its centre (Abel, Kellehear, and Karapliagou 2018b). Compassionate spaces incorporate and build ‘cultural literacy’ drawn from experience garnered through the valuing of local knowledge (Kellehear 2019). A compassionate space can be anywhere; in an institution, in the community, or in someone’s own home. It is created by careful and considerate negotiation of responsibility and an adherence and grounding within the philosophy of death as a shared social process. This is an example of how the process by which a space is physically and philosophically constructed is of more importance than the actual space itself and returns us to the underlying philosophies of the movement.

Beyond the home, other social platforms were understood to provide structure to the processes of rippling out and communication flow. The Café Conversations’ activities described by McLoughlin et al (McLoughlin, McGilloway, Lloyd, O'Connor, et al. 2016; McLoughlin, McGilloway, Lloyd, Rhatigan, et al. 2016) and the use of arts and social media described by Shyla and Jason Mills (Mills, Rosenberg, and Mills 2015), are examples of how social spaces can be built whereas places of worship, cinemas, parks and even hospitals contain existing spaces that can be recreated in such a fashion when viewed through the appropriate lens (Sawyer et al. 2018; Byock et al. 2001).

Experiences

The aim of new public health approaches is to positively influence what is experienced at the end-of-life. Across the literature experiences tend to be viewed as a product, something that we have some form of control, possession or ownership of. This is in contrast to an experience being something that is played out through sequences of complex drama, something that may surprise us, capture our imagination or thrust us into an arena in which the individual is in contact with something far greater (O'Donohue 2010). Conceptualising an experience using the latter framework is a useful way to understand the potential outcomes of new public health approaches.

Self-perpetuating community development and sustainability

There is a notion that good end-of-life care not only requires community development but also assists it (Abel et al. 2013b). This is modelled by the idea that reciprocal actions of compassion are not limited to dyadic relationships (Sawyer et al. 2019; Sallnow 2017). Instead the skills, knowledge and experience developed by caregiving can be utilised in the wider community creating a network for the exchange of such commodities that contribute to an economy of care and compassion (Leonard, Horsfall, and Noonan 2015b; Horsfall, Noonan, and Leonard 2014). Such notions are also thought to build a community's capacity to be compassionate and self-sustaining (Horsfall 2018; Kellehear and O'Connor 2008) whilst allowing for emergent, community-based leadership that is culturally, economically and needs based. This is however far from a universally experienced phenomena and is likely to show significant variation amongst different age groups and disease types (Gott et al. 2018). The challenge is understanding in what context this phenomenon can be usefully developed.

For communities to develop around end-of-life caregiving, it is important that the experience of community growth is not viewed solely as a product with corresponding notions of ownership. Rather the experience of community development may be seen as participation in something more ultimate than one's own needs or ego. This may refer to notions relating to the 'spirit' of a community. Typically outside of the technical language of academia and palliative care, invoking and awakening the spirit of community is inextricably linked to the work conducted by new public health approaches to palliative care yet conspicuous only by its absence from the literature.

Continuity of care

Following on from this concept is the idea that informal caregiving networks also provide a continuity of relationship that allows for sustained support in addition to knowledge development (Huang, Huang, et al. 2019). At a surface level, such continuity bridges the gaps that occur between medical sub-specialties (Byock et al. 2001; Aoun et al. 2018; Fook and Kellehear 2010; Abel, Kellehear, and Karapliagou 2018b). This is increasingly vital as the timescale for the dying process in conditions such as dementia and other chronic diseases are likely to be measured in years. At a deeper level, the experiences, revelations or epiphanies that arise from forming sustained and continuous caring relationships contribute to the notion of

death as a shared social process, giving a connection to a metaphorical ‘web of belonging’ that can sustain and nourish even during the darkest of times.

Shared ownership and awareness of death

Currently health systems hold power that greatly influences the relationships formed (Noonan et al. 2016). By sharing the locus of ownership and responsibility and creating a platform for discussion that highlights an accurate reality of the caregiving landscape, people can begin to redress the power balance (Noonan et al. 2016). Significantly some of the greatest challenges faced by caregivers at the end-of-life originate from formalised medical structures and the bureaucratic processes that support them (Horsfall 2018; Rosenberg et al. 2018). Furthermore, regulatory systems focussing on risk management, privacy and confidentiality constrain service providers from working directly with informal networks (Horsfall 2018; Rosenberg, Mills, and Rumbold 2016). Such measures have led to some describing the current situation as ‘working together - apart’ (Horsfall et al. 2013). New public health approaches have the potential to provide a universal set of practice principles that allow for shared ownership and responsibility thus overcoming such barriers.

Discussion

This integrative review critically evaluates the underlying philosophical assumptions, processes, structures and outcomes inherent within new public health approaches to palliative care. By integrating rival theories from a range of disciplines I have highlighted previously unconsidered tensions embedded within the movement. The review attempts to dispassionately acknowledge and work with these tensions to provide a sound basis for the sustained implementation of a new public health approach to palliative care. Much of this lies in bringing into sharper focus the underlying philosophical principles upon which this movement is founded. Articulating how death and suffering are conceptualised allows us to understand issues of responsibility and motivation in greater detail. Such factors are crucial when looking to enlist the support of a range of stakeholders that hold differing perspectives.

Despite a growing evidence base, which has expanded significantly since my original search (Mills et al. 2020; Vijay, Whitelaw, and Clark 2020; Tziraki et al. 2020; Bakelants, Vanderstichelen, et al. 2023; D'Eer et al. 2022; Lessard et al. 2023; Liu, Huang, and Wang 2022; Vanderstichelen et al. 2022; Bakelants, Van Droogenbroeck, et al. 2023; Quintiens et al. 2022),

the philosophical underpinnings and their inherent tensions are often poorly discussed. Ignoring such topics runs the risk of a new public health approach morphing into a one size fits all solution that ceremoniously hands back care of the dying to communities as a means of addressing the challenges faced by end-of-life care. To avoid such an eventuality, I suggest there is a greater need for cross-disciplinary collaboration to help bring such tensions to light. My attempts to integrate work from the fields of sociology and social gerontology are a step forwards, however for death to be truly understood as a social process, work from the fields of arts and culture, theology, economics, architecture and design, social work and education must be integrated into research and practice. This will help create a more collaborate culture that can accommodate notions of shared responsibility, knowledge and trust. Furthermore, I encourage academics and activists alike to articulate their underlying philosophical principles in relation to a new public health approach. If the social nature of death is not acknowledged in explicit terms, there is ample opportunity for the development of interventions under the banner of a new public health approaches that only serve to distance palliative medicine from the social roots of death and dying whilst creating structures that obstruct people in their desire to partake in the caregiving process. Since my initial search and the writing of this paper, there have been additional publications in the field that are beginning to address some of these issues (Vijay, Whitelaw, and Clark 2020), however as new interventions are developed and implemented (Mills et al. 2020; Liu, Huang, and Wang 2022) and the scope is broadened (Tziraki et al. 2020) there remains an inherent need to acknowledge the arguments laid out in this review.

A diagrammatic summary of my findings can be found in [figure 2](#). Here the epicentre of the diagram may represent any singular event with the repercussions represented by the rippling out of waves from this point. Where repercussions lead to the meeting of new bodies or structures the wave is altered in direction and form and its energy dissipates quickly. Such changes may be welcome or necessary yet produce a wave form that is fragmented with a smaller body of resource as its product.

Where the repercussions are unheeded a larger wave form exists. In this larger wave form it is possible to see how notions of individualism, interdependence and collectivism can co-exist and work together rather than be seen as mutually exclusive ideas. As the wave falls there is a process of re-integration into a larger body that then gives energy and momentum to the synchronous movement of the wave. Framing this in the context of new public health approaches enables us to see how seemingly apparent tensions and contradiction can work in unison. However only by understanding where such tensions lie can new bodies or structures be strategically positioned to

create an intentioned or augmenting effect. Similarly, by limiting the addition of new structures, a greater body of resource may be allowed to develop which can have a wider reach and impact. Momentum is built within the wave itself and crucially the wave can still hold the seemingly opposing or random movement of individual particles that contribute to the wave form without influencing momentum.

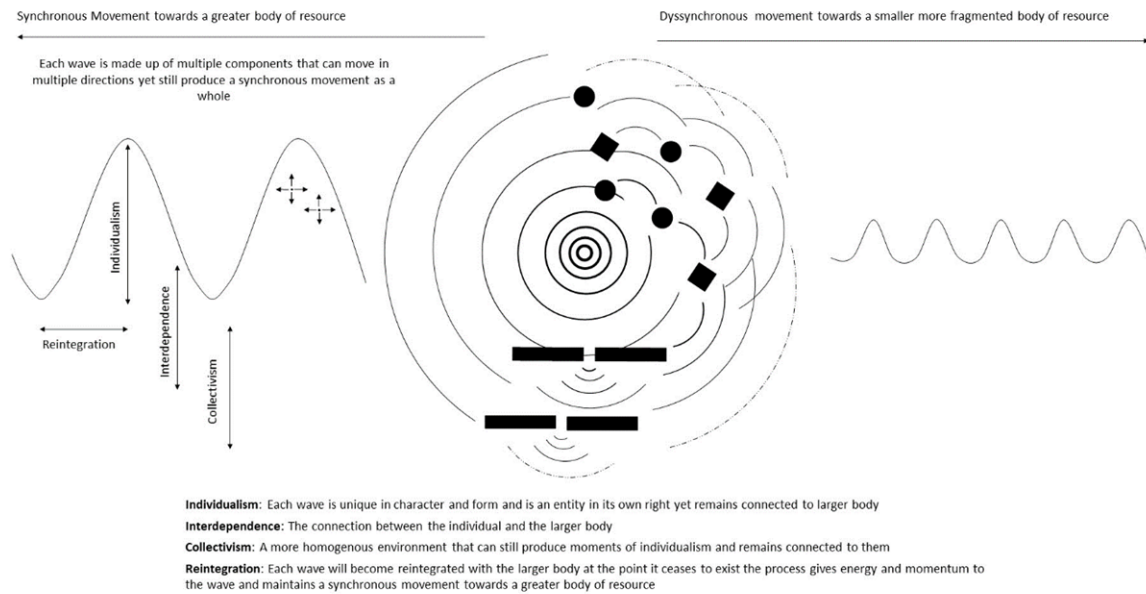


Figure 2: Diagrammatic representation of core themes

Strengths and limitations

The use of a broad search strategy has helped build pan-disciplinary links that have generated previously unconsidered tensions within the movement. Naturally my findings are limited by the breadth of available literature and the human and technical errors inherent within the online search process. Whilst I have attempted to include all relevant articles it is possible the search process failed to identify some articles. Public health and palliative care are most frequently examined from a single professional perspective and the associated blind spots will undoubtedly have led to the dismissal of subsections of community life. New public health approaches to palliative care were felt to be more representative of a movement with a broader socio-political agenda than that of a systematic scientific approach. When considered from this perspective, it can be argued the data presented is inherently limited by the systematic scientific approach

employed in the methodology. This irony is not unnoticed and is taken as another example of the tensions that arise when framing that nature of this work in academic terms. This however is a discovery in itself and the systematic nature of this review reinforces a key finding that academic platforms in their current form are fundamentally restricted in their ability to embrace and understand such broad-based concepts within their full complexity. I also recognise that what may be considered a limitation by some is also perceived as strength by others, as such by employing both systematic and reflexive methods to data collection and analysis, I hope my findings can be generalizable to a range of contexts. At the same time, gaps in the empirical and theoretical data alongside evolving understanding means that my work will undoubtedly need to be modified as the knowledge base expands.

Conclusion

The body of work I have identified holds great potential, not just in revolutionising the way people view, access and experience end-of-life care, but also in leading the field of medicine and healthcare into a new ‘moral’ era. Here co-production and co-design through collaborative practice pave the way for us to recognise people’s voices in terms of what matters to them, establish what is truly important to measure and perhaps bring the notion of healing and ‘whole person’ care to the forefront of medicine and social care.

There is perhaps no better driving force behind such ideas than the way we conceptualise death and dying. Where death is understood from the perspective of one of its constituent components the response can feel constrained, fragmented and muddled. Where death is understood from the perspective of the whole, the response is sought from a greater breadth of creative resource including, but not limited to communities. In this way the path forward comes into sharper focus through the amalgamation of the shadows of death and the light of those living and working within them.

New public health approaches provide a lens through which we can begin to view and understand death in relation to the whole. How we now progress knowledge in this area is of vital importance. Do we conform to the model of evidence-based practice, showcasing Compassionate Communities and Compassionate Cities as an intervention or an entity to be evaluated? Or do we see them as a lens through which people can view and evaluate their own actions helping to build trust, membership and ‘know how’ to develop community capacity in real terms.

Such work transcends not only the academic and professional disciplines but also cultural and spiritual boundaries. Here in lies perhaps the most significant problem. In a field seeking to incorporate such diverse philosophies, it can be difficult to forge a unified, collective approach without generating tensions. In the quest for a solution to what can feel like an impending crisis of care, I feel we must acknowledge such tensions, work with them and through them where possible. However, we must also not fail to accept that such tensions are indeed the essence of what gives life to a situation. In the words of the Sufi poet Rumi 'Out beyond ideas of right and wrong, there is a field. I'll meet you there'. Whilst this review goes some distance in bringing to light the complexity and tensions inherent within new public health approaches, what is clear is that if we take a reductionist approach and ignore them in our quest for an idealised 'perfect' system we will soon return to the place from which we began.

Chapter Three

New public health approaches to end-of-life care and their relevance to dementia

Contents Three

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Introduction

In tracing the origins of public health palliative care and defining the constituent components of the approach I had become sensitive to a level of complexity I had not fully anticipated. My increasing concern was that unaccounted for tensions might destabilise the theoretical foundations of my work, risking misrepresentation of core findings and creating an overly simplistic and reductionist approach to what are more profound questions. Understanding how the newly systematically mapped components of public health palliative care might work in the context of dementia was therefore a vital step in creating a theoretical ‘ground zero’ on which to build. With this in mind, this short chapter describes how the salient points identified in my literature review might be applied in the context of dementia, highlighting potential for success and areas of possible contention.

Philosophical perspectives

Dying as a relational, spiritual process

The re-framing of death as a relational, spiritual process represents a significant intervention in the context of dementia. Until now, measures to counter a narrative of loss and generate moral worth have revolved around the promotion of personhood and citizenship (Higgs and Gilleard 2016e; Kitwood 1997a; Bartlett and O'Connor 2010a). Understanding death's presence, not just at the point of death, but throughout the life course, foregrounds dependency and decline within a paradigm of human interdependency that is fundamental to our being. At the same time, it brings into sharper focus the locus of care and the responsibility for delivering it. From the carer, spouse or family (Moore and Crawley 2020); to the ‘dementia dyad’¹ (Fletcher 2020b), and finally the person with dementia (Manthorpe and Samsi 2016) and the broader social and environmental structures that shape this (Bartlett and O'Connor 2010a), the locus and responsibility of care in dementia has long been a source of tension.

The intervention provided here, is to define dying, and the dependencies this process brings, as a presence within all of us that instils a collective responsibility realised through social relationships (Sawyer et al. 2021). Death then becomes a transformative presence in each of our lives that

¹ The dementia dyad is a term that recognises dementia is often a shared experience. Typically this is with cohabiting spouses, a parent or child or both. Such dyads are part of a growing appreciation that dementia affects dyads and relationships rather than individuals.

accommodates new ideas and redefines care of the dying as a ‘gift’ containing moments or treasures of tremendous beauty (O’Donohue 2003c). Beauty is rarely discussed in the context of advanced dementia, where it might be seen as incompatible with the fractured, hollow and painful side of human experience. Yet O’Donohue, a prominent theologian and poet, describes how we might understand beauty as something that “is such an attractive and gracious force precisely because it is so close to the fractured side of experience” (O’Donohue 2003c). He describes how beauty cannot be “confined in some untouchable realm where she can enjoy a one-sided perfection with no exposure to risk, doubt and pain. Beauty dwells in the palace of broken tenderness” (O’Donohue 2003c), it would seem that death, and the darker side of human experience are no exception to this. The question is therefore, not how to remove the sense of pain and suffering that death can impart, but how instead can we be faithful to the vacancy of loss, understanding the beauty concealed within its legacy.

The white shadow of suffering

I have described how new public health approaches to end-of-life care also challenge our understanding of suffering, especially in relation to the notion of a good death. Suffering as an academic concept, is scarcely discussed beyond a loosely defined discourse that considers it something to be remedied or removed (Gilleard 2021). It is considered almost exclusively within the notion of ‘unbearable suffering’ and the debate surrounding medically assisted suicide and euthanasia (Dees et al. 2010).

Attention to the nature and meaning of suffering in advanced dementia has become complicated by the relentless pursuit of a positive way of living with the condition (Bartlett et al. 2017). Yet suffering at the end-of-life in dementia is common and broad ranging. It may manifest through physical and emotional challenges, but also from the social response and the quality of care, services and support offered (Peisah et al. 2014). As Bartlett and others have suggested, “the need to form a positive approach to dementia must not deny that suffering does occur” (Bartlett et al. 2017). The display and acknowledgement of suffering is key to accessing support and generating social action and is an example of how lightness and dark combine to bring a greater focus that might help define a path forward. There is much work required to understand the complexity around the intensely personal experience of suffering in advanced dementia. However, addressing it beyond something that is to be eradicated or denied can create new avenues for social change whilst helping to forge an understanding of dying and loss as an integral part of the life course.

Challenges in managing and allocating responsibility

Conceptualising not just death, but the suffering inherent within the dying process, is important in generating a framework that offers a coherent programme of care for people with dementia. New public health approaches to palliative care provide a platform to discuss these issues beyond health and social care driven priorities, yet tensions remain. For example, how is a collective responsibility for care defined, allocated and negotiated between individuals, professionals and services? That people provide care out of a duty or obligation created by collective moral responsibility neglects the wider social context that shapes ideas on the ‘proper thing to do’ in dementia (Connidis 2009). With dementia, decisions relating to someone’s care can reflect the legacy of past relationships between carer and cared for (Davies and Gregory 2007) but also the capacity to accommodate profound personality changes that might be violent or abusive (Wharton and Ford 2014), or withdrawn and apathetic (Bozzola, Gorelick, and Freels 1992). At the same time, where care is framed as part of a loving relationship, the boundaries between being a carer, spouse, or kin become blurred (Henderson 2001). This means close contacts can become responsabilised beyond their capabilities whilst newfound duties can encroach on existing social and cultural roles (Rose and Bruce 1995; Mackenzie 2006; Katbamna et al. 2004). As is common in dementia, where people transition from their homes into full time care, expectations and capabilities change necessitating a renegotiation of an informal carer’s role and responsibility (Egdell 2013). This is often poorly acknowledged and can lead to feelings of guilt and trauma on behalf of close contacts where the absence of caregiving duties can impact on how people understand and value their relationship (Walmsley and McCormack 2021; McCormack, Tillock, and Walmsley 2017).

Challenges to initiating and maintaining change, what motivates communities to care?

As I have highlighted, the literature on new public health approaches to palliative care alludes to altruism, interdependence, reciprocity and compassion as motivational forces (Kellehear 2007). Dementia adds a layer of complexity beyond the issues I have already raised. For example, in a state of near total dependency, people with dementia may be unable to reciprocate acts of care and compassion in the traditional sense (Kurzban and Leary 2001). Thinking outside of the confines of dyadic, transactional interactions, participatory arts programs have demonstrated reciprocal engagement, and the capacity of people with advanced dementia to initiate as well as respond to verbal and embodied engagement (Kontos et al. 2017). Similarly, health care professionals have described non-verbal communication as key to understanding a bi-directional

caring relationship whilst looking after someone dying with dementia (Sellevold et al. 2013). This has been used to support a relational approach to citizenship that is premised on the importance of interdependence and reciprocity (Dupuis et al. 2012; Kontos, Miller, and Kontos 2017). There is also some evidence that acts of compassion are reciprocated beyond the dyadic caregiving relationship and at a community level, allowing the generation of new pathways that can build community capacity (Sawyer et al. 2019). However we try to understand the complexity in social relationships present at the end-of-life, there is no denying that they are amplified in the case of dementia. This ultimately necessitates a greater theoretical understanding, reinforcing the identified need for fluidity where issues of responsibility and motivation are concerned.

Structural components to a public health approach to palliative care and their relationship to dementia

Communities as independent agents of care

Using these underlying philosophical perspectives, new public health measures in palliative care expand on the traditional components of health promotion to promote communities as independent agents of care. Traditionally ‘community’ has emphasised the “presence of the life cycle within the constancies of place and person” (Gilleard and Higgs 2005). It may be understood as something that forms in response to social change, such as industrialisation and the distinction between rural and urban landscapes that helped produce the ‘neighbourhood’ (Tönnies 1957). Yet more symbolic notions of community may be understood where increasingly limitless forms of communication emphasise shared values and characteristics over physical proximity (Webber 1964). In whatever ways we understand community, society or neighbourhood, depicting them as a unilateral force for good is to deny the experience of those for whom this is not reality. Greater effort is therefore required to understanding communities beyond the strongly moralised values to which they attached, this is especially so if they are to be repositioned as a solution to the problems of end-of-life care in dementia when for so long the social response has been a source of suffering (Duggan et al. 2008).

Over the past decade the relationship between ageing, dementia and local environment has been re-examined in a way that such a shift is made possible (Hillman and Latimer 2017; Thomas and Milligan 2018; Keady et al. 2012). Here, authors describe a multi-disciplinary terrain that re-spatialises dementia beyond the exclusive concern of health and social care services. Awareness is growing into how the settings people move between act as a platform for routine social

interaction that generates relationships and maintains a sense of belonging and wellbeing for people with dementia (Clark et al. 2020). These relationships can define a sense of place that experiences both contraction and expansion in response to both dementia and the dynamic nature of social relationships whilst also defining wellbeing beyond practical and functional parameters (Clark et al. 2020). Despite progress in this area, there is a need to understand the role of community or neighbourhoods in more advanced stages of dementia. This is crucial to avoiding the paradox brought by a narrative that prioritises active participation as a means of maintaining agency within a context defined by its progressive loss.

Empowerment and Social Capital

I have described how empowerment and social capital are fundamental in the move from paternalistic to a participatory healthcare (Rappaport 1987) which drives a community's ability to care (Horsfall, Noonan, and Leonard 2012; Abel et al. 2013a) but also creates tension depending on the level of interpretation (Sallnow and Paul 2015). In the context of advanced dementia, where empowerment is understood at the level of the dying person this can suggest that agency and enterprise are dormant and in need of re-activating. This can lead to confusion for the individual, who may now depend on alternate structures or people (Clark et al. 2020). Placing value in power in this context can also mean responsibility for upholding it lies with others. This can create moral distress for carers as they feel conflicted in doing what they intuitively feel is necessary, knowing that it might be considered paternalistic or disempowering and therefore incongruous with 'good care' (Smebye, Kirkevold, and Engedal 2015).

Where communities are empowered to help people with dementia die at home this can force people to relinquish traditional family roles (Stajduhar, Funk, Jakobsson, and Öhlén 2010) whilst also accentuating the highly gendered dynamics of caregiving (Paoletti 2002; Gott, Morgan, and Williams 2020). Similarly, people for whom the home is a place of work, stress or abuse are denied the relief that comes with finding an alternate place of care (Gott, Morgan, and Williams 2020; Wharton and Ford 2014).

At the level of policy and public infrastructure, empowerment might build facilitative, non-prescriptive structures that foster a more equitable distribution of power at the levels of community and interpersonal relationships. However, this must also consider that not all individuals, families and care groups have the same thresholds to maintain and provide care to the intensity required in dementia (Schulz and Sherwood 2008).

How empowerment works at the end-of-life in dementia therefore requires careful consideration. Crucial to this process is the fact that dementia does not remain static in its effects, necessitating a dynamic response that meets the fluctuations across expanding and contracting resources. At earlier stages of dementia, empowerment may mean affording a sense of control and a voice to influence decision making. In advanced stages, empowerment might not be bestowed upon the person, but collectively built around and from within an inner circle of support.

In a similar vein, dementia adds yet another layer of complexity when considering the impact of social capital. It is generally accepted that social networks dwindle towards the end-of-life, especially for those in advanced old age or those affected by dementia (Gott et al. 2018; Duggan et al. 2008). When taken from a 'health promoting approach' where health and longevity are the reference points for intervention, this can lead to a narrative that describes the problem in terms of an 'epidemic of loneliness' (Holt-Lunstad 2017). This can risk generating a set of interventions that responsabilise the lonely themselves whilst neglecting a set of values that might exist within the process of social withdrawal at the end-of-life. As previously described, dwindling networks might be understood as an important component in the process of transitioning to a new phase of life where the space created allows for a deeper connection to our immediate environment and those relationships that hold particular value (Clark et al. 2020). It follows that the capacity of social capital to be operationalised by new public health approaches in the context of dementia requires a greater theoretical understanding of the tensions at hand so as not to encroach on an inherently intimate time of life in way that degrades it of meaning.

Conclusion

The rising numbers of people dying with dementia will pose significant health and social care challenges for generations to come. Until now, such challenges have been examined from the perspective of how best to expand existing capacity and resource for professional care in ways that limit suffering and bring a sense of control. By tracing the social and cultural origins of the West's conceptual understanding of death, I argue the success of humankind's instinctive desire to seek answers and meaning from the unknown has caused an inability for humanity to define its outermost limits. This has resulted in the uncertainty and unknowns inherent within the dying process being conceptualised in negative terms thus leaving little room to approach the disorientating and unfathomable void of death in dementia with anything other than profound discomfort. The response to such discomfort lies within the scientific evidence-based approach

to control. Here, the 'good death' has come to represent a surrogate marker for control, where advance care planning and adequate symptom control are used to create an image of death where people can die on their terms and in line with their individual choice.

The rising prevalence of dementia has brought the limitations of such an approach into sharper focus. The chronicity of dementia's effects combined with the progressive dependency and loss of cognition means Western culture is forced to reconsider the uncertainty of dying as something that can be countered until the moments before death. Whilst personhood and citizenship has done much to give people with dementia a moral identity and thus motivate an imperative to care, their adoption as central facets of delivering high quality end-of-life care in dementia are more contentious. At the end-of-life, valuing control, choice and preference brought through rationality and agency can deny the reality for many people affected by dementia. Here control may feel more illusionary than anything, meaning those people responsabilised with its maintenance are consigned to failure. At the point of our outermost limitations, countering uncertainty with further measures that seek to control and maintain a depreciating resource is futile. This leaves us with little choice but to trust in death as the reaching of life's aim whilst understanding the dying process as something bound to life in way that makes it an integral part of human existence. People affected by dementia can be left to navigate this position yet without a supportive framework that offers anything other than the pain associated with absence and loss.

Perhaps then we are looking for support in the wrong places with the wrong tools. The absence of control that comes with decline and dependency may convey fear and unease, yet within it, or in the effects that surround it, reside moments of joy within which there is transformative beauty. To look within the bottomless well of humanities capacity to inflict and endure suffering offers little other than deep despair. To view suffering alongside the caring response it invokes offers a different perspective, one that contains both hope and beauty. To find reference points better suited to the roles and identity of the dependent dying it is therefore not enough just to focus on the emptiness of death, this only feeds the nihilistic narrative of deficit and loss in dementia where death, and the period running up to it, is devoid of meaning and value. Instead, the focus needs to be broader. Higgs and Gilleard's cosmological black hole as a representation of the near total dependency that defines the fourth age must be viewed in conjunction with its event horizon, namely the legacy that death creates within which human relationships are shaped. This way, the end-of-life in dementia is its own distinct phase of life, itself with an intrinsic beauty that provides value to human life.

New public health approaches to palliative care seek to reimagine a better system for death and dying. Many programmes are already underway that encourage people to re-conceptualise dying and grief in a way that rebalances our relationship with the darker side of human existence. Communities are challenging the norms about caring for dying people whilst models of citizen and community action, such as Compassionate Communities, are emerging. These innovations provide a new lens through which to evaluate the complexity provided by dementia and capture the value death holds for human life. As we learn from the step changes brought by interventions on personhood, citizenship and other models of care, engaging with new public health approaches to palliative care necessarily comes with a warning. This being that social, political and academic discourse must recognise the balance between what might be considered successful or unsuccessful care at the end-of-life in dementia is one of a constantly shifting equilibrium. How we reach out to meet the needs of people dying with dementia therefore requires careful consideration so as not to create divisive practice where death is characterised as either success or failure. Rather death might be considered the ‘white shadow’ where light and dark are opposites but eternally bound together as one (O'Donohue 2003c). Here beauty is created through the close association of all that is broken, damaged and lost, rather than in spite of it. The beauty within the white shadow of death is not an end in itself, but points to a far greater embrace of belonging that holds everything together as a focal point for the generation of a more integrative approach to dementia care. Such an approach is played out in a context that reaches beyond the confines of professional services and embraces individual, social and cultural understandings of dying and loss. The challenge for services therefore lies in discovering how best to support these differing contexts rather than in increasing their access and reach to meet clinical need. The broader challenge is to radically change our approach to decline, dependency and human suffering in a way that these processes are understood not only as avoidable, but as holding intrinsic value.

The complexity and breadth of the issues I have identified poses questions about how this topic can be researched, both methodologically and also within the confines of a PhD. Put simply, the intention of the original research protocol was to position a public health palliative care approach as a possible solution to the challenges in providing access to meaningful end-of-life care for people with dementia. I would then evaluate the potential within this relationship through a realist analysis of a mixed methods data set. The research protocol ([Appendix One](#)) had been constructed in a way that complexity would be embraced using a realist approach to the evaluation of complex social interventions (Pawson 2013a; Pawson 2004). This would produce

an iteratively developed programme theory that would focus on what works, for whom and in what circumstances (Pawson 2013a; Pawson 1997). Mapping out the constituent components of a public health approach to palliative care and theorizing how they might work in the context of advanced dementia is the first stage in the generation of such a programme theory. Over the course of this chapter, I have discussed in detail how evolving theory might cut across multiple different contexts to create a range of potential outcomes. In the following chapter I will discuss the genesis of my precise methodological approach in more detail. I will describe how the process of organisation, prioritisation and consolidation of this theory evolved in response to the data and ultimately came to challenge a realist programme theory as the organizing feature of my analysis.

Chapter Four

Methods and the evolution of the research

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Introduction

In early conversations with collaborators, funders and practitioners experienced in public health and palliative care, there was a perceived need to focus on how existing theory might work *for* people with dementia. That established theory might be applicable in the context of dementia care was supposed to create a series of outcomes that might improve care and subsequently shape public health resources that have been prioritised to meet the care needs of an increasing number of people (WHO 2012; Etkind et al. 2017).

My clinical experience as well as my prior work in the field had contributed to this notion, highlighting a realist philosophy of science as a way of handling the complexity inherent within socially mediated interventions (Pawson 2013a, 2005; Pawson et al. 2005; Pawson 2004; Pawson 1997). I completed a realist review of the literature that sought to understand how social capital inherent within social networks translates to care at the end-of-life in dementia (Sawyer et al. 2019). This, combined with my literature review and subsequent theoretical constructs outlined in chapters one, two and three would form the basis of an early programme theory that would then be tested and refined using empirical data.

Application and suitability of critical realism

A realist theory of science was originally proposed by Bhaskar (Bhaskar 2008a). He places his philosophy between classical empiricism and transcendental idealism. In the former, the objects of knowledge are ‘atomised events’ that constitute a series of facts or truths. These truths are contained within our response to a given stimulus that is experienced at a surface level. In the later, the objects of scientific knowledge are models or ideals of natural order. Knowledge is the structure that interprets the surface. Transcendental realism regards the object of knowledge as the ‘structures and mechanisms that generate a given phenomena’. Here, knowledge is produced in the social activity of science. These points of knowledge are not empirical phenomena nor human constructs imposed on the phenomena, but real structures that operate independently of our knowledge, experience and the conditions that permit us access to them.

Bhaskar argues that his approach to realism is the only way that can sustain the idea of a structured and highly organized natural world that exists independently of human knowledge, thus occupying the space between empiricism and idealism, bridging their respective deficiencies. Central to this philosophy is his transcendental analysis of experience (Bhaskar 2008b). Here he

proposes that events or momentary states are not, or should not, be the sole focus of human perception. Rather there is another domain, the domain of actualities, which exists independently from an experience. In this way, the ultimate object of scientific understanding are not patterns, events or observable behaviours but instead the ‘mechanisms that generate the flux of phenomena of the world’. These mechanisms constitute the focal point of scientific discovery as their existence is what generates causation in a world that is open to subjection.

By applying Bhaskar’s theory of science to the process of scientific evaluation, Pawson and others have been instrumental in developing a distinct methodological practice (Pawson et al. 2005). This ultimately seeks to address the question ‘what works?’ in social interventions by trying to establish causal relationships that combine to create the distinctive notion of ‘generative causation’. This differs to a more successionist model where each intervention acts as a switch in moving from X to Y. Pawson operationalised a model that suggests that an outcome between two events (X and Y) is observed when the underlying generative mechanism that connect them is aligned to a specific context which enables the relationship (Pawson 1997). A realist synthesis is therefore a theory driven approach whereby a hypothesis is tested using different configurations of context, mechanism and outcome. This has led to the now common hallmark of a realist enquiry that it is not just about what works, but also for whom and in what circumstances (Pawson 2013a).

The more recent methodological approaches draw on Bhaskar’s philosophy to distil three aspects of the world that co-exist but remain distinct. The ‘empirical’; what we experience, the ‘actual’; events that occur, and the ‘real’; generative mechanisms that are often hidden but non the less real. This distinction implies that any singular event can be perceived differently when influenced by different mechanisms or that the same mechanism may lead to a different event depending on the context. The core principle of this approach is to make explicit the underlying assumptions about how an intervention is supposed to work. In Pawson and Tilley’s realist approach to evaluation this is to seek out and define a programme theory which guides evaluation and is iteratively refined (Pawson 1997). In this way, the product of research, or the scientific ‘intervention’ is theory. This is representative of a fundamental realist claim, that interventions *are* theories rather than more tangible entities such as a new technology, personnel or structure. For realists, such tangible entities are theories incarnate (Pawson 2013a).

The nature of critical realism and its emphasis on ontological questions (what is X, and how does it work?) over epistemological questions (how can we know X?) means it accommodates a range

of methodological techniques (Vincent and O'Mahoney 2018). Indeed, many have argued for including a range of methodological approaches across both quantitative and qualitative domains is necessary to create a richer conceptualisation of mechanisms that might be at work in the social world. Amongst others, critical realism has been used to analyse discourse analysis (Sims-Schouten and Riley 2014), grounded theory (Kempster and Perry 2014; Oliver 2012), interviewing (Smith and Elger 2014) and ethnography (Rees and Gatenby 2014).

The initial premise was therefore to model the core components of a public health approach to palliative care as a complex, naturally occurring social intervention. Through an iterative, theory driven approach to a heterogeneous data set I would explore how they might work for people with dementia at the end-of-life. For a study on complex social interventions where multiple profound and intricate tensions had already been described, this seemed an eminently sensible approach that would create a blueprint for the design and implementation of public health palliative care interventions and how they might translate into meaningfully supportive actions at the end-of-life.

Initial programme theory generation

I approached the PhD having already been immersed in the field of public health palliative care and as a proponent of the approach. I had published in the field (Sawyer et al. 2018; Sawyer et al. 2019) and spent time reading widely on the subject and talking to experts in the field. As such, the process of building an initial programme theory had informally and subconsciously been unfolding for some time. This is evident in how the research question had been constructed and how data collection had been planned to provide evidence for its different dimensions ([See Appendix One](#)).

My funding application states the overall aim of the PhD would be to “develop an understanding of how Compassionate Communities can improve outcomes for people affected by dementia at the end-of- life, and the challenges they face in doing so”. The protocol takes this further, asking more specific questions in realist terms such as:

- 1: What are the social contexts in which caregiving occurs at the end-of-life?
- 2: How is the identity of a person with dementia viewed and acted upon?
- 3: How do these contexts influence caregiving?

4: In what circumstances, and for who, are Compassionate Communities effective in improving end-of-life care for people affected by dementia?

Much of the theory outlined in chapters one and two is applicable to these questions and is representative of how theory was iteratively evolving in response to my reading. Developing a more formalised approach to theory involved both abductive and retroductive thinking (Jagosh 2020). At this stage, the process of retroduction was limited by a scarcity of relevant empirical data to support theory generation. As such I relied heavily on abductive reasoning whilst considering the intrinsic and extrinsic dimensions to the theory². Here ‘intrinsic’ relates to the specific programme architecture, the working parts of the theory. ‘Extrinsic’ refers to how the programme theory actually works in the real world. I considered whether the intrinsic components of the theory reflected generative causation whilst discussing increasingly detailed components of the theory. I would cluster similar components of the emerging theory to see if there were overlapping parts that would reveal a single facet of causation as opposed to an implementation chain of events. To assess the extrinsic components, I would seek out rival or opposing theories that might explore alternative outcomes before attempting to organise and prioritise components that seemed most important to take forward and test with empirical data.

Much of my initial programme theory, and its broad ranging features, are outlined in chapters two and three. At this stage I was particularly focused on how the underlying philosophical perspectives identified in chapter two might be applicable to people with dementia. Asking specifically how decline and loss in dementia might be understood within the ‘joy and grey hollows’ of human suffering and what framing death and dying as a socially mediated experience might mean for people affected by dementia. Beyond this I was concerned with the role of responsibility and motivation to care and how people might respond to these ideas through the relationships that evolve during the process of caregiving. I felt that this relationship would uncover mechanisms of importance that would influence how people respond to processes such as empowerment, network building and social capital that had been identified as fundamental to public health approach to palliative care. I was careful not to overdevelop the initial programme theory into strict configurations of context-mechanism-outcome. My concern being that in doing

² I would like to credit Justin Jagosh for these terms and the steps involved in creating an initial programme theory. I learnt much of this by attending his course on ‘Constructing Excellent Initial Programme Theories’ at the Centre for Advancement in Realist Evaluation and Synthesis (CARES), online in 2020

so I would become strongly attached to concepts that do not have the empirical data to support them making it difficult to remain open to what the data might be saying.

Despite progress here I was also aware of an emerging tension between the nature of what I was finding and how this might fit within the methodological approach. This tension centred on the ontological approach to the subject matter. My literature review had identified a multitude of permeating and deeply embedded tensions. These tensions were understood as part of the essence of what gives life to any given situation, suggesting that paradox, enigma and mystery have their own intrinsic value and meaning as opposed to being something that can be conquered through a systematic and structured approach to reality. At the same time, I recognised the research as being inextricably linked to the processes associated with loss and absence that death, dying and dementia can bring. As I describe in chapter one, this can cause profound difficulties when the structures created to understand such entities are orientated towards what is of form as opposed to what we might come to learn from absence, emptiness and all that is unstructured and formless. In the case of critical realism, the stratified approach to reality helps in identifying false paradox and untangling the surrounding complexity to reveal a forward path, however there is still the prospect of true paradox, a state of formless entanglement that resists such processes. Applying structure here, in the face of an empirical void such as that brought by increasingly advanced states of dementia, is at best disorienting and at worst risks denying the existence and potential values that come from understanding paradox, enigma and mystery as part of reality.

In summary, I have made the case as to why a critical realist approach was first adopted and how it was used to organise my initial theory generation. I will go on to describe how I used critical realism in the analysis of mixed methods data set and how this approach led me to refine my theory. In doing so I describe some of the challenges I faced in more detail. I highlight how reflexive practice allowed me to critically engage with the methodological and ontological assumptions of critical realism and how this meant data analysis did not build up into a programme theory in the expected way.

COVID-19, reflexive considerations, and their impact

Regardless of the ontological and epistemological position, the participatory nature of the research, and my role as both a clinician and a scientist working in end-of-life care, means that the thesis as a construct is inextricably linked to me and my experiences of the social world and

the real-world events that unfolded over the course of my studies. Rather than a source of bias, my role was reflexively observed and acknowledged as a source of creative and analytical use (Davies 1998).

I graduated with a degree in medicine in 2011. After completing my general medical training in a range of specialties I chose to do specialist palliative care training in 2016. Reflecting on my time in practice I had often been aware that much of what I understand to be palliative care has existed at the periphery of the medical gaze. I can recall being part of traumatic deaths as a junior doctor, not necessarily because of the nature of the physical components of death, but because of the narratives that ran in parallel. Of broken relationships, misplaced hope and unspoken words. Many of the conversations I had regarding these topics occurred within spaces that existed around the dying person, in stock rooms, corridors and broom cupboards. I came to understand the spaces death and dying creates, as spaces of work. Either by habit or by natural inquisition I have always be drawn to these spaces, finding myself within them and learning to negotiate them has been a seminal part of my training in palliative care. Perhaps the biggest shift in my understanding of this was my move outside of medical institutions and into the community. Here I was alerted to the enormity of what occurs in spaces that are often restricted to the periphery of the medical gaze. Working within these spaces, within the intimacy and domesticity of people's homes and communities, has taught me of the value and potential this can have in shaping and defining the object of focus. In the context of this thesis and my work as a palliative care physician, this means understanding and appreciating what death, dying and loss means as a point of focus, by careful attention to the knowledge and learning to be had from inhabiting the spaces that exist around death.

Shortly after I began my PhD in February 2020, COVID-19 and its effects became widespread. This caused a fundamental re-orientation of the social world. Whereas previously the industrious nature of society was the object of focus, the virus had created a void. Absence, and the associated emptiness, was an unavoidable presence in the lives of everyone. At the same time people were forced to work and exist in the quiet and concealed peripheries of conscious thought. During the first wave of the pandemic, I worked as a community palliative care physician for four months. Here I would traverse the vacuum created by lockdown, navigate the empty streets, the deserted trains and busses to arrive in people's homes as a place of work. I drew parallels between this and my regular work with death and dying people. In many ways this is what I had always done, only now it became unavoidably obvious. More so it sharpened my perception of the vast amount of work that occurs at the boundaries of our collective perception

and how this can conspire to shape our understanding and approach to the point of objective focus. I returned to clinical work during the second wave of COVID-19. This was at Christmas 2021 and lasted one month. Here I worked from my bedroom conducting phone consultations, often helping people to navigate someone's death from afar having never met them. Ultimately, this re-orientation of the social world, and my reflections from traversing the now clearly defined boundaries between presence and absence helped shape my thoughts regarding care at the end-of-life. That our understanding of the object of our intense and relentless focus is shaped not only by a greater knowledge of its constituent parts, but also by the processes that occur in the spaces surrounding it would be helpful perspective in addressing complexity and gathering a rich data set.

On my return to academic work, I found myself working to unpick the tension in what we understand by a good death, grappling with how meaning and value might be perceived at a time of profound sadness and grief. Persistent isolation from the social world because of lockdown led me to inhabit a profoundly isolated position, both in terms of my physical presence in time and space but also within the cognitive spaces I came to occupy. I became preoccupied with the notion that all structures, all meaning and all that is rationally created will ultimately come to pass, but somehow, existence would remain. Indeed, I could claim to have experienced the meaning and presence of this aphorism during moments of my own life. Sitting in the company of a dead body and the total and complete stillness of space that surrounds such an experience, sitting on the end of a phone listening to the pain of loss as experienced by an acutely bereaved person now left alone to sit and look into the distance at the juncture of living and dying. At times I became pre-occupied with my own death but realised that the object of my focus was greater than any apprehension that my own life will ultimately come to an end. Instead, I was overcome with a far greater and more pervasive sense of meaninglessness. Spending much of my working life to date at the borderlands of an objective, structured approach to understanding care and meaning at the end-of-life I found myself once again looking into an abyss of emptiness. That people care for one another, that they experience enormous and terrible pain at the point of loss seems at odds with the relentless indifference with which life seems to pass by. Yet even this creates the impression of some sort of stability and constancy that might infer an orientating foothold within such a vacuous abyss. It does not capture the essence of the true and profound disorientation such a void brings. That in fact life is not simply just 'being' but instead is experienced as something of constant change, as something that is eternally in the process of becoming something else. That life's indifference to repeated and exhaustive attempts at finding

meaning are compounded by the endless progression beyond what is familiar, constant and structured is more representative of the profoundly disorientating state of the void in which I found myself. During this time, I read extensively on theoretical constructs designed to help people navigate such an emptiness, to rescue them from within an expanse of meaninglessness and uncertainty. Yet such practice only ever offers reassurance when the systems they are part of have some point of constancy, some final focus of satisfying resolution. With the constant cycle of passing and becoming, these structures will ultimately cease to exist, leaving people in a state of waiting at the coming to an end. Yet waiting is perhaps the wrong word, for there is no transition on which we are waiting on. Instead 'waiting' is the state of being one finds oneself in. It is different too to a state of liminality where disorientation exists within the transition between two fixed planes. What I am trying to describe is a permanent state of unknowing, less a frontier from which we might 'stand on the shoulders of giants' to reach out and conquer, but an end in itself. This state of being that is central to what life is, a constant, permanent and impenetrable state of unknowing. Somehow, at these depths of disorientation there was a familiarity. I have been here before. And will be here many times more. Yet at the same time, I also remain here, in the words of this page, bounded within structures that search for meaning. This perhaps more accurately depicts the ontological approach to this thesis. That in any given moment, the nature of being is the inseparability between presence and absence. This is accurately described by Holloway's theological exploration of the human search into meaning (Holloway 2004a).

"The day is wearing on. It is late and a kind of peace has come over me. It is the peace that comes from accepting duty, but before I try to define it I have to describe the final mood of the day. I call it 'encountering presence in absence'. I can no more explain it than I can account for the experience of the abyss. All I can say is that, as well as moments of deep emptiness, the mystery of Being affords us fleeting moments of encounter with what feels like a kind of presence"

Encountering presence in absence was fundamental to the progress of my own personal journey which in turn is intrinsically and inseparably related to that of this thesis. It is the essence of what underpins this body of work and the essence of what motivates and defines my clinical practice. In this way, the impact of world events and my own personal life experiences, in particularly the effects of COVID-19 have sharpened my focus on this and been a fundamental component to the development of this work.

These experiences combined to make me aware of the fundamental need to conceptualise an approach to decline and loss that accommodates value and meaning alongside tragedy and

suffering. Without this, harnessing the collective support of entire communities, and the range of different perspectives they may hold, was likely to be an enduring and possibly insurmountable issue for a public health palliative care approach in dementia. Despite knowing this, I struggled to accommodate these issues within the research structures I had created. In retrospect this was perhaps symptomatic of an evolving tension between a critical realist ontology and what the data, in combination with my real-world experiences, were leading me to understand. To move forward I initially chose to revert to the structures of my original protocol and organise my data collection and analysis around the evolving programme theory. In doing so I would set aside some of my reflexive considerations. Rather than abandon them they were written up and presented within the research department I was working within and integrated into a paper on how dying might act as a focal point for defining a more integrative approach to health and social care (Sawyer 2022)(See [Appendix Two](#) for full publication). I would revisit these considerations at regular intervals during data collection as part of the process of triangulating my findings with my early work and my clinical experiences.

Mapping social networks as a means of understanding the social context

A participatory approach to social network analysis was chosen as a unique methodological technique designed to be different from traditional questionnaire-based models usually employed by network analysts (Borgatti 2018). Adapted from the works of Granovetter, Robins and Knox (Granovetter 1973; Robins et al. 2007; Knox, Savage, and Harvey 2006), the aim is to progress network analysis beyond an examination of the structural characteristics of a network and embrace the theoretical work of Mische and White. This emphasises the need for qualitative description of the nature of relationships, how they are maintained and their role in wider society, as a means to creating a fuller cultural and discursive understanding of social networks (Mische and White 1998; Mische 2003; Riles 2000; Leonard, Horsfall, and Noonan 2015b). Such methods have been described as a more meaningful way of understanding the individual attributes of actors (Crowe 2007) within the broader complexity of social relationships (Abbott 2009). More recently this approach has demonstrated not just whether or not networks are growing, but whether community capacity is being developed in the process (Leonard, Horsfall, and Noonan 2015b).

As such it was envisaged this method would create a socially and culturally embedded way of charting how and why social networks change over time in advanced dementia. This would shed light on the social context to end-of-life care. I would learn how relationships evolve or dwindle and how new, or remaining networks might negotiate the terms of care in such a way that translates into meaningful support at the end-of-life. This would give valuable data in understanding how supportive networks might be built through the processes associated with empowerment and social capital. These had been identified as core processes in ‘invoking and awakening the idea of community as an independent agent of care’ ([Chapter II, page 49-50](#)), and I envisaged these would become a key part of the evolving programme theory. Beyond this, I anticipated that I might identify key points around which tailored interventions might assist community growth and provide a framework for the expansion of Compassionate Communities.

Participants and recruitment

Recruitment, and the experiences contained within its processes, were understood to contribute to the research as data rather than existing as something that was under the sole control and jurisdiction of the researcher. Participation was encouraged via the Alzheimer’s Research Volunteer Network and the Join Dementia Research website. A short synopsis of the study was posted online and sent to people via email where they had signed up as interested. Following a brief email exchange, I met with participants either via Microsoft Teams or on the phone. I would record my reflections on these discussions, and the recruitment process in general, as part of a set of field notes that were kept throughout this phase of the research.

The idea of creating a focus group for the discussion of networks was a significant barrier to recruitment. Many people cited the logistical issues of convening several people together at the same time. More commonly people were unwilling to discuss what had happened with others given that relationships had sometimes been fractious, isolating or traumatic. These reflections were analysed as part of the data set as a whole and influenced how the mapping exercise was conducted. Nine interviews were held from the caring networks of nine different people. Five were held on a one-to-one basis, three had a group of two people and one had a group of four (N=15). The sample was from a mix of urban and suburban areas. Table two shows the characteristics of participants involved in the exercise.

| Interview | Participants and their relationship to each other | Location of care | Location of death | Care arrangement |
|-----------|---|--|-------------------|---|
| 1 | Daughter of person with dementia | Daughter's home | Daughter's home | Care provided by daughter and other family members |
| 2 | Husband to person with dementia, two children and daughter in law | Family home | Family home | Provided by visiting carers from an agency in addition to family who had moved in |
| 3 | Daughter to person with dementia | Daughter's home | Daughter's home | Provided by the daughter, support from district nurses and professional services |
| 4 | Daughter of person with dementia | Sheltered accommodation then the family home | Family home | Daughter with support from daily professional carers |
| 5 | Daughter and son in law to person with dementia | Daughter's home | Daughter's home | Provided by daughter and son in law |
| 6 | Husband to person with dementia | Family home | Family home | Provided by husband and daily professional carers |
| 7 | Wife and daughter to person with dementia and | Family home | Family home | Provided by wife and daily professional carers |
| 8 | Daughter to person with dementia | Family home | Nursing home | Provided by daughter before support from social services |
| 9 | Wife and daughter to person with dementia | Family home | Nursing home | Support from family, then moved to nursing home |

Table 2: Characteristics of participants from network analysis

Procedure

Participants were asked to bring a plain piece of paper and a selection of different coloured pens. At the beginning of the exercise participants were asked to describe the person with dementia with respect to their character and person. This helped contextualise findings and set the tone for the exercise. Participants would label nodes with the initials of people whom they felt contributed significantly to the process of care. They were asked to draw arrows on the lines that connected nodes, this was to indicate whether a relationship was considered reciprocal or not. A 'tie' between two different nodes might therefore have one arrow, if care was given but not

reciprocated, or a double headed arrow, where care and support was reciprocated. The meaning of 'reciprocation' was discussed with the group at the beginning of the discussion. Participants own unique interpretation was applied when drawing the maps, whilst the reasoning for this became qualitative data. Participants were asked to draw a solid line between nodes to represent a strong support and a dotted line where the relationship was more superficial or deemed to be 'weaker'.

Two network maps were drawn; time one which signified the start of the caregiving process or where these points converged, the time of diagnosis. Time two was the point of death. On completion of the maps, participants would discuss their observations, accounting for any perceived differences. The discussion would add to the socially constructed understanding of the network whilst providing additional, and perhaps as yet unconsidered insights. Discussions lasted between one and a half to two hours. Due to the COVID-19 lockdown they were conducted online and audio-visually recorded before being transcribed verbatim for analysis.

Ethics

Approval was obtained from University College London Research Ethics Committee. Project ID/Title: 14509/001: Identifying changes to social networks and their impact on care for people with dementia at the end-of-life. ([Appendix Three](#))

Analysis

Quantitative analysis

The network maps were transcribed into an adjacency matrix on Microsoft Excel. NetDraw 2.117 with UCInet (Borgatti, Everett, and Freeman 2002a) was used to turn the network adjacency matrix into computerised network maps where the thickness of lines indicates the strength of tie. UCInet was the used to measure size, density, transitivity, reciprocity, the clustering coefficient and betweenness centrality scores. The following definitions were used:

Size: The number of individual nodes in the network

Density: The number of ties divided by the number of possible ties. An increase in density indicates people are developing more connections. In this study, density considers the strength of the tie which ranges from 0-2. This means the density also ranges from 0-2.

Reciprocity: When an actor or node receives a tie from another actor or node before then returning a tie to that same node or actor.

Transitivity: Refers to the balance and reciprocity in the relationship among three individuals. High transitivity indicates that people are connecting with each other in egalitarian and cooperative ways.

Betweenness centrality: This indicates the degree to which the carer acts as a bridge between two other individuals. A decrease in the betweenness or bridging function of the main carer indicates that she, or he, no longer needs to be the sole coordinator of the caring.

Clustering coefficient: This is a measure of cohesion. The clustering coefficient of the principal carer is the density of the carer's close connections, that is, all the other individuals that are directly connected to the carer. An increase in the main carer's clustering may well indicate that the carer is gaining a stronger inner circle of support.

Qualitative analysis

Empirically observable observations

In accordance with a realist ontology data analysis began with the identification of a set of events and observations (demi-regularities) that exist at an empirically observable level (Lawani 2021; Vincent and O'Mahoney 2018; Pawson 2013a; Pawson 2004; Fletcher 2017). This was largely provided through the quantitative findings and revolved around how network characteristics changed over time and across the different groups. The observed patterns were explored in more detail using the qualitative data. To begin, a list of codes was created in NVivo. These were drawn from my literature review, my existing theoretical framework, the quantitative findings and key realist concepts (Fletcher 2017). Codes were organised into Maxwell's description of two types; organisational and theoretical (Maxwell 2012). Organisational codes were used as a place to put data of interest that did not 'fit' into existing theory. Theoretical codes were based on existing ideas identified in my literature review. Provisional coding in this way helped guard against a rigidity that would stifle an objective and interpretive approach (Saldaña 2021). Codes were amalgamated, deleted or fragmented into increasingly granular detail in response to the data. This process created in excess of two hundred codes as well as multiple written memos containing theoretical constructs.

Progressive theorizing: induction, deduction and abduction

This large number was reduced during the next cycle of data analysis where I re-organised and grouped codes into a conceptual map informed by my evolving theory. At this stage, nodes were loosely categorised into one of either context, mechanism or outcome. I also used written memos containing potential theories recorded in NVivo and linked them with different nodes to help with this process. These memos used inductive and deductive reasoning to build an evolving theory. As a crude example, deduction is illustrated by the move from the general theory that people affected by dementia become isolated towards the end-of-life towards the particular inference that social networks dwindle at this point. Induction is illustrated by the move from evidence that people become isolated, to the general theory that all people affected by dementia experience unavoidable losses to their social networks. In attempting to understand how relationships change for people affected by dementia at the end-of-life, standalone induction and deduction orientate the researcher to an associative rather than generative relationship between phenomena, in this case, 'isolation' and 'dementia'. To move beyond this 'flat ontology' (Sayer 2000) and the deficiencies associated with induction and deduction, I engaged with abductive and retroductive approach to theorizing (Jagosh 2020; Fletcher 2017; Danermark, Ekstrom, and Jakobsen 2005). The product of this process would be a programme theory which sought to separate out potential outcomes, imagining how they might be generated through the fulfilment of the necessary contextual conditions that enable the causal mechanism to take effect. In practical terms this meant looking at the data with an understanding that aspects of what is happening are not amenable to empirical testing yet hold the key to understanding the complexity and finding creative solutions. For example, acknowledging a feeling of reciprocation that is crucial to the generation and maintenance of social networks is generated by a set of unobservable and empirically untestable mechanisms that trigger in certain contexts.

A worked example & the emergence of context alongside its associated outcomes

The adoption of these techniques led to the identification of new patterns within the data, specifically semi predictable events that would arise in certain contexts. Context was understood as Pawson's set of 're-usable conceptual platforms' (Pawson 2013a) rather than a source of bias (positivism) or something that is inextricably linked and unique to any given individual experience (constructivism). Here context is considered the route to middle range causal explanations and is generalisable as semi-predictable patterns begin to emerge between context,

mechanism and potential outcomes (Greenhalgh and Manzano 2022). Context therefore has a broad scope (Coldwell 2019) and moves away from being a ‘thing’ but instead a set of relational and dynamic features that unfolded around the processes of care giving and dying.

For example, initially I had a large number of nodes that revolved around a description of uncertainty. Examples include not knowing what the person with dementia wanted, not knowing if and how they might respond or how to interpret meaning behind individual actions, words or relationships. I recorded memos that described these data points as representing the outermost limitations of what people could rationally describe of their experiences. Continued reading of the data, in combination with inductive, deductive and abductive reasoning led me to understand that the empirically observable ‘uncertainty’ that people described was generated from a more pervasive sense of ‘unknowable unknowing’. Here the work of informal care, the generation, loss and constant flux of relationships was seen to exist within an expansive and unstructured void created by the person with dementia’s inability to respond in the empirical domain and according to the perceived norms of social engagement. Nodes that characterised this further, such as the empirically observed ‘emptiness’, ‘meaninglessness’ were grouped together. I used memos to experiment with what these ideas meant, paying careful attention to language and the assumptions and connotations that might be implied. I also considered whether or not the theory I was producing reflected the nature of the interview and what I felt the person was trying to convey at the time.

This sense of ‘unknowable unknowing’ was found to be re-usable across the entire data set, more than this, where it was encountered it would give semi-predictable events that influenced how relationships would unfold. As such it was categorised as context and a folder was created for nodes describing similar phenomena. These included things that would characterise the absence and loss people described. I would map how people would move into this state of ‘unknowing’ as the person with dementia withdrew or became unable to negotiate the norms of a highly cognitive and social world. I charted transition points, and the decision-making processes that unfolded around them. At this stage, all codes were considered important and potentially relevant as outcomes that might emerge from this context. The most dominant codes were used as a starting point to identify similar patterns. Where I found data that challenged my ideas, a ‘rival theory’ would be created in a memo before being promoted or discarded based on supportive evidence from the data.

Following this process led to a significant regularity in the data. This was the description of new relationships and new experiences that existed in conjunction with isolation and the loss of social contact. These phenomena were not described as positive or negative, or more towards one side of this binary than another, they were just as they, inseparable from each other, yet at the same time profoundly transformational in terms of meaning and relevance. It was as if people were responding and reacting to the absence created by loss as an independent entity, something that has agency and paradoxically, something that one might form some sort of connection with. The relationship with loss, how it is accommodated and how people work with and within the emptiness brought by loss was noted as something that profoundly impacts on how relationships change in advanced dementia and towards the end-of-life. Importantly, how people engaged or responded to absence and loss was seen to produce a different set of outcomes when compared to engaging with structure.

For example, I would ask people to describe relationships as either reciprocal or one directional. This would often lead to an in-depth discussion relating to the nature of reciprocation and what it meant in their unique context. Without exception, this was a difficult conversation which reinforced the sense of ‘unknowable unknowing’ that dementia can bring. People would reflect on their relationship with the person with dementia but without an empirically observable reference point on which to base their conclusions. The application of a structured and empirically defined term such as ‘reciprocal’ to the relationship created confusion and was inherently disorientating because of the vacuum into which it was being applied. This would cause participants to fall back on a structured definition of ‘reciprocal’ which would often lead them to conclude that the relationship, and the nature of care was one directional. In my field notes and reflections post interview I noted how participants would often convey a sense of dissatisfaction with this process. They would often revisit the topic several times during the interview. This came to represent how the available structures could not capture what the totality of what was actually happening. Some people articulated how reciprocation was understood beyond the generally accepted face value definition, yet all participants bar one would ultimately record high levels of reciprocation with the person with dementia at both time points (see [Chapter Six, Table 3, p169](#)). Struggling to make use of the orientating frameworks and expected outcomes that structure provides whilst sitting within the disorientating spaces defined by absence and emptiness became a core feature of the data.

By comparing structure to data points that described its absence led me to see how people were often left to navigate two worlds; one that relied on structure, rationality, agency, knowledge and

expertise, and one brought by the person with dementia, characterised by a structure-less unknown when actions and reaction are unpredictable in their spontaneity and where meaning can not necessarily be interpreted at face value. This led me to code 'structure' as another context that was distinct to the 'unknowable unknown'. As I had done previously, I mapped how people responded to relationships through the use of structure, and how this would influence what happened to the caring and supportive networks that changed around them. These were noted as context specific outcomes and coded accordingly.

I noted that where people were occupied a state of 'unknowing' they might be forced to create, innovate and experiment. Whilst engaging with absence of structure might be hard and emotionally painful, it also brought new opportunities and outcomes. Where people operated within clearly defined structural parameters this might bring a degree of comfort and familiarity, but it would often generate paradox, contradiction and confusion. This is highlighted in the text below which is taken from one of my interviews. RES1 is the spouse and carer of someone with dementia and RES2 is their daughter.

INT: What kind of support was particularly helpful for you at this early stage?

RES1: Oh, the early stage. Well, I don't know how much I talked about it (her husband's dementia diagnosis), because maybe...because of loyalty to your husband, you know? That you perhaps don't want to tell everybody what's happening, I suppose.

RES2: I feel, and it will be interesting to see what you (RES1) think, but I feel you almost - at the start, Dad didn't really acknowledge his diagnosis, which made it quite difficult.

RES1: He never did really.

RES2: So then you felt you couldn't talk to him, because obviously you said he didn't want people to know, he was in denial. But I felt like that then created a bit of a barrier between you guys (her parents) and your friends. Do you remember when me and Anne (sister) organised that surprise joint birthday for you guys and invited a lot of your friends and they all came to the pub? I felt after that it made you reconnect to some of them, because I think you sort of thought people wouldn't understand or that you couldn't see them. And actually, I think you discovered by then that me and Anne had told most of your friends, because we'd had a diagnosis, because we didn't really buy into the same thing you did.

And again with the neighbours, you didn't want to tell them, and I think it was when we ended up in Germany... Mum and Dad had gone on holiday and Dad ended up in hospital because it had all gone a bit wrong, so I rang up (the neighbours) to basically say, "We're still there (In Germany), can you look after the cat still while we're away?" And she said, "Oh, is everything okay?" And I said, "Oh, it's Dad's dementia, and he's just ended up being in hospital," and it was afterwards, my sister was like, "Oh, I don't think they knew," and I was like, "Well, they know now!"

Here RES1 is seen to be following a rational approach, she is respecting her husband's wishes with respect to privacy. She might be seen to be respecting his autonomy and personhood by sticking to his wishes that appear to be in keeping with his character, personality and response to the diagnosis. It is a pre-meditated response, born out of 'loyalty' – a well described foundation of the structure of marriage.

RES1: Who was it (the person she told)?

RES2: I told Margaret, but that's when Margaret said that her mum had it, and actually that was when you were able to meet and talk to her. Because I think the thing is it's a big thing to not be able to tell people, because then when they say, "How are you doing?" and you can't say, "Well, I'm living with someone who's slowly deteriorating and going a bit mad." So I think that, weirdly in some ways, you ended up with more support once it was too far gone, we couldn't really deny it anymore.

RES1: Yes.

RES2 does not follow the same structured approach. This is helped by the fact her relationship to the person with dementia is different. Where these structures are not as visible or binding, people are freer to innovate, to act without thinking and be more creative in their response to what is happening. It is this that triggers the relationship with Margaret to develop into a more supportive one. After this, the conversation moves on and they discuss how there was very little support, particularly from professional services. I am told about a commonly used technique for deescalating agitation when talking to people with dementia and how, whilst it 'works' and is logical, it might also cause distress of an emotional nature.

RES2: Because actually you were saying before we came on the call about how it's only since Dad went into the home you were sent YouTube videos about how to manage someone with dementia, about not contradicting them. Things that were simple to do and you know to do them, but actually no-one told Mum, "This is how you have a conversation," how do you handle a conversation with someone with dementia, and it's very hard to get it right when you're then also under stress and you're having to have the conversation while you're, you know... (emotional).

RES1: I saw these YouTube things that somebody recommended, and the thing is, I still think it's hard, because he'd say things like, this is near the end, but he'd say, "This isn't my home." And I would say, "Well, it is your home," and he would say, "No, it's not. I don't live here." And I think that's partly why he was running off because he was trying to find his home. But it's hard if somebody's saying, "It's not my home," it's very hard not to say, "But it is your home," if you see what I mean. From what they're (the videos) suggesting it sounds like you're better not to really contradict them, but try and, I don't know, it's hard. How do you get round it?

INT: And I would imagine that it's quite a painful thing to hear when your husband is saying, "It's not my home," and you know full well that it is. That must be very hard for you to hear, and your gut reflex is to, you want him to know that it is, don't you? It makes complete sense to try and correct him than to go along with the non-truths. It is exceptionally hard to do...

RES1: Yes.

RES2: Yes, I think that's it. The logic makes sense, and it does work, and that's fine when you're doing a conversation for an hour. But when you're living in that mad world...it's very hard.

The idea of people responding to informal caring relationships using either a structured, rational approach or a more creative, intuitive approach that is open to happenstance would come to represent the broad social context in which care occurs. With increasingly granular detail applied to the description of these two contexts it was noted there was often significant overlap and people would navigate both at different times and different situations. Thus, a parent code was created; 'shattered yet converging worlds'. This came to represent the broad context in which

informal dementia care takes place, how people meet and accommodate the unknown that is brought by absence, loss and all that is unknowable, how this might give rise to something beyond pure emptiness, something with its own influence which has potential and value, and then how this might work alongside the highly structured and organised world of how we understand networks of relationships and the care and support they might deliver.

The search for latent mechanisms and their activation

To understand how people might respond to social relationships within the context of emptiness and the unknown to generate a sense of opportunity or how people respond to relationships in the context of structure and form to generate tension and paradox, I needed to delve to a greater 'ontological depth'. This is a core component to the philosophy of critical realism I described earlier. That the world is stratified into layers. The empirical, the observable outcomes I had encountered, the actual, where mechanisms have been activated to produce the observed outcomes and the real. By establishing the contextual conditions that might generate causal mechanisms I had already driven towards this realm, to find the scientific constancies that might be seen to exist independently in a latent form would be the final step in analysis before the theory is then iteratively refined.

Yet to some extent the data, in combination with my reflexive considerations, resisted this process and challenged some of the methodological assumptions I had made in reaching this point. My literature review had already identified the notion that something gets lost in the separation of complex entities into component parts ([Chapter II, "The whole as greater than the sum of its parts; p41](#)). I go on to write in my concluding statement that paradox, tension, mystery and enigma are perhaps the essence of 'what gives life to a situation'. I go on to describe how "While this review goes some distance in bringing to light the complexity and tensions inherent within new public health approaches, what is clear is that if we take a reductionist approach and ignore them in our quest for an idealized 'perfect' system we will soon return to the place from which we began". Revisiting the statements led me to question whether I was indeed losing something of importance by separating out context, mechanism and outcome to understand a generative chain of causation. At this stage, this was nothing more than a generalised sense of unease I felt when analysing the data, that somehow the structures were working to conceal something far greater.

From the outset of the PhD, I had been concerned that work in this field can feel meaningless without an in-depth appreciation of what end-of-life care is trying to achieve for people affected by dementia. This had been reinforced by my early engagement with the literature, through my clinical practice and experiences working on the front line during the pandemic. At regular intervals I would reflect on moments of my clinical practice and the constant search for meaning in the face of the relentless indifference with which life seems to pass by. In the face of loss brought by death, the only constancy is one of constant change. That life, and all its component parts are eternally in the process of becoming something else seems at odds with the search for scientific constancies.

By reflexively engaging with data analysis in this way I was presented with two problems. Firstly, a concern that in creating a highly structured programme theory that paid respect to a stratified reality and separates out experiences or outcomes into discrete entities, I would lose the essence of meaning from the subject matter. My experiences working with people with dementia and listening to the study participants recount moments of profound struggle, pain and loss in conjunction, and often inseparable from, moments of transformational value became representative of something of an endpoint in itself rather than a point at which to lay out a theory of inquest. In this sense to separate out an outcome as being generated by a discrete mechanism is to deny a version of reality that exists as structureless, where the meaning, value and knowledge exist within this state and become lost when trying to categorise and delineate the complexity.

The second issue, which is intimately linked to the first, is that the ontological and epistemological approach to the data was changing. The idea of a highly structured reality was seen as operating alongside a separate and distinct ontology. The state of being that exists in the face of death and with advanced dementia was seen as fundamentally different to that proposed by a critical realist ontology. Here, instead of an ontologically deep 'real' level of reality, where scientific constancy is seen to generate events at an empirical level, there is instead little to no structure or constancy but simply just a constant state of flux. Here existence is defined by a relentlessly metronomic movement between passings and becomings, losses and gains. There are parallels with this and Higgs and Gilleard's description of the fourth age as a cosmological black hole, something that exerts a powerful effect on the surrounding field but at the same time exists in a featureless state that resists all forms of structured understanding. Whilst cosmological black holes question many of the established norms of physics and material property, death, dying and

loss question social, epistemological and ontological norms, throwing structure into doubt and forcing us into a void defined by unknowing.

A state of being that is defined by constant flux as opposed to constancy questions the stratified ontology proposed by critical realism. For example, the very idea of a surface level 'empirical reality' is fundamentally disrupted by the effects of dementia. Whilst realism offers a window into what is concealed and hidden, it necessitates some sort of foothold in the empirical realm from which to explore. Where there is no empirical domain, where the intervention, the outcome and the context are united by their inseparability but eternally and formlessly bound, the process of retroduction becomes disorientating and circular. Instead, the data was pointing towards reality being orientated in a different way, a way that resists structural stratification, where what is important to know, understand and value exists within, or rather part of, all that is absent and empty.

Essentially, dementia, and the absences and emptiness it brings, were becoming obstructive to the process of retroduction. But more than this, the idea that there is a realm of scientific constancy that is the object of enquiry, where complexity can be separated out into discrete outcomes to understand 'what works' was found to neglect the fundamental problem that we do not know how to define success here. We do not have any concept of what 'working' truly means. In many ways, critical realism offered me a perspective from the outside looking in, when I needed to be on the inside, looking out. I needed to inhabit the void, the spaces created by dementia, to better understand how progress might be defined and how we might understand meaning and value at the end-of-life.

These differences are important to articulate as they shape an approach to paradox, mystery and enigma that perhaps explains the underlying tension I felt throughout the analytic process. In critical realism paradox and enigma exist as entities to be resolved through a process of retroductive theorization (Jagosh 2020). Here structure can be applied to disentangle complexity and delineate constancy and truth. Yet the multiple paradoxes presented by the data resisted such processes, to resolve them was to deny their potential value and the specific reality that is defined by the absence of structure. Here because life exists in a state of constant entanglement, the presence of paradox is something to learn from, not by resolving it, but by accommodating it. The process of abductive and retroductive theorizing taught me that organising my analysis around a highly structured programme theory would be possible, but it would only analyse one side of the data. Instead, the nature of what it means to be dying, moving from an empirically

observable and social realm to an alternate formless and structureless reality would be left unexplored.

In summary, the stratified world of critical realism where one might observe and separate out experiences into outcomes and their contextually triggered generative mechanisms fails to appreciate an alternate reality that was reflexively identified within the data. As participants pointed out to me, the empirical domain of critical realism is defined by absence and emptiness, what's more, where structure is applied to understanding this, the emptiness is defined as true nothingness, and therefore understood as devoid of meaning or value, diverting the researcher's attention back to what is empirically definable. This research is inextricably linked to the processes associated with loss and absence that death, dying and dementia creates which poses difficulties when research structures designed to understand them are orientated to structure and form. My data re-enforced this notion presenting me with transformational moments or epiphanies that occurred the closer people came towards the 'nothingness'. Applying structure here, in the face of the empirical void brought by advanced states of dementia, is at best disorienting and at worst risks denying the existence and potential values of understanding paradox, enigma and mystery as part of reality. This was found to challenge the epistemological assumptions of critical realism, that knowledge is obtained from digging deeper from the empirical realm as opposed to being found as a presence that emerges directly from the emptiness.

Factoring in these considerations led me to an important juncture in my analysis. I could either continue to orientate my findings around a realist philosophy of science and produce a programme theory that would describe how networks might change and give rise to the generation of support and care, or I could explore the notion of an evolving alternate realm, analysing its relevance to how we understand what it means to live and die with dementia and how care is organised and performed in such a way that accommodates meaning and value. Importantly the two processes were not seen as mutually exclusive but that orientating my analysis to the strict methodological form of a realist programme theory would limit my ability to understand meaning within the data I had identified.

To move forward I reflected on the entirety of my research. I re-evaluated my initial aims and objectives whilst considering what would be of most relevance and use when considering the need and complexity of delivering end-of-life care in dementia. I became preoccupied with a phrase I came across in the work of Allan Kellehear, that how we conceptualise death defines

the response. I have argued in chapter one that the absence of such a conceptual understanding of death and decline in dementia has fundamentally limited the response, leaving communities and professional services disorientated in their approach to care.

I also considered what would be of most value to the public health palliative care movement. Chapter two highlights the multiple tensions that arise when seeking to accommodate a diverse range of philosophical and ontological perspectives into a consistent and unified theoretical approach. My work argues that such tensions underpin the debate as to what might be considered success or failure and might conspire to undermine progress. An in-depth appreciation as to what end-of-life care is trying to achieve for people affected by dementia had confronted the frontiers of my personal and academic understanding of death, dying and loss. I felt that understanding the dying process in dementia, how loss and absence are accommodated with a distinct ontological approach, might act as a foundation upon which these tensions might be addressed thus providing a way of accommodating them with an a more integrative approach to health and social care.

Lastly, and perhaps of most importance, I considered the ethical obligations in conveying the narrative set forward by research participants. These people had provided me a window into some profoundly intimate moments, conveying their agony, strife, sorrow and joy. I felt a sense of responsibility in conveying the reality of their situation and their experiences in such a way that values what is important to them as opposed to using aspects or part components of their experiences as a means of testing my own theory.

Considering each of these factors it became necessary for me to orientate my analysis around the emerging analytic of two separate yet entangled worlds; one of form, of structure and constancy, the other of non-form, where structure can create tension and deny the value present within the perceived emptiness. Breaking down this world into its constituent components was seen as counterproductive to understanding its value, its existence in an entangled, formless state might have inherent value from which we might better understand the processes associated with care of people affected by dementia at the end-of-life.

Taking this approach is not to say that using a critical realist approach to the data did not work. Rather following the logic and philosophy only lead me so far, to an outer limitation where existing theoretical structures are of limited help and the search for empirical and actual fails to penetrate the spaces that dementia creates. Here the methodological structures begin to fall away, and yet, in the emptiness something remains. A presence in the absence, felt and acknowledged

not necessarily through formulated structures but by simply dwelling with this emptiness, sitting and looking out into the distance. A critical realist approach had taken me to this point, yet the data demanded further steps into the dark yet without providing the assistance of the light afforded by access to and understanding of the empirical world.

The ethnography and a deconstructed programme theory

Recognising that relevant parts of the data could not be condensed into a context-mechanism-outcome format meant I had to decide which parts of the evolving theory to take forward and which to discard. I recognised the network mapping exercise and the structured approach to scientific realism as being embedded within a carefully formulated and structured view of the world. Rather than being of no use, this data would be helpful in taking me to the outer reaches of their potential. I could then compare and contrast this alongside an emerging understanding of a structureless world that was also being developed in response to my own reflexive considerations described at the beginning of the chapter.

I conceptualised the issue of absence and loss, both in terms of dementia but also in an ontological and epistemological sense, as central to understanding the role and function of public health approaches to palliative care for people with dementia. I felt that without an appreciation of loss, absence and emptiness, the design of supportive structures would be confined to an alternate ontology, and therefore offer no valid grounds for support. Without an appreciation of absence and loss, support and the notion of care becomes confined to discrete moments, temporally located around 'pressure points' such as diagnosis, transitions in the caregiving environment, changes in mobility and incontinence. These moments are typically socially configured to run in conjunction with professional services. From the outset of the PhD the approach has been to understand dementia from the 'other side', from the perspective of the whole whereby events, or their absence, leading up to these points are what comes to define the experience and what we understand by meaning and value. An approach that focuses on the tangible entities and ignores the absences or empty spaces that surround them would therefore be inadequate. These concerns motivated my approach to what would be an ethnography of care for people whose lives are affected by dementia. In this next section I will situate my work as a form of community-based ethnography. I describe my field setting and make the case for an open hearted, open minded and open willed participatory approach to the study of absence and its associated, but often hidden presence as a means of conceptualising a more integrative approach to end-of-life care in dementia.

Location

The ethnography was conducted at various locations across the city of London. London is a sprawling city that remains under constant construction and re-construction. It extends well beyond the square mile that geographically defines it. It is divided into north and south by the river Thames, transport links are plentiful but concentrated north of the river. The city is littered with multiple green spaces of varying size. The smaller of these are often nestled within housing estates or lost within a labyrinth of backstreets. In the UK, the national health care system is state funded and administered locally. People suspected as having dementia are often referred to secondary care services for diagnosis. Ongoing medical care is generally managed by a General Practitioner. Beyond this, care is provided by a range of private and charitable organisations and is generally considered as social care. As care needs increase it is common for people to access professional carers. These are privately funded with financial support available from the state depending on the outcome of a financial means assessment. For people unable to stay at home there are multiple care homes available. These are all privately run, and a financial assessment is conducted to decide if there will be state contributions to costs which start at roughly £1,200 per week. End-of-life care services are generally provided by a general practitioner with specialist support from palliative care services. Hospice based palliative care is approximately twenty to thirty percent funded by the NHS with charitable donations often covering the rest of costs (Garner et al. 2022). Palliative care teams are split between the hospital, hospice and the community. The hospice offers admission for people thought to have a life expectancy of two weeks or less, or those in need of an intensive period of symptom control before going home again. Regardless of the reason, admission is usually restricted to two weeks. If an admission is likely to extend beyond this, an alternative place of care would usually be discussed and sought. Community teams are composed of nurse specialists who hold a case load of patients and are supported by a team of consultants and junior doctors. Their primary function is to visit people at home for either symptom control, to support advance care planning or provide end-of-life care.

In general, and in theory, there is good access to health services across London, however the effects of COVID-19 have greatly disrupted provision (Maddock et al. 2022). At the same time, people with dementia have been shown to have poor access to services including palliative care (Maddock et al. 2022). The discrepancy in care and support is in part met through charitable organisations such as the Alzheimer's Society, Age UK, Alzheimer's UK and Marie Curie who provide various platforms for engagement. Informal community led initiatives also exist and are

often led by lay people with first-hand experience of dementia and want to help others. Despite this, community supports remain few and far between and there is little integration into mainstream health and social care. This has not been for a lack of effort. In 2012 Prime minister launched a challenge to make England ‘the best place in the world to live well with dementia’(Kmietowicz 2012). Efforts were made to increase diagnosis, raise awareness and build a society that is equipped to support people with dementia. Off the back of this, initiatives such as dementia friends and dementia friendly communities expanded (Hebert and Scales 2019; Shannon, Bail, and Neville 2019). The challenge was relaunched in 2020 which seeks to build on progress by focussing on four key domains: risk reduction, health and care, awareness and social action and research (Care 2020).

Covid-19 had a significant bearing on dementia services (Wang et al. 2020). During national lockdown it was not possible to arrange face to face appointments with GPs and all non-essential services were scaled back. The effects on this for people with dementia are likely to have been profound, however evidence is still emerging. At the same time outbreaks of Covid-19 in care homes did much to unmask the social stigma associated with dementia and reverse important progress in building a moral imperative to care for old people and those affected by dementia (Benbow and Jolley 2012; Nguyen and Li 2020).

Beyond the healthcare landscape, London is a socially, culturally and economically diverse city. Many of the traits associated with an individualist culture are found in London (Triandis 1993). Here the autonomous individual is seen to exist in a largely heterogenous and competitive society. The breadth of variety promotes a tolerance of difference but can also breed a dependency on services. This is in opposition to more collective cultures which are formed on the interdependent self to create a more homogeneous culture (Triandis 1993). Here, the roles, rules and values of a society are well established but difficult to break free from. The cultural variety of London inevitably means that each individual community will vary as to where they fall on this spectrum, adopting traits from each. Understanding this is crucial to understanding how the intricacies of care are negotiated.

In recent years, London has also experienced a social and spatial transition from an industrial to a post-industrial economy. This has brought shifts in the nature and location of work and also the occupational class structure which has had a knock on effect on income and the structure of the housing market (Hamnett 2003). In short, London is a very expensive place to live, and with costs continuing to rise, families are now more geographically dispersed whilst there are often

spatial limitations in people's homes. These factors combine to add further challenges to the provision of informal care.

Working within the spaces created by dementia

That I might in some way be able to focus on the spaces created by dementia as a means of understanding the multiple and profound tensions that I had uncovered seemed to me the only way to proceed. To inhabit these spaces, I would need to learn how to identify them, how to situate myself within them, and how to learn from them. To do this I would foreground 'a sense waiting' as a distinct state of being. This, alongside my reading of other ethnographic works, highlighted the need to focus on the 'open-endedness of peoples becomings' (Biehl and Lock 2017). Biehl and Locke advocate a 'ethnographic sensorium' that exists in contrast to intellectual judgements and instead 'opens new channels of communication and conceptual work, calling attention to the plethora of existential struggles, improvisations, ideas and landscapes that shape what life means' (Biehl and Lock 2017). Such a framework was helpful in moving from the highly structured realist approach towards more creative methods that were open to the opportunities inherent within the experiences of others. In many ways, I would come to reflect that my work involved situating myself at the juncture between two worlds. One that was attuned to emptiness and its constant yet disorientating presence within life's never-ending cycle of passings and becomings, and one that contains the structures with which to depict the unfolding narrative.

In October 2021 I was given ethical clearance to start my ethnography (IRAS project ID: 281423, REC reference: 21/YH/0184, [Appendix Four](#)). This involved a lengthy and detailed proposal which was subject to scrutiny by a designated NHS ethics board with specialist interest in involving people who might lack capacity to consent. This culminated in a face-to-face review of my plans and me being awarded the authority to begin data collection. In terms of recruitment and observation, my initial plan was to use the hospital as a starting point and built outwards from here. After a productive discussion during my PhD upgrade it was felt that the medical gaze would be of less relevance and data more relevant to the developing themes would be found embedded within the community and people's daily lives, outside of formal healthcare settings and services.

Recruitment was conducted through the Alzheimer's Society Research Volunteer Network and also the Join Dementia Research website. A lay summary of the research was sent out to

members of each network. This led to people contacting me via email. For the Join Dementia Research website, I would email specific people who had been matched to my study. This was done with reference to their geographical distance from the university. Given the focus on end-of-life care I was often matched to carers of people with dementia. If people expressed interest in taking part, they were invited to a phone conversation. Here I introduced myself as a clinician experienced in palliative care but also as a researcher interested in understanding how people are supported and cared for beyond the borders of professionally led care. An ethics committee approved information sheet was given and we discussed the nature of the persons dementia and what taking part might look and feel like for all concerned. No time limit was placed on people to decide whether to take part. All participants expressed a willingness to proceed without prompt which led to an in-person meeting with the carer. During this meeting we collaboratively explored how my visits might be accommodated and what might happen during them. We discussed the consent process for each of them but also the person with dementia, how I would need to assess their capacity at the beginning and also at regular intervals as part of the process of ensuring my presence was welcome and not burdensome. This led to a second visit which included the person with dementia. This staggered approach to recruitment was intentional to begin the process of rapport building, but also to carefully assess capacity in line with the Mental Capacity Act.

Overall, I undertook long term participant observation with five people with dementia, their families and close friends. Typically, people would tell me about their experience of dementia, the diagnosis and the changes it brought. People would also talk about their broader life experiences, their personal histories, relationships, work and travel patterns. Informal discussions were always unstructured and responsive to what was happening for people in that particular moment. For people who were mobile I would accompany them on walks, at social events and trips out to the shops. For people who stayed at home I would accompany them and their carer observing the routine of daily life. Sometimes this would mean sharing a silence or being present during meals and times of personal care. As these relationships evolved over time I would learn more and more about the individual lives of people. I spent times in cafes, pubs and on walks through London's many green spaces. I also attended dementia café's put on by local volunteers. Such experiences were vital in extending my perspective beyond discrete moments such as those associated with a crisis and their subsequent interventions. This was instrumental in bringing me closer to the empty spaces I had identified as having potential in progressing knowledge.

Overall, I spent one year conducting observations and informal interviews. I would spend on average two to three hours every week or every other week with each participant and their family. My field notes included my reflections on travelling between points in the city and the numerous walks and meetings in coffee shops, cafés and community gardens. Timings to the visits were sometimes planned but would also be ad hoc but were always suited to participant's convenience and willingness to accommodate me.

As expected, and as planned, many of my observations were conducted at points where participants had reached a stage of near total dependency, where communication was limited, and the social norms of interaction had been replaced by what might be perceived as an emptiness. In terms of charting these experiences I draw on the social imaginary of the fourth age as described by Higgs and Gilleard (Gilleard and Higgs 2010b). Here they focus on the darker side of old age by grouping the experiences of abjection, shame and limited agency into an imaginary likened to a cosmological black hole. They argue such a black hole may be 'understood by examining not the experience itself, but its impact on the discourse that surround and orientate themselves to it' (Gilleard and Higgs 2010, Page 1).

The black hole to which they refer was representative of the void I would experience in being in the company of a person who was unable to reciprocate or engage with my presence in an immediately recognisable way. Focussing my attention at the interface between the empirically observable world and the empty spaces created by dementia became one way of navigating the ethnography. As Higgs and Gilleard claim, it is here, in the 'event horizon' that we might begin to understand more about care where people dying of dementia are concerned (Gilleard and Higgs 2010b). As with the event horizon, it is not necessarily its existence that needs explanation but more its 'nature, meanings and the relationships through which it is realised' (Higgs and Gilleard 2016b, Page 91). Working in such a way necessitated a more systematic approach to unfolding events, 'being ethnographic' or using the body as a mode of data collection so that it might detect and record the unfolding of events (Madden 2017; Pink 2015a).

Ethnographic methods and their deeply immersive practices led me to be invited further into the lives of participants. This afforded me the opportunity to move beyond the 'event horizon' and came to represent a second approach to recording my experiences. Such practice involves letting go of structure, sitting within the void to see what arises in response. This is more representative of being open to the sensibilities of human existence, and of people existing in a state far removed from the highly structured world of social norms and rational thought. In practice, such

moments would often, but not exclusively, involve deep silence. Here the body would act as a mediator to an “ethnographic sensorium: a multifaceted and affective point of contact with worlds of inequality, hovering on the verge of exhaustion while also harbouring the potential for things to be otherwise” (Biehl and Lock 2017)p3. I also took guidance from the work of Sarah Pink and her description of ‘sensory ethnography’ (Pink 2015a) where she investigates the possibilities afforded by attending to the senses in ethnographic research, how ethnography might situate the researcher in “similar, parallel or related places to those people whose experiences, memories an imaginations they seek to understand” (Pink 2015b). I also drew on theory from Arawana Hayashi’s Social Presencing Theatre (Hayashi 2021). This is described as a ‘social technology of collective awareness and systems change’ and draws on theory from Otto Sharmer and his approach to shifting the ‘field structure of our attention’ (Sharmer and Senge 2016). Here he blends the idea of sensing and presence as a means to detecting the emergence of future possibility. He describes four principles that underpin this process 1: Letting go and surrendering to the unknown 2: Inversion; the start of a process whereby a person begins to link with an emerging field, 3: Presence and Self; the process of moving from empathic listening to listening from a ‘deeper source or stream of emergence that connects you to a field of future possibility’: 4: The power of place; this involves harnessing its different components to help generate a new type of relationship between the individual and the interconnected self (Sharmer and Senge 2016). Such practice was not followed explicitly but articulates some of the processes by which I sought to inhabit and then navigate the losses and empty spaces that dementia creates. Ultimately this would allow me to accommodate loss and emptiness and understand their presence as a source of knowledge production as opposed to an impenetrable emptiness devoid of any meaning or value.

Participants

I have divided my description of participants in my ethnography into five groups. Each group contains a person with dementia and their surrounding support network composed of individuals who I have observed and discussed aspects of care. I have summarised the details of the people with dementia in table three but also provided a description of their unique and relevant support networks below. This is meant merely as an introduction. More details of their situations become clear through the detail of my field notes in chapters five and six.

| | Participant with dementia | Features of dementia | Location of care | Care arrangement |
|---------|----------------------------------|---|---|---|
| Group 1 | Patricia (Pat) | Can recall childhood and early to mid-adulthood with some consistency. Little to no short-term memory. Physically independent | Initially home, moved to nursing home during field work | Full time nursing home |
| Group 2 | James | Fluctuant memory, short term memory noticeably declined during fieldwork. Physically frail but can walk with a stick. Needs help with housework. | Home | Supported mainly by friends and neighbours, has one professional carer who visits twice daily |
| Group 3 | John | Able to feed himself and brush his teeth. Needs full support with everything else. Can transfer from bed to chair with help but otherwise immobile. Will occasionally make a statement but not able to engage with conversation. Little to no memory. | Home | Provided in full by his wife Betty |
| Group 4 | Sandra | Impaired short-term memory which becomes apparent on more detailed conversation. Physically frail and needs assistance with a frame but can move out of the house | Home | One live in carer, one visiting carer once a day, weekly visits from son and daughter |
| Group 5 | Angela | Needs full and total care with all aspects of daily living. Not able to converse or make needs known in an obviously identifiable way | Home | Has three live in carers who are privately funded. Visited weekly by her daughter |

Table 3: Characteristics of participants from the ethnography

Group 1: Pat (person with dementia), Donald, Linda and David

Pat is in her 80s and has dementia. She is physically independent, her memory focusses on her childhood and adult life. She has previously worked to raise the family whilst also holding secretarial and administrative positions. I first met in her at her home in a town roughly two hours outside of London. She lived here with her husband Donald. Donald is in his early 90s and has his own health problems resulting in physical frailty. Over the course of the ethnography they moved to a nursing home together. Previously they had lived in a house in a quiet cul-de-sac

with a garden centre just opposite. Pat would often visit the garden centre by herself, staff there knew her and were friendly with her. Donald could not accompany her on walks due to his own poor health. Pat also enjoyed feeding the birds in her garden. On a few occasions Pat ventured further than the garden centre and became lost. This had resulted in the police and social services becoming involved, a care package was put in place. Pat and Donald were also supported by their daughter Linda and their son Charles. Linda lives in London and has a daughter who has significant mental health needs. Charles lived outside London with his wife and children who have autism.

Pat and Donald's time in the family home ended shortly after I met them. A combination of issues, including Pat getting lost whilst out walking, difficulties maintaining the house, and Pat's enthusiasm for feeding the birds in the garden which had led neighbours to raise environmental concerns had prompted social services to force a move. Linda facilitated their move to a nursing home in London. The idea was they would move closer to her so she could visit more often. The move was fraught with issues causing them to move home a further two times within six months. During this time both Linda and her husband David have had their own health problems whilst they have also been heavily involved in the support and care of Linda's daughter who had been detained under the mental health act.

Group 2: James (person with dementia), Robert, Elizabeth, Mary, John, Michael, Richard and Jennifer

James is in his early 80s. He has vascular dementia and other chronic health problems. He is physically frail but can still walk, he needs help with most household tasks. He is a writer and has also worked as a teacher. His memory fluctuates significantly with some days being much better than others. He lives alone in a flat as part of a housing co-operative. He has a particular interest in literature and the arts in general, his small flat is filled to the ceiling with books. He had lived in London for most of his life and enjoys the cultural diversity it offers him. He has a niece, Jennifer, who does not live in the UK. He is mainly supported by a close network of friends who include Robert and his partner Elizabeth, Mary, John and Richard. These people have come to know each other through James. They take him out to the theatre, cinema, to restaurants, cafes, for short walks across London and to various community events. James also has a professional carer, Michael, who is employed to visit James twice a day to assist with the flat, medications and meals. Each friend has a particular activity they support James with. Robert assists with a literature and translation class, Elizabeth has taken the role of lasting power of attorney for his

finances, Mary will help him with medical appointments but also take him to the theatre, restaurants and cafes. John takes him to a community garden as well as other events. Richard will often take James for a walk and enjoys sketching with him. Richard also has his own mental health problems and cannot always attend. His friends have the objective of keeping James in his own home for as long as possible but have said that one day they expect him to go into a nursing home.

Group 3: John (person with dementia), Betty, Megan and Ted

John is in his early 90s and has dementia. He lives in a large Victorian home in London with his wife Betty and son Ted. He has little to no memory and rarely speaks. Physically he can feed himself and brush his teeth but otherwise he needs full assistance. He used to work as a Dentist. They moved house a couple of years before I met them as John was struggling with the many stairs in their previous house. Currently they live on the ground floor of the house and the upstairs has been converted into independent living quarters for their son. Betty does all the care for John. He has a small world. He moves from his bed to a commode which has been fashioned into a wheelchair. He is then wheeled to the bay window in the front room where he will play with a 'poppet board' (a type of fidget toy that is like bubble wrap where the person might poke small bubbles from one side through to the other) or occasionally thumb through and read sections of old books. He has an afternoon nap and goes to bed early in the evening. Betty and John have a daughter who lives in Scotland and is a professional musician. Ted, their other son, was also a musician but has recently quit to retrain as a tradesman. Betty is open and pragmatic when talking about caring for John, she talks regularly about wanting him to die and waiting for this eventuality.

Group 4: Sandra (person with dementia) and Alex

Sandra lives in her home which is a large, detached house near a park. She is physically frail and needs assistance to walk and transfer but can get out of the house with a walking frame. Her memory is focussed on her early life and raising the children, although she retains some short-term memory as well. She enjoys conversation and is still very socially engaged. She previously worked to support the family as well as holding a position at the citizens advice bureau. She grew up in relatively humble beginnings near the docks of South London. She is supported by a live in carer and also another carer who will visit and take her out on trips to cafes and parks. Her husband died a short time before my meeting her. Sandra has a daughter Alex who is retired and

visits her weekly. Sandra also has a son who lives close by who visits regularly, but I did not meet him as part of my research.

Group 5: Angela (Person with Dementia), Sharon, Nicola, Helen and Samantha

Angela is in her early 90s. She lives in her own home with three live in carers. Angela is totally dependent on others in all aspects of her life. Previously she worked as a nurse and was well integrated in the community, many of her friends and family have now died. During my early visits she would make eye contact and smile or utter a 'hello' or 'goodbye'. During my later visits she was most often asleep. She has three live in carers, Nicole, Helen and Samantha, they are not from the UK. They tell me she can still indicate verbally or non-verbally that she needs the toilet, or has been to the toilet, and that she might hum to music they play for her. Other than this there is little communication. Until recently they would try and take her out to the park or to cafes in a wheelchair. This has now become too difficult. Instead, they stay at home and move her into the garden if the weather is nice. Angela has one daughter Sharon who lives locally with her husband and children and co-ordinates the care whilst visiting most weeks. The carers are paid for privately.

Participating in the lives of those at the periphery of conscious thought

Participating in the lives of people with dementia required a dynamic approach that would shift between being structured and systematic to being creative and open in the face of spontaneously evolving moments of engagement. It also required an appreciation and awareness to the unique sensitivities, practices and vulnerabilities of the people involved. Part of this involved being ever conscious of the formality associated with both my research and clinical practice, and the ability of these structures to disrupt and alter tense, valuable moments and how they are viewed and understood.

In practice this would mean following up on specific points of observation, discussing with participants the nature of what I was seeing and triangulating this with the experiences of other participants and my own personal and professional experience. Where appropriate I would anonymously discuss my own personal experiences from clinical practice and family life with participants. This was helpful in triangulating what I saw, heard and sensed but was also important in presenting my own vulnerabilities to participants. This was crucial to establishing a depth of relationship that would transcend the traditional paradigm of the 'researched' and the 'researcher' and would help generate a more open, participatory approach.

Moving toward this type of approach, knowing when to be present and when to be absent, at times felt at odds with the formal rules of engagement that surround research processes. I frequently found myself in situations where I was privy to hugely sensitive information, but in a participatory way. This created ethical ‘grey zones’ where the academic structures and their accompanying ethical frameworks were insufficient in their ability to help me navigate this. Given that such structures will always be limited in their ability to foresee every eventuality, there was a need to generate and cultivate a kind of ‘ethical sensibility’³ which was attuned, dynamic and responsive to individual moments of the ethnography and would help find balance between interpersonal and analytical sensitivities (Arteaga and Llewellyn 2022).

During the ethnography, I bore witness to peoples suffering, to moments of profound distress with no clear route to resolution. Knowing what to do, what to say and how to respond in these situations can be difficult when the nature of the relationship is difficult to place. My presence in the moment, as a witness to somebody’s distress necessitated a sharing of the intersubjective space through which suffering takes form (Kleinman and Kleinman 1991) and was therefore unavoidably participatory. I found my clinical practice invaluable in negotiating these moments. Over many years of being in intensely sensitive moments, often of a profoundly distressing nature, I had experienced the value in listening to and holding people’s distress, often recognising there is no resolution. Responses that counter people’s despondency, offering sympathy or erring people towards positivity can deny the reality of the situation. Rather, being with someone during intensely emotional situations involves letting go of our own insecurities so that our presence might deepen within the moment. Here departure from a prefabricated approach to sympathy or empathy brings an evolving intimacy through which we might experience a newfound presence (O'Donohue 2003b). Rather than turning away from moments or phenomena defined by their intensely personal nature, we might learn to inhabit them and through this learn to navigate an approach guided by the evolving relationship. Ultimately these experiences become part of a deeply reflexive approach that enables participants to feel supported and heard whilst enabling personal and professional progression that is analytically useful.

The process of seeking out, accommodating and understanding absence from within it was an iterative process. My understanding of absence, enigma and paradox evolved in real time and in

³ Ethical sensibilities in ethnographies of care: I would like to credit H.Llewellyn for this phrase. It was introduced to me over discussion of the topic of ethical practice in ethnography

response to the data and my interpretation of it. Whilst this defines the directive vision of the ethnography the practice was defined through an approach that foregrounds a reflexive approach to deep presence. Paying attention to the importance of shared vulnerability and understanding the value in sharing moments of complex emotion enabled me to engage with people's experiences in a more participatory way. Performing the research therefore became inseparable from the notion of participation, which in turn was inseparable from an open hearted, open minded and open willed approach to being present through deeply attentive listening (Sharmer and Senge 2016). This in turn facilitated a sensibility to the multiple ethical issues experienced and an ability to accommodate people's experiences, understanding and interpreting them at an embodied, intuitive and rational level.

Analysis and presentation

Situating the ethnography outside of the hospital and away from medical structures of care allowed me to focus on the spaces that surround the objective of focus. For me personally it was instrumental in breaking from a deeply engrained way of viewing health and the challenges that illness can pose. Engaging with ethnographies that have sought out a similar perspective was instrumental in giving me a range of theoretical frameworks on which to situate and understand some of my observations, whilst alerting me to the potential of what is yet to be understood and experienced. I took particular inspiration from the work of Sharon Kaufman in understanding the role of medicine existing as part of a chain of social, economic and bureaucratic forces that combine to make interventions seem 'ordinary, necessary and desirable' (Kaufman 2015c). Situating this analytic in the context of advanced dementia and the end-of-life helped with the process of unpicking what defines success or progress in this area. Similarly her work with people in a persistent vegetative state alerted me to how knowledge production occurs at the interface between life, existence and person (Kaufman 2000).

My analysis of transcripts and field notes was conducted iteratively throughout field work and in conjunction with my earlier work. The writing of field notes at the end of each day would lead to written memos and a consideration of the position and relevance of data to an evolving theory. When field notes were complete, they were imported into NVivo where I built on the analytic nodes developed through the network mapping exercise (See [Appendix Five](#) for excerpts from NVivo workings). Further analytic memos relating to meaning and potential links between data were collected in NVivo.

As my conceptual understanding of absence or emptiness developed, my analysis became more focussed. This meant a clear and distinct move towards understanding how people conceptualised, negotiated and inhabited the losses dementia brings, and how this might influence and orientate supportive care. Central to this was my ideas on a state of waiting without anticipation as an ontological state of being that exists within a chain of constant passing and becomings.

By this stage I was deeply immersed within the data and could quickly draw on examples from memory, pinpointing them in time and place within my field notes. As the process was conducted iteratively and throughout fieldwork, I was able to pose some of my ideas to participants during visits. We would discuss their relevance and potential meaning as part of regular discussions. I became struck by a central paradox that seemed integral to people's experience. That whilst dementia brought suffering, there were also many moments of elation and joy. Rather than existing in amongst the trauma, as isolated and discrete moments of relief, they often existed in the very same moment. This is as if to say the two seemingly polar entities could not be separated out and existed together in some sort of unfathomable and formless state. This became an important analytic focus when understood in relation to the multiple permeating tensions and apparent paradoxes that had been identified in chapters one and two. An evolving theory was refined during the process of writing and at various presentations to academics and lay people with experience of dementia.

This thesis presents aspects of the ethnography that illustrate specific points as opposed to the full account of each participant. Importantly this does not mean that each account is entirely typical of aspects of the theory that has been created. Indeed, the theory is designed to be used more as a heuristic, which can be populated based on people's own individual experiences. In most instances I provide relatively longform descriptive vignettes as opposed to short quotations. This is specifically done to illustrate complexity and the multiple component parts that combine to generate and understanding of a specific point. Field notes are presented within quotation marks, where a person is being quoted verbatim, I use an asterisk to mark speech. To maintain confidentiality, I have pseudonymised all participants and place names. Other personally identifiable features such as location are also concealed under generic description.

Conclusion

My thesis began by mapping out the constituent components of a public health approach to palliative care and trying to understand how existing theory might infer benefit to people affected by dementia towards the end-of-life. Given the complex nature of naturally occurring supportive relationships, a realist logic of science was identified as means to help understand how public health palliative care might work *for* people with dementia. Throughout the early stages of the PhD, it became clear that there were multiple tensions within what might be considered ‘benefit’ or ‘progress’ in this context. These centred on the human approach to loss that defines death and has come to be a hallmark of dementia and its progressive effects. At the same time, modelling death and dying as a shared social process was found to raise its own issues ([Chapter Two](#)) suggesting that existing theory cannot simply be transposed to the field of dementia and end-of-life care. Crucially, the idea of tension, paradox or enigma was evolving beyond something that exists merely to be resolved, but something with its own intrinsic set of values.

This posed somewhat of a destabilising threat to how my research had been positioned in the original protocol ([Appendix One](#)). The prospect of the tensions I had identified existing as part of a wider state of unknowable unknowing, a fixed and impenetrable enigma, where value lies within their reality as opposed to the potential in overcoming them, created somewhat of a paralysing juncture in the research. The value in setting out on an enquiry into this point through social network analysis had evolved beyond the parameters set out in the original research protocol ([Appendix One](#)). If anything, my findings outlined in chapter two had reinforced the need to understand the dynamic nature of relationships that are central to moments of tremendous value, and sorrow towards the end-of-life. However, there was an additional, perhaps unintended value in persevering with social network analysis as the next phase of data collection. It provided a rigid, highly structured platform without which allowed me to move forward in a reasoned and systematic way. It was through engaging with the highly formulaic and structured world of social network analysis, and by observing participant’s attempts to abstract meaning from their relationships rather than recount empirically observable phenomena, that I was able to highlight how dementia’s disruption to cognitive and social norms means that the empirical and actual worlds as defined by Bhaskar become blurred to the point of being unrecognisable.

The value in pursuing social network analysis in conjunction with critical realism was therefore two-fold. It allowed me to move beyond a point of academic paralysis, to metaphorically put one foot in front of the other and move forward deeper into the unknown. At the same time, it highlighted the tensions that become apparent when rigid academic structures are employed to understand value through the resolution of complexity, tension or enigma rather than from within its existence alone. Using social network analysis in conjunction with the process of retrodution, led me to identify a theoretical and ontological void in which people with dementia had occupied, a void that could not be fully acknowledged through the methodological confines of a realist programme theory alone.

The discrepancy between seeking to understand ‘what works’ and the reality of participants experiences as conveyed to me through the network mapping exercise only served to sharpen my focus on an ontological domain that existed beyond the structures usually employed to understand such phenomena. This ontology is best defined by a state of ‘waiting without anticipation’ that exists as part of a ceaseless cycle of passings and becomings. Such an approach accommodates paradox as a valid and valued component of human experience and became the foundation point for my analysis in terms of all that is form and non-form.

My understanding of how knowledge would be constructed in the face all that is absent and lost was brought into sharper focus by COVID-19 and its evolving effects. The chasm this created in my own personal world of work afforded me the opportunity to dwell in the nothingness. My experience of this, alongside what I came to understand as similar experiences in working with the dying and dead, became instrumental in reorientating the focus of my analysis. Instead of understanding how public health palliative care might work *for* people affected by dementia through a carefully formulated programme theory, there was instead a realisation of the learning to be had from inhabiting absence. In this way, the question becomes, not ‘what do we know that might be of help?’, but rather ‘what can we learn from people with dementia that might help us better understand absence, loss, dying and grief?’. Within this lies the more detailed questions relating to how we understand value alongside the paradox that everything so intricately grown and loved can be lost to existence. How one might accommodate such loss, not as something to be unpicked and overcome, but as something that defines our state of being is the starting point to an ethnography that breaks from the traditional structure of a realist programme theory. Instead of filling the void in knowledge by searching and understanding what works, for whom and in what circumstances, I ask instead what can we learn from a state of absence and

emptiness that might be applicable to how knowledge is constructed and value is understood and acknowledged.

The ethnography became an embodied study of absence. Of the pain and suffering this brings, but also the healing that comes through accommodating absence within our lives. I have argued that this was made possible by a participatory approach that is driven by a willingness to inhabit the empty spaces that are found at the periphery of conscious thought. Here joining people in the emptiness that dementia creates can be profoundly disorientating. Structures fall away whilst meaning and value can at once seem intangible and distant whilst fleetingly obvious and profound. Yet accompanying people in these spaces, accommodating vacancy, loss and the disorientating notion of emptiness into our lives can also bring about ethical sensibilities and an understanding of human existence beyond that which our corporeal and intuitive senses can define. This has been the unique contribution of not just ethnography, but my ethnography, which has sought to reflexively embrace my own experiences and understanding as a clinician working in palliative care.

In the following chapters I will present the findings from a deconstructed programme theory and their relevance to the public health palliative care movement. From the perspective of a realist programme theory the findings are presented 'back to front'. I will begin with a detailed account of my ethnographic findings and the two worlds I encountered and theoretically developed – the 'form' and the 'non-form'. This is intentionally done to orientate the reader to the wider context in which the structures of public health palliative care operate for people affected by dementia. I will then present the findings from the network analysis in conjunction with the ethnography by way of critically examining the potential for a more integrative and productive relationship between public health palliative care theory and the needs of people affected by dementia.

Chapter Five

**Introducing the world of the form, non-form and its
entangled nature**

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Introduction and overview

In chapter one I argue that the success of humankind's instinctive desire to seek answers and meaning from the unknown has caused an inability for humanity to define its outermost limits. I suggest this has resulted in the uncertainty and unknowns inherent within the dying process being conceptualised in negative terms thus leaving little room to approach the disorientating and unfathomable void of death with anything other than profound discomfort. Through an analysis of the Western social and cultural response to death I argue that the dominant human response to such discomfort lies within the scientific evidence-based approach to control. Here, I suggest that the 'good death' represents a surrogate for control, where advance care planning and adequate symptom control are used to create an ideal of death whereby people can die on their own terms and in line with their individual choice.

I go on to argue that the rising prevalence of dementia has brought the limitations of such an approach into sharper focus. Qualifying this stance, I describe how the chronicity of dementia's effects, combined with the progressive dependency and loss of cognition, means Western culture is forced to reconsider the uncertainty of dying as something that can be countered until the moments before death. Whilst incorporating ideas on personhood and citizenship has done much to give people with dementia a moral identity, their use as points on which to orientate, design and deliver end-of-life care in dementia are more contentious. For people affected by dementia, control may feel illusory, meaning those people responsabilised with upholding it are ultimately consigned to failure. This leaves people with little choice but to inhabit and accommodate the losses that dementia brings. People affected by dementia can be left to navigate this position amidst a set of supportive structures that are orientated towards autonomy, independent choice, maintenance and preservation of a constantly depreciating resource. Beyond denying the reality, this can lead to uncertainty, tension and moral distress.

New public health approaches to palliative care seek to reimagine a better system for death and dying. In chapter two I identify a series of principles and processes that encourage people to reconceptualize loss and grief in a way that rebalances our relationship with the darker side of human existence. Whilst these innovations provide a new lens through which to evaluate the complexity provided by dementia, they also throw up familiar tensions. Dementia follows a trajectory towards dependency whilst social relationships are fundamentally disrupted in such a way that empowerment, network building and enhancing social capital can be contradictory processes. From this perspective, I suggest that the locus of change has not shifted from an

underlying desire to seek control in the face of the disorientating void of death and the fourth age.

As I have argued in chapters two and three, understanding how to operationalise public health palliative care theory is dependent on an appreciation of tension, paradox and enigma as entities of value rather than something to be countered and challenged. Taking a more reductionist approach, as part of a quest for an idealized ‘perfect’ system risks returning the narrative to the place from which it began ([Chapter two: Conclusion](#)).

As humanity learns from the step changes brought by interventions on personhood, citizenship and now public health palliative care; social, political and academic discourse might recognise the balance between what is to be considered successful or unsuccessful care at the end-of-life in dementia is one of constant change. The decrease in control that comes with decline and dependency may convey fear and unease, yet within it, and around it, reside moments of profound beauty and transformative value. To find reference points better suited to the roles and identity of the dependent dying it is therefore not enough just to focus on structuring processes. Instead, perhaps there is a need to trust in the unknown. Here we might move beyond polarising notions of success and failure to a realm where death might be considered a ‘white shadow’ where light and dark are opposites but eternally bound as one (O’Donohue 2003). Here beauty is created through the close association of all that is broken, damaged and lost, rather than in spite of it. I have also suggested that the beauty within the white shadow of death is not an end in itself, but might point to a far greater embrace of belonging that holds everything together as a focal point for the generation of a more integrative approach to dementia care.

To help rebalance the near constant pursuit of a positive way of living with dementia and its effects, alongside the inevitability of death and its associated grief, I propose a model that defines both ‘form’ as a structured domain, designed to bring control through increased knowledge in the face of uncertainty alongside the ‘non-form’. The latter being a structureless space that refutes the idea of polarizing entities, of health and illness, or sorrow and joy, of success and failure but rather understands that paradox, enigma and mystery are part of what comes to define our existence. In this chapter I will give a full account of both the form and the non-form. I will introduce their character and nature before describing the expectation and potential outcomes that come from working in these different spaces at the end-of-life. As it will hopefully become apparent, components of each exist together, often in the same moment, whilst form is created from, and through, non-form and vice versa. Separating out my description of each has therefore

not been easy. I would however justify it as necessary to present it in this way as means of orientating the reader and familiarizing them with core concepts. Whilst all that is of form might be intuitively familiar, the non-form is often strange, unfamiliar and can evoke a feeling of discord. By providing a distinct account of each realm, but with weighting to the novel components of the non-form, I hope to draw greater attention to what the non-form is, to highlight its presence as something that exists as more than just absence.

By separating out my description in this way I also recognise I have created a structure that is foreign to the reality of my experiences. Through a reflexive approach to data collection, I have seen that the reality of care is often played out at the interwoven and sometimes colliding interface between the form and non-form. The final part of this chapter attempts to give a more realistic account of how form and non-form might operate once the reader has become familiar with their character. Within these entangled, and sometimes colliding borderlands, I will argue that an appreciation of the non-form and its fluid components can help accommodate tension, building a more integrative and sustainable model of what is understood by 'good care' and 'dying well'.

Introducing the Form

The Form exists as a highly structured and organized domain. Through the lens of all that is form, when complexity, paradox or uncertainty is encountered, it is understood through a set of supportive frameworks that combine to rationalize meaning and define progress through designated and clearly defined end points that can be mutually understood as successful or constituting the 'right thing to do'.

Elizabeth now attempts to move the conversation on towards what might be considered the 'next steps'. Having been largely quiet so far, John now joins the conversation. He outlines how they recently had an 'annual review' with social services and that the outcome of this process was that James would be recommended to have another care visit of about thirty minutes. This recommendation is being put forward to a panel for approval. John suggests that Ed, from the local pensioners association, had also been involved with this. He also describes how they did not apply to have this means tested as James has the means. John mentions that the situation has however changed since this review and they might need more than this. John qualifies this by describing how James is not dressing himself in the morning anymore, nor

is he eating breakfast. He also feels that he is not eating his evening meals because he is not 'supervised' and whilst he retains a 'voracious' appetite, he only tends to eat in the presence of others.'

By creating a set of outcomes which can be achieved through the tools available, interventions from the field of the form have brought a measured success that has helped to build trust in this way of working. This is most obvious in the realms of professional care. Below are my observations of meetings James' carer for the first time.

Michael (professional carer) sits down at the table, I explain my research to him, and what taking part would involve for him, he is enthusiastic in his words, but has a serious facial expression. He tells me that he was the carer for his mother who died only a few months ago. He is also involved in caring for other people with dementia. He references someone who has alcohol related dementia. His language is very formal, frequently referencing biomedical terms relating to disease and illness. I am aware this might be put on for me, he continually refers to me as Dr Sawyer. He talks about how he carers for James and continually comes back to his role in 'mitigating risk'. He tells the story of an 'incident' James had with the microwave. He put it on for thirty minutes instead of two and the contents caught fire. It set the smoke alarms off in the building and the neighbour upstairs came down to help. Following this Michael organised a 'risk assessment'. This resulted in James' gas cooker being shut off despite it not being involved in the fire. He points to a yellow and red sticker that is attached to the aged cooker in the corner of the kitchen. James chuckles at the story from his seat opposite. Michael says the changes have helped to make James 'safer'. He goes on to say how he sees a significant part of his role as trying to maintain James' memory, he encourages him to record things in a diary. Sometimes the language in the diary changes to James' native tongue. Michael says the diary doesn't make much sense sometimes. During our conversation together Michael asks James' about things he has done recently in what sometimes feels like a bit of a test. James seems to be getting progressively more uncertain and hesitant in his responses as it transpires he cannot answer many of the questions, it gets to a point where he can't recall anything. His friendly laughter has stopped, and he becomes less engaged with the conversation. Michael has been in the flat for about fifteen or twenty minutes and during this time has done a lot, medications, cleaning, food preparation, sorting the bins and recycling as well as talking to James about his day. He is now ready to leave. I am struck by the formality of the language and protocols used in James' care however also recognise they are perhaps performed for me as a researcher and also as a Dr, as if done properly they represent 'better' care, yet paradoxically they seem to have depersonalised the experience and tipped James

into a state of confusion. Michael frequently told James that he had days of 'very bad memory loss' and other days that are 'not too bad', the conversation and activities of care were performed to mitigate against this.'

The sequence of identifying a problem, forming a solution and evaluating the impact is a positively reinforcing chain of events when the entire process is understood from the vantage point of the form. This builds trust in the process and means that further answers are sought almost exclusively from this domain until such point that they are no longer considered an option, but represent an absolute necessity. Ultimately, this feeds into the idea that people with dementia can 'die well', this is presented as achievable, perhaps even an entitlement. Conversely, the 'bad death', characterised by undue suffering and dependency at the expense of others, is depicted as avoidable through the provision of improved access to structured care and support.

Whilst most obvious in a professional context, within institutional care and its accompanying protocols, structuring processes were also used in community-based groups to fill spaces created by dementia where there are perceived gaps in care. Over the course of the ethnography, I attended community groups for people with dementia. I made several trips to one group that was run by a team of volunteers who all had personal experience of caring for someone with dementia. The group was labelled a 'café' and included an entertainer, dancing, bingo, quizzes and food.

'The other volunteers tell me that later an entertainer will come, people will sing songs and dance. I am told enthusiastically about the dancing and also how people with dementia will often remember the words to songs and sing along, even when there is little else they can remember. They tell me it is a joyful experience and that people love it. One of the women whose husband used to attend, and is now dead, tells me that continuing to volunteer 'fills a hole'. She has memories of him being here and had gotten used to the pattern and routine of caring for him. His death had taken not just him, but all the additional experiences and relationships that caring for him brought. She was very busy throughout the morning serving cups of tea, cleaning up. She rarely appeared to be still and later remarked how afterwards she would go home, put the food away and then 'collapse'. She remarks that people often ask for them to run the club more than once a week, but this would be too much for her, she tells me that she would be exhausted and that she 'has a life' as well. I wonder if her activity is a form of service or duty rather than something she sees as part of her life.'

Here the café provides an invaluable service to members of the local community affected by dementia. The support is structured and organised with a clear focus and goal. Yet it is also exhausting work, whilst the motivational forces that drive its formation and progress are not clearly defined.

The choreography to the form: a rousing crescendo

Humans are brought up in the realm of the form, as such people are accustomed to its tempo and rhythm and the various forces that impact on this. There is a familiarity in the passing of time and the changing of the seasons, the expectation and demands of childhood, adulthood, old age as part of the life course, a path to which those before us have left a set of navigational tools and norms. Yet as dementia progresses, it becomes increasingly difficult to keep pace and time with this rhythm. This can cause conflict, around which further structures are put in place to help mitigate against this. This can result in quite a frantic pace, a rhythm where we move quickly from one thing to the next. Below is a description of events that occurred shortly after Donald and Pat moved to a nursing home. The entire process unfolded over just a couple of weeks.

'The next event to occur was that Pat became lost. Linda says she had been visiting her parents to discuss the option of them moving to a different nursing home. She says at around 1620 she said goodbye to Donald as she needed to get off to support Alice with her medications. At 1830 she said she got a call from the home asking if Pat was with her. Linda describes the tone as accusatory, as if to suggest that she had taken her out and not informed them. At 1900 she got another call to say that Pat had been brought back by the Police. The accusatory line of questioning continued; Linda was asked if she had followed her out of the home when she left. Linda said that at the same time there were issues accessing the CCTV footage. The staff said that whilst they were in operation, any request to view the files had to go through head office and it was therefore not possible to get access. In fact over a week later, Linda says she has not heard any update and as far as she knows there has been no access to the CCTV. Linda says that the police and social services were both involved and that they will report it to CQC⁴ (the Care Quality Commission), or she will. One of the upsides to the process was that Linda got to meet her parent's social worker who was sympathetic and kind, taking the time to ask her 'how do you feel about

⁴ The CQC is the independent regulator of health and adult social care in England. They 'make sure health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.'. They 'monitor, inspect and regulate services', their findings are published in a publicly accessible document whilst they also hold power to take action where poor care is uncovered. <https://www.cqc.org.uk/about-us>

it all'. Linda is shocked that she has still heard nothing beyond a couple of emails from the care home. One of the emails was from the manager that I am yet to meet who described himself as being 'devastated' by events, Linda says that that may be true, but she can't help but feel that he is 'devastated but not for the right reasons'. She also found it disconcerting that other people were cc'd into the email but without introduction. Having googled their names she found out they were area managers and other senior staff. Linda's follow up email was replied with what she considered an unfriendly tone 'I did tell you I would be investigating' and further accusatory statements 'she must have gone out after your visit'. Linda has informed the home of her and her parents' desire to move. She was told that she would need to give four weeks notice by somebody in accounts who reminded her of the initial contact that was signed (Linda did not sign a contract and this, she thinks, refers to the papers that Donald signed without really knowing what he was doing (An event I had been present at and had discussed previously with Linda). Linda appears to be incensed by this and tells me 'I don't think so', she says she replied about the conditions of the contract being broken by their 'negligent' care – this word was used by social services in conversation with Linda which perhaps empowered her to feel justifiably angry at the care her parents had received. Linda goes on to list a host of problems that she has encountered. It starts with her belief that the home 'miss-sold' aspects of the care, the location of the rooms was not made clear, the contract was signed by Donald, and she asked for a copy but was not given it, her mother, despite being a vegetarian, was given a ham sandwich. Linda also recalls visiting her hairdresser whose wife used to work at the home and described it as having a bad manager – it is unclear if this was a previous manager or was the current manager but adds to the negative picture that has formed. Linda then decided to go and visit some different care homes. Linda describes how the appearance can be misleading, she describes some as being 'perfect on the outside' or 'like visiting an Italian villa' but that they were unlikely to be a good fit for her parents – 'there is not much chance they will be talking about football!' (in reference to the type of people that live there). Linda describes going to see homes like this as an important step 'I had to get that out of the way'. She also describes how some nursing homes are more 'homely', residents are encouraged to take part in everyday activities, like what would happen at home. Things such as 'hanging the washing on the line'. I describe how, during my last visit Pat had appeared almost to be bouncing between the walls at the home. This is in reference to her searching for a gate to go for a walk but bouncing between locked doors with nowhere to go. We talk a bit about the approach to risk, how risk is understood from the perspective of the person with dementia, from the perspective of the family, and from a professional perspective. We describe how she can navigate to her boundaries and to me, she seems quite aware of those boundaries. We

discuss how this differs from when people without dementia get lost, how we react, respond and convey a need for help that might be subconscious. To me this also relates to the issue of responsibility and who feels, enacts and holds this responsibility.'

For Linda, Pat and Donald a series of events occurred which spawned a highly structured response that sought to identify a problem, collect evidence and form a solution. These events involved multiple different people, creating a large amount of correspondence and work. They also occurred in a short space of time, contributing to a feeling of stress and anxiety. People, words and phrases such as police, senior manager, CQC, 'devastated', 'incensed' and 'negligent care' are part of a response that appeared to set off a chain reaction causing it to grow exponentially in volume and gravity. This is the 'rousing crescendo' of the form, a noise that is all consuming and holds the focus of our conscious attention, almost unapologetically demanding a response in such a way that the empty spaces brought by dementia and loss become filled with what we are more familiar and accustomed to – namely structure, meaning and purpose which might deliver us to a positive solution.

Expectations and outcomes from working with the form

The Aesthetic Ideal of Care

At the centre of humanity's prolonged discomfort with suffering and death, is the eternal human search for meaning. That people might suffer beyond reason, or that in any single, unpredictable heartbeat, we might lose all that has been so intricately grown seems completely discordant to the choreography of the form, the rhythm of our carefully constructed world to which we have grown into.

In dementia, progressive decline and dependency of our structured cognitive and corporeal form creates a perceived emptiness over which life seems to be precariously stretched. The tension compels people to seek structures that provide meaning and value. Yet to search for these within the infinite and inescapable void of loss is inherently disorientating because of its absoluteness and its incomprehensibility. Instead, the temptation is to examine such a void through the lens of how best to avoid it, and where this is no longer possible, to guard against the pain caused by loss.

Such logic originates from a rational interpretation of the world around us. As discussed in chapter one, the response to decline and dependency in advanced dementia is intimately linked

to our understanding of death and how this has evolved in response to various structures designed to interpret meaning and provide support. These structures, shape our experiences and organise our judgments with regards to decline, dependency and death in such a way that they are given moral imperative. Here, what care for a dependent person in the face of death looks like, is a carefully constructed ideal, designed to preserve meaning by first prioritising and then protecting the most valued aspects of our human form. An 'aesthetic ideal of care' is therefore the idea of what care *should* look like. An image of warmth, tenderness and compassion that is brought to remedy the meaningless void of the fourth age and death.

Nicole and Freda (Angela's live in carers) come back in to bring Angela a drink. She is asleep, and they gently wake her and encourage her to respond. They make noises and facial expressions much in the same way people might do with a new-born baby, trying to get a reaction or a smile or something similar. Angela offers nothing on this occasion; however, she does eventually open her eyes. She has been sitting in a wheelchair opposite Samuel (Nicole's partner) and I for the last thirty minutes or so, seemingly asleep. As she opens her eyes there are smiles and coos from all three carers. Samuel calls her darling, the others call her mum, even though they are of no blood relation. Nicole has brought freshly squeezed orange juice which has had thickener added to it. She is encouraged to drink but struggles as she coughs significantly as she tries to swallow. Nicola massages down her sternum as she drinks and says 'thank you' each time Angela appears to swallow. Samuel, Nicole and Freda all discuss the possibility of aspiration, they are well trained in preventing such an occurrence and know what to do to minimise risk yet acknowledge that it can never be removed entirely. To me Angela looks like she has lost weight, perhaps not around her middle but the muscle mass in her legs appears to be reduced, I ask if she is still able to stand or walk. They say they are using the hoist almost all the time now (previously they had sought to mobilise her at every opportunity and to great physical effort, in the hope of preserving her mobility). They tell me that eating can take an hour or more, just for a small portion. It is a slow process that I imagine is quite boring to engage with yet, at the same time, it requires meticulous attention to detail given how hard it is to know if she has swallowed her food or not. I ask if she can still communicate her needs, Freda says that she will call out Nicole's name, this can mean she needs the toilet or something else, however there is often nothing more specific than this.'

An aesthetic ideal of care is a direct product of working within the form. Loss, emptiness, and the absence of meaning is understood as the problem, with the solution being care that preserves against such losses. Here 'ideal care' is understood to be the marker to which we are collectively

and individually judged meaning that it is commonly ‘performed’ in a way that signals to others the success of care and the virtues which it bestows. In this way the ‘ideal of care’ becomes an intuitive outcome measure that goes unchallenged, universally accepted as a force for progressive good. Instead, the focus shifts to access to such care, and the resources required to deliver this. It becomes a self-fulfilling cycle where the aesthetic ideal of care is depicted as achievable, or even an entitlement and anything other than this is representative of poor care.

I describe the performance of care that might be associated with professionals who provide care in a way that might be perceived as good (e.g. good food, nutrition and hydration, moisturised skin etc) and how this contrasts with her (Betty’s) approach which by her own admission is more pragmatic. Betty talks about her own methods as ‘unconventional’ or ‘unique’, she talks about the bed and how she has personalised it with a detachable side. I ask where the pressure to perform may come from. Betty finds this topic less applicable to her, she does not feel judged, nor that her friends, or other people, are analysing her methods. She says this is perhaps something that is unique to professional care, where they have to report back to others, including family or senior members of staff. I describe to Betty the care delivered by Angela’s live in carers and she says, ‘yes I would imagine they would be given five stars by CQC’. There is a recognition of what ‘five-star care’ looks like and what also it actually means to the person. The focus on the person and their identity according to what it was may not always ring true of the current situation. She cites her own circumstances and how John often disengaged with things that he would previously enjoy, things such as going to the theatre, music, or watching the snooker. Another example is that she doesn’t bring him to the dining table when the family gather to eat. She says it disrupts their meal, and she doesn’t feel it adds anything to his experience. He is happy where he is, doing what he does. She can however understand the analogy of performing care in relation to professionals and gives the example of someone coming once for a home assessment and she moved the rugs and footstool out of the way for fear they would be seen as a trip hazard. In this way she performed according to the expectations of the professional establishment, rather than what her friends or family may think or be thinking.’

Ideal care and the exclusion of all that is unacceptable to human existence

An aesthetic ideal to care can be rationalized as a hopeful, virtuous pursuit, yet it can also deny the reality of loss, and within this, what it is really like to care for someone in a state of profound physical and cognitive dependency. In the extreme, the aesthetic ideal to care works to deny

suffering in both the literal and the figurative senses of the word. More broadly, it excludes everything from its purview which is essentially seen as unacceptable in human existence.

We talk about Betty's (full time spousal carer) caring methods and how they differ from what I would categorize as a perceived 'conventional' or 'ideal' care. Betty has never shied away from this topic, she recognizes that many people would find what she does as wrong, as constituting poor care (she has not replaced his hearing aid, she allows him to clean his own teeth, she doesn't change him every day and washes him just once a week). I describe how it has never felt that way to me, but when I get home and write about what I have seen, and re-read it, it sounds somewhat cold. She nods and agrees as I describe this. I believe she has similar feelings. She tells me that when she describes to others what she does, she has to be careful how it comes across, we agree that the description is different to the reality of the situation. We talk about what I term 'real care' which is strife laden, which is murky, fraught with opposing emotions to those of kindness and compassion. Frustration, monotony, resentment, anger are words that come to mind, and ones that Betty has used with me previously. She again describes getting frustrated and angry at John, she recounts stories of her 'yelling at him' saying things like 'I wish you would die', but then him forgetting. She has told me about these stories before. I tell Betty that, to me, these aspects of the caring relationship are what I might expect. Like with any loving relationship there are arguments, indeed it is perhaps more concerning if this side of care is not present. This, I describe, is something that makes me feel uncomfortable when I observe professionally lead care. Where people are given the full package of what I would consider 'idealized care', skin is moisturized, make up done, fresh clothes every day, constant encouragement but in the face of a deteriorating resource. Betty says this is what concerns her about John going into to a nursing home (if she ever had to do this). I am reminded about how I have tried to broach the topic of monotony, boredom and frustration with professional carers but that they would not entertain this notion, or any hint of it.'

This phenomenon also contributes to societal perceptions on dementia. Here the reality of dementia's effects, the profound behavioural change, incontinence, sexual disinhibition, violence, aggression, social withdrawal and profound loss and emptiness is hidden by the pursuit of the aesthetic ideal which has been created to shield us from these issues.

'Sarah (a volunteer at a community dementia support programme) gives the example of her mother, whom she says had dementia but is now dead. Prior to her diagnosis, she used to care for the old people who were local in her neighbourhood. She is keen to tell me a story of one old woman who was admitted to hospital

with a delirium on a background of dementia. She went to the hospital and unbeknown to her, Prince Charles was also visiting at the same time for the opening of a new building. She says there was an entourage of people, and she somehow ended up with Prince Charles in the lift. He asked her who she was visiting, and she explained. When they arrived at the right floor, Sarah's mother looked into the ward through a glass door and could see her friend. She was sitting on the edge of her bed furiously punching a security guard who was effortlessly holding her back. Prince Charles said something like 'oh dear, somethings going on there'. It transpires that the hospital staff had not wanted him to visit this ward and Sarah's mother was too embarrassed to admit to Prince Charles that this angry, delirious woman was indeed her friend whom she had come to visit. She laughs at the story and says that her mother would tell everyone and was very proud of this as a 'claim to fame.'

That placing value, meaning and virtue alongside the pursuit of a positive way of living and caring for people with dementia can reinforce the socially perceived unacceptability of its effects rather than accommodate them. This was seen to explain the relevance of the colloquial term 'NIMBYism'. NIMBY (Not In My Back Yard), describes the social phenomena of how people outwardly express a desire to help, or care, yet when the reality of the situation is placed 'in someone's backyard' it becomes unacceptable or incompatible with an accepted way of living.

'Soon after this event (getting lost in the park), Pat began feeding the birds in the garden with food. She would leave bread and other items on the floor of the garden, and this has attracted birds, in particular seagulls to the area. Neighbours also reported seeing rats. As a result of this, a complaint was made to environmental health. This happened again two weeks ago. I ask Linda if this was discussed with anyone first or was their first port of call was to lodge an official complaint. She said they did have a discussion with her brother first by phone. He lives some distance away and was co-ordinating the care in Linda's absence as she had an operation and was in hospital for a time (she does not go into detail with me). She said he had told them 'If that is what you feel you need to do, then do it'. There does not appear to have been much negotiation and Donald was served with a notice threatening a fine last week.'

I have described how the darker elements to living with advanced dementia at an individual and a social level are concealed by the structures that create an aesthetic ideal to care. This can mean people living and working in these spaces can become disconnected or concealed from meaningful view.

'As I sit with Angela and eat, her neighbour opens the side gate, Nicole brings her a chair to put next to Angela. She tentatively sits down, she does not talk to Angela but says to Nicole and Freda that one day she will be needing them, she lavishes praise on them as carers of the highest order. She says she is entertaining her brother next door but does not invite him through. Eventually the neighbour sits down opposite me, she says her and Angela used to do many things together, they travelled and would often spend time in each other's garden. The conversation is tinged with sadness. The neighbour wants to ask me whether or not Angela has any awareness, whether she can hear or understand us. I say it is hard to know what she can understand, I am pretty certain that she can hear us. The two of them do not seem to interact as friends, there is perhaps some fear, she says that she is spending time with her brother today and says goodbye fairly quickly. She leaves through the back gate that leads to her garden. She closes the gate as she leaves.'

'Sharon (Angela's daughter) goes on to talk more about her own position and describes herself as 'sitting in anticipation' but changes this perspective saying that she has perhaps moved on from here now and is now comfortable with the fact that there is no control anymore. That intervening in any shape or form is only going to generate work, angst and strife but without any significant gains. She thinks about how the care her mother receives is over and above what is necessary, that three carers is excessive and that she should have extra financial support, but to intervene here is only likely to open a hornets nest of issues. She does not know whether her mother will die soon or much later. In many ways it doesn't matter anymore. She says that when she meets people who know her, she can tell that many of them don't even know if her mother is dead or alive anymore. She has become 'hidden' Sharon says, people who used to drop in and support have fallen away, she is not resentful. She says she visits up to once a week and would not go any more than this. I reference her neighbour and the interaction I observed between them, the tension of not knowing what to say or do, the closing of the gate.'

Introducing the non-form

Where form is navigated in a structured, systematic way, the non-form is unmappable, boundless and open ended. Structures traditionally used to help navigate uncertainty do not apply and quickly fall away or lead to paradox and tension. When rationalised or described, the non-form might appear as emptiness, absence or deep silence, a meaningless empty void that is both disorientating, isolating and bleak. Yet to move into the non-form is to discover that it is indeed full, full of opportunity if we are willing to move beyond the structuring process that have a

limited function here. As I will describe, working in the non-form holds great potential, for example, it is the space in which healing might occur. Paradoxically, it is also the exact space where grief and suffering reside. Such is the nature of the non-form, these seemingly polar entities exist together, unbounded by divide or border.

Below is an excerpt from my field diary which documents my experience of being left alone with Angela for the first time. We share a silence for close to an hour, with occasional interruption from her live in carers Nicole and Freda.

Nicole comes back in the room briefly to put Angela's false teeth back in, she wears latex gloves and has to wait until Angela opens her mouth slightly, allowing her to do it without force. It takes a moment or two and Nicole holds the teeth next to her mouth, gently and patiently touching them against her lips as a prompt to open. Nicole then goes into the kitchen with Freda, I can see them washing and cleaning through the glass door. Angela sits eyes closed, her feet occasionally twitch and jerk and she flicks her toes to a seemingly random rhythm.

My attention is drawn away from the music that has been left to play on Nicole's phone, and towards the nothingness that seems to engulf the space I am in. There is a moment where the stillness of the space comes to dominate the room over and above the loud music. Somehow, the nothingness absorbs everything else, it is a disconcerting feeling, as if nothing has any role or relevance, there is no function of time, no record of events, no significance of place, it is entirely empty, the silence is deafening as it drowns out the music. I jot down in my note pad that I feel quite alone, despite the human company that I am close to. I do not necessarily feel Angela's presence initially, more an emptiness. I look at the fireplace that is opposite her, the photographs of family positioned on the mantle and hearth act almost as a mirror to her, reflecting the life and the relationships that have come to define her to me.

As time bears no function, I think about what is creating a rhythm to the environment I find myself in. I recognise Angela's gentle breathing and try to focus in on this as a connection to her presence. The music is now just a distraction, as if it plays in the room next door or can be heard as a muffled sound through a wall.

I reflect on the 'busyness' of Nicole and Freda in the opposite room. I wonder why today they have not decided to join me, is it that there is nothing to do anymore? I think of what one woman told me at a dementia café – 'end-of-life care is just about personal care really', in a task orientated way this is

perhaps true, yet at the same time I think of the description of the death bed from one of my other interviews. The participant described the dying person and the role of the body as something to congregate around, almost as some sort of social platform or stage.

The song draws to a close and there is a pause in the music, this is filled by the noise of a passing aeroplane and birdsong from the street outside. Occasionally Nicole's phone pings with the alert from an incoming text message.

In a relatively short period of time, I have travelled within the emptiness I find myself in the disorientating feeling of being in a space where time moves slower or even stands still, where each action and reaction might as well exist or not exist – there is no recordable nature of life, it is as if it did not happen. The space swallows everything and induces a soporific feeling, I start to yawn. I struggle to think how the rhythm of this environment can be compatible with the pace of life outside, the pace of life that continues to move around Angela who sits motionless, connected, but in an alternate existence. Yet at the same time our presence together is real, my presence in the room is real as is Angela's, I wonder what my role is here, beyond the obvious as a researcher, what is my role in relation to Angela. It strikes me I stand to learn a lot by occupying this space, it is so far removed from day-to-day experience that it has challenged my perception of what is of value. Within this space there must be some sort of value to me and by default others that would enter and be present in this space.

Notes from my workbook at the time 'the work of end-of-life care disappears into the black hole, the vast and open yet seemingly meaningless emptiness over which life seems to be stretched.' This is in relation to the seven years of care that Nicole and then the others have put into looking after Angela. I see it fading away, into the black hole within which her presence creates in the room. I think also of the relationships they have formed with her, how they are perhaps hidden to the outside world, there is no one to bear witness to such relationships and the spaces that I have been privileged to be a part of these last few months. What do you learn from being in such proximity to death, both physically and mentally?'

It is only on return to the office where I write up my field notes in more detail, that I come to realise the empty space within which I sat was indeed full. When I next visit Angela's daughter, I describe my experience to her, and she offers her reflections:

"I talk about how on a recent visit Nicole and Freda did not sit with me and Angela and I was left to sit in silence. I tell Sharon how this was perhaps the first time that I had moved position to sit alongside

her. To meet her where she was, as opposed to bringing me and my cognitive, rational world to her and being greeted by absence I was in fact stepping into a world that was indeed 'full' (the non-form, an empty space within which we might find things about ourselves, about death, about all manner of things). This seems paradoxical in essence but this is also the nature of my work, it is replete with paradox, it is a struggle to find something that is not paradox. Sharon seems struck by this. She says whenever she visits her mum, Nicole, Helen and Freda are with her in the front room. Intuitively she says she doesn't necessarily need or want them there but has never thought to ask them to leave, to be alone with her mother. Sharon says that she would probably cry. But this is not a sad or sorrowful statement. I can tell this immediately, but Sharon explains none the less. She would see nothing bad in sitting and crying with her mother, in some way, it would be nice. It might be healing, it is real. It is an expression of something that transcends the cognitive dimension of our being that is of irrelevance to people with very advanced dementia. It is perhaps what would happen if she were to meet her mother where she is, in a language that is universally applicable."

In chapter one I discuss how viewing dementia through a lens of loss has been seen to contribute to widespread fear of the condition contributing to a widely acknowledged perception that it constitutes a 'living death' (Lefever 2011). I outline the widely acknowledged argument that this approach may have contributed to the social exclusion of people with dementia, contributing to their systematic marginalisation in economic, cultural and social terms. Yet, despite arguments for a capacity oriented approach to dementia (Bartlett and O'Connor 2010a; Kitwood 1997a), losses remain, unavoidable in their constant presence whilst causing tension in advanced states of dementia where narratives and practices of care remain orientated towards a fading reality. My observations point to the idea that it is not the loss or emptiness per se that drive these narratives, but instead how they are conceptualised in the first instance.

Through the lens of the form, it is hard to characterise the empty spaces created by dementia as anything other than a meaningless void into which the work of care is poured. Narratives that relate to dementia the 'disease' but also its effects on the person, the relationships they hold and the social world of which they have grown into are unified by their focus on the structuring processes that make up a perceived reality. From this perspective it is hard to understand the loss of these entities as bringing anything other than a meaningless emptiness, a sadness created by profound grief. It is this, not loss per se, that causes the phenomena of a shrinking world, the social exclusion and the systematic marginalisation of people with dementia. But what is the true

nature of loss in dementia? What if these spaces are not simply empty, but instead contain some sort of presence?

Betty talks about 'transitions' for people with dementia and how they might occur in one of two ways. For 'big' transitions there are often singular events where it becomes obvious there is a change. Betty tells me of taking John to Verona on their last holiday. It is poignant because it was the time she decided not to do this again. She had booked an open-air theatre for the opera. The venue was an ancient amphitheatre with stone seats with cushions to sit on. It was candlelit and very warm so held in the evening. She knew John would have loved it. The journey was challenging and adjusting to the heat was an issue. Because the performance was at night, and because they had come back to the hotel to change (where there was air conditioning), John had been convinced that it would be cold. Getting dressed became a fraught process as he wanted to wear his long johns and it was boiling hot even in the evening. Eventually they got to the performance and John sat with his head down, completely disengaged throughout. The experience sounds relatively minor in terms of drama compared to others. However, it was hugely poignant for Betty and the memory is certainly a sad one, despite the beauty she describes in the setting of the candlelight. Betty says that when nothing comes to replace an element of someone that disappears, it is not necessarily that there is nothing. Rather 'something does come in, it's just that that thing is nothing'. Her implication is there is value in the space created. It perhaps sharpens the focus on other things but also provides a space for her maybe.'

At the beginning of the ethnography, I was confronted by empty spaces and understood them as a stumbling block to data collection. By the end I understood them as the richest source of data and was actively seeking them out to see what I could learn from within them. Initially the emptiness might feel strange and alien because people are used to living within a world that is full of structure, where the rational human mind can work things out to define progress and meaning. But nevertheless 'emptiness' is still part of the world to which we belong. The more these spaces are occupied or filled with new things, the more they are understood as having no value and the more we grieve at the prospect of emptiness.

The choreography to the non-form: stillness and silence

If the non-form is a realm in itself, it follows that it too will have a rhythm, a pace that dictates flow and movement. Much in the same way that the losses dementia brings are profoundly and painfully apparent despite being invisible to start with, the choreography of the non-form is

created, can be felt, heard and acted upon yet is also silent and still. It is unpredictable, formless, shaped by intangible entities that combine to move us outside of the confines of space, time and the structured world we have created. As the non-form is boundless and unstructured there is often an amalgamation of positive and negative entities, of joy and sorrow, of the mundane and extraordinary in close proximity, existing together rather than in spite of each other. Frequently such paradoxical emotions might exist in the very same moment.

Betty says to him, 'do you want to play the piano?', John says yes and nods, she positions a well-thumbed book of music in front of him, they are simple songs she says. She says he will play sometimes for an hour or so and then it comes to a close when he picks up the book and thumbs through the pages. This signifies the end, and he is then wheeled into the front room, and placed in front of the bay window. Betty says she will wander round the house and do her own thing whilst he is playing. She asks where I want to be whilst she awkwardly hovers by the door. I say I will sit and listen to John for a bit. Betty moves in and out of the room.

'At the start John's movements are very jittery, his arms and fingers tremble and are wooden in their movements. He more hits the keyboard than plays it, his fingers reach out and are in the right position, but they do not bend or stroke the keys. He moves them up and down and the keyboard wobbles under his brisk movements. The sound is discordant and jarring. Betty comes back and forth before settling into a position by the door where she lingers, half in and half out of the room as she watches him. She says that he has never played from memory, and that she thinks him reading music has preserved his ability to read some words. The discordant noises continue as John rattles the keyboard. Betty says, 'he's only messing about now' and will start to play soon. Although the sounds are discordant there is a rhythm to his movement now. This shifts into playing one or two keys with a finger, it seems he is stuck on this for a while and Betty points out 'oh dear he's got stuck on that', she is anticipating him playing but seems anxious that he might not do it. Suddenly and seamlessly, John's movements transform into a fluid motion. His arms legs and fingers stop trembling, and he begins to stroke the keys to a tune. The left hand has come down and now sits redundantly by his side. The right has developed a dexterity that is alien to his previous movements. The keyboard no longer trembles under the force of his movements but sings to the tune he plays; the timing is perhaps unique, but the music has a lovely sound. Betty remarks that he has 'always had a nice touch' when playing the piano and it seems this has been preserved. He reads the music but skips out the left side of the page, focusing only on the right. He plays with his right hand only now, pausing to turn the pages with the same hand, I had not detected a dominant side to his movements before

today. Randomly the left hand will come up and play a perfect cord but in the main it stays down. The music is quite beautiful to listen to, it is gentle, and he looks calm, Betty remarks that he is 'happy' doing this and might play for an hour or so, she says this is great because she can get on in the house and do things knowing that he is safe and content through the sound that he makes. I am struck by the transformation in him, and also the gentle nature with which he plays. Betty shows me a book of music that is well worn and says he will often make his way through this, although she has not given it to him in a while. I say the music is lovely and she agrees, she says that she is pleased that I have heard him play.'

To me, the beauty and sadness of this moment are inseparable to the rational mind. At the same time, it arose out of the nothingness, the empty spaces that I had sought to seek out and inhabit. I had sat with John for many hours, watching him play with a poppet board or staring vacantly out of the window. I did not see John play the piano again, but would not come to forget this moment of transformation that arose seemingly out of the 'empty' space created by his dementia.

Expectations and outcomes from working with the non-form

Whilst the form searches for a positive way of living with dementia by structuring our experiences and shaping our understanding into binary modalities of good or bad, positive or negative, the non-form rejects such an organized framework. The non-form accommodates the entirety of human experiences. Its existence provides us with the recognition that no life exists without its broken and empty spaces. In the non-form, beauty resides and is intimately related with all things broken, damaged, stunted and soiled. Its presence is recognition that true joy and beauty cannot be confined to the realm of the form, where the ideal of one-sided perfection exists without exposure to risk, uncertainty or pain. The pathos of beauty, the poignancy with which beauty transcends our rational senses to make us feel alive in our hearts resides in the non-form.

Whilst the form produces an aesthetic ideal to care, a carefully constructed image, that our minds eye is trained to choreograph, the non-form prescribes no such vision. Instead, the non-form plays to our imagination, inviting us to create and innovate into the space. This is the universal language of the non-form, it is distinct from our rationality, agency, reflexivity and will. It is a space in which the structures of personhood or citizenship have no relevance, it is also the same space where death takes place, a space where the inner life of the person is gathering in preparation to move completely away from all that is form, to all that is non-form. The process

leading up to this point is a collection of all the experiences of life in one final unstructured, messy, yet perfectly formed weave.

In the sections below I will describe how the perspective brought by the non-form might alter how the multiple tensions identified through the previous chapters are viewed and understood. I will describe how the non-form offers potential in accommodating paradox as a means of defining a more realistic approach to care. I will also describe the potential for healing that might be found within all that is non-form, offering a set of processes by which people might come to accommodate the transformational presence afforded accommodating absence, vulnerability and loss into our lives.

The pathos of beauty: A central paradox from which to understand multiple permeating tensions

Much of chapters one, two and three highlight the many tensions that exist when trying to rationalise out a what good care, a good death and the role of community means and looks like in the context of dementia. Viewed through the lens of the form, such tensions might appear as paradoxical. Here, paradox is understood as something to be resolved through the application of rational thought that brings knowledge development and progress. The aim is to shift the needle on the dial from uncertainty towards certainty, so that we might navigate such borderlands with assured footing and a greater sense of control. Yet, in the face of death we are confronted by the outermost limitations of this approach. There is nothing with which to help navigate the ultimate paradox, that we are created only to experience suffering, decline and death. Instead, the non-form appreciates a true paradox as something different.

I can't help thinking of Rembrandt's paintings, where the light is so glorious that it makes even the darkness look beautiful.'

Anonymous quote, taken from 'Palliative medicine, just another specialty?' (Kearney 1992)

To understand dependency, decline and death in the context of a seemingly meaningless void into which all elements of somebody's person will ultimately fall, requires us to accommodate and inhabit this void. It is here that paradox resides, not as something to rationalise and resolve, but as something that exists in its own right, with both value and purpose.

Central to this is the pathos of beauty. That Beauty is such an inspiring and transformational force precisely because of its intimate existence to the fractured underbelly of human experience. That beauty dwells in the seemingly unfathomable darkness of the fourth age, in the homes and

relationships broken and scarred by dementia is a central paradox. When examined through the lens of the form the question becomes how we might untangle or separate out these entities to find reason and purpose whilst removing the sense of pain and suffering that progressive loss might impart. When such a void is understood as being part of the non-form, a realm where absence is indeed already replete with meaning and value, the question becomes how can we be faithful to the vacancy of loss, understanding the beauty concealed within its legacy.

*Nothing can fill the gap
When we are away from those we love and it would be
Wrong to try to find anything*

*Since leaving the gap unfilled preserves the bond between
Us. It is nonsense to say that God fills the gap.*

*He does not fill it but keeps it empty, so that our communion
With another may be kept alive even at the cost of pain.'*

Taken from 'Letters and papers from prison' by Dietrich Bonhoeffer

Lessons from journeying the non-form: accommodating paradox

James is supported by his friend and local neighbour John. He takes James from his flat on a twenty to thirty-minute walk to a community garden where he is a volunteer. The walk takes us across many busy roads, through housing estates and across a selection of the many green spaces that litter the City's landscape. There are landmarks along the way, a school, a set of streetlights that are persistently turned on during the day and presumably off at night, road names, signs and a constellation of people; footballers in the park, dog walkers, school children and shop keepers. They none of them know James or John personally but contribute to how he navigates the world around him.

The walk is highly significant in introducing me to James' fascination and eye for the natural world, but also demonstrating the importance of the spaces between points of focus. Whilst the

journey might be considered as a functional thing, to reach a point in time and place, for James it is an entirely independent experience through which he engages with the world around him.

'As we walk, we stop several times to look at various plants. Sometimes they have appeared between the cracks in the concrete paving, sometimes they are in dedicated flower beds. We stop to look at geraniums, daisies, tulips, wisteria and jasmine to name a few. He is particularly taken with the trunk of an old plane tree. It is thick with knots and knobles and the bark is rough and cracked. He is very impressed and stops to admire it sprouting up and through the paving slabs. We pass a school, 'are they closed at the moment?', we have just had easter and John tells him they are in the summer term and will have exams soon. There is the faint sound of children's voices in the background. We turn down quieter streets, more flowers, a park with a mosaic bench that they both point out, a tree stump of another huge plane tree. It has been cut to stand less than a meter high, yet new shoots continue to sprout. John remarks that the tree is a 'lesson for us all'. James remarks on some of the road names, one reminds him of a famous heroin of his. She rebelled against the church, but he can't recall the full story. We pass through football pitches. Skyscrapers rise above the tall buildings as we approach the garden. James navigates the streets at a ponderous pace but with apparent ease. An electric car silently creeps on us as we stroll down the middle of a quiet road, John ushers him back up onto the pavement.'

The garden is a site with extraordinary history. For centuries it was a pauper's graveyard that served one of the poorest and most violent slums in the city. According to local lore, it was also the burial site for medieval sex workers licensed by the bishop to work in the local brothels. By the time of its closure, it is thought that the graveyard held the mortal remains of approximately 15,000 paupers. The site was left to decay and was repurposed in 2006 from a derelict industrial work site to create a shrine and garden of remembrance. Its very existence as a place of tranquillity and splendour is symbolic of the close association between beauty, suffering and despair. More than this, the site is symbolic of a present absence that reflects the impact of James' dementia. There are moments when observing him sitting, standing and moving around the garden that he resembles the stereotype of a slightly confused, disorientated, old man. The effects of dementia mean that he does interact differently to the accepted social norm:

'On entering the garden James and I move around its boundaries and landscape independently, at times he looks perhaps a little lost, he stands under a tree for some time, apparently staring into nothing, then he moves next to a table and chairs but does not sit down. I talk a bit to John who mentions the hardy plants that have survived the extreme heat of the summer, he points out the evening primrose that grows

up and out from within the cracks of the thick grey concrete. The cherry tree that has blossomed, Dave (another volunteer) makes a joke that there are likely 'good nutrients and plenty of calcium in the soil underneath'. James stands close to the plants and flowers at times transfixed and motionless, he waves his stick gently in front of him as if marking something out. John remains near the entrance, to greet visitors and explain the local history. I have done a lap of the garden, taking in any new installations and familiarizing myself with the poignancy of the place. I see James standing alone under a tree and decide to sit at the bench next to him and bring out my sketch pad thinking that he may join me. He doesn't this time however, he moves around looking at the plants, carrying his bag with sketch book and pencils around with him. John comes over and asks if I want to use some of the pens to draw on the wooden logs. This is a feature set up by a local artist to commemorate the many women whose stories and lives have been lost to history. John brings the pencils and pens and there is an accompanying A4 sheet which describes the idea in more detail. It suggests the artist could draw a face on the wood and hang it on a tree or place it somewhere in the garden, to bring back to life or commemorate the many women buried here. There are some images on the sheet to give some inspiration. I sketch on the wood using a brown acrylic pen, the wood is home to lots of bugs and some of them get squashed under the nib of my pen, becoming part of the picture. Meanwhile James is meandering around the garden, his actions might look a little odd to the passer by as he takes a level of interest that is perhaps outside of usual social norms. He stands quietly, content by his own company but in the presence of many.'

The spaces that dementia creates represent a significant loss in terms of the form. Filling them with parts of a world to which there is a fading relationship ultimately works to reinforce the pain and suffering that loss creates. Below is an extract of my field notes where I am discussing the issue of companionship and loneliness with James' friends and family who had called a meeting to discuss his ongoing care. The first passage is a description of the perceived problem and the second relates to my observations and interactions with James and how they relate to this same issue.

'Others then join in the conversation to highlight that James possibly either cannot, or no longer wants to read anymore. This is significant given how much of an avid reader he was. John points out this is exactly problem, and that it is all well and good saying James is an introvert and enjoys spending time alone, but that was when he had things to do in his spare time, like reading, whereas now John fears that in the many hours in which he is alone, he is 'disoriented, frightened and confused as the world passes him by'. Elizabeth agrees and says that the computer (laptop) has now been put somewhere 'carefully', as if to

imply that it has been removed from his life. Robert says that James asked him something interesting the other day 'have you any advice for me' his response was just to 'keep on as you're doing', Mary says it is a difficult question to answer as there are 'no solutions to the challenges he faces.'

Elizabeth invites me to talk more on the topic of companionship in relation to James. I say that I have observed him gradually put things to one side that he is no longer confident or happy in doing, this includes reading and his computer. I describe how our instinct is to 'fill the spaces' but that I have observed this can also create tension. I suggest the spaces are appearing for a reason, namely that James is no longer enjoying what occupied them before, or that they are causing him stress. I am asked specifically about relationships and companionship services that might be of help to James. I explain that they do exist, and I refer to programmes at a local hospice that might be of interest. Tara also mentions the Namaste programme run through a different hospice. However, I caveat this by saying that for people with dementia, making new relationships can be hard, it can be stressful and a source of mistrust, paranoia and social discomfort. I move on to talk about the 'spaces' that form as things 'fall away' and how they can sometimes be filled with a closer appreciation of one's immediate environment. I say this is especially true for James, who I have observed form a close bond with his local environment. John laughs with great enthusiasm at this, 'yes, anything to do with nature is great!' he agrees with my observation and says that this is a way for others to connect with James, if they don't know what to say or do, then pointing to nature is an effective bridge. I suggest that whilst he might well be lonely, he is also perhaps forming more intimate connections, it is difficult to know for sure, however this is most definitely a pattern that happens in very old age, and advanced illness where people are moving into the end stages of their life. Jennifer (James' niece) tells me this is very helpful for her to hear, she talks about a walk they had taken in a park recently and his slowness really concerned her, she said she felt sad that he had stopped and stared at a tree for such a long time, assuming this once energetic man, full of life, was now fading away. She says that what I am saying is like his life is moving towards a different state and focus, 'it's like an exercise in meditation in a way?' she muses.'

That isolation and intimacy, absence and presence, might be inseparable entities, existing as intertwined and unformed when viewed through the lens of the non-form is representative of many of the participants experiences of dementia and was crucial in understanding and harnessing the potential of the non-form. For example, someone with advanced dementia might also be happy, healthy and content despite a perceived loss of autonomy, agency and even dignity. Where dementia takes us to the face of death, reality and illusion are no longer poles of a

spectrum but experienced simultaneously. This can destroy the polarising notions of success and failure and questions the very belief systems upon which the ideal of good care or a good death has been formed. Below is an extract of my time observing James with his carer Michael. It highlights the tension that might arise when form is applied to non-form, how all that is form can sometimes crowd out the non-form, arresting the appearance of its transformative value.

Michael sets to work in the kitchen. He puts on some latex gloves, and says hello to me, before asking If I will be doing an assessment now? In return I say there are no formal assessments for me to make and ask if it is alright that I stay. Michael says that is fine and that Robert (James' friend) normally sits in the front room but given my interests it would make sense for me stay and observe. He says 'Right. I will act like the doctor isn't here' he seems nervous. I try and reassure him. James is subject to a flurry of questions from Michael, about what he has done this morning, about what he did at the weekend, what he had for breakfast. James cannot answer any of them. Instead he says 'I can ask Robert' at various intervals in the questioning. Yesterday James can recall that there was a storm, he didn't go out, he remarks on the intensity of the sound it created. Michael reminds him that it was him who had warned him not to go out in the afternoon or evening to avoid the bad weather. Michael asks about dinner and puts his medications on the table for James – six pills on a white piece of paper. Michael is multi-tasking at pace; he has a lot to do in a short space of time. He puts the recycling away behind my chair, does the washing up and cleans the toilet as he continues to ask questions to James. He asks about his guests, dinner and any other visitors, especially about yesterday (Monday) and the weekend (he knew Jennifer, James' niece, was coming and it was a significant weekend for him). 'Ok so it looks like you did have a memory laps,' Michael announces. James picks up a book off the table, he knows it has some relevance, but he is not sure what. Michael pushes him 'that's the third time from my observation you've opened that book, but you don't recall anything about it' he tells him. He goes to get James' diary that is in the front room. The diary is Michael's initiative. He gets James to write something down daily, so as to help him remember. Michael reads something about a phone call, so he asks James about it. He can't recall so Michael gives him the diary. James reads it, a call from a friend – he called to say that his wife is unwell, and she has been admitted to hospital. Michael says, 'right so you do recall these events?' this phone call happened after Michael had gone, so the memory is solely dependent on James and the diary. The bad weather has also been written down, this, Michael says, was what he had asked James to do – he offers him positive encouragement as the task has been completed successfully in this instance and it appears to have helped James remember – certainly the phone call. The questions slow in terms of frequency and

depth, this is in response to the fact James has clearly been struggling to answer them. There has been a lot going on today with the multiple visitors, the zoom call, and the building work going on upstairs. 'Let's not confuse you' says Michael. Michael has heated James' food for later, he is now preparing to apply cream to James' leg. As he does so he says, 'this is what I can't comprehend, you remember some things in detail like nature, the arts and your trips to the community garden, and the bOLDr walks but the academic detail you can't remember', 'oh really?' James replies.

***bOLDr is the name of a group of likeminded people set up by James' friend John. The name came from the fact that they were all getting old, but they wanted to maintain an influence, hence the reference to the word 'bolder'. It was initially envisaged there would be talks and guest speakers, but now it is more of a social gathering.*

As he applies cream to James' leg he tells James (and perhaps me) that 'I don't like to talk about these events unless you've written them down because it might be an old memory and you might be living an alternate reality, sometimes you confirm that'. Michael looks up at me and says, 'when I see him start to soul search I cut it down'. He continues at pace to fold the sheets, finish the washing and tidy the kitchen surface, he asks if James is warm enough (James has complained that it is cold a couple of times during my visit), it transpires that he was cold yesterday and Michael had found a portable heater for the front room. James can't remember. Michael tells me that he has noticed that James' memory is different for different people. He explains that for example, he can often recall well the events done with John and Mary, but not always as much detail where other people are involved. Michael tells me that James' accounts of past events can blur into one sometimes and that there is sometimes a difference between the actual unfolding of events as compared to James' personal account of it.

Michael goes on to talk about James' 'welfare' saying that it is important, especially when he is out and about. James has always been able to navigate the local area very well, even when out on the tube or the bus he apparently can find his way home without issue, but Michael admits he is often worried. James agrees with Michael that his welfare is 'most important'. He says on more than one occasion that James would need a lot more care if he did not have the supportive group of friends around him.

Michael momentarily leaves the room, James has not been at ease since I arrived earlier this morning, he looks at the floor and announces 'so that's Joe' pointing directly at me as if to find a point of reference on which to orientate himself. I say yes and leave a purposeful silence, 'that's fine', James says. The

conversation has been fast and task orientated with little time to ponder, this is not a criticism, more a statement of fact. Indeed, the pace and rhythm of events is largely beyond anyone's control, we all have time schedules to keep. Michael has a lot to put into a short visit and is operating at a vastly different speed to James and also perhaps with a different agenda. James goes to take his tablets. He puts them in his mouth one by one and swallows them purposefully but slowly and with a grimace.

Michael comes back into the room and continues the conversation, discussing events of recent days and whether or not James can remember them. James cannot remember today's date and has gotten lost in his diary, so Michael says, 'if in doubt of the date, what is the procedure?'. James does not know the answer, so Michael says, 'look at the clock on the wall'. It is a dementia friendly clock that was bought especially for James. The digital display is completely out of keeping with James' flat, it stands out immediately, mounted on the wall above the microwave and displays the time boldly with the day and date underneath written out in full. James bursts into very loud laughter. Michael does not laugh at all. 'Now, what am I doing now' James says, 'we'll get there' he says calmly and with a smile.

Michael tells James that he wants the diary entries to come from James, this happens as James starts to write down what Michael is telling him. James flicks back continually from today to yesterday in his diary as if stuck, unable to navigate the structure of serial time. Each page in the diary is a single day and he turns back and forth continually. Michael tells me this is what happens every day. Lost in the pages James now refers back to the previous entry in his diary where he has written something down about a phone call with a friend. He does this periodically and as a result James has revisited the phone call several times, it is now lodged in this mind when it might otherwise have been lost entirely. Michael recognises that James is struggling with the diary in general. He tells me 'what I don't like to do is ask repetitive questions, it's counterproductive'. James tries to write about a visit from Ed who was part of the local pensioners team. He is lost in the days and asks, 'so I have this wrong?'. Michael looks at me and says 'I'm not sure if this is working' it seems more a question than a statement, he wants to help, but is not sure what to do, how to support his independence and memory but at the same time not draw attention to its progressive failure and the distress this might cause. I can see what Michael is trying to do, I suggest that it could be a useful exercise, but James is operating to a different time scale, the questions take time to process, and the answers can be slow in coming, Michael finds this helpful to know, he says 'ohh, perhaps I should start the diary exercise as soon as I arrive?'. I appreciate the difficulty he is faced with, the diary is helpful, as proven by James' now clear recollection of the phone call with his friend, yet it

also causes him distress and if done at the wrong pace can confuse him and disorientate him. Michael has to leave now and attend his next visit, he has been here for about half an hour, we thank each other for the time shared.'

Beyond an aesthetic ideal and towards the reality of care

Positioned from the non-form, where people imagine, create or innovate into the spaces created by dementia we might move beyond an aesthetic ideal to something that more accurately translates the reality of care. Here, the effects of dementia still leave their wounds. The imprint is both raw and undeniably deep, to the point even where it is close to breaking everything and anything we hold in high value. Below is an extract from a conversation I had with a woman who cared for her husband who had dementia. Their daughter was also present, and together they tell me about a perceived 'crisis point' at which they felt they could no longer care for him at home.

Daughter: For me the incontinence was the breaking point.

Spouse: Yes, I think that is true. He was incontinent, and we had so many nasty messes around.

Daughter: Yes, and I think, it wasn't just that accidents happened, but it was...I mean he was placing faecal matter in places that he shouldn't have been. There was a lot of scrubbing out the carpet and things.

Spouse: And that's one, another reason why the social interaction with other people was hard, because with family they knew, but with other people you couldn't really go to their homes because -

Daughter: - That's it. You didn't know, or you were worried about him sitting on sofas and things just in case. Again, if he kicked off you didn't know if he would have broken stuff or injured someone.

Spouse: Yes.

Daughter: So definitely, feeling like he needed to be in a safe environment to help us not be anxious about him.

Spouse: Yes, because he busted that door.

Daughter: Oh yes, the French window's broken out.

Being able to spend a significant amount of time with people in their daily lives allowed me to see past the aesthetic ideal of care towards a harsher reality. Below Betty tells me of her overriding impression of caring for her husband over so many years.

'The conversation moves on and John continues to play the poppet board. We talk about the 'ideal of care' and how as Betty had once told me 'care-giving is mostly about shit'. She laughs, it is a favourite quote of hers from Allan Bennett and she has mentioned it many times. Indeed, this is what she has quite literally allowed me to see. We discuss how people are happy to think of care in terms of compassion, kindness and all things 'nice', but there is a darker side, symbolized by physical shit and the process of toileting. It extends to frustration, monotony, boredom and isolation, yet it also co-exists with the beauty of caring for someone approaching death.'

Where we find ourselves in the realm of the non-form, able to acknowledge the reality of loss and create into the space then the dark wisdom of suffering has the potential to somehow and at some unpredictable point, illuminate our lives. In the following extract an interview participant tells me of a desperately sad but equally heart-warming moment of intimacy between her and her mother.

'And it might not have been much, but I think I mentioned, you know even towards the end (of her mother's life) if I put my head, sort of, into here (she gestures to the side of her neck), her hand would just come up and stroke my hair, which is what she used to do when I was a kid, when I was upset. I put my head in her lap, and at various times during that journey (towards the end-of-life), if I got upset, I'd just sit down in front of her and put my head on her lap and she'd just sit there, and you know, we'd just talk and she'd stroke my hair, and it was very much...In fact, that was something she needed. In fact sometimes she got really, you know, quite upset and...almost aggressive, verbally aggressive because she just was so frustrated about the whole situation and 'I'm useless' and you know, 'You do everything for me' and 'I shouldn't, I don't like this, it isn't me'. I think one time I just couldn't do anything else, I just burst into tears and realized that actually, that's exactly what she needed. Because when she felt she hadn't got use in life, well...she had, she's my mum.'

Creating into space as a means to healing

‘Breakage, whatever its cause, is the dark complement to the act of making; one implies the other. The thing that is broken has particular authority over the act of change.’

Louise Gluck

The notion of healing is rarely discussed in the literature around dementia or indeed the end-of-life. It has become something of a lost word, something that might be difficult to define or capture the essence of. When used in the context of the dying process it might appear contradictory, of limited meaning or value, yet this would depend on the lens through which we view the word, and where the locus of meaning is placed.

Healing is distinct from the notion of a cure which might be achieved through the systematic and meticulous attention to correcting processes that have become disordered, returning them to the state to which they were before. Healing is about accommodating tension, bringing a greater sense of balance so that people might face the future, and the challenges within it, unconstrained by fear and welcoming of the potential such challenges hold for growth and change.

In this way, the places which we heal are distinct from those that seek to cure. Whilst the process of cure drives us away from the source of pain and suffering, restoring our carefully assembled form, the process of healing is intimately associated with all that is broken. Learning to accommodate the dark providence of all that is fractured and broken is the very nature of the non-form.

Dementia provides a powerful lens through which to understand this process in greater detail. How people confronted by loss might move into the spaces that are beset by fear and grief, whilst learning to navigate them in such a way that acknowledges the authority all that is broken holds over the transformational impact of what is made in response. It is here in the non-form, unbounded by the structures that work against loss, that people might encounter moments of transformation, moments where there is potential for the growth and change that is fundamental to how we heal. In the following sections I will describe what I see as a series of events that allow people to create into the non-form as a means of healing. In no particular order these include; innovation through moral experimentation; losing control and trusting in the space of the non-form; developing roots and wings as a means to becoming literate in loss and finally accommodating the transformational presence that loss might bring.

Innovation through moral experimentation

It is common for structure to be used to remedy the uncertainties brought by dementia, directing us to towards a perceived 'right thing to do'. Advance care planning, advance directives or the Mental Capacity Act and the Best Interests decision process, are just some of many examples. Such structures can occupy our focus, distracting us from the reality of the spaces in which uncertainty's persistent but concealed presence resides.

Betty reminisces about her last visit to the hospital with John, he had haematuria and had been referred by his GP for consideration of further investigation, Betty says there was a conversation with the urologist, following a hilarious attempt to gather an MSU (Mid-Stream Urine: a sample of urine caught mid-stream). The conversation was completely in line with Betty's thinking and the outcome was to leave things well alone. She also tells me that John has been complaining of intermittent tooth ache. She notices it when he eats and occasionally it catches him, he jumps and winces, she says 'I think it must be an exposed nerve' or something like that. She doesn't think he is in pain the rest of the time as she would be able to tell. There is certainly no indication he is any discomfort throughout my time with him today. In fact, as I remark to Betty, he is on particularly good form today which she agrees with. Betty says that she asked John if he would like to go to the dentist and his instant reply, 'no, definitely not' which she says she was relieved about. Since asking him she has decided to leave it alone and has been encouraging him to eat on the other side of his mouth, which she says, has led to some interesting conversations as he often does not understand or cannot hear what she is saying. I am quite taken with this idea but do not explore it immediately with Betty. I am struck that she has asked him and listened to him on this topic but on multiple others she seems to act more on his behalf, in his best interests so to speak. She makes decisions for him, there are multiple examples....

..... Betty shares a story about how she poured herself a glass of sherry the other night and sat with it in her armchair. John said, 'oh that looks nice!', Betty replied 'yes it is' but she did not offer him any. She goes on to qualify her actions by describing a Burns Night sometime in the past where he 'downed' his glass of wine, he moved onto whiskey and became quite transfixed on it to the point that she felt he was 'tipsy', so she put a stop to him having alcohol. I ask if this was in part to help her, as caregiving might become more of a challenge were he to be drunk. She says yes, but there is more. Her view is that he was not enjoying the drink, he was 'just knocking it back' which to her defeated the purpose entirely.

This to me is something of a contradiction, I am surprised that she will listen to his views on dentistry – especially when his teeth are essentially rotting, whilst she will overrule him on decisions such as drinking occasional alcohol – where the harms might be perceived as minimal, yet he indicates clearly that he would like some. I decide to use the two examples and their apparent opposition to explore this in more detail with Betty.

I ask what it is that she takes from John to help make these decisions. I give her the two examples, the ‘no’ about dentistry and the ‘yes’ from alcohol and wonder how the decision gets made. She talks about dentistry and how the process of what is involved is deeply engrained within him, it therefore makes sense to talk to him about this, she says. As if his knowledge of what is involved is etched into his mind in a way that transcends the effects of dementia. There is more; it is her knowledge of what ‘dentistry is to him’, I suggest that she has an intimate knowledge of his association with dentistry, almost an intuitive sense of what is right or wrong because of their relationship. She sees and agrees with this point. I ask her what she would do if John had said ‘yes’ to the dentist’. She hesitates for a moment and says she might put out the feelers to organize a domiciliary visit. But then she goes on, it is unlikely that he would open his mouth even in the event of getting a dentist to visit. There is also a question as to what ‘yes’ would mean. To Betty she thinks he would only answer yes if he was in persistent troublesome pain, it is not so much a yes to the visit of a dentist but more of a ‘I’m in pain and need help’ response. By the same logic, ‘no’ means that I am fine, and doesn’t necessarily mean I don’t ever want to see a dentist.

To me this process is entirely foreign to the professional approach, and I tell Betty this. I describe to her what it would be like for me as a doctor, that I would have to make a unique capacity assessment to the decision in question, I explain that it is highly unlikely that John would demonstrate mental capacity and that therefore, regardless of the ‘no’ it is likely a dentist would be called after doing a best interest’s decision. There is a clearly defined structure to the process, despite elements of it being open to interpretation, it generally follows a predictable pattern. Especially in this scenario given it is a health issue that can be ‘fixed’ or treated. Betty listens and is interested by the topic. She questions who the decision is for, perhaps implying that she is excluded by the professional model that, despite involving family and friends, is still very patient or person centred. Betty’s decision making is often centred on her and the impact it has here, but also their relationship, as if this is an independent entity deserving of its own recognition.’

The effects of dementia will often lead us to these increasingly narrow borderlands where uncertainty and the unknowable unknown resides. Here, beyond the closed systems we have created that are ethically and morally governed, there are other forces at play. Moral experimentation and how this impacts on our interpretation of meaning can shape decision making and contribute to what is understood by ‘the right thing to do’.

‘Sharon arrives, we had not planned to be together, it is an impromptu visit on her part. She sits by her mum (Angela) to say hello, but she does not stir. She says out loud ‘I was going to ask about the medication, Nicole what medication is mum on?’. This seems to be the purpose of her visit. They go into the kitchen together to discuss this in more detail. I stay with Angela in the front room. I can hear their conversation through the door, Sharon is wanting to wean her off her quetiapine ⁵, she is currently on a daily dose. They discuss amongst themselves and Sharon suggest that they give it on alternate days and think about stopping it. She had previously reduced the dose from the original prescription that was written by a psychiatrist some years ago during a time of challenging agitated behaviour. Sharon gives them a direct instruction to go with alternate days for a ‘week or two’ and then stop it, ‘depending on how mum is’. She returns to the front room and sits on the sofa next to her mother. I sit in the chair opposite and ask how Sharon has been. She describes ‘doing the garden’ recently and she is now stiff. I sympathise and we have a laugh about this. Nicole and Freda come into the room and stand. Sharon recounts the conversation they had in the kitchen to me. Sharon says, ‘because Ruth isn’t on anything at all’. Ruth is another person with dementia who attends the dementia club on a Friday with her carer Irene. Ruth was thought to be dying at one stage, she had Covid-19 and her medications were stopped and they have not been restarted, if anything her condition has improved. Nicole says they did halve Angela’s quetiapine dose some time ago and tried missing it out altogether but ‘she started swearing’, she covers her mouth after saying this, expressing some sort of embarrassment. Sharon is aware of the side effect profile of quetiapine, especially the risk of stroke as this was explained to her at the time of prescription, she asks me what would be reasonable, but she insists not in a professional capacity and she understands I cannot give medical advice as her doctor. I explain how these things often follow a trial-and-error type process as it is not always clear what is causing what where these drugs are concerned. As a general principle, a less is more approach to the medications she is on might be considered positive. I can tell this is not new news, and Sharon is already set on this principle. We talk some more about Ruth. I have met her at the Friday

⁵ Quetiapine is an atypical antipsychotic medication often used in psychosis, mania and bi-polar disorders. It is prescribed for challenging behaviour in dementia and this was how Angela came to be taking it.

club and spoke to her carer Irene. She was in a wheelchair and was being looked after by the palliative care team. I had discussed with Irene some of the challenges she was facing. She was particularly concerned as she was no longer eating anything, and her swallow had deteriorated significantly. She had been syringing small amounts of fluid into her mouth, but the palliative care team had been cautioning against this concerned about the risk of her aspirating. There was tension here and Irene wasn't sure what was best to do to do. It transpires that Irene and Nicole know each other and often phone each other for advice and support. Nicole said she had sided with the Irene's opinion, that it was right to continue syringing fluid into Ruth's mouth. Sharon doesn't say anything, I acknowledge that this is a very difficult scenario. Sharon says she was planning to check the garden, I ask if I can join her. Both Nicole and Freda say that would be good as they think Angela has 'done something'. They want to change her. They move her onto the commode and close the curtains front and back.'

Where there is no set way, no obvious right or wrong thing to do, there is potential for tension and distress. But it is also where there is potential for healing. Moral experimentation was identified as the first step in this process, allowing people to enter the world of the non-form in such a way that they might begin to acknowledge and accommodate its potential.

Losing control: trusting into the space of the non-form

Where structured approaches no longer offer a point of reference on which to orientate a path forward, participants described a process whereby they would have to learn to lose control, to let go and trust that something, at some point, will come to meet them.

'There is a pause in the conversation. We look at John who continues to methodically plod away at the poppet board 'he never got the notion of turning it over, it's all fine, it's all lovely' Betty says. She imagines him briefly in a nursing home, with a plastic beaker for his tea, 'I hope he never goes to a nursing home' she says, 'it is important that he gets ignored'. It is said almost with humour, but she is being sincere.'

Developing roots and wings: the process of becoming literate in loss

Ultimately this was found to be part of a cyclical process. As people learnt to inhabit the non-form, to lose control and become lost in the void, they inevitably come to meet the person with dementia where they are, away from a definition of loss that understands it simply as a nothingness that is bereft of meaning or value. When this happens people begin to build a

confidence and literacy in what it means to care for someone with advanced dementia in the face of death. Resource for the development of death literacy was found to exist in abundance within the non-form.

John breaks the conversation by mumbling something that is indecipherable, he gestures with his finger. Betty says his language is getting worse, but then says that is because 'I don't talk to him, I gave up' she says. I say this is perhaps understandable as it relates to what the end goal is, I say that it is normal to talk to a child and encourage their speech as you will see it develop and blossom. The same is not true for John, he is on a different trajectory where fostering and maintain resource is fundamentally different in relation to supply and transference of energy and effort. Betty says there is not a need to maintain, but to 'accept him for who he is now'. In a similar vein, she refers back to her frequent statement about wanting him to die, she says it is that she wants him to die 'whilst we are ahead'. By this she means 'before he is worse'. The cat jumps down from her lap where it has been sitting peacefully as she strokes its back. John points to the cat and mumbles something with a smile. Betty nor I try and decipher what it is that he is getting at. Instead, she observes that before dementia he did not pay any attention to the cat, but now appears to be quite fond of it.'

The process of learning to lose control, before meeting someone where they are, was found to be cyclical, repeating constantly with each new change that dementia brings. This process allows people to develop both roots in the form, and wings to journey the non-form.

Betty goes to the back of the room to fish out an old photograph of John. She shows it to me, he is wearing a red polo shirt and wears a rucksack, he is out walking somewhere. He looks very different, he is a strapping man, and has chiselled good looks. I say he is a very good-looking man and Betty agrees, he has white hair in the picture despite being only in his forties or fifties. She shows the picture to John saying, 'I don't think he's seen this one before'. He stares at the picture for a moment and says that the person has a 'funny face', Betty laughs and asks, 'do you know who it is?', 'I haven't got the faintest idea' he replies. These moments of conversation often surprise me as his communication is often very limited. Betty laughs and tells John 'It's you!', she then quickly takes the picture away. John goes back to playing the poppet board, not in the slightest bit affected by the transaction, not upset or surprised that he can't recognise himself anymore. Betty turns and says to me, 'see, some people might get upset by something like that, but it doesn't bother me, it doesn't matter, in fact I feel sorry for the people who get upset by things like that.'

Betty turns the conversation to a current news story, that of a twelve-year-old boy on intensive care. There is currently a court battle raging about whether he should be allowed to die. She talks about how distressing this must be for all those involved. She talks about how children teach us to let go with this being the ultimate example of this. She says the milestones of getting old, gaining independence and so forth are important to the parents as lessons in stepping back, detaching and letting go. She provides a quote delivered with a tongue in cheek tone 'I'll tell you something now young Dr Sanyer...having children is all about giving them roots and wings', I talk about how such a phrase is also important in death and caring for a dying person, Betty laughs that John has the roots 'but the bugger won't fly!'.

The transformational presence of loss

Being able to move between form and non-form allowed participants to recognise that the vastness of the non-form, its indecipherability, and its disorientating meaninglessness can also become a place of great intimacy and presence. This was frequently seen on trips to the community garden with James. Here he would stroll the garden, seemingly lost within the detail within its varied colours, scents and sounds.

I notice that James has become rather obsessed with the scent of some of the plants, he is now tugging vigorously at a bush and sniffing his hand. John says it looks as if he is 'getting high' off the smell, reflecting the intensity of his actions. I wonder over to James to see what it is that has caught his attention in such detail. Dave comes with me. He wants to show James the rosemary bush and how strong its perfume is. On route Dave is distracted by some people who want to ask more about the site. I carry onto James as he repeatedly and vigorously strokes the bush and sniffs at his hand. I don't recognise the plant as having a scent and so check for myself, copying his actions, I am surprised to find that it has a strong and sweet smell. I use my phone and a plant identifying app to find out it is called 'salvia', 'baby sage' or 'hot lips' colloquially. As well as a strong scent it has tiny white and red flowers, the red has an intensity to its colour. James seems particularly taken with it and we stand together for a few minutes sniffing the scents, he notices the bees that collect the pollen and points them out, I watch with a level of detail that I have probably never done before, their tiny legs moving in and out of the flower head.

Dave now joins us and shows James the rosemary. James is now awestruck with the scent from this new plant. After several more minutes sniffing the rosemary and sage James comes over to John by the entrance and sits down on a chair. John asks him if he has been enjoying the scents and smells and James laughs.

John remarks again that he looked like he was 'getting high' off the smell. He says we should take some home for him and Dave offers to go and find some secateurs and make a small bouquet. He disappears and comes back after a few moments with a beautifully made bouquet of sage, thyme and rosemary, there are small flowers on each and he ties them together with a bit of twine. It looks beautiful and James takes it gratefully. James has been on his feet for over two hours now, wandering the streets and the garden. In each moment he has been immersed in the landscape, intimately engaged with nature and the wildlife. It is a wonderful example of a relationship that is strong and blossoming through his dementia.'

That intimacy exists within the harsh, inhospitable and disorientating spaces created by dementia is another example of the very essence of the non-form. Here, the effects of dementia mean people are no longer bound by the structures that define our rational and cognitive world. Instead of something that only invokes fear of loss, dementia becomes something that teaches us about the absolute and irreversible event of change that is normally only experienced at death. Here the departures brought by dementia bring grief and sorrow whilst simultaneously providing an opportunity for transformational presence. The potential for this speaks to the nature of the non-form. An emptiness into which an irreparable grief is created, yet deep within these spaces is the realisation that nothing can fill such a gap, instead warmth and shelter from grief and loss is provided by the intimacy created by new relationships and a realisation of an unending depth to existing ones. The gap is left unfilled as a means of preserving the bond we have with our own vulnerability and mortality. This point of transformation is found deep within all that is broken and is symbolic of something that comes alive within us, when faced by the presence of loss.

'Sharon offers to take me back to the station in her car, we talk about her work, she runs a property letting company and her work is therefore very flexible and can accommodate the relationship she has with her mother. She says she dedicated Thursdays as a 'mum' day. She talks about how it has been like this for some years now and she wonders when she will die. We talk about death being a relief. Many people have told me about the relief death can bring in my clinical work, most people broach the topic as something that is a taboo, often conveying to me a sense of 'am I allowed to say this?', however this is often in the context of cancer or some other relatively short-lived illness. Sharon has no pretence as she enters into this topic. She straight away says that it will absolutely be a relief when her mother dies. She implies that she has almost been anticipating the relief that will come as if almost yearning for it, yet she quickly follows this up with a comment that seems to have only recently become relevant. She says that 'sometimes I wonder if it won't be as much as a relief as I expect'. I ask her what she means, she tells me

that caring for her mum has become a 'chapter of her life', her week and lifestyle is organized to accommodate her mother, even though she does not do the practical care, in some ways this has preserved her ability to maintain the mother-daughter relationship. Her death would create an absence now that would be significant. In the same way that death in other contexts creates an absence through the loss of the person, she has perhaps acclimatized to this notion but not that her dying will create another type of absence, a hole in time and space that has not yet fully revealed itself. How will her relationship with Helen and Nicole change when her mother is no longer there to bring them together? Sharon points out a 'memory loss café' on the way back to the station, she still goes on a Friday, even though her mother is unable. Her life has been changed by dementia and new avenues and relationships have formed.'

The entangled borders between form and non-form: opportunities and outcomes

My decision to separate out my description of form and non-form was taken to demonstrate the difference in perspective the two might bring. Yet my experience of them in the real world was that they exist as entangled entities, with components of both often operating in and around each other. Here, form is born out of non-form and vice versa. The rational, cognitive structures that hold and contain us collide, entangle and exist alongside a structureless world where people have no choice but to innovate, to create and experiment with what works for them and their situation.

'As we chat the entertainer arrives. He is introduced by Martin (a volunteer at the dementia café), as Jonny. He is short with a very slight build. His skin is of an Asian complexion, he has dark hair and a neatly trimmed short beard. He starts up some music and starts to sing. I make my way back to the kitchen to write some notes. In the Kitchen I stand in the corner and jot a few things down in my pad, I am approached by a woman I do not recognise, she asks what I am doing so I give an overview of my research. She tells me 'I was housebound with my husband for one and a half years until he died'. She delivers this dead pan and as a matter of fact. She describes how he spent the early part of his diagnosis in complete denial. This meant that he would not engage with any of the clubs or organisations that she sought out to support them. When she did manage to persuade him to attend, he would complain to her that 'they made me feel stupid' and refused to go back again. She tells me as a matter of fact that I 'shouldn't be writing notes but should be out on the dance floor' she says I need to see how people move and 'feel it' to get a better understanding. She leads me out of the kitchen and into the hall, she points out

Trudy, a Caribbean woman who is a former nurse. She tells me that she will 'cling on tight' when she dances but doesn't explain the significance of this to me. As she talks, she begins to move her hips and dance to the music. Ken approaches us, delighted that I am on the dance floor. He dances with the two of us, he swings and pirouettes in a joyful manner. I feel self-conscious, but no more so than I do as an observer. As we dance, I see Ken's wife at the periphery, she is dancing on the spot cautiously and I say hello to her. She says that she hurt her back last week and is trying to keep it rested, I complement her on taking part, she says she will 'pay for it next week' when she feels stiff and sore. The new woman points out other people, there is a woman dancing with her husband who she says is in complete denial which is causing his wife to struggle a great deal. She takes me over and introduces me. The woman and her husband are young, perhaps in their sixties. The man is dancing furiously, moving every inch of his body in a frantic and what appears to be disjointed manner, he is sweating but does not let up for one second. His wife is pleased to talk to me. She tells me that he spends all day at home not moving from the chair, she give the picture of him being almost in a state of stupor and says to me, 'you wouldn't believe how he is here unless you saw it with your own eyes!'. I ask if he has always enjoyed music and she says he has, in particular rock music. She points out another man who she thinks I would be interested in talking too, he is also young and a former 'accountant'. After dancing for some time, I go and sit next to him and introduce myself. I explain who I am and what I am doing. He does not say much initially and so I probe a little into his background being cautious of what to say and which words to use with respect to dementia. He says he is a retired solicitor. His wife is a couple of seats down from him and is a teacher, his son lives in Australia he says. The music changes to rock'n'roll and he is given an offer to get up and dance, we go together, joining the woman I was speaking with moments before. Next to me another woman is introduced to me., She is the daughter of someone who is slowly moving her way around the dance floor, she often comes up to me and tells me 'there is no talking allowed on the dance floor'. Her daughter laughs at this as we are both the recipient of her scorn on this occasion. She tells me, shouting over the music, that it is a real struggle for families. She says that currently she is meant to be at work, but she has 'bunked off'. Her sister normally brings her, but she was unavailable today and there was no one else so she has assumed the responsibility and gambled that she will not get called by her boss, 'I hope my boss doesn't call me whilst I'm here' she tells me. It is not said in jest and there is no smile, but genuine concern. She talks about the financial strain and feeling emotionally exhausted, it pours out without probing as if it is uncontainable, an overflowing cup of struggle, she talks loudly over the volume of music and amongst the raucous and joyous dancing that follows in its wake.'

The meeting of these two worlds is not necessarily a hard interface but more of an interwoven landscape whereby individual moments may contain aspects of both. In such moments people might feel crushed by the colliding weight of the two worlds, or liberated by the opportunities presented by an appreciation of what either can offer. The difference revolves around how loss, deficit and vulnerability are conceptualised. Where the maintenance and preservation of all that is of form is understood as the central endeavor, a route to achieving meaning, value and purpose, the proposition of all that is non-form is to be remedied. We are encouraged to value the social contribution of people with dementia without recognizing that this too will wane, leaving us with nothing to value but everything to fear. The more the non-form becomes present in our lives, the more structures we build to conceal it. The weight of irresolvable pressure breeds tension and conflict which does not come to rest. We struggle to ascribe value and moral worth to loss in a rational, structured way or in a way that is uniformly positive for all.

'Betty also talks about the idea of a completed life. She again says that me introducing her to this has been of great significance. She has spent lots of time thinking about it, and reading around it, and she feels it is a useful concept for her to relate to, something that explains some of the things she feels and has experienced. She comes back to the idea of assisted dying, how she does not want to be like John and would want to end her life if faced with a similar situation. She says she feels 'fairly sure' that John would also think like this. Betty is unsure how dementia and the problems of long-term care of the elderly with significant needs and dependencies can be sustained, and that a solution would be to 'bump us off' she says in her customary blunt tone. We talk about this briefly, I am careful not to deny her feelings, but introduce the nuance that I feel is so important to this topic, I cannot deny the idea of death being a welcome thing for her and John, intuitively I feel this too, but at the same time I also sense value in my own relationship with him and what I have learnt from the both of them. It is something that agnosies and does not come to rest.'

The relationship between structure and space

That there is a relationship between structure and space is central to navigating the entangled junctures between form and non-form. To describe this, and the potential of working here, I will focus on the concept of time as an example of how structure interacts with space.

'Betty says that Megan (John's daughter) had wanted to play her viola with John when she was down to see him. She said they will play a duet, they tried but Betty says it is not possible because he 'plays in his

own time', she thinks it will be interesting for me to see John play, I am open to this and Betty says it is about time that she gets him up now anyway.'

Humans have a universally intimate relationship with time. We dance to the rhythm of the passing of time, pulled along its current towards the vast and empty timeless planes of death. We live by time, we inhabit it, and in doing so exist firmly in the structuring world of the form. What could possibly be more universal and obvious than the passing of time, the rising and setting of the sun and the changing of the seasons? And yet, time has been shown to be more complicated than this. Much in the way the sun appears to revolve around us when it is us humans who are really spinning, the structuring forces of the form only give us part of the picture. The same is true of time. In his seminal work, 'The Order of Time', Carlo Rovelli describes how the characteristic features of time have been proven as approximations (Rovelli 2019a). Such approximations have been made based on our perspective, of the search for order and meaning. Yet the growth of knowledge on this subject has led to a slow disintegration to the familiar notion of time. He describes what we call time is actually a 'complex collection of structures', that under increasing scrutiny fall away to leave 'an empty, windswept landscape devoid of all traces of temporality, a strange alien world which is nevertheless still one to which we belong'(Rovelli 2019a). This is what I observe as the non-form and how people with dementia gradually move from the highly structured realm of time towards a world that is largely 'timeless'.

I ask when John's birthday is. He will be ninety four years old in January she says, they don't make a big fuss for it. I might have expected. However, his grand-daughter Kate enjoys having a cake and candles, it strikes me the process is more for her than for him, it would be strange to have a grandfather who doesn't have a birthday, I suspect.'

That people might be stuck between a place that is time limited, a place where we have deadlines, work commitments, and a timetable to follow, and a place that is timeless, where the time is empty, as if not moving, yet at the same time all consuming, poses great tension.

'Alex says that 'I have to be careful not to break the speed limit now!'. This is in reference to two things, firstly it has been altered relatively recently to twenty miles-per-hour from thirty, but also, as we discuss, the pace of life, the rhythm of the environment in her mother's house is slow, it is in some senses a timeless place, where things just happen, and she just exists outside of structured norms. When Alex leaves, she feels a wave of 'rush', the pace of normal life is far greater, she has places to be and timescales to meet, also the frustration of listening to repeated conversation and the 'desperation' of having to think of

something new to say can build up a head of pressure. On leaving, the pressure escapes with a rush which can result in her speeding.'

'As the time passes Sharon looks at her watch and says she needs to get going. The time has passed quickly, and I will also need to leave. I say goodbye to Angela, she is slow in her response as I wait for it by the door, eventually and after a long pause, it does come. A simple smile and a nod. Sharon is already by the door and ready to leave. We get in the car as Sharon has offered to give me a lift back to the station. In the car Sharon talks about how things seem static to her, the waiting seems endless. I suggest there are subtle changes - her swallow is worse, and they are using thickeners all the time (although this maybe through an abundance of caution that the diligence of their care often necessitates). She is also very sleepy and has been for my last few visits. Sharon is almost relieved to hear this perspective, something she says she does not notice. She says how she 'doesn't really do anything' towards her mother's care but that she still feels a weight of responsibility.'

Integrated not opposing worlds

I have learnt and discussed how through the non-form tension, paradox, conflict and vulnerability might be considered as part of what makes us whole. In the 'pathos of beauty' ([Page 138](#)) I describe how the beauty of human nature is such that it cannot be confined to some untouchable realm, a realm in which there is a one-sided relationship to perfection. Without an element of risk, doubt or pain, the essence of our humanity, of what makes us whole, is lost. In the same way the form and the non-form exist together, not as opposing worlds but as existing as part of a constantly shifting equilibrium. Here it is the structures of the form, that navigate us through life's complexity, taking us to the frontiers of our outermost limitations so as to introduce us to the non-form. That we might move into this space and realise its potential is as a direct consequence of all things form rather than in spite of it. It is also the process by which all that is form is created from the non-form before ultimately returning to this same state. It is this transition however which can be troublesome, having come to rely on the proven success of the structures we have created, it makes little rational sense to then abandon them. Yet this is exactly what is required to help people navigate this intersection, to help people accommodate loss and transition from living well to dying well. We might learn to do this from people affected by dementia who have walked the well-trodden paths of the form only to dance into the spaces of the non-form.

Pat says she likes to go to the garden centre to help the 'old ladies who are less fortunate'. I find myself feeling a little nervous and holding some responsibility for her whilst we are out. Legislation and risk assessments from academic institutions flood through my mind momentarily. I look back to see if Linda or Donald are still around, but they are not. I presume this walk is well known to Pat and represents a well-trodden path. We come to cross the road, Pat remarks how many cars there are. I find myself in a situation where I am not sure who is leading who, I respond to her lead yet want to cross the road as quickly as possible. Once in the car park we stop to look at the houses, she points out things that she ponders over without giving a specific point of wonder, mumbling or giving the impression of conversation without actually forming it. We look at the back of houses and the sacks of soil, sand and building material that lie in the forecourt of the garden centre. We begin to walk round the side of the garden centre that takes us to the plant area out the back. She points to various old people that are using wheelchairs and highlights these people as the ones she likes to help. She asks me 'have you seen him at the back?', initially I'm not sure what she means, 'he's so lovely, I'm not sure he's here today' she says. She gestures towards an animal pen at the back of the garden centre where I can see a goat sitting in the grass. 'Yes, he is there I can see him' I say, we move closer past some trees for sale to have a look, she remarks on the goat's beard and its length. 'he's all alone' she says. As we walk and look at the flowers I ask if she can recall who I am and why I am here. She has no recollection. I remind her about my work in non-specific terms (Donald and Linda had told me earlier that she remains in complete denial of her memory problems, so I am weary of using the word dementia with her). As we meander back through the garden centre a man heads towards us with a wheelbarrow 'hello Pat!' He calls out, 'is this another boyfriend?!' he laughs and gestures to me with his head. We all laugh, I say 'so I'm not the only one?', 'oh no far from it!' he replies. He stops the wheelbarrow and asks how she is. He smiles with a warmth but does not chat for long, he moves off with his wheelbarrow and I don't get to introduce myself properly. We come back into the forecourt and Pat wanders into the shop. She reads the signs 'no time to bake? pick up a cake!' and giggles. We look at shelves stacked with preservatives before moving towards the exit. There are entrance and exist queues, perhaps a relic from Covid. We are in the exit queue and I am not sure how we will navigate it without buying something. Instead, the cashier waves and says, 'hello Pat, how are you?', outside Pat tells me they are 'lovely girls'. We stroll back to the house. The cars are patient as we sometimes block them in the car park to look at seemingly random things in the forecourt or to do with the surrounding houses. Pat has only gotten lost once since being diagnosed with dementia a few years ago, yet she goes out walking daily. The involvement of services has led this type of activity to be defined and

labelled as a risk. A risk to which there is an assessment and structured response. Yet to walk with her into the spaces I find many relationships that are supportive, protective and enabling'

To create an ideal solution to end-of-life care by extracting and distilling notions of control and autonomy, beauty and joy from a process that is inextricably linked to uncertainty, dependency, suffering and profound sadness is unjustified by the evidence presented. Using the construct of form, non-form and its multiple and interwoven borders requires such tensions to be accommodated, to be understood on within constantly shifting spectrum. The description of this analytic is designed to help make sense of what it means to care for someone with dementia at the end-of-life beyond a reductionist systematic approach. Understanding the role of paradox and tension and how certain practices and narratives around care can both protect, and at times erode our capabilities to heal is important when designing services or making interventions to support those people affected by dementia.

'As we pass through the door, Sharon goes straight upstairs to use the bathroom. I go into see Angela in the living room. The curtains are drawn because of the heat, Angela sits in her normal chair asleep. She has her makeup done, her hair brushed and washed and her clothes smart and clean. I sit next to Angela and rest a hand on her arm she turns briefly and smiles at me before returning her head to the other side and going back to sleep. She does not speak. I go to sit on the chair opposite that has been positioned for me by the carers. Sharon comes down and sits next to Angela. The conversation that follows does not really revolve around Angela or involve her in anyway. Occasionally she hums or smiles but for the vast majority she sleeps to the sound of our chatter. We talk about a selection of things. Everyone remarks that the expectation was she would have died by now. They talk about their experience of the memory lane café. It transpires that Helen also knows many of those in attendance and she asks after them. She also knows their back stories and history as she used to take Angela when she was mobile. She is concerned about Irene, another carer who looks after Ruth. She is pleased to hear that Ruth is doing better. They reminisce about people who have now died including Sarah's mother 'what a character she was!', their memory lives on through conversation. There is discussion about Sharon's family, about the weather, the experience of looking after Angela in the heat. Sharon asks how her mother has been, Helen talks about using thickeners all the time now, they had decided themselves to reduce the medication she was on, and this has had no negative repercussions. She is not any more restless or agitated and remains calm but withdrawn. Angela snores and breaths regularly as we talk. She does not affect the conversation but instead provides the platform for it. She is the reason for the meeting of people, for the flow of conversation

and the updates people seek and receive. She is also a platform for rest and recuperation. Sharon is served tea, fruit and biscuits, as am I. There is an absence of pressure in time that is often so palpable during my travelling across London to visit participants. Here time stands still, there is a peace and contentedness where the only purpose is to be present, and from this the conversation evolves. This is highlighted towards the end of the visit where nearly two hours have elapsed without me really noticing.'

Summary

In this chapter I have introduced the idea of two worlds, form and non-form. My description of all that is form is provided through the lens of advanced and advancing dementia, as such it may appear to be critical of the structuring processes it provides. It is not my intention to devalue or dismiss the importance of structure and the organisation of care, more so to point out previously unconsidered limitations that, if left unrecognised, can impede progress. Similarly, my description of the non-form is not designed as an antidote to the multiple tensions that I have described. It is more an attempt to portray a realistic account of the complexity that arises as we sit at the juncture between these two worlds and the implications this has when considering how to respond. I have attempted to describe what I see as the lessons to be learned and the potential that might arise from a closer affiliation to all that is non-form, paying particular attention to the idea of healing into space. The final part of the chapter attempts to depict the reality of the relationship between form and non-form, how they might exist as integrated rather than opposing worlds, and how viewing them in this way might allow for genuine progress.

Chapter Six

**Understanding and operating form and non-form in the
context of public health palliative care**

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Introduction and overview

In this chapter I take the learning from chapter five and apply it to public health palliative care. I will focus on two main areas. How supportive relationships are understood and operationalised, and how we understand and construct the idea of place, specifically place of care. I will describe how applying the lens of either form or non-form can influence what is seen and understood, whilst also shaping our perception of what is important to know in the first instance. I will discuss the notion of risk and safety in advancing states of dementia, how these have come to influence how care is delivered and how the approach may differ when considered through the lens of the non-form. In the final part of the chapter, I will address what I see as the fundamental component to dementia care, how we respond and accommodate to the very notion of loss and the suffering and healing to which it is associated. I will describe how components of both form and non-form are necessary in orientating a response that might come to shape what is created from the void.

The architecture of supportive relationships

'Sharon and I talk about how the relational component of care is so important, how it facilitates a transition from transaction-based models of care to something that is deeper and how in turn this deeper level of care is what is required to bring nuance, an attention to how and why we suffer as humans and then how we might begin to heal. We reflect how Nicole, and the others, talk in terms of love in the care they deliver. How they call Angela 'mum' how there is a depth of relationship that means care is not simply the exchange of a commodity. I reflect back to Sharon that this is perhaps in part due to the fact they have the space to develop such relationships, something she has been instrumental in providing. In care homes there is often bureaucratised structures in place that fill such space, how if a cup of tea is made, this must be documented in some form, and does not allow for the sharing of the tea or the flow of an interaction that nourishes and facilitates the relationship, allowing it to grow beyond its initial parameters of transaction into something greater.'

As our bodies change in the face of accident, illness or age, we can become dependent on other people for care and support. Such relationships, and the terms on which they operate, have a fundamental impact on care. This is especially so at the end-of-life and, as discussed in chapter two, is one of the fundamental premises of a new public health approach to palliative care.

As I have discussed in chapters one and three, where cognition is significantly changed or impaired, a person's ability to form new relationships and maintain old ones is fundamentally altered. Moreover, studies have continually shown a gradual waning of social relationships in dementia and very old age (Curelaru et al. 2021; Xiang et al. 2021; Gott et al. 2018). At the same time, the mechanisms by which we understand and navigate a functioning relationship, including reciprocity, altruism, compassion and so forth are distorted in dementia where people exist outside the normal structures of social interaction. The potential benefits held in the acquisition of social capital and forming caring and supportive relationships is therefore called into question.

Using the heuristic of form, non-form and its entangled interface, I will attempt to describe how we might begin to understand the nature of relationships alongside their value and potential in shaping the experiences of people affected by advanced dementia at the end-of-life. This is of crucial importance in understanding how interventions in the field of public health and palliative care might operate and their potential for impact.

Form

My enquiry begins with a structured description of relationships that was obtained through social network analysis. Table 3 gives a broad overview of the results.

As I have described, an undue focus on the form, in this case, the structural components of relationships, can create paradox and ultimately deny the reality of dementia's effects. Yet by understanding that there are inherent limitations to the form, it allows us to navigate towards the outer limit of its potential in such a way that we are not forced to rationalise out a theory that 'fits' but instead enables us to move into another domain that is better suited to understanding such topics more freely, unconstrained by the polarities of success and failure.

Changes in network size

Four of the nine networks decreased in size whilst five of them grew between time point one, the point of diagnosis and time point two, the point of death. At a crude level this demonstrates how caregiving and support at the end-of-life can be a catalyst for the formation of new relationships whilst also challenging the widely accepted assumption that networks universally dwindle for people with dementia. One example of this is Hilary and Katy's network. Hilary, who had dementia, lived some distance away from her daughter, Katy. She lived in a flat and her dementia caused significant and profound personality changes. She was often rude and became

sexually disinhibited. This meant she was frequently ‘not welcome’ and often asked ‘not to return’ at public venues such as cafés, shops and garden centres. By all accounts her personality change had decimated her social networks to the point where she had become completely isolated. The one exception to this was the relationship she maintained with her cleaner. This was a relationship that was described as existing based on mutual need and convenience. As her care needs increased, Katy decided to move her mother out of the flat to live with her. At this point Katy, who had spent her life to this point relatively disengaged from her immediately local community and was not well connected to other people other than her immediate family. Together they were quite isolated, and the network is small (Figure.3).

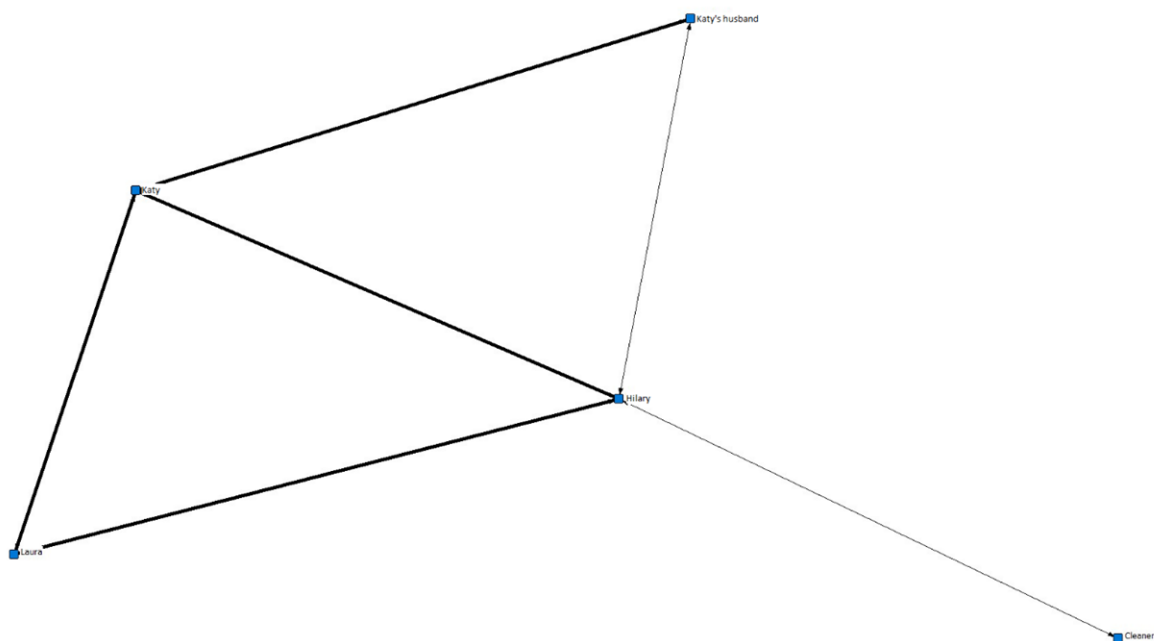


Figure 3: Hilary and Katy's social network at time one

Moving her mother into the family home was the start of a new chapter of Katy’s life. The experience brought new relationships and Katy developed new skills and qualities that she did not know she had.

I hadn't really been a community person before, I'd always been busy doing my own thing, you know, busy raising my children, busy working, or whatever. And because I'd made friends through my mother in the community I had so much support when my mother was dying, you know, I was so lucky. It wasn't practical support obviously, but people would, you know... my mother had the dining room when she moved here, that was her room. It was a nice big Victorian room with a high ceiling on the ground floor. And so people would come in, and you know, we'd sit around her bed, and we didn't used to eat, because

she couldn't eat, but we'd have a cup of tea around her bed, and it was sociable, you know, her dying was sociable'

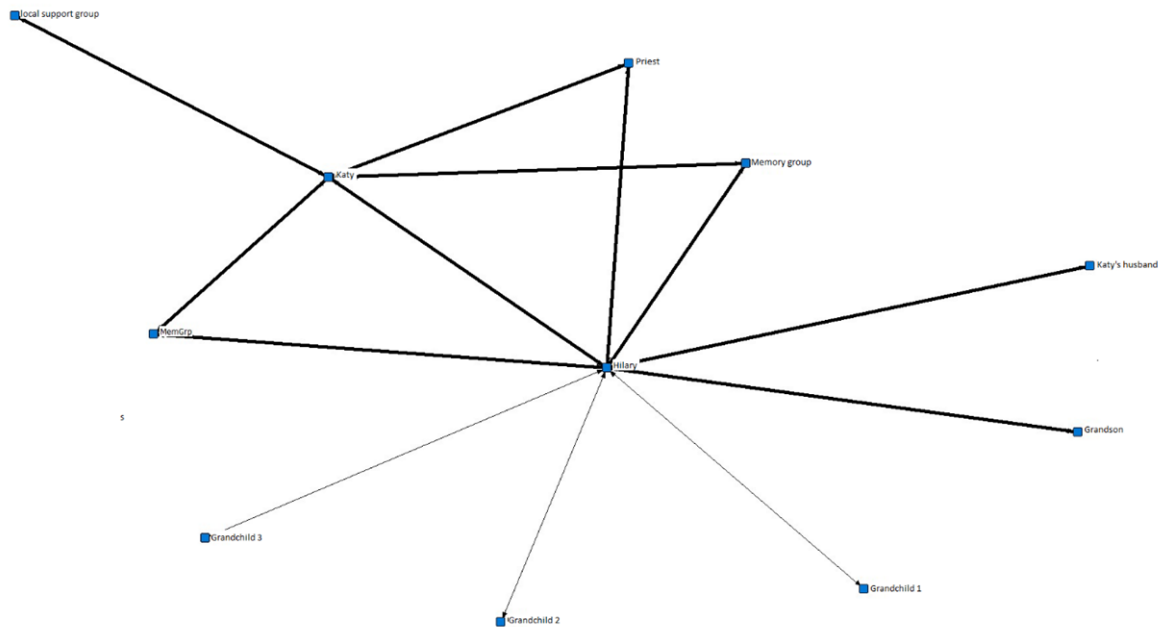


Figure 4: Hilary and Kay's social network at the time of her mother's death

By the time of her mother's death, Katy had developed relationships across the community and local neighbourhood. She had taken an active role in campaigning for people with dementia as well as seeking out and acquiring new skills to help care for her mother.

'...and so this marvellous woman was employed, to, you know, to get carers to give their opinion, and I don't know how I came across her but I remember she handed out this piece of paper, and we were supposed to write on it what we're good at. And, and I was so embarrassed, and horrified, because at that point I didn't think I was good at anything. And I remember writing, that I was good at spelling, but that was, that was it. And that if they had any flyers, or what have you, or newsletters I could, you know, I could do something with that...'

With time and experience, Katy's perspective changed. She had a newfound confidence having had to overcome many of the challenges posed by her mother's needs.

'...having cared for my mother for nine years at home, having not sent her to the hospital, they (district nurses) still didn't feel that, that they should come every day and see my mother, and I, umm I had to

stamp my foot every day...And they even sent the top, top (nurse), that guy at the top of the tree and, and I remember when he started on me I remember thinking; gosh, are you going to dare tell him that you still want it, and somehow I managed to, (laughs) but it used to upset me after they'd gone.'

In the second map, Katy's and Hilary's network has eleven members. Various new relationships spawning off from the central image that is carried through from the first. Although Katy was benefitting from her wider network of supporters, she also needed to 'bridge' to connect other people within the network, this is reflected in her betweenness increasing from 0.5 to 10.5 (see table 3 for full results). The bridging score for her mother also increased from 3.5 to 36.5. Whilst she was not co-ordinating care herself, this is representative of the role of people with dementia take in providing a platform for the formation of new relationships, connecting or uniting people through their own needs.

Because the newcomers to the network are not so well-connected, the density of the network decreases from 1.0 to 0.4. The enhanced support means that local clustering for the main carer decreased from 1.0 to 0.6 indicating there is less onus on this person to co-ordinate care.

Changes in density and transitivity

Density of networks frequently decreased, one exception to this was that of Rachel, who was cared for by her daughter Margaret and her husband, Henry. Rachel lived some distance away from them at time point one, and they were reliant on a constellation of people to support her informally. This included neighbours, shop keepers, taxi drivers and other people who Margaret and Henry would liaise with remotely. The network, although higher in number at time point one was not well connected. This can be seen in figure five where there is a central point with many independent and poorly connected prongs.

| Network Characteristic | | Network Number | | | | | | | | | | | | | | | | | |
|---|----------------------|----------------|-------|------|-------|-----|------|-----|------|-----|-----|------|------|-------|-------|------|------|-----|------|
| | | 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | |
| | | T1 | T2 | T1 | T2 | T1 | T2 | T1 | T2 | T1 | T2 | T1 | T2 | T1 | T2 | T1 | T2 | T1 | T2 |
| Size | | 22 | 24 | 23 | 31 | 5 | 11 | 11 | 19 | 15 | 13 | 8 | 16 | 39 | 29 | 17 | 10 | 21 | 19 |
| Density | | 0.5 | 0.6 | 0.5 | 0.3 | 1.0 | 0.4 | 0.2 | 0.1 | 0.1 | 0.2 | 0.6 | 0.3 | 0.3 | 0.2 | 0.2 | 0.3 | 0.3 | 0.2 |
| Transitivity | | 0.9 | 0.9 | 0.7 | 0.6 | 0.6 | 0.2 | 0.5 | 0.5 | 0.0 | 0.9 | 0.5 | 0.4 | 0.6 | 0.5 | 0.2 | 0.2 | 0.9 | 0.8 |
| Reciprocity | | 1.0 | 1.0 | 1.0 | 0.9 | 1.0 | 1.0 | 0.1 | 0.1 | 0.0 | 0.0 | 0.3 | 0.4 | 0.9 | 0.6 | 0.3 | 0.5 | 0.2 | 0.1 |
| Clustering coefficient | Person with dementia | 0.3 | 0.6 | 0.4 | 0.4 | 0.7 | 0.2 | 0.3 | 0.2 | 0.0 | 0.2 | 0.6 | 0.3 | 0.2 | 0.3 | 0.1 | 0.7 | 0.3 | 0.6 |
| | Principal carer | 1.2 | 0.7 | 0.7 | 0.3 | 1.0 | 0.6 | 0.1 | 0.1 | 0.0 | 0.1 | 0.2 | 0.2 | 0.2 | 0.2 | 0.1 | 0.1 | 0.2 | 0.1 |
| Betweenness centrality | Person with dementia | 220.0 | 81.5 | 81.3 | 441.7 | 3.5 | 36.5 | 2.0 | 0.0 | 0.0 | 0.0 | 0.0 | 12.0 | 430.0 | 95.0 | 48.0 | 0.0 | 0.0 | 0.0 |
| | Principal carer | 0.0 | 141.5 | 81.3 | 441.7 | 0.5 | 10.5 | 5.0 | 22.0 | 1.0 | 1.0 | 17.5 | 91.0 | 719.0 | 458.0 | 77.0 | 44.0 | 2.0 | 11.0 |
| No. of nodes with betweenness centrality >1 | | 1 | 2 | 5 | 8 | 2 | 2 | 2 | 1 | 1 | 1 | 1 | 7 | 6 | 2 | 3 | 1 | 3 | 1 |

Table 3: An overview of network characteristics

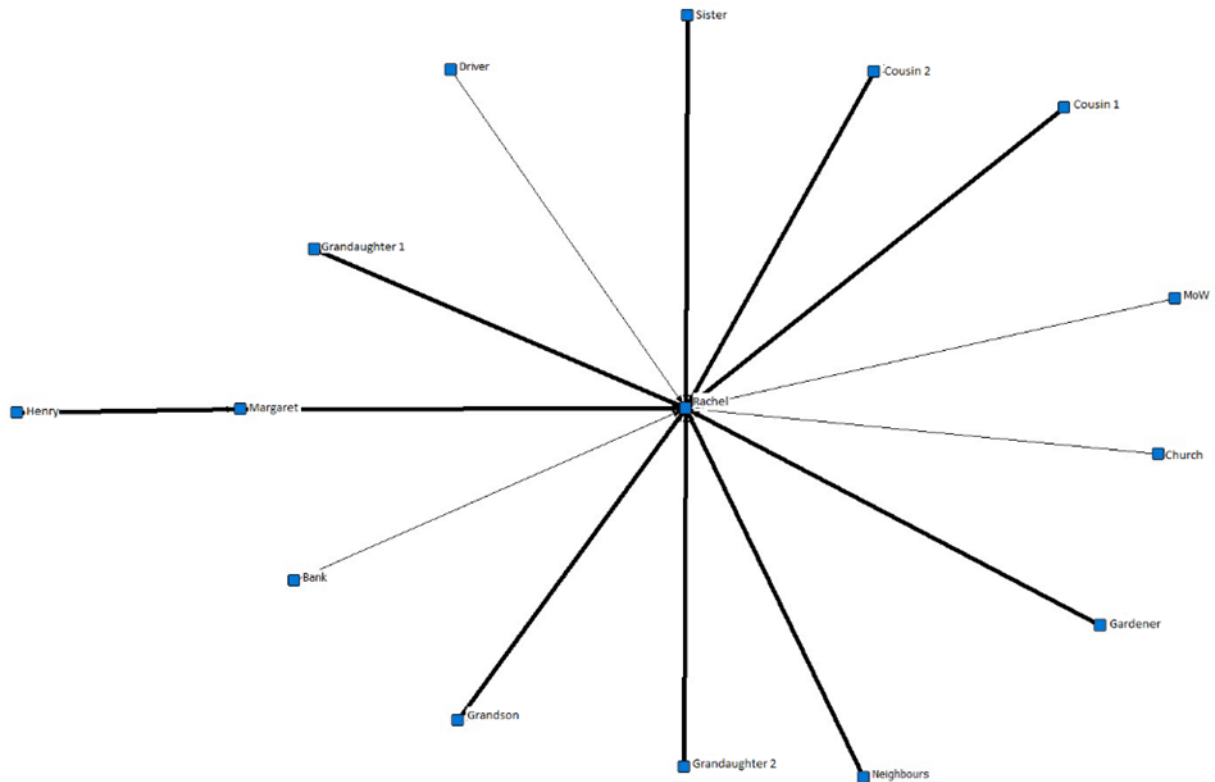


Figure 5: Rachel's support network at time one

As the situation became more difficult to manage from afar, Margaret and Henry decided to move Rachel in with them. The change in location created a more intimate network, of smaller size but higher density. Margaret continued to coordinate care, but the rising levels of transitivity indicate an interconnected network of people symbolised by a central network of strong ties with an outer network of additional singular ties (figure 6).

Margaret and Henry described how the relationships with family members was strengthened by the move and subsequent need to provide care. Their son took her to Canada, she would come on family holidays and generally be more engaged with their lives. This built a depth of relationship that carried through into the later years where Rachel's needs became more significant.

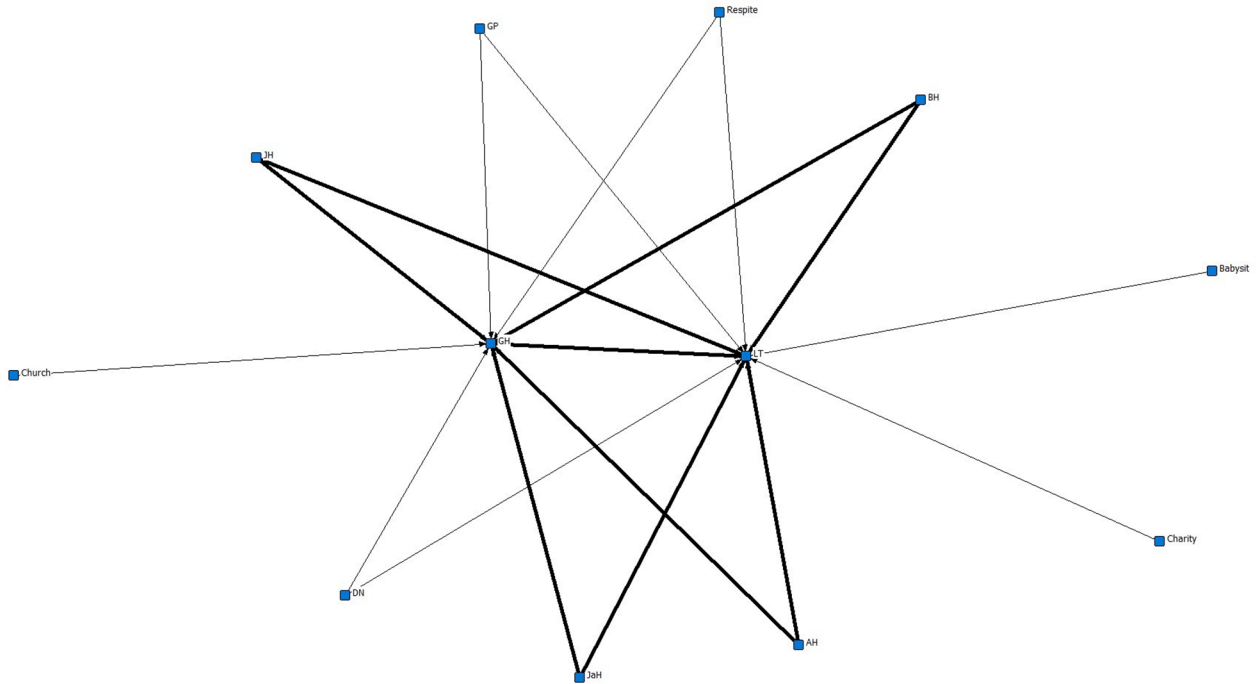


Figure 6: Rachel's network at time two

Beyond the patterns identified in table one, the qualitative data was helpful in shedding light on how some of the commonly perceived elements of social relationships operate in the context of dementia.

Talk

Verbal conversation is complex and requires capacity to navigate a fast paced and constantly changing landscape. People with advancing dementia might struggle to do this which requires an adjustment in how we might engage through talk.

'Richard and I do not ask questions about James' recent trip to France other than generic things. Also, I notice they are not really posed as questions that necessitate a factual response e.g. what did you do, who did you see? They are more statements like 'the weather has been so hot here, probably hotter than in France' they might also refer to feelings, such as 'did you enjoy seeing the house' rather than specific factual points. James can't remember who he was with during the trip, so I show him a couple of pictures, he does not recognise his friends Robert, Elizabeth or indeed his niece Jennifer. I show him a couple more photos from inside a house, he recognises this, and also an old man who he is chatting with, he recalls his name and how he knows him, even though it is a distant relationship.'

Conversation between people with advanced dementia, was noted to be important beyond just the exchange of ideas and the rational trajectory of a reciprocal conversation. Occasionally conversation made little or no sense. Yet engaging in it still helped maintain existing relationships and indeed build new ones.

'Occasionally Pat comes in and sits down in the chair by the widow. She joins the conversation sporadically. She brings up her family, her father, mother and brothers. She asks Donald what family she has left now? He is hard of hearing and so looks at me as if to translate, so I do. What follows is a conversation at cross purposes, they each have their own topic which is seemingly distinct and unrelated. Pat continues along her lines whilst Donald continues along his. There are facial expressions, eye contact and body language appropriate to a fluid conversation as it shifts and moves with the flow of an entirely coherent and engaging topic. However, it is anything but. It eventually peters out and Donald continues to tell me stories of his younger years including the second world war and how he actively served in the army.'

Reciprocity

The topic of reciprocity was interpreted in a variety of ways when discussed during the network mapping exercises. When considered through a highly structured and formulated lens, where each action is exchanged with another person for mutual benefit, it was often found to be absent. Where people sought reciprocation from within the spaces created by dementia, as a means to finding value and motivation to care, they would be left empty handed. This might cause people to struggle to find meaning or purpose.

'So, I think certainly mum found it very hard. She said before she just found it thankless that, you know, almost when she was trying to do things for him, he'd be shouting at her, telling her off. You know, because she would be trying to get him to take his pills and he wouldn't want to. Trying to get him to eat his dinner when he wouldn't want to. And I think there's a slight- Again, the thing is you know you're caring for kids for them to ultimately achieve independence. So, there is that goal and that sort of positive end point, whereas when it's caring for older people or people with a long-term illness or whatever it is, like there isn't that end point where you can kind of step back and be like ah, I've taught you everything. It's just going to get harder.'

That people with advanced dementia cannot reciprocate acts of kindness or care consistently and in the traditional sense is not surprising. Despite this, participants would often agonise over the

idea of reciprocation and its meaning in their unique context. Below a participant tells me about a complex relationship between her mother, who had dementia, and her sister, who had significant mental health difficulties. The relationships between the two of them became hard to describe as she agonised over how best the concept of reciprocation might work here, and how it might differ between other members of the network.

'so there were things, you know, things she (mum) couldn't get her head around or understand or whatever (in relation to her care), but I'm not saying she didn't provide some emotional support (to the family and in particular her sister), but I think some of it would have been more, what's the word I'm looking for now, not accidental but not particularly deliberate in a sense, if you see what I mean. So just being there, in a sense, would've been, you know...When my sister would come and visit, it would be a kind of emotional support to my sister, and my sister would see it that way, um but I'm not sure that, you know, the degree of that would have been a lot less than, and that sort of deliberate degree of it to me...so I don't quite know how to quantify any of that.'

Despite a very clear 'absence' in a person's ability to reciprocate acts of care, all networks bar one expressed high levels of reciprocity between members and the person with dementia (Table.5).

'It's important to realize that if you want to create a support network, hopefully, but obviously not always, but hopefully a lot of the support is going to come from the person that you're trying to look after.'

It is as if there is a recognition this notion exists beyond a language that can be clearly and logically articulated. It exists beyond the structures to which the word is commonly understood. More commonly the essence of a reciprocal relationship was observed in the narrative rather than the rational structures that have been created around the moral imperative of care.

'Nicole gives me an example of how after a period of agitation (she would often get distressed at Nicole's presence in the house and throw her belongings out of the door, even contact the police), and Nicole was feeling tired and exhausted, she sat down next to Angela. Angela guided Nicole's head into her lap and she lay there whilst Angela stroked her hair. She shows me a picture of this on her phone. It is a selfie. They are both smiling.'

Duty

In the absence of a clearly defined reciprocal component to acts of caregiving, participants

searched for alternate structures on which to build motivation and rationalise their actions to me. A common theme was that of duty.

I wasn't sure if I should find her an old people's home there, but my husband, who she had never been that nice to throughout my long marriage, said she must come and live with us. And, and I said, but, you know, how on earth can you want that? And he said, 'it's what you do', and so she came, there was never any big thing about it.'

Duty has been discussed extensively in the literature around dementia and primary care givers (Brodaty and Donkin 2022; Balouch et al. 2021; Bressan, Visintini, and Palese 2020; Muangpaisan et al. 2010; Samson et al. 2016). Whilst a commonly attributed reason to take on the caregiving role, it is associated with significant psychological distress with people more likely to end up resenting their role (Pyke and Bengtson 1996; Brodaty and Donkin 2022).

Duty was observed to be closely related to the concept of 'ideal care'. The notion that as a family member there is an ideal of what should be done and the way that this might look. Duty is the mechanism by which ideal care might be delivered. In the same way that ideal care can deny the reality of decline, dependency and all things incompatible with an acceptable way of living and dying, duty denies the existence of monotony, frustration and anger and provides no space to accommodate them as real entities that hold specific function and value. Therefore, whilst duty might set people on the road to caregiving, it is limited in its ability to carry people through the challenges it invariably brings.

We talk about the notion of duty, and how some people feel compelled to care out of duty. Helen is quick to say this is not enough. She says that 'you must ask yourself if you can do this' and then choose; 'either do it out of love and compassion or do it out of duty'. She says you must understand this distinction first before you can feel it. She tells me that duty alone can lead to feelings of fatigue and burden, her argument is that through love this won't be the case. Her point fits with the early dismissal of the monotony of caring for someone who is withdrawn and disengaged from the excitement and drama of the social realm.'

Altruism

In chapters two and three, I discuss the role of altruism and how this is described as another motivating force for the generation of supportive networks at the end-of-life (see [page 45](#) and [page 67](#)). Altruism is dependent on the reciprocal moral value it imparts, the feeling of 'being

good' or 'doing good'. Yet in advancing states of dementia, there is an ever-diminishing list of things somebody can be helpful with. For example, where someone has hobbies or activities that they enjoy, this requires facilitation. Yet the effects of dementia mean that a person might eventually stop or withdraw from these activities. This leaves the carer, or 'Good Samaritan' and their act of perceived altruism as redundant, the help serves no value and there is no longer any need for it per se. Below are two passages that highlight this point in more detail. The first is my observations with James and his friend Robert over lunch. That morning we had been at James' flat for a book club held on Zoom. Robert spends a lot of time preparing the material for James so that he can take part in the class, yet increasingly it is difficult for James to engage with, and he seems to be taking less and less from it.

'As we eat there is a conversation about the book club on Zoom. James says that he is a 'silent participant' he can't really recall what was happening today and most of it, he suggests 'passed me by'. Robert asks him 'you're not thinking of giving it up, are you? James expresses uncertainty 'well...' he says with a facial expression to match. It's not clear if Robert wants him to continue or not, his visit is revolved around the delivery of the zoom meeting (he is currently busy trying to organise the technology so that he can access James' computer remotely when he is way in Spain next week to set it up for him). Robert does not pressure him to continue. James does not definitively admit to wanting to stop it, it is more that he expresses a pointlessness to it. At worst it may disorientate and confuse him although he does not express this, it is more an idea that has come from my observations in the flat. There is no definitive plan made in the café but perhaps a change is on the horizon.'

This was one example of many where people with dementia actively disengage or withdraw as opposed to 'no longer be able to take part'. These points of loss are a hallmark of dementia and I discuss how they are acknowledged and accommodated in relation to altruism with Betty during a visit to her and John.

'After Betty finishes on the phone we continue our conversation about moments of transition. Where perhaps something changes or disappears from a person's persona or identity. The challenge, as it is framed, is that care can focus on maintaining memory or aspects of enjoyment but at the same time, memory and hobbies change, disappear, sometimes they are replaced by other things, more often they are replaced with nothing. This can make care challenging. Challenging in the sense that the carer no longer has an easily identifiable purpose, their role has no quantifiable value, no meaning, so they too might also slip away.'

A moment ago Betty gave John a book to read, now, and as my conversation with Betty is getting into full swing, he starts to read sections or page numbers out loud. 'Oh sorry' Betty says to me, she says she gave him the book without thinking, and that he will now proceed to 'intonate' bits of it. He carries on loudly, she doesn't take the book away but tells him to 'zip it!'. There is a curtness, but also humour to her delivery. She tries to continue along her line of thought, but John has now started reading the page numbers aloud; 'just shut up!' she says. He moves on, but silently this time.

Betty goes onto to describe the '24/7 business' in more detail. She says that it comes back to 'who are we doing it for?'. If people are doing it to feel good about themselves and that eventually the person with dementia no longer benefits from this person (the example of Robert setting up James' zoom for the book reading club is used anonymously as an example) then ultimately this person may feel useless. They no longer get the positive feeling associated with being helpful. Somebody that is depended on. The risk is, that when altruism ceases to be of value, when the help is no longer helpful or needed, then its motivational power is also gone, and the care and social contact goes with it. Betty explains this is why it's hard for 24/7 carers, and for her, why altruism doesn't come into play. Indeed she has told me how much she hates being put on a pedestal, being told by others 'I could never do what you do.'

This is the essence of what was meant by a seemingly throw away comment by a volunteer at a dementia café. She had lived experience of caring for someone with dementia, as I told her about my clinical work and my research focus on the very end-of-life, she told me "end-of-life care is just about personal care really". At the time, I did not feel she was belittling the importance of end-of-life care, more just describing the situation as it is seen. There is indeed a profound absence, a nothingness into which the human understanding of reciprocity, altruism, duty or meaning fall and to which personal care is the only objectively identifiable task with which to engage.

Non-form

That reciprocity exists in some way, that new relationships are created without the recognised tools with which to build and maintain them, speaks of an alternate domain where rational structures that contribute to reason are limited in their function. Here, forces that shape people's actions and reactions, emerge from within the spaces that dementia creates to exert their own influence.

In this realm, where seemingly polar entities exist together, intertwined and unrestrained by divide or border is where the reality of what it means to love and care for people might be found. Such forces transcend preconceived ideas on duty or indeed morality and form the basis of what motivates people to care.

I ask Betty where she gets her confidence from. How it is that she can talk to people about things that perhaps lay her open to criticism, how she feels perhaps unsure that it is ok to wash him once a week but then is comfortable standing at a podium of an international conference and telling lots of people that this is what she does. She cites two things, first is her personality. She has always been quite direct, and this is certainly my experience. The other thing she says it that she has been doing this for a long time now. She has gained a lot of experience; she knows what works and why. I liken this to death literacy, that her experiences have made her literate in the processes surrounding death, loss and dependency. She likes this expression and tells me so. She immediately says that being death literate is most definitely not about altruism though. She says there is a selfishness to what she does, it has been her way of surviving. She says that people have often remarked that they admire her enthusiasm, but she has a different approach now, she is not fighting the Alzheimer's Society or campaigning for services, but more just trying to forge some space for herself.'

The network maps describe the empirically visible structures around relationships, whilst also shedding light on how networks might grow in the face of loss, and reciprocation may emerge from within the empty spaces created by dementia. Yet how caregiving relationships evolve in advanced dementia cannot be extrapolated from this data alone. This is representative of how the rational structures of the form only take us so far. Persevering with their use, trying to demonstrate reciprocity, or describing altruism or compassion as motivational forces, can breed tension and deny the reality of people's experiences. This is not to say the reciprocal relationships cannot occur, that we cannot 'talk' to people with dementia and that duty and altruism are of no relevance. But rather that these entities have an outermost limit and can only lead us part of the way in understanding the role of caring relationships in the face of decline, dependency and death.

Relationships as independent entities

In the non-form, relationships might exist as independent entities, with a corresponding set of forces that dictate the ebb and flow of our actions and emotional response. To illustrate this

point, I will use the case of Betty and John. As I have described, Betty cares for John in a unique way that does not necessarily fit with preconceived ideas of what care might look like.

Betty goes to the kitchen to make me a coffee, I rest a hand on John's shoulder and say 'hello, how are you?', he looks up at me, I wasn't sure if he had known whether or not I had entered the room as he hadn't looked up and was engrossed in his poppet board. He smiles and replies 'all the better for seeing you' which takes me a bit by surprise and makes me smile. I suspect this is one of John's rehearsed one liners. At some point later in the morning we talk about this, and Betty confirms this is a common phrase that always brings delight to the recipient who will then take great joy in enthusiastically recounting the story to Betty whilst laughing out loud. Betty finds this type of reaction tedious; she admits 'it's nice for the recipient'. Betty describes how such an interaction creates an impression that John is a warm, cuddly old man, who is 'rather easy to care for'. Perhaps Betty resents this to some degree, caring has been her life for so long. Betty goes on to say that she doesn't talk to John much anymore, she says 'I've said all I've got to say' that and 'I can't be arsed anymore', her comments make me reflect on the idea of their life together being in many ways 'complete' maybe also that their relationship is also complete.

Betty tells me that talking about the idea of a 'completed life' has had a 'big impression' on her. She goes on; 'It has helped me identify why I do what I do' she clarifies what she means by this by describing her approach to caregiving, how she will take a pragmatic approach to John's care. What is essential to do, what will he truly benefit from, and have quite fixed boundaries with respect to this. She describes how she feels that other people can 'make a rod for their own back' by trying to do too much. She gives the example of someone she knew or knows who made fresh orange juice for the person with dementia 'only for them to piss it out'.

I am intrigued by Betty's very 'real' approach to care and how this works, but if put into a professional context it most certainly wouldn't. I ask her directly why it is that her style of care 'works' but if a professional carer were to do it, it would be unacceptable. She takes a moment to think, first, she agrees that if she saw a professional carer doing what she does, then she would be unhappy. She ponders 'I often think, how would I feel if he was in a care home?', she conveys a sense of unease without pinpointing a specific reason as to where this originates from. The idea of him being washed and dressed daily and fed high quality meals perhaps creates a sense of him being 'pushed and pulled' around, rather than him enjoying it or valuing it. It is as if she recognises and understands that he exists in a different space, his values are different, needs are different, and this type of care is a charade and fails to acknowledge this.

She talks about how most people end up in a home because of some sort of crisis. She says she has been waiting for one in some senses, anticipating what might be on the horizon but instead she has just been greeted with a long plateau with the occasional gradual change, 'will he end up bed bound?' is the next thing on her mind, along with incontinence.'

Betty tries to rationalise her approach to care along the basis that much of their relationship has changed beyond recognition. In many ways she's sees his life as complete, and she tells me this on many separate occasions. Her approach therefore prioritises her own wellbeing, knowing that this is the only viable way she can survive in the role. Yet at the same time she discusses with me how, deep within the emptiness, alongside all that is absent, there is a warmth of presence, an intimacy or love of sorts.

I suggest that one of the most obvious building blocks of a relationship is the idea of love, before I can finish my question Betty takes the idea and runs with it 'do I still love him? Yes, I often think about that' she says staring at the fireplace opposite us. John is positioned between us, blissfully unaware of the conversation, he continues to play with his poppet board, most likely he is also unable to hear what we are saying either. Betty compares the idea of a 'deep affection' vs 'love', she seems reticent to say she does love him but equally cannot say that she doesn't. She says that 'caring is a manifestation of my love, even if I can't rationalize it'. This to me makes perfect sense, love being something that does not lend itself to rational thought. I offer this reflection to Betty. Going on, we discuss how love is dynamic, people can acceptably fall in and out of love, love can also perhaps come to an end, yet it may endure unbeknown to the naked eye or our empirical or rational senses. Here it might be found within the spaces, the voids of loss that characterise dementia. This is what I observe in my work, and I reflect my thoughts back to Betty as part of the conversation. Betty describes other types of relationship, the stormy marriages where you might suppose something like dementia would be something that breaks it, 'yet love will prevail' she says, I ask her if love has persisted for her. 'It is there, yes. But then there are times I hate him...not him but...' she tails off, implying his dementia is the root of her ire. Betty reflects that maybe she is 'bitter' because she 'can't live her life how she wants – she wants to be busy and do things' she says that maybe this isn't the right word, she swings into a more positive approach, describing how 'I have never felt isolated, you have to be proactive' she describes how she will pick up the phone or do something, however small, to engage herself with others if she is feeling lonely or isolated. She says these small acts or small interactions (like feeding the neighbour's cat, she says) are of importance to make you feel you are still 'in a world other than the one where you are a carer'.

On one visit, I put forward my observations to Betty that their relationship is central to how she cares for him. More than this, their relationship exists and has grown to be its own entity. Such a thing is part of what occupies the spaces created by dementia's apparent losses.

We talk about the dementia trajectory and how it is littered with moments of loss, stripping back the outermost layers to reveal the core of our being, the body, its physiological processes but also perhaps this other, more hidden, dimension of our being; the soul, spirit or other such entity. I ask Betty how she has managed through these periods of loss, how she coped when he stopped playing the piano so often, how she felt when he stopped enjoying listening to music, to TV and other forms of entertainment, how his religion and religious beliefs slipped away. Betty initially talks about the little practical things that have come in to fill the space, she references the poppet board and how he will sleep more. I have been thinking about how relationships might come to fill this space. A closer, more intimate relationship with people, place or other things either living or non-living. I pose this idea to Betty; it is not something that she has considered before. I describe how, with her and John, I see them as a couple and also as two people, with unique needs, but that their relationship is also something that exists in its own right. Almost as a separate and distinct entity that when added to an equation alongside both her and John's 'being', creates something far greater. I suggest that this is why Betty's approach to care works so well for her and John, as it is based and centred on their relationship with each other. I contrast this with a professional approach that might offer a surface level of 'quality' through the food they eat or attention to personal care and hygiene but that the absence of care and attention to the relationships that person holds and carries would mean if they were to do what Betty does it would be deemed 'poor care', 'and that would be right' Betty instantly replies, reassuring me instantly that I have not offended her.'

That a relationship is its own entity suggests that any action or intervention that bears influence on it will provoke a reciprocal opposing reaction. This was evident in Donald and Pat's case, where their relationship was impacted by dementia, a solution from the realm of the form was to build a structured approach to risk and safety. They were referred to social services and told that they would need to move into a nursing home within a two-week window. In the home, they were separated. Pat was placed in a specialist dementia part of the home and Donald was in a more general part of the home, the rationale being that Pat would be safe whilst Donald can preserve some form of independence. Their separation resulted in a powerful and forceful rebuttal.

I knock on the door, and am welcomed in, Pat is sitting on Donald's lap in a playful way, almost as if they were teenage sweethearts. Donald has had a haircut and has almost completely no hair. Pat moves from Donald's lap to sit on the edge of the bed. As the initial smiles fade, Donald seems to be in a state of stress. He launches into conversation about how the care has been very bad. He says he doesn't see anyone anymore and talks about how his cornflakes this morning were mushy, that his tea was cold and that it was brought late. He tells me again how he needs a warm cup of tea to start the day as it helps him go to the toilet.

Donald seems angry at the last home and is pleased to be gone, but he is also dissatisfied with the care here, sometimes it seems to me that the two places have blended into one. He tells me that 'all this business is bringing her (Pat) forward with her illness'. I ask him what he means but he can't really specify.

He wants to talk about the 'Jamaicans' who worked at the previous care home, he says they are 'hard and have no feeling', he doesn't want to speak ill of people and says so, but he is angry. Pat joins the conversation saying 'I don't know why some people are like that really, it's like downstairs', it's not clear to me what she means by 'downstairs' but she refers back to it regularly. Donald says the place was 'like a prison', there was nowhere to go and nothing to do. He goes on to say to Pat that 'they keep trying to separate us, but we are soul mates', I ask if they are in separate rooms here and they say yes. Donald is on the ground floor and Pat on the first floor, which I assume is a specialist dementia floor. He says the other day he did not see her from seven pm till noon the next day and today just now is the first time he has seen her since last night. It is about 11:30am and it now makes sense as to why Pat was sitting on Donald's lap when I arrived.

*Donald tells me with a nervous chuckle that on Saturday he 'put a belt round his neck' but what he really needed 'was a rope'. He did this in the presence of staff, I assume as a demonstration of his sheer frustration at the situation. I believe this relates to what Linda had told me recently by email, that after many years 'father has snapped'.**

*Shortly after this event Pat was moved in with Donald and they now share a room together.

Where relationships are understood as existing beyond just the people that compose them, as entire, yet dependent things in themselves, it follows that they too are an amalgamation of both light and dark. No single entity is complete without imperfection, this is the hallmark of the non-

form, the 'pathos of beauty' which contributes to what we value and appreciate as making 'the whole'.

Relationships bring both tragedy and pain in addition to love and warmth

That relationships can produce profound euphoria and joy and at the same time a tragedy and pain beyond compare is something the rational world of the form may struggle to resolve; in essence it is the pathos of beauty. From the perspective of the form, and the aesthetic ideal of care, the loving warmth of social relationships brings solace in the face of decline, dependency and death and is something to be valued, harnessed and welcomed into care. Yet what of the pain and tragedy to which these notions are inescapably bound? Whilst the form might acknowledge this component of a relationship, it can be identified as risk when put into the context of care. This can mean informal relationships cannot be trusted as safe and secure given their potential for manipulation, hurt and damage (Rosenberg 2011). Yet, as I have learned about the non-form, trusting in this space is where the potential for healing and for experiencing transformational beauty is perhaps at its highest.

To illustrate this concept, I refer to the case of James and his network of friends. Initially, I had assumed that the group had been formed prior to his dementia, a close network of friends that had drawn close during uncertain times. However, I realised some way into the ethnography that the opposite was true. Below is an extract where Mary describes how the situation came to be:

James then came to move into the housing co-operative in which he still lives now. I ask if John was also part of this group of intellectuals he used to live with. But he is separate. Indeed, Mary only came to meet John recently. Mary describes how it was about two years ago in November when James was diagnosed with dementia. The person who raised concerns to the GP was the lady who now has heart failure (I met her on a visit in the street, she is another neighbour who was previously involved in James' care but is now too frail to help). Mary herself did not realise his memory was failing him. In fact, she says she and James had been out for dinner the night before he was due to fly out to France. She did not arrange to meet him until sometime after and had assumed he had just gone on the trip. It had never occurred to her that he wouldn't have gone. But, he never left the flat. She says he came home and became too anxious and worried about the trip and never left the flat. James does not contribute to the discussion here. He either cannot remember, or does not want to discuss it. It comes up again later too and his response was 'I never went?'. Mary says she went with James to the appointment with the care of the elderly consultant. When

they got home Mary wrote up all the notes from the appointment, what was said and what the outcome was. She typed it into an A4 piece of paper and put a photograph of the consultant at the top of the page. The first she heard from John was after he had come around to visit James and found this on the kitchen table. He had no idea of James' dementia and no idea that a diagnosis had been made. Somehow, Mary can't remember how, he reached out to her, and they began to build a support network around him. The document has now been translated into James' native language so others may read it and the English version has gone missing. I tell Mary and James that I had assumed the group had been one that had grown together, with each of them being pre-existing friends, but this couldn't be further from the truth. In fact, James' dementia is the source of their coming together. I joke that James seems to have many different groups of friends rather than one network they seem to be arranged in satellite clusters and they have converged to support him. Not just this but also, he seems to have friends that are very strategically placed. Mary laughs and talks about how John was a councillor for many years and as soon as he found out about James' diagnosis 'you've never seen things move so fast!' She laughs that with her being a doctor and John a councillor the only significant base is law they don't have covered then she realises 'that's not true is it?!' she points at James and together they remember a contact that has some legal standing although they have not had need to call on their advice yet'

James' network is unique amongst the study's participants but is also a rarity for people with dementia in general, where the responsibility for care often falls on families, and when this is not possible, professionals. In many ways the situation is a celebration of the power of supportive relationships. He is supported by a group of people who have the skill and motivation to care, but also an in depth, almost intuitive sense of who he is and what he needs. This is reflected by Michaels spontaneous acknowledgment of James' often bright and cheery affect when he has been out with his friends, how even his memory is better, and he is generally more engaged with the rational, structured world around him.

'Michael has heated James' food for later, he is now preparing to apply cream to James' leg. As he does so he says, 'this is what I can't comprehend, you remember some things in detail like nature, the arts and your trips to the community garden and the BOLDR walks but the academic detail you can't remember', 'Oh really?' James replies.'

However, within the spaces that surround this observable network of support was a depth of relationship and a web of ties that ran far wider and deeper than what was suggested at first

sight. As the ethnography progresses, I learn more about the nature of relationships, their history and other characters that become part of the story.

'...the conversation turns to James who has been sat comfortably, chipping in now and then with the odd comment and observation. Mary starts to map out James' week with him, describing how Richard has now been back to visit him. I learn that his friend Richard has been unwell with mental health problems and has recently been in hospital. Mary does not know the full story but has 'picked things up' from Anna (Richard's mum) which she openly admits 'sometimes leads to assumptions'. I am unclear how Richard and James are connected and ask them how they know each other. Mary tells me Anna is James' close friend. James struggles to articulate the connection and so Mary asks politely 'do you mind if I talk?'. Mary explains that it was an early symptom of James' dementia that he just could not recognise Richard as Anna's son. It was as if a specific part of James' memory had been erased, Mary describes this colloquially as the vascular nature of James' dementia 'taking out a specific part of James' brain that corresponds to that memory'. Mary explains some of Anna's background to me and how she came to know James early on in life. She tells me 'James gets quite discombobulated when he can't recognise that she has children'. James joins the conversation now, 'I'm listening with my ears but getting quite muddled' and 'also quite sad' Mary adds, alerting me to the sensitivity of the conversation by conveying an emotion that was not immediately obvious to me.

James says, 'I'm trying to figure out how Richard came into my life...' Suddenly the doorbell rings – it is the delivery person who was scheduled to bring a bin for Mary's new kitchen. She pops out momentarily to collect it, on return James says, 'I'm just puzzled...' to which Mary asks 'What about?'. He goes on, 'I'm not sure. How did I get to know Richard? I seem to know and don't know, there is something in there, but I don't have the language.' The last word is emphasised and full of angst and frustration. Without talking, Mary gets out her phone and makes a video call to Anna. She appears on screen and Mary introduces everyone in the room, including me. She explains the purpose of the call to Anna, which is to help James figure out for himself how he knows Richard.

'I do know how I know you' James says, relieved. Anna begins to help him navigate to points of reference from within a complex web of relationships. James talks directly into the phone looking at Anna. The phone sits on the table with me behind it and James facing the screen, he is at ease with this format and the technology that has been set up for him. They talk about where they used to live, familiar landmarks and points in time. James brings to piece things together with some help. He uses relationships with people

and places as orientating factors. He can recall Anna as a family friend, whom he has known for a long time. As the conversation goes on, I notice how sometimes the social relationships appear disjointed and difficult to pin down for James, yet the relationship with various places is more concrete. Many different people mentioned and eventually James settles on who Richard is. The whole process takes five or ten minutes. He says goodbye, acknowledging that he had gotten confused but has now arrived at a point of clarity. When the phone goes away James goes to use the bathroom upstairs.

Whilst he is upstairs Mary goes into more detail about the nature of these relationships. I am privy to details that are sensitive and shocking. How James' relationships, and those that have convened around him are complex, how they bring a sense of unpredictability, perhaps even risk of upset or distress, yet they are also the ones that support and protect him. When James returns to the room Mary is talking about a specific person and quickly brings the conversation to a close. James seems a little on edge, but I do not read anything into this at the time.

Later, when I am leaving the house, Mary tells me that she regrets speaking about James' relationships in his absence. She said she saw James coming out of the corner of her eye but wanted so much to tell me that she blurted it out in his presence when she should have 'kept her mouth shut'. She says that he was furious with her. I tell her I didn't feel James was angry, but she is adamant he was. She likens it to a previous experience where she and his other friends and carers (Robert, Elizabeth and John) were discussing something to do with his care without him. She says she feels bad because he will not remember why he is upset or angry. This is an important point for her about dementia, that although the memory of the experience will fade almost instantly, the emotion attached to it does not. She says that James will be uneasy and upset, potentially for some time, yet won't necessarily be able to recall why. Mary says this can work in the opposite direction too, that the emotion attached to a fun, happy and uplifting experience can persevere for days and indeed weeks even though the specifics of what happened are not retained at all.'

The drama, tragedy and suffering that we endure through the relationships we form is precisely what drives their enduring beauty. Here the power of supportive, caring relationships cannot be confined to a realm which entertains a one-sided perfection with no exposure to risk or harm. Rather than tainting their beauty, the darker side of the relationships we form, awakens within us the presence of loss, the reality of human decline, illness and mortality, so that we might accommodate the transformational beauty that exists alongside of all that is broken, shattered and tender.

Shared vulnerability

Meeting people in the silent, empty spaces of the non-form is where the potential for new relationships unfolds rather than closes up. Instead of relying on reciprocity, altruism or conversational talk to negotiate the formation and maintenance of relationships, there was an observed need for people to present their own vulnerabilities to each other.

Participant 1 (daughter of Person with dementia):...I think it's about shared vulnerability, so when the carer shares with you like, here's what I'm going through, I've got this really horrible, you know, divorce going on that I wasn't expecting, and you know, then you kind of reciprocate, they're in your home, and you know its...

Participant 2 (husband of person with dementia), father of participant 1): I think that's very important, I feel, now that the people I relate to, and listen to, when I don't know them, are the people that make themselves vulnerable to me'

This concept was applicable, even in the most advanced stages of dementia, when reciprocation might be expected to be absent.

'And it might not have been much, but I think I mentioned, you know even towards the end if I put my head, sort of, into here (gestures to the side of her neck), her hand would just come up and stroke my hair, which is what she used to do when I was a kid, when I was upset, I put my head in her lap, and at various times during that journey, if I got upset, I'd just sit down in front of her and put my head on her lap and she'd just sit there, and you know, we'd just talk and she'd stroke my hair, and it was very much...in fact that was something she needed, in fact sometimes she got really...You know quite upset and...Almost aggressive, verbally aggressive because she just was so frustrated about the whole situation...I think one time I just couldn't do anything else, I just burst into tears and realized that actually, that's exactly what she needed. Because when she felt she hadn't got use in life. Well she had, she's my mum...and she needed to be my mum, you know, and right up to the end, she was, she was... even when she didn't quite remember, she was still my mum. The kind of actions and the way she behaved towards me. So she didn't seem to be conscious of the labels if you see what I mean, but she somehow knew'

Finding supportive relationships in the non-form: the importance of non-human connections

As I have described, to inhabit the empty spaces of the non-form is to see that they are indeed full. Relationships are no exception to this. When understood through the lens of human relationships, there might be an apparent absence but this ultimately comes to be filled by a greater intimacy. At the same time, the non-form also points to a greater breadth of relationship, beyond just human encounters. This was first noticed in the network mapping exercise when participants argued for the inclusion of non-human entities as deserving of their own node and corresponding tie. That dementia might move someone from the social realm of the form to a different realm whereby connections beyond the 'relational' come into focus more clearly.

'But I did have this this table over the bed, and we had all of the pots so she could see all of these things coming up. Because we didn't have to worry about her kicking them, she couldn't move, so, mostly, towards the end part (of her life) we're doing everything for her, but sometimes she'd kind of like point at a potted plant, so I'd bring it further up (to her) and we'd be talking about the, you know, we'd be talking and she'd nod and point at different things, and I remember quite often if I got distracted with the door or a phone call or something, or I'd go to make a cup of coffee, and I'd come back and she'd have her fingers in the pot, and she'd love having dirt under her fingernails. Yeah, and she'd show you 'I've been gardening'. It was so important to her that, that connection, literally that physical connection with soil.'

The local environment evolved as a significantly supportive structure that was crucial to care and its potential outcomes. Such a thing is perhaps present throughout life but comes into much sharper focus in dementia through the spaces that it creates. Below is an extract of Mary discussing her and James' relationship to the city where their friendship blossomed.

'Mary begins to tell the story of when James first moved down to the big city. She describes him as being 'a man in love with the city', there is a story about them going out for a drink one night in the summer. It was relatively uneventful other than Mary's memory of him being absolutely 'drunk' on the love he had for the place. They strolled the streets and found a ticket for the opera, it was £99 for a summer's worth of performances, probably equivalent to over £500 in today's money, she says. They instinctively bought it and enjoyed many evenings together. She describes the outing as 'an evening of utter joy and silliness'. James smiles and stares at Mary as she recounts the story with a beaming smile.'

The effects of dementia stripped away the structures of this relationship, but the essence of the connections prevails and was still visible despite the effects of his advancing dementia.

We pass into a small hall like place, chairs stacked up at the sides, a noticeboard with community events, through to the back of the building and a laundry room. It is a shared space of the housing co-operative. We pass through another locked door and out into garden. It is walled which creates a feeling of seclusion, trees line the edge and offer privacy from the road, there is a bench and an old rusty BBQ in the corner. Mary tells me property developers bought some of the land and exchanged it for a narrow passage of garden that runs at a right angle to the main part. James' shows me down, it is largely overgrown, wildflowers and Ivy cover a windy narrow path. As we walk around the garden, we do not exchange many words, it is largely silent, the flow directed instead by movement and the physical navigation of the space. There is a seat at the end, big enough for one to sit. James and I go back into the main part of the garden. There are shoes, hats and other things strewn across the garden likely stolen and dumped by foxes. A tree divides the central space from the end part of the garden which is shaded and private. James and I walk there and stand for a minute in silence. He points out the birds singing in the tree. There are multiple obstacles to James' path, 'trip hazards' as I have been trained to describe them, his feet scuff the floor, yet he is sure in his direction and movement. He is free and comfortable in the familiarity of it. We head back along the path and sit on a bench that has been gnawed by foxes or cats. Mary joins us and chases up on the Uber cab, she is anxious about booking it too early or leaving it too late. James points out the line of the treetop with his finger, how it curves and blends with the others to form a canopy and how the light hits it creating a multitude of different greens. He points out small wildflowers and remarks on their colour. We listen to the birds. Mary says it is sad to see the garden looking neglected. The woman who normally tends to it has been ill and it is now overgrown, but perhaps no less beautiful to James' eyes. It is accessible by all people in the co-operative, which would amount to quite a number of people yet there is nobody here and it looks like there has not been anyone here for quite some time. Mary says the cab will be ready outside soon, so we make our way back through.'

The intersection between form and non-form: Relationship centred care

An appreciation of the non-form shapes the understanding of the architecture of supportive relationships and also begins to shed light on how we might think to evaluate them or understand their impact. Growing into the spaces created by dementia can bring a newfound realisation of the existence of relationships as independent entities that become the locus of care and support.

That the relationship, human or otherwise, is what exists in the non-form suggests that this is the

true locus of care. The thing that grows into the spaces created by dementia, that needs nurturing and embracing, ultimately towards the final and ultimate relationship, that which we hold with our own existence, and ultimately our death.

We talk briefly about responsibility to care, professionals earn money for their work which perhaps fuels the performance of care. You have to be seen to be doing a 'good job' to justify your wage and be described as a 'good' carer. With informal care, Betty argues that it is not just as simple as doing it 'for the person with dementia', she gives the example of Megan (their daughter) doing John's strip wash. Through most people's perspective this would be a challenging thing to do, to see their father naked and to 'wash their bits' as Betty puts it. And it was awkward for Megan initially. But then she was not doing it for John I am told, she was doing it for her mother, Betty, so that she could have a break. Relationships exist as distinct things that are deserving of their own care and attention. Also, they are not simple dyads where reciprocal acts move back and forth, they are part of a wider contextual web or network it would seem.'

The architecture of place

Communities, neighbourhoods and locality have long been discussed as having some sort of therapeutic potential. The Compassionate Community, as defined by Public Health palliative care, is the reinvention social networks as a human resource for the provision of care that transcends the confines of professional structures. In chapter three I describe the tensions in operating this concept in the context of dementia and debate the role of community as a place of healing and care for people with dementia at the end-of-life. I will now examine how the idea of form and non-form might influence the imagination and creation of a Compassionate Community that accommodates people affected by dementia.

Form

The structured realm of the form is orientated towards a clearly identifiable point. Such a point of focus allows interventions that affect it to be clearly identified, understood and measured. This is the foundation on which the chain of research, technology, and innovation are built on, helping to manufacture a perception of what might be right or wrong. In the below passage I will use 'risk and safety' as a commonly understood point of focus on which the idea and subsequent architectural form of place is often focussed on.

Risk and Safety

In the realm of the form, the place of care, be that a person's long-standing home, a care home, a hospital, a neighbourhood or a community is prioritised as an appropriate place of care based upon safety, comfort and access to needed care and support. Below is an extract from an interview where I discuss the context that surrounds a man with dementia moving to a nursing home. His wife and daughter describe to me what it had been like to care for him at home, simultaneously conveying events that led up to the point where a move became necessary. The conversation starts with a description of how he had been the carer for his spouse, but their roles soon reversed.

Daughter: But what I mean is I remember him saying to me, "I'm kind of your mother's carer now" whereas before he, as in....because I think you had sort of started to need a bit of help with walking.

Spouse: Oh yes, he would help me on and off the bus.

Daughter: Yes, exactly.

Spouse: Until the later stages.

Daughter: Until he was incapable. That was the danger, that we had someone who had been supporting you with physical, practical needs, then increasingly he didn't understand how to do it. For me the incontinence was the breaking point.

Spouse: Yes, I think that is true. He was incontinent, and we had so many nasty messes around.

Daughter: Yes, and I think, it wasn't just that accidents happened, but it was, I mean he was placing faecal matter in places it shouldn't have been. There was a lot of scrubbing out the carpet and things.

Spouse: Yes.

Daughter: That was where it felt to me-

Interviewer: Very difficult.

Spouse: And that's one, another reason why the social interaction with other people was hard, because with family they knew, but with other people you couldn't really go to their homes because-

Daughter: That's it. You didn't know, or you were worried about him sitting on sofas and things just in case. Again, if he kicked off you didn't if he would have broken stuff or injured someone.

Spouse: Yes.

Daughter: So definitely, feeling like he needed to be in a safe environment to help us not be anxious about him.

Spouse: Yes, because he busted that door.

Daughter: Oh yes, the French window's broken out.

Interviewer: What happened there? He broke them, did he?

Daughter: Yes, I think he was trying to, he thought you'd locked him in the house. Well, you kind of had.

Spouse: It was one of the times when he was saying that he didn't live here, and he wanted to get out and get back to his home.

Daughter: So he tried to open the French windows, and I think just got angry with it and just-

Spouse: And just pushed-

Daughter: -smashed it. Yes.

That care should occur in a place that is synonymous with safety makes rational sense. In the above example it less an option and more a necessity. This example is so stark, and the response so obvious, that there is not the space or time to consider what we understand by safety and risk in relation to place. Moreover, there is an accompanying framework that presents the solution to the challenges posed as less of an option and more of an ethical and moral necessity. Ultimately, this can result in a blanket approach to how we understand risk in the context of dementia and the end-of-life. As a result, the anticipation of heightened risk, and what this might lead to, was often the driving force behind interventions relating to place of care.

'Betty's main fear at present is that John continues to slowly deteriorate towards death as opposed to suddenly dying. She does not want him to reach one hundred years old, but she can now see that eventuality, something she never would have thought possible when he was diagnosed. Betty brings up a neighbour who fell and broke his hip some six or eight months ago. She says about ten days ago he went for drink in the local pub with a friend and then died in his sleep that night. She said her immediate reaction was 'why can't this happen to John?' we talk about the seemingly random nature of death and its unpredictability. It prompts me to ask what success looks like to her, how can John die successfully? She says he can die now, so as to pre-empt the deterioration in swallow, the complete incontinence and him being bed bound, where she will need extra support and maybe even a nursing home. She says the whole process of his deterioration and the prospect of things getting 'worse' will undoubtedly be more distressing for her than they will be for him.'

Through the lens of the form, safety, and the risks that threaten it, are understood in relation to the preservation of structures that enable us to find and utilise control. Risk was frequently

discussed in relation to accident, injury, or anything that might contribute towards a functional, physical or cognitive decline. Risk was also discussed in relation to being cut off or isolated from the wider world.

Jennifer asks a direct question, saying 'what would residential care be like?'. There is an expectation and general consensus amongst the group that this will be required at some point, but I am told that the aim of their concerted efforts is to keep James in his own home for 'as long as possible'. John, well connected within the community and its available services, talks about one local facility as a possibility. He says he can begin getting information on this, yet there is not a response to encourage this from the others, more a general interest, almost of reassurance that there is an option but that it is not currently a priority. I wonder how the stress associated with such processes might be slightly removed by the fact each of them, other than Jennifer, are not family connections. John describes the home as an 'extra care facility for people with dementia' and after a brief discussion says, 'I am not inclined to pursue unless others think it necessary'. At this point, the option of moving into care, as far as John is concerned, is a balance between increasing his social contact, counteracting a perceived isolation, vs the disruption of changing setting from what has been his home for many years. The group are thinking about it as an option, but not pushing. There is a comment from Tara that it is normally a crisis that tips the scales in one direction and that sometimes a move 'has to happen'.

Regardless of the context within which risk was discussed, the commonality was its orientation to the preservation of 'form' and the guarding against emptiness, an emptiness that appears inherently disorientating because of the absence of any meaningful structure that might enable us to navigate it. It is here that we might realise that human morality, and the ethical frameworks we have developed to support it, only take us so far. At the interface between form and the perceived emptiness of the non-form, decline becomes understood as a the 'slippery slope' towards death, a point of absence or loss to which there is no longer the potential of healing our corporeal form. Yet dementia, old age and frailty teaches us something different. It is a profound reminder our body will undergo a process of decline, whilst always being susceptible to accident, illness or injury that can alter the rate at which this is experienced. Dementia alerts us to the probability that this process can unfold in a certain way, one where the rational, highly structured world of the form to which we have grown accustomed will begin to fall away, our existence will move at a different pace with different reference points. This point is distinct from the concept of liminality, a phase or situation through which we might pass through on return to the presence of structure and rational meaning, it is instead, an end in itself. Here the frequently unchallenged and taken for

granted concepts of risk and safety and their orientation towards maintenance and preservation of our controlled form comes into question.

In the early days I tended to be really protective of her, you know. If she'd got near a knife, I wanted to pick it up and take it off her. It was very much that: 'Oh, you know, I can't let you get hurt', and we talked about it, and she said well, you know, 'I've got to live'. We (mum and I) did a piece of work with the council looking at what people wanted out of life, she was in the last year of her life, maybe the last eighteen months or so. And it was a lot about, you know, still doing things we wanted to do. Not being put on a shelf, and this wasn't just people with dementia, it's old people in general, and as I'm getting there myself, I'm very much aware of that. There is a sort of thing you know, you've got an old person and we'll put them here, do what we think's best for them, and to them, but we can't do it with them because, well, they're old. And you throw dementia into the mix and it's like 'oh definitely not', no, wrap them in cotton wool, put them in a plastic box, put them on a shelf, make sure they're safe. The very last meeting we had, only about three or four months before she died, was talking about 'how do you describe the piece of work we're doing', and she said well it's about 'there's no point keeping us alive if we don't have a life.'

Understanding risk through the lens of the form presents us with a paradox. As a person's dementia progresses then the 'risk' of social isolation, physical accident, illness or injury only increases. Yet at the same time, in the face of exponentially increasing risk, our approach to it tightens, there is less of a willingness to entertain it, especially where there are means of controlling it. This represents an enduring tension in how, and where, we care for people with increasing vulnerabilities in the face of death. Below is an extract from my fieldnotes where I discuss with Linda plans to move Pat into a care home.

Linda describes the search for care homes as difficult. She says for some of them, her parents are 'not unwell enough', especially her mother. Whilst their differing care needs means that it was not always possible to find a place that would accommodate them both. She said things had rapidly progressed following the environmental agency letter (a neighbour had complained that Pat was feeding the birds and it was attracting seagulls and vermin) and the fact that carers found Pat near the main round by the garden centre last week. This was escalated to social services and they were told they 'had' to go to a care home. Linda did the assessment for her parents 'on their behalf' to speed things up and is using cash from their savings to fund the move until the house is sold. After the money from this is gone, Linda is not sure

what will happen. She says she has arranged to speak to a 'financial person' on Friday to take some advice. She says there is a possibility that the home may seek funding from the local council but that she has also heard stories of people having to give up their room when the money runs out. She tells me about some care homes that are run as charities, and here you have a 'place for life'.

Linda tells me how social services first came to be involved. One year ago, Pat went missing in a park near her home. By coincidence, there was a family who met her and were willing to put her in the car and try and find her home. They must have passed the nursery (a reference point for Pat) which she recognised, and from there she found her way home. The family that picked her up spoke to a neighbour and her going missing was reported to social services by them and also Linda herself, once she found out. From this point forward, carers were put in place. The relationship with the carers was not successful and she describes how they went through three or four different carers before settling on the arrangement they have now. Linda also questioned whether it actually mitigates her risk of getting lost and wandering. They only attend for an hour each day, and given her father's immobility, she is essentially left to wander free the rest of the day. Despite this there has never been another significant episode of her getting lost. The police have not been involved. As far as anyone knows, the 'worst' that happens is Pat wanders to the garden centre opposite her house, as far as the side passage entrance that is on the main road. Donald had told me she never goes further than this. At the garden centre Pat is known by the staff and they will keep an eye on her, although there is no guarantee of course and no formal sense of accountability. We discuss the approach to risk and juxtapose this with the fact that risk of 'an event' increases the closer our proximity to death, old age and frailty. Linda likens this to her experience of looking after her daughter who has needed support from mental health services, through her experience she tells me that professionals 'do not always know best'.

Here, risk is understood in conjunction with a series of measures that offer a potential solution. Amongst other things, the doors and gate to her house could be locked whilst care could be upscaled. Yet these measures do not work because understanding place in this way denies the reality of the other components that define it. I am told later by Linda that Donald refuses to lock the doors and gates because he was abused as a young child by his father. He was locked in a cupboard and beaten and therefore cannot bring himself to lock Pat indoors.

'Pat says she will need to go 'up the hill shortly' to 'look after the old ladies'. Donald says 'you're not allowed', he references Jack and Jill, the reference is lost on Pat and he explains he doesn't want her to

fall down the hill. There is no response from Pat as she continues to ready herself, Donald says 'it is your last week (living in the house), I don't want to lock you in'

*This extract is taken from my fieldnotes notes from a time before I knew of the abuse

In a similar way, moving to a nursing home might limit her ability to wander, keeping her safe from potential harm, yet it also denies the role risk has in bringing life to a situation. Below are my early reflections from visiting Pat in the nursing home and trying to walk with her within the confines of its fixed boundaries.

Pat has her jacket on and is keen to get going, she goes to the patio doors and tries to open them, but they are locked. She is again in a stuck position, feet planted firmly on the ground a little distance apart. I suggest we head to the garden and that the doors in the corridor might be open, so we set off. We get to the doors, she is hesitant to go through, I say it is fine and we enter the small courtyard that has a selection of olive trees about shoulder height, a concrete paved path that goes in a square around the perimeter with the trees central. Outside we can hear the voices of children playing in the nearby school. Donald told me Pat went out the other day with Linda to the park that is just behind the home. I see Donald through the window and point him out to Pat, they wave at each other. Pat turns around and looks at the back of the home. It has three or four floors and is quite tall, Donald earlier described it as 'imposing' for Pat. Pat says, 'they were trying to take me up there yesterday (she points to the upper floors of the building), I wouldn't go to that part'. It is clear to me that the garden is not the destination that Pat has in mind when we set out for a walk, more that it is perhaps something that you pass through on route to somewhere else. Almost like a front garden of sorts, or perhaps her back garden at home that she would pass through on route to the garden centre. There is a fence at the back, which is lined with tall trees, the eye cannot see more than twenty meters at a time. Pat makes for the gate on the left side of the garden. She lifts the latch as she chats to me and pulls but the gate does not open. It is bolted at the top and there is a combination code lock that prevents opening. She is confused as to why it is locked. We walk a few meters back along the path, I have noticed there is a similar gate on the other side of the garden, about ten meters away which is open, I do not know if this is by mistake. I am unsure of the rules and feel myself guiding Pat back inside. She notices it from the corner of her eye and points it out, 'there's another one'. We walk over to it and head through the open gate into a smaller, narrow garden perhaps seven by four meters. There is a large fig tree at the end and the branches hang low with large leaves. There is a shed immediately to the left of the gate with some power tools left on the floor outside. We walk straight to

another gate that is in the corner, I can tell this one defiantly leads to the front of the home. It too is locked in the same way as the other. As a means of distraction from the disappointment of the locked gate I point out the tree and remark that it is beautiful. Pat agrees and goes up to it, she holds a leaf from a drooping branch in her hand for a moment before we go back to where we came from. She makes her way back to the initial locked gate, forgetting that it too is also locked. She is literally and metaphorically bouncing between the walls. I suggest we go back to meet Donald inside. She seems a bit despondent but agrees. We go to the patio doors that lead back into the corridor, she is hesitant, and I encourage her to go through. Donald is there at the entrance to the sitting room.'

Through the lens of the form, place is a static entity, a stage to which the performance of care is enacted. Place of care facilitates the endeavour of avoiding risk as far as possible, whilst providing or maintaining safety. Here, these entities are understood, in part, through clearly defined professional practices that are supported by accompanying moral and ethical frameworks. This can mean the approach to risk, and ultimately the place of care, becomes more of an ethically accepted norm rather than something to which there is debate, something that can be experimented with.

From this point, it follows that dementia 'belongs somewhere'. In essence, this suggests that decline, dependency and suffering belong in this same place. This is opposed to its natural home being part of life's rich intricacy, part of the drama that brings sadness, pain and suffering but also contributes to beauty, excitement and joy. Outside of institutionally defined structures of support, participants would carefully negotiate risk, but when examined in any depth would often reach an impenetrable point that was unsolvable to the rational mind. A point where the light brought by the potential mitigation of risk would cast a corresponding shadow elsewhere.

John brings up the potential for James to wander and get lost. It is not a great concern for him, 'I don't think he will wander on his own' he says, this appears to be somewhat of a gut feeling but one I can associate with having spent a lot of time walking with James. Despite his confidence in this, John has been putting things in motion to have the 'Herbert Protocol'⁶ put in place for James, Mary is also involved with this and apologises as she has not yet done the paperwork. John talks about the paperwork and how it is stored in a box under the stairs in his flat. This raises an interesting point. People discuss how the box

⁶ The Herbert Protocol is a UK based national scheme that encourages carers, family and friends to provide and put together useful information, which can then be used in the event a vulnerable person going missing. It is co-ordinated and shared with local police.

exists because without it, important documents go missing, James is unable to organise them or keep them safe. However, its existence is a source of tension. It can feed into his paranoia if others are looking inside or trying to find things, Mary is particularly sensitive about James finding out about the Herbert Protocol, as it involves giving some of his details to the police. Without being able to rationalise why this would be necessary, it is not hard to understand how this might cause James great distress.'

At this point, what became important was not so much finding a resolution, but navigating the process in a way that was least distressing, in a way that accommodates the approach to risk as something that is constantly shifting, something that is perhaps nuanced or part of the unavoidable reality of life.

That the place of care is often equipped with the tools to counter risk, to conceal it from view in such a way that excludes all that is seen as unacceptable in human existence as a means to finding a solution may suit our rational minds but will always breed tension for those who are forced to negotiate risk as part of their day to day living.

The architecture to a supportive place of care for people with dementia, be that a Compassionate Community, a neighbourhood, a home, care home or nursing home, is perhaps irrelevant until we better understand what it is people from dementia are truly at risk of, and how we then delineate what it means to focus care and safety from this point. Part of this process is understanding the components of place that exists beyond the form and how they interact to fulfil their therapeutic potential.

Non-form: coming home to death

'She would say that dementia is like looking through a glass where it's been raining, and you can still see outside, but it's blurred by the rain.'

That the carefully formulated understanding of place only part explains its apparent function is suggestive of a deeper complexity that contains other, more fluid components. That people with advancing dementia increasingly exist outside of the form, it makes sense to try and understand the notion of place from their perspective. This involves inhabiting the empty spaces that dementia creates, and rather than turning to look back, at the increasingly blurry rational structured world from which they are leaving, to turn and look outwards, towards the empty spaces and the accelerating yet undulating path towards death.

I have already described how relationships may exist as independent entities here and that paradox and enigma are common in a space that is unbounded by the polarities with which the rational mind might focus. It therefore follows that whilst such spaces might be seemingly empty, devoid of meaning and beset by risk, they are also the same spaces that contain opportunity. They are also the same spaces in which we come to heal the pain associated with loss. A paradox when considered through the lens of the form, we might learn from people with dementia, that risk is also a space for opportunity, for growth and for healing.

The healing potential of 'place' is perhaps realised beyond the structural components to its being. Here, place of care is understood as something beyond a static entity, the platform or stage on which care is performed. It is much more than this. It is its own ecological unit, something with which people can form an intimate relationship which in turn has the power to nurture and heal. As with all relationships, the potential for growth, transition and healing exists in parallel with the potential for harm. As discussed, these seemingly polar notions often exist together in the same moment when considered through the lens of the non-form. Below I will discuss how the non-form might allow us to better understand locality and the relational components to place that contribute to it being understood as its own ecological unit to which we might form a more intimate relationship as part of 'coming home to death'.

Locality

In the non-form, where place might be understood beyond its geographical boundaries to encompass relational ties that are part of a wider ecological network, the notion of locality is much broader than first imagined. For people with dementia, locality was observed to be a dynamic entity with a temporal and relational component. Temporal in that the person might be in a place and time different to our formed reality. In one interview a widower who cared for his wife qualifies this idea succinctly:

'People with dementia are time travelling constantly, and the first thing to do, is find out where they are, so that you can be beside them'

At the same moment place might also be considered relational, 'He is home because he is with me' as another participant tells me in the context of describing how she moved house with her husband who has dementia. In this sense, how we understand place cannot just be limited to just its geographical boundaries nor its potential restricted to a pre-defined appreciation of risk and

safety. In the extract below I am at Mary's house, with her mother, Daisy, and James. Her mother also has dementia and three of us sit and chat in her kitchen.

'After putting out drinks and getting everyone acquainted, Mary says she needs to go out and do some shopping. She takes her phone and keys and leaves us three to chat. I notice there is a photograph on the wall of a large kitchen, with a large farmhouse table and a traditional Aga. Mary had told me it is her mother's kitchen from the family home in a rural part of northern England. I ask Daisy if it is her kitchen as a conversation starter. She says that 'yes, I suppose it is' but 'it doesn't look like it, except for the blue wall at the back', she tells me. I suspect this is because the photograph is taken with a wide-angle lens which has distorted the room, making it look a lot larger than it is. Daisy and Mary are there in the picture and it strikes me as poignant how it is situated in Mary's own kitchen, a home within a home. I learn that Daisy often travels between her home and those of her children. To me this is symbolic of the meaning of the word 'local' to people with dementia, how there might be significant geographical space between points of locality, the length of the country in this case. For Daisy, who goes on to talk about her regular visits to the city that has become Mary's home, both points might be considered 'local', they are certainly part of their mutual support network.'

Here, the home and place in which we live and are cared for might be something with which we form an intimate bond. Rather than a static thing, that is shaped and moulded according to our will, it is something independent and dynamic, something with which an intimate relationship is formed.

The relational component to place

Acknowledging the relational component to place is crucial to understanding how Compassionate Communities might cater for people with dementia. Here, the local neighbourhood becomes defined through a changing constellation of experience and interaction, of relational processes rather than just material forms. Below is an extract from my notes, Mary and I had accompanied James to a podiatry appointment which has now finished and we are outside the building.

'The plan is to walk back to James' flat, Mary says she and James would normally go for a drink but that she has an evening engagement and needs to get back home for this. We walk and talk a few meters down the road and I say that I feel like we are close to the community garden that James visits on a

Thursday with John. James and Mary agree so we agree to take a slight detour and bump into it. James recognises it immediately. He says there is another park just down the road opposite, we walk down the street and discover that he is right. Mary takes a picture of the sign – she is part of a community gardening organisation and wants to show them. We all go in and browse. James meanders behind Mary and I. There are people sunbathing and a gardener with a wheelbarrow. He drops something as we pass and Mary picks it up for him, sparking a brief interaction. We cross a small stream and then come out the exit of the park. We make our way onwards and towards home and as we do Mary notices an old-fashioned cobbler's store. She is enthralled by this as you rarely see such a trade now. In the window it says they will repair anything. She goes to take a closer look. A man inside calls out to her 'yes we'll fix anything you like' he is an old Caribbean man with an apron and a flat cap. He comes to the door to chat. Mary has a suitcase that needs repairing, the man says he can do it and Mary is delighted. She wants to take pictures of the shop and the man is happy for this, he wants her to post it on social media. There are smiles and the conversation is energetic with a joyful tone. James is standing with us. He does not speak to the man but laughs along and smiles. He stands with his stick in hand as the three of us form a small circle and chat on the street. We are there for only a couple of minutes, but it is a pleasant interaction which forms a lasting memory for me. Mary is delighted to have found the place. We continue to walk, Mary says 'we can walk your normal way now James'. As we stroll, Mary changes her mind and asks to go along the main road so she can go to Sainsburys and get James some flowers for his flat. The main road is much busier. The loud buses and lorries and occasional car horns cause James to stop and stare with a frowned expression on his face. There are lots of people walking at speed. Crossing the road is trickier to navigate, a car kindly waits for us to cross with James at a large roundabout near his home. James doesn't stop to look at the trees and plants that he habitually does in the back streets.'

With the local environment now acting as a more malleable and fluid entity that reaches and impacts beyond its function of a stage, it is possible to sense an ecological rhythm that is created by the place in which we find ourselves. It is this that comes to exert its own impact on the ebb and flow of interaction. In the below extract I am at the community garden with John, James and another volunteer called Dave.

'As we get to the gate, John puts in the code, and unlocks the padlock, Dave arrives, having thought he was going to be late he arrives dead on time at 12:00, he is in a bit of a fluster. Dave and John go into the little office and get their volunteer jackets on. James and I hover at the entrance. I browse over the written history of the place again as I familiarize myself with the garden. There is a conversation about

how it has been busy recently, they use a clicker counter to mark the number of people passing through during opening hours, John says there were over eighty people the week before, despite the rain, the number is much higher than my conscious recollection. On entering the garden James and I move around its boundaries independently. At times he looks perhaps a little lost, he stands under a tree for a while and then next to a table and chairs but does not sit down. I talk to John who mentions the hardy plants that have survived the extreme heat of the summer, he points out the evening primrose that grows from within the cracks of the thick grey concrete, the cherry tree that has blossomed. James stands close to the plants and flowers, at times transfixed and motionless, he waves his stick gently in front of him as if marking something out. John remains near the entrance, to greet visitors and explain the local history. I have done a lap of the garden, taking in the new installations and familiarizing myself with the poignancy of the place. I see James standing alone under a tree and decide to sit at the bench next to him and bring out my sketch pad thinking that he may join me. He doesn't this time however, he moves around looking at the plants, carrying his bag with sketch book and pencils around with him. John comes over and asks if I want to use some of the pens to draw on the wooden logs. This is a feature set up by a local artist to commemorate the many women whose identities are lost within the mass burial site discovered under the garden. John brings the pencils and pens and there is an accompanying A4 sheet which describes the idea in more detail. It says is to draw a face on the wood and hang it on a tree or place it somewhere in the garden. There are some images on the sheet to provide inspiration. I sketch on the wood using a brown acrylic pen, the wood is home to lots of bugs and some of them get squashed under the nib of my pen, becoming part of the picture. Meanwhile James is meandering around the garden, his actions might look a little odd to the passer by as he takes a level of interest that is perhaps outside of usual social norms. He stands quietly, content by his own company but in the presence of many. People move around the garden silently, alone or in small groups within the contained environment, they seemingly bounce off parts of the garden and also each other, a plant, a tree or a shrine, pausing momentarily to absorb its significance as they are deflected off in an unpredictable and seemingly tangential direction. It is as if there is an embodied energy that might cause such deflections, that dictates the pace and direction of people's pathway through the garden. James is part of this interaction, alone but present within the invisible ecological unit we all find ourselves within.'

Place as its own ecological unit

'As Pat comes into the room again, I ask her if she would like to show me her garden? 'You're a gardener, are you?' she asks me. I explain how I enjoy the outdoors and together we move into the garden, joining it through the utility area that abuts the kitchen. We step outside and Pat immediately points up to the sky at a cloud constellation, 'Is it moving? I think it is' she says, 'look at that one, it's like someone lying down'. We stand and stare at the sky together for a short while. She takes me over to the back border of the garden and we crouch down to look at some of the plants. In amongst the weeds and wildflowers are a few small rose shrubs, I point them out and she follows and points out more. There is a pile of leaves and garden debris in the border that she has been tending too on and off since I arrived. She fiddles with it again before saying she will deal with it tomorrow. We walk along the border looking at what is growing within them. We reach the garage after five meters or so, it is not a big garden. Pat says the things inside the garage belong to Linda and her daughter. The back gate is open and a woman in uniform is standing there with a mask on. She is coming in, I'm unsure if they know each other at first but it quickly becomes obvious she is Pat's carer. She is here to make them lunch, or perhaps dinner? it is around three pm. Pat continues walking out the gate, she shows me the borders in the front which are untended. The wheely bins are by the gate, this is where she will tidy the garden waste tomorrow, she says. We continue down the street. She says she likes to go to the garden centre to help the 'old ladies who are less fortunate'. I find myself feeling a little nervous and holding some responsibility for her welfare whilst we are out. Legislation and risk assessments from the academic institutions flood through my mind momentarily. I look back to see if Linda or Donald are still around, but they are not, I presume this walk is a well-trodden path for Pat. We come to cross the road, Pat remarks how many cars there are. I find myself in a situation where I am not sure who is leading who, I respond to her lead yet want to cross the road as quickly as possible. Once in the car park we stop to look at the houses, she points out things that she ponders over without giving a specific point. We look at the back of houses and the sacks of soil, sand and building material that lie in the forecourt of the garden centre. We begin to walk round the side of the nursery that takes us to the plant area out the back. She points to various old people that are using wheelchairs and highlights these people as the ones she likes to help. She asks me 'have you seen him at the back?'. Initially I'm not sure what she means, 'he's so lovely, I'm not sure he's here today' she says. She gestures towards an animal pen at the back of the garden centre where I can see a goat sitting in the long grass. 'Yes, he is there, I can see him' I say, we move closer past some trees for sale to have a look, she remarks on the goat's beard and its length. 'He's all alone she says'. As we meander back through

the garden centre a man heads towards us with a wheelbarrow 'hello Pat!' He calls out, 'is this another boyfriend?!' he laughs and gestures to me with his head. We all laugh, I say 'so I'm not the only one?' 'Oh no, far from it!'. He stops the wheelbarrow and asks how she is. He smiles with a warmth but does not chat for long, he moves off with his wheelbarrow and I don't get to introduce myself properly. We come back into the forecourt and Pat wanders into the shop. She reads the signs 'no time to bake? pick up a cake!' and giggles. We look at shelves stacked with preservatives before moving towards the exit. There are entrance and exist queues, perhaps a relic from COVID. We are in the exit queue, and I am not sure how we will navigate it without buying something, I fear her dementia being unmasked and a convoluted conversation explaining who I am and what we are doing. Instead, the cashier waves and says, 'hello Pat, how are you?'. Outside Pat tells me they are 'lovely girls'. We stroll back to the house. The cars are patient as sometimes we block them in the car park to look at seemingly random things in the forecourt or to do with the surrounding houses. Linda meets us in the garden of the house, she has been washing the pillowcases. She tells me that Donald is saddened by the garden, which is why the blinds are half closed. I suggest it serves an important purpose, she agrees and says this is why she is searching for a home with outside space. As we go up to the house, Pat wants to show me the summer house. She refers to the move to a nursing home on and off and in uncertain terms. It comes up when looking at the plants and things in the garden, who will look after things and where will they go? she asks.'

Pat explores the empty spaces created by dementia through the environment that surrounds her home. Here, whilst there is an undeniable, yet theoretical risk to her welfare, it might be seen as existing in tandem with the potential that accompanies this freedom. This is the nature of risk when understood through the non-form, how it cannot be restrained to a realm that entertains its function in purely negative terms.

Within these spaces Pat has found new relationships, both human and non-human. The environment has created these entities. Just as it poses a risk, it also serves to nourish and protect. In this way place is dynamic. It is its own entity. Far from one that is static, it is one that exists as part of a network of relationships that exist in both positive and negative terms.

Disaggregating these components into discrete units can help us rationalise place as a formed entity, but this is not how people with dementia were found to navigate place. Instead, like Pat, they creatively move into the non-form that dementia brings. In doing so they are open to the opportunity of what this might bring, but also vulnerable to the forces contained within it.

Ultimately, the place in which a person with dementia finds themselves will be navigated in such

a way that is not formed in a structured or rational sense. Rather they will create into the spaces that lead us to the reaching of life's aim and humanities ultimate home, a place of rest that accompanies the end-of-life.

The intersection between form and non-form: The Compassionate Community

Using the lens of the non-form I have described how an understanding of what constitutes a place of care cannot just be limited to an appreciation of safety and risk. Instead, how we understand the place of care, be that a community, a neighbourhood or an institutional setting must accommodate the notion that place is indeed its own ecological unit, with both temporal and relational components to what we understand by what is local, accessible and resourceful. In this way the place of care is the thing that gives people roots, the safety and security that comes with feeling listened too, nurtured and understood, not protected from death and decline but from the prospect of having to fight against its impending reality. Yet at the same time, what we understand by place, also provides us with wings. The wings with which we might move away from the structures that have held and supported us for so long. Whilst so much of the research narrative focuses how on people become cut off from the places where they live, segregated from the wider world, the non-form understands the emptiness of this process as the growth of increasingly intimate relationships, and ultimately an increasingly intimate relationship with our finitude so that ultimately, we might come home to death. It is here, in this new place and the risks we take in moving there, that transformational opportunity may reside, unbounded by polarity, inseparable from the pain of grief and suffering, yet indisputably present.

Betty moves on to talk about assisted dying, she says it is a topic she's not mentioned before when in actual fact we have spoken at some length on this. She says she is a member of a charity for assisted dying, she is not active in the charity beyond providing a monthly donation. She never says that if it were an option then she would take John for this. It is always discussed at a distance, as if it would be helpful for other people but she does not relate it to John personally, more his 'situation'. She says there is a bill being discussed in parliament and that she thinks it 'will eventually come in'. She says she has considered writing to her MP but was discouraged on finding out that they are strongly opposed to the idea. She says that perhaps more than this, she just does not have the energy to write or campaign on such matters anymore. It strikes me as something that would put you in an emotionally challenging position, campaigning for the death of your husband when he is still alive, and you are still caring for him. Betty goes on to talk about how she needs to make a living will, she says it is conversations like this that always

remind her, but then it drops to the back of the priority list, for a moment she considers the possibility that she might get sick and die before John and looks completely forlorn at this prospect. Still, she recognizes it as a possibility. She says that 'no one wants to hang on', the idea strikes me as a bit of a contradiction that many palliative care physicians might grapple with. This being that we promote the idea of a living will and encourage the idea that if severely incapacitated then lifesaving treatments can justifiably be withheld, yet at the same time we promote the value in caring for someone who is severely incapacitated, such as John. Betty continues her commentary 'we don't want to hang on, but then again John is happy...but at my expense'. We talk about the idea of a completed life. Betty likes the term, and it resonates with John's situation, she feels that his life is indeed complete, to her eyes there is very little meaning or value left, which makes caring hard to do. Betty turns the conversation to the twelve-year-old boy on intensive care where there is currently a court battle raging about whether he should be allowed to die. She talks about how distressing this must be for all those involved. She talks about children teaching us to let go and this being the ultimate example of this. She says the milestones of getting old, gaining independence and so forth are important to the parents as lessons in stepping back, detaching and letting go. She provides a quote which is delivered tongue in cheek 'I'll tell you something now young Dr Sawyer....Having children is all about giving them roots and wings', I have not heard the expression before but it strikes me as a poignant in the context of death and caring for a dying person, I tell Betty this, she laughs that John has the roots 'but the bugger won't fly!.'

Using the lens of the non-form tells us that a Compassionate Community cannot simply manage risk and expect to accommodate the transformational influence care at the end-of-life can impart. There is a need to acknowledge that places of care are inherently also places of risk. Working with risk is where the potential for growth and healing might be found. That we might be comfortable with this is essential to progress in an area that has become stuck by the multiple tensions that have arisen through the efforts to 'place dementia' by means that inhabit either an 'impairment led' or 'capacity oriented' approach to a condition that is unbounded by such polarities.

An integrative approach to healing, suffering & grief in dementia

As I have discussed in chapters one, two and three, long standing and poorly acknowledged tensions underpin what is considered success or failure in the field of dementia care. A desire to formulate a positive way of living with dementia has led to a discourse focussed on stabilisation,

prevention and preservation that systematically conceals the value inherent within the empty space dementia creates. This has exacerbated tensions with how we attend to the nature and meaning of human suffering but also how we attend to the very human notion of loss. Such tensions threaten to undermine and limit the generation of new ways of thinking.

Arguably, whether one adopts a capacity orientated approach, or an impairment led approach, the legacy of multiple concreted efforts to support people with dementia promotes a discourse that is explored from the perspective of what is already of form. Here the approach comes to be defined by the effects of the condition itself as opposed to one that explores the wider contextual spaces that unfold around it. By situating the experiences of dementia beyond a singular focus on its effects as a disease, but within a broader web of connections that transcend the physical and social realm, there is potential to discuss an integrative approach to understanding human suffering in dementia. In doing so, we might learn that our dependency and vulnerability are as much as what makes us human as our autonomy and rationality. Such an appreciation allows us to move away from values entrenched within notions of success and failure and towards a more a more nuanced and meaningful approach to suffering and what this means in the context of death, dying and loss.

Human suffering and healing

Where we are positioned and understand the world around us from only the perspective of the form, suffering is defined by the destruction and loss of the things that make up this world. Everything that threatens what has been carefully constructed to support and protect us, leaving us exposed to the unpredictable will of the non-form, is the point at which measures are built to protect us. A diagnosis of dementia brings into sharp focus the prospect of dependency, decline and withdrawal from the cognitive and social world to which we have grown into and been supported by for so long. The rational mind looks on at the prospect with a deep sense of unease, anticipating the horrors of what the experience might bring. Anticipatory fear was a common theme when discussing the nature of my research with people informally both in and outside of data collection.

I mention that I will be going to the memory lane café again this Friday. Sharon and Helen remark on how Angela used to enjoy going, Sharon tails off and says they can't do it anymore 'for obvious reasons'. I do not necessarily know what she means so probe some more. She tells me mobility is the main issue, implying that it is no longer appropriate. I reflect on my experience and how Sarah (the organiser) had

said to me not to mention dementia and called it 'a dancing club', I put it to Sharon that if this is the culture then, to me, it makes it difficult for Angela to attend, as she clearly has dementia. Sharon agrees. I also reflect that I detected a certain amount of fear from some of the carers at the memory lane café, fear as to what the future holds and where a diagnosis of dementia may take them. If this were the case, I ask Sharon how this makes her feel and whether it influences her decision to take Angela to the café. Sharon replies immediately and without hesitation to say that this is in fact the main reason Angela no longer attends. She is conscious of making people feel uncomfortable, she distinguishes this from any form of 'embarrassment', something that had not actually occurred to me, but does not take her because she 'does not want to make people uncomfortable'.

Yet anticipation and retrospect are different to the reality of being in the moment. This is not to say that the suffering that might be associated with incapacity, dependency and a perceived indignity does not exist, more that light and dark are sometimes intricately and inextricably linked. This is simply described in the reflections of a woman who cared for her mother through to the end-of-life.

'My mother was always very clear to me, because I was an only child, that that she wasn't to be a burden. And that I was to just 'stick her in a home'. But then, when homes became payable, when it wasn't free anymore, she actually made a suicide kit, which she had in her flat. A whole load of co-codamol and a bottle of Southern Comfort, umm and she intended, whenever she felt the right time was right, to take her own life. But thankfully, that was a positive thing about getting dementia. She, she wasn't able to do that. So, yes, you know, you've got to find your silver linings where you can.'

On many occasions I discussed the concept of being happy and healthy with advanced dementia with many of the participants and their families and was reliably greeted by the sentiment that they were in good health, often in state of happiness or contentment.

I ask Sharon and the carers what success might look like in advanced dementia and the end-of-life. This initially leads to a detailed conversation about what advanced dementia even means. Sharon reflects on how Angela is actually very 'healthy', I agree. She looks in excellent physical condition, her skin is good, her eyes bright, she eats well, but needs full assistance. I suggest it is complicated as the term advanced (insert any disease) often has connotations with an intensity of symptoms that make someone 'unwell', feeling sick or having pain or being physically weak. Sharon talks about the seven stages of Alzheimer's as written about by the Alzheimer's Society. She remembers reading and now laughs at the inaccuracy or

irrelevance in relation to her lived experience. How the stages interlink, overlap and move back and forth and their relation to what constitutes being healthy calls into question our understanding of these terms.'

Later on, when Sharon has left, I continue this conversation with Helen and Freda.

Helen tells me that they went out on the bus yesterday, for MacDonalds – Angela enjoys the chips and chicken nuggets. She said it was a good day, and when Sharon came in that evening Angela was 'chatty'. Today she is fatigued, Helen thinks this is because she used a lot of energy the day before. As we chat Angela's eyes close, and she falls asleep. Freda mentions that she was sad a few days ago, occasionally crying and they took her into the garden, and it brightened her mood. We talk about the narrowing of a person's environment so perhaps there is a more intimate connection with things that perhaps we take for granted. Helen agrees and cites the impact the weather has and things like the changing of the seasons. This leads me to ask them about their personal understanding of Angela's health. I explain that to me she seems healthy in many respects and how this perspective would sometimes be at odds to a description of 'advanced dementia' the state of incapacity, dependency and indignity that is often portrayed as part of the general narrative. They both feel she is healthy; they do not consider her to be 'suffering'. They do talk about moments of sadness. Helen gives the example of Angela meeting her sister some time ago. She felt that Angela recognised her and in that moment she re-engaged with the social world and became sad at her inability to navigate it as she once would. Helen describes how these moments of sadness exist in parallel and are part of what is a 'healthy life'. Helen says her being sad is 'part of that which makes us human' but that it also depends on the person as to how this might be interpreted.'

Such reflections were in no way designed to belittle or dismiss what had been a challenging and difficult process. More so they shine a light on the contextual spaces that exist at the periphery of conscious thought. It is here, where a larger, concealed body of suffering was found to reside. Without exception, participants would talk to me of moments in their lives that were highly traumatic and representative of a deep and profound suffering. These moments might be directly or indirectly related to dementia and its effects. Regardless of the relationship, they contributed to an undercurrent of profound trauma that ran through people's lives, hidden in the spaces around the object of our focus.

'At this point Sarah's expression and enthusiastic nature changes. She seems to be recalling something from a dark place. She tells me there were two occasions when she was caring for her mother, where she called the Samaritans. This was at Christmas when she hadn't wanted to trouble anyone else. She was

not suicidal she says, she just needed to talk, and they were there. She feels that she was able to this because of her own personal experience with depression, and also that of her family. She says that her cousin died by suicide, and this had a huge impact on the family. She felt that if she had been able to talk to someone it would not have happened, she will always therefore reach out, this is what she has learned. Sarah tells me that the nature of the suicide was highly traumatic, she locked herself in her car and burned herself to death. The trauma is visible in her face, and I am also struck by what she tells me, feeling almost winded by the weight of her words.'

That dementia is often the point of focus, be this from an impairment led or capacity-oriented approach, neglects the wider context which shapes our experiences and perceptions with respect to suffering. Through the lens of the form, where human experience is understood as something to be controlled, we might attempt to separate out the component parts of an experience into either positive or negative. This can influence our understanding of what suffering is, what it looks like and what should be done in response. From the perspective of the non-form, an experience might be seen as something played out through sequences of complex drama, something that captures the imagination and leads us on a transformational journey. Here positive and negative entities exist together, unbounded by polarity and inextricably linked.

This has important implications on how we think about both suffering but also what it means to heal. Through the lens of the form, where suffering is ascribed to the malignant effects of dementia that strips away meaning and value, the response is often confined to the realms of stabilisation, prevention and preservation. Through the lens of the non-form, where suffering is understood to exist as part of the human experience, dementia can help define the human response to decline, dependency and loss that is inherently part of life. Rather than something to be 'solved' or remedied, the question is how we can accommodate the transformational experiences brought by loss, understanding value and potential within its presence.

This, in essence, is the process through which we might come to heal. Healing into decline and death might seem an oxymoron. Yet, as I have discussed in chapter five ([creating into space as a means of healing p.143](#)), the processes are inseparable when considered through the lens of the non-form. Human suffering will always be present to some degree. Understanding what is avoidable, and in what context, is crucial to then being able to integrate its transformational value. Below are some reflections on my time dancing with people with dementia at a local community group.

'After a time, I make my way back to the kitchen to write some notes, and I am approached by a volunteer to ask me about my work. Her response to my synopsis is that it's 'not about the people with dementia, they are ok, it's the mental health of the carer that is important'. She described how her father, who is now dead, used to shout at her when she bought him his medications. It was a stressful time and she felt overwhelmed yet her opinion on this was not considered at the time.

I finish my notes and head back out to the music and dancing to speak with a woman I had met some weeks before. I sit down and ask how she is. She is a teacher, and she is relieved it is coming up to the summer holidays. Before we can get talking Yvonne, a Caribbean woman and former nurse, dances over to me and holds out her hands, 'I think you're going to be taken away' the teacher says to me, and before I know it, she has pulled me up. The song is 'take me home, country roads' by Toots and the Maytals. Jonny (the entertainer) substitutes West Jamaica for his home country and then invites various people to say where they are from into the microphone in time with the music. Yvonne holds me tight on my upper arms, she dances in rhythm with a broad smile. She has not previously talked to me when I have sat with her, but she sings every word to the song as we dance. She pauses to give me a tight hug and exclaims 'Oh I Love you!!!'. I think of her husband, the common reaction to Yvonne's displays of love and affection is to mirror her. Her husband's reaction is more subdued, he rarely smiles, he does not dance, I wonder if it is difficult for him seeing her express love to others when she can be verbally and physically abusive to him at home. Jonny the singer encourages us to form a circle for the next song and he stands in the middle to dance so others can follow suit.

Soon after the music draws to a close. Jonny is given a round of applause and people make their way back to their seats for food. Towards the end of the meal a choir pours into the room. The choir master and pianist is a large man with an extrovert personality. The choir assembles behind the piano. He introduces himself and the choir, He has several staged jokes that are dry and draw groans from the volunteers and some of the audience. The choir wear blue, they are mostly in their sixties and seventies and there is a mix of men and women. We are told their aim is to 'sing songs and bring joy'. They launch into some songs about summer, the audience face the music and listen intently, there is applause at the gaps between songs and more jokes and entertainment from the choir master. He introduces a song that is designed for us 'in case we forget who we are'. It is a song about who they are and what they do and was written by one of the choir members. The songs are simple and easy to follow and overall, they are bright and uplifting. The next set of songs are introduced as folk songs, at one point they sing the old Irish song 'Danny boy'. The

song is melancholic and there are people who begin to cry. Some people hug each other whilst others look away in tears, shielding their emotion from a partner or from a wider audience. Others stare with a vacant look as if soul searching. There is another song, 'You are my sunshine', some people sing along. I notice the daughter whose mother was telling various people to be quiet on the dance floor. She sings the lyrics as if on autopilot, her eyes are hollow and she stares at the table, present, but a million miles away. Her mother turns to face her during the chorus and her complexion changes to a loving smile, back in the present and away from her concerns perhaps. The choir master lifts the mood with some cheeky humour between songs. They draw to a close with a round of applause and the volunteers bring them all tea and snacks.'

Importantly, an integrative approach to suffering can exist alongside the pursuit and development of measures that seek to avoid it, I have discussed this in Chapter five ([integrated not opposing worlds, p.157](#)). Re-visiting this section might help in understanding how accommodating the value with death and loss whilst seeking a cure for dementia are not necessarily mutually exclusive endeavours, but instead are representative of a false paradox which arises when a situation is understood exclusively through the lens of the form.

Grief: Its anticipation and obstruction

The topic of grief is intimately linked to the notion of suffering and has been discussed extensively in the literature on dementia (Sweeting and Gilhooly 1990; Sweeting and Gilhooly 1997; Blandin and Pepin 2017; Doka 2010; Chan et al. 2013; Noyes et al. 2010; Meuser and Marwit 2001; Sanders et al. 2008). From the grief that accompanies the therapeutic nihilism associated with the disease, to anticipatory grief that accompanies the progressive losses to a person's identity, much of the narratives and practices around grief contribute significantly to how we understand dementia and begin to formulate a response that supports those affected.

Many people will have watched the components of the person they love or have loved change to a point beyond recognition. Moments they would share together are no longer and the prospect of them returning are non-existent. This brings with it a sadness, a grief at what was and is no longer. Yet in these same moments is where the presence of a relationship might be felt most. Here, with all else seemingly stripped away, the relationship is revealed as its own entity with a corresponding influence on the decisions and interactions that compose the performance of care. A feeling of loss and distance combined with a newfound intimacy with the nature of

human relationships can be difficult to reconcile, especially when approached rationally or from the perspective of the form.

I have described how the non-form teaches us that the locus of grief and healing are inextricably bound together rather than poles apart. We grieve at the gradual loss of components of someone's person, the aspects of their character that fade and cease to exist. Yet within these spaces is where healing occurs, where intimate relationships are built and nurtured, where we innovate, create and experiment into the space. Letting go of structure is essential to making the most of these healing opportunities. Ultimately, honouring the grief we hold for all that is lost is what preserves the connection, creating a profoundly intimate form of presence. That the relationships we have formed through life are created through love means that their loss will unavoidably cause extraordinary pain. This, at once, is the irreconcilable beauty of grief and the point at which we might begin to heal. The rational mind and the structures of the form have no bearing here, people simply have to move into the space, into the non-form and trust in its potential.

Where we seek guidance from the structures of the form is where tension can build, and moral distress can prevail. That we might preserve or tend to someone's personhood in the face of near total dependency and decline, that we might rationalise into existence an ideal of care that maintains an illusion of the person who once was, can obstruct us from our grief. With this we are also obstructed from the potential to heal that comes from inhabiting and ultimately accommodating the void of loss.

I wonder how Betty feels their relationship has changed through the course of John's dementia and pose this as a question. Betty thinks how best to answer, her answer surprises me in that she feels it is in many ways 'very similar'. She qualifies this statement by describing how she was the one who was always 'running the house anyway', she says she would 'sort him out every day, just as I did in the past'. John would work and bring home the money to support the household, whereas she would maintain family life and domestic duties. In this sense, she says, their relationship is very similar. She brings up the idea of 'chronic sorrow or grieving' independently and says she has 'never really felt that', I wonder if this is in part as he is still alive and that there will be a time to reflect on his life, their relationship and its loss when he does eventually die. Betty says, 'it's more of an annoyance than a grief'. This is an interesting perception, the idea that you can't grieve because he is not dead, and this itself is perhaps an annoyance,

as well as what I understand her to mean – that having to care for him and engage with the tasks of care is ‘annoying’.

Rather than people anticipating grief through progressive decline and dependency it was understood that many people’s grief was obstructed. They were unable to reach into the depths of despair, deep into the non-form, partly because of a person’s persistent existence in physical form, but also by the structures that have been built to support us. These structures keep us grounded in the realm of the form, protected from the uncertainties of where grief might take us.

Where grief is supported alongside the ongoing care of a person with dementia, people might face the future challenges dementia brings unconstrained by fear, free to express what is right for them in such a way that accommodates the potential such challenges hold for growth and change.

I meet Sharon in a coffee shop by the station. As we sit down, I ask how she has been. Sharon says things are much the same, she describes feeling acclimatized to the situation, at ease with her mother’s almost static but slowly deteriorating state. She talks about how there are some fluctuations, she was there recently, and she perhaps recognised her face and maybe said ‘Sharon’, Nicole and Helen had reacted with excitement and positivity to this, enthusiastically greeting what they thought was a recognition of her presence and the use of her name. Sharon is more pragmatic about it. She is not sure if she recognised her or not. More to the point, she says, it is not necessarily important to her anymore. She knows that her relationship with her mother has fundamentally changed, and most of the time she is not aware of who she is or whether Sharon is present or not. I describe how the last time I visited Angela she had stared straight through me. It made me feel as though I wasn’t there. Sharon says she has experienced something similar and celebrating moments of lucidity and the mention of her name is not of value to her anymore. She is accustomed to her mother’s state. She is comfortable with what is important and perhaps what is of value, yet at the same time she is conscious that she does not know how she will feel when her mother dies. She has spoken of the relief she expects it to bring, but also concern that it will be less of a relief than she thinks.

Sharon says that she has been enjoying getting on with life outside of her mother’s condition. She says she has been busy. I ask if it is work related or other things. She tells me she has been to visit their holiday home with her family, and that they took Derek’s (her husband) mother with them. This leads her to tell

me that Derek's uncle had recently died. It was an unexpected death. He was a bachelor and lived in a house on his own. His body had been found after some time. They are not sure how long but possible longer than just 'days'. There has been a post-mortem and toxicology analysis, but no cause of death has been established. He was not known to be unwell. The description to me is traumatic. Sharon doesn't seem to see it in this way, she is more caught up in the unravelling of events that this has caused. The family dynamics and complexities in relationships that have revealed themselves in response to this event have been a challenge. Accommodating this within the procedural nature of things that follow a death has been hard. Organising the funeral and executing the will has been stressful. The description mirrors my experiences at death, where my medical training is of limited use and the reality and complexity of managing such situations often resides within the relational component of care. I share with Sharon a story about my father-in-law, who is dead, how he was a 'character' and that there are similarities with her description of Derek's uncle. The story is offered in reciprocation of what she has told me, it also is meant as a way of demonstrating that in some small way 'I know what you mean'. I think it is received in this way and the conversation begins to flow.'

Summary

I began this chapter examining the role of supportive relationships in the care of people with advancing dementia. I discuss how network analysis highlighted how social groups changed in shape and form around the person with dementia. I also discuss some of the underlying mechanisms by which they might change, before pointing out the limitations of understanding this through a highly structured lens. By applying the lens of the non-form, I discuss what else becomes apparent. I revisit several of the tensions that I describe in chapters two and three, how, for example, relationships might be therapeutic, but at the same time destructive and damaging. I analyse how this reality might be accommodated and better understood when we depart from notions of risk and safety that, as an orientating point on which to base our actions, are better suited to a different phase of life. I introduce the idea of 'shared vulnerability' as point on which to understand the approach to relationships and connections that are transformative and hold particular value at the end-of-life. I then discuss how form and non-form might work together when considering relationships, how relationships might exist as independent entities upon which we can place the focus of care and attention. In the second part of the chapter, I discuss an approach to place of care. I expand on my ideas relating to risk and safety before introducing the concept of 'coming home to death' and how this might influence how a Compassionate

Community is understood and created in such a way that accommodates the needs of people affected by dementia. In the final part of the chapter, I discuss how my characterisation of both form and non-form might influence what we understand by loss, suffering, healing and grief. How, by paying careful attention to what exists in the spaces around our collective conscious focus, we might come to understand these topics from a different perspective, one that accommodates the pain of loss as the route by which we might come to heal.

Chapter Seven

Forming an open-hearted kinship with absence

Contents Seven

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A summary of the preceding chapters

In chapter one I set out the thesis as a response to the increasing rates of dementia and the challenges this might pose for high quality, accessible and equitable care at the end-of-life. I analyse the evolution of the conceptual approach to loss and how this has been adopted and refined with mixed success in the context of dementia. In chapter two I discuss how palliative care's evolving relationship with public health has led to a set of principles that seek to restore balance and reorientate practice in such a way that death's meaning and value are more widely acknowledged. I map the constituent components of the approach, describing previously unconsidered areas of contention. In chapter three I discuss how this approach might work in the context of dementia suggesting further analysis of multiple permeating tensions is required to define a path forwards.

In chapter four I discuss the methodological challenges I faced in addressing these tensions. I highlight the difficulties in conducting research where the familiarity of the empirical world is warped by the effects of dementia and the seemingly 'empty' spaces it creates. I describe how using critical realism to pursue a programme theory could not fully accommodate my data, and how this led to the reflexively generated account of form and non-form. In chapter five and six I characterise these worlds, describing the potential that comes through an acknowledgement of their presence.

In this chapter, I provide a discussion of the theoretical implications of my work. I will focus on the field of dementia and public health palliative care, assessing how my findings might work as broad organizing concepts on which to orientate a theoretical and practical response to end-of-life care. I will then take a broader view and discuss how form and non-form might work at the level of a systems-based approach to death and dying before highlighting how my findings might work alongside the academic structures designed to help navigate the unknown.

In my concluding chapter I will describe the practical implications of my work, before discussing the future, what remains and the importance of endings, or perhaps the absence of them, how form and non-form are both necessary in understanding not just where we are going, but what we are going to do when we get there.

Defining and redefining progress: Integrating form and non-form alongside existing dementia theory

In chapter one I suggest that the current theoretical approach to dementia organises our judgements in such a way that aspects of advanced dementia most associated with fear and disdain; the loss of agency, identity, reflexivity and independence, come to define what it means to suffer (Jakhar, Ambreen, and Prasad 2020; Diehl-Schmid et al. 2017; Gilleard 2021). Put simply, human ideas on suffering might be traced to the disorganisation and disruption of the carefully formed and structured world to which we have grown accustomed. Here, the ethically and morally binding imperative to care (Higgs and Gilleard 2016d) can only be orientated towards processes that seek to remedy such losses by creating a sense of meaning on which to collectively gather. Yet I have also presented the futility of concerted efforts to achieve this. To bring any sense of control, certainty or indeed meaning in the face of a prolonged state of decline and loss works to deny the reality of the situation, ensuring the pursuit of meaning becomes lost to paradox. As such, current theoretical constructs such as personhood and citizenship are found wanting when used as components of an orientating theoretical framework that sets the parameters for a successful and progressive approach to end-of-life care.

Framing the context to my research in this way highlights first the absence of an appropriate theoretical approach that might orientate the response but also, and perhaps more importantly, it demonstrates the implicit constraints in understanding what success or progress might mean to begin with. At the end-of-life, any attempt at understanding progress, meaning and value can be lost within the cosmological black hole of the fourth age (Gilleard and Higgs 2010b). My findings have illustrated how personhood, citizenship, interdependence, compassion, community and any other such conjectured force for good can provide a shield, for a momentary period at least, from the unfathomable and disorientating emptiness associated with the progressive and ultimate losses associated with dementia and the end-of-life. Where our moral and ethical structures demand the pursuit of betterment in an attempt to bring us closer to some sort of positive, utopic endpoint, there is little time to stop and inhabit the emptiness within which we have arrived. This reinforces the notion that whatever balance between successful and unsuccessful care is achieved, each success can yield a new set of problems and with this new possibilities of failure (Davis 2020b; Higgs and Gilleard 2016e) ([See chapter one: Conclusion page 27](#)).

The challenge therefore becomes how we identify with death and loss as the marker of humanities outermost frontier, where the tools, theory and structures that bring us to this point are of limited utility in designing a response precisely because they are designed with the primary function of creating certainty and delineating right from wrong whilst defining meaning in such a way that allows people to collectively engage. A state of advanced dementia, and the dark shadows of the fourth age, resist this structured approach and any attempt to define meaning, leaving people beset by fear and grief at the anticipation of all that is unknown.

Taking part in the social lives of people with advanced dementia has afforded me the opportunity to enter the empty spaces that are the object of our discomfort. What I have ultimately found is that, at the frontiers of humanity's lived experience, there is no ultimate unifying force for good, beauty, joy or success. It simply does not exist other than in an ideal, a perfect image we hold of ourselves and what it means to be in existence and act with greater certainty and moral authority. This is the lesson that people with dementia have imparted on me. That our inherent vulnerability to accident, illness, injury and death strips away this ideal, exposing humanities relentless pursuit of perfection through the application of all that is form to all that is of non-form. In this way dignity, equity, justice, happiness, joy and beauty, a system of perfect contentment is not its own end. Instead, these forces point to something beyond, a state of being where seemingly polar entities are held together in a state of intimate belonging. As I have argued, this is the essence of the non-form, an alternate realm devoid of structure brought through systematic rational thought, yet one to which we all belong. Much in the way a river opens out into the ocean, the structured world of the form unravels into the non-form and its accompanying state of intimate yet disorientating belonging at the end-of-life. I argue that the data I have presented in chapters five and six provide evidence for this notion. So, if positive progress brought through personhood, citizenship or palliative care is not the end-point we think it is, and at life's end everything converges into the isolating yet intimate presence of the non-form, the obvious question becomes, so what?

As I alluded to, my description of the non-form challenges the existing theoretical approach to dementia. Perhaps it also challenges the very notion of what dementia is. Fletcher has argued that institutional representations of dementia stem primarily from biomedical research paradigms, a broad array of discrete neuropathological processes that cause cognitive decline (Fletcher 2020a). Acknowledging that there is some foundational element of truth in such models, he also argues that building such a powerful representation on these foundations alone remains to be largely conjectural and metaphorical for those experiencing the changes

themselves. This leads to the term ‘mythical dementia’ (Fletcher 2020a), the proliferation of which, it is argued, has infiltrated activities of dementia related charities, government policy and media portrayals in such a way that demands a particular response. My description of form and non-form describes how ‘mythical dementia’ can work to deny dementia’s existence as a window to the non-form. My aim now is to offer a more detailed account of the implications of my work in navigating and integrating it as a novel approach to dementia care that accommodates the end-of-life whilst building an awareness of what might be of value.

Broadly speaking, current dementia related theory might be seen to originate from either one of two camps. An ‘impairment-led’ approach or a ‘capacity orientated approach’ (Droes et al. 2017; Vernooij-Dassen, Moniz-Cook, and Jeon 2018). I discuss in detail the merits and drawbacks of both in chapter one ([deficit and loss in advanced dementia, page 23](#) & [personhood, citizenship and the moral standing of people dying with advanced dementia, page 24](#)). I outline how a focus on deficit has highlighted the need for action in the form of enhanced diagnostics, new therapies and improved access to services, yet at the same time has cast a shadow on the underlying person and their capabilities and agency. Viewing people’s lives through a lens of loss and incapacity has created a stigma (Benbow and Jolley 2012) and with this, contributed to the systematic social exclusion of people with dementia (Walsh, Scharf, and Keating 2017). Calls to progress towards a ‘capacity orientated approach’ (Droes et al. 2017; Vernooij-Dassen, Moniz-Cook, and Jeon 2018) have done much to re-affirm the notion that people can, and do live well with dementia (de Boer et al. 2007; Bartlett and O'Connor 2010a). Yet I, amongst others, have argued such theory sidesteps issues relating to decline, dependency and loss that are highlighted by Higgs and Gilleard’s description of the fourth age (Gilleard and Higgs 2010b; Higgs and Gilleard 2016e).

Here the reality of advanced dementia comes to represent failure, a product of the unsuccessfully aged and cared for (Davis and Scherz 2020). This can create both moral and existential distress for family and carers who are left to navigate the vast empty planes of loss without an orientating framework. This has the potential to create its own stigma. Recently, during a visit to a research participant we discussed how she felt there is often a perceived right or a wrong way to engage with care and that she frequently found herself on the wrong side of this binary, despite her best efforts. She described how unforeseen challenges, or the realisation of an unavoidable event, is often perceived as the result of something that has been done wrong, something that could have been prevented. She described how, for her, this was representative of a ‘new type of stigma’ whereby carers are inevitably led to feel guilt and shame at their perceived incompetence.

These issues are of particular relevance to Kitwood's theory on personhood and well-being in dementia (Kitwood 1993, 1997a; Kitwood and Bredin 1992; Kitwood 1997b). Acknowledging personhood of people with dementia continues to be a defining aspect of contemporary practice and policy in institutional settings and forms the basis of 'person centred care' which is now widely considered as a marker of 'good care'. In chapter one I discuss the existing critique of this approach, how the preservation and replenishment of personhood in the shadow of the fourth age and the end-of-life can lead to feelings of futility and failure.

My findings have perhaps taken this one step further, suggesting that to try and define what constitutes good care at the end-of-life is to understand value through what is of form. For Kitwood, value resides in the preservation and replenishment of personhood, and it is through this that 'good care' may be defined. My findings identify value as originating from the non-form, as a gift that reveals itself through the unravelling of life that dementia brings. My data has shown that where the maintenance and preservation of personhood is understood to be a defining feature of high-quality care, people are left open to feelings of incompetence, which can in turn conspire to conceal rather than illuminate what might be of value in the first instance. In many ways Kitwood's reorientation of the approach to dementia is symbolic of a shift from a deficit-based model to a capacity orientated model. Yet by introducing the concepts of form and non-form, I argue that an approach founded on either deficit or capacity are simply differing approaches to the same end point, that being the preservation and maintenance of all that is of form. Displaying absence, emptiness or suffering as a point on which to bring action defines success in terms of the removal or remedy of such entities. Foregrounding the capacity and capability of people with dementia defines success as living well, as active agents that contribute to the carefully constructed ideal of what human existence means whilst guarding us against the pain of loss. Ultimately, both approaches are centred on how loss is conceptualised and understood, and are united by their focus on maintenance and preservation of the structuring processes that make up a perceived reality. Neither theoretical approach prioritises the accommodation of loss, absence and the transformational potential it holds for human life.

Positioning dementia related theory as either impairment focussed or capacity oriented is therefore representative of a false dichotomy. A tendency to either of these seemingly polar approaches can at once deny a life left to live, or the reality of peoples suffering brought by decline, dependency and loss. Here success is understood as something to which we arrive at *despite* the presence of all that is fractured and broken. Whilst there might be an acceptance of an ever-shifting balance between these two polarities, they are none the less conceptualised as

independent entities which drives the relentless pursuit towards one and away from the other. In the enigmatic quest for meaning and value that occurs within the absence and loss associated with advanced dementia, such a pursuit inevitably leads us back to the polarity from which we were trying to escape in the first place. This can be seen in more recent calls that caution against the pursuit of citizenship and personhood where it might also work to deny the reality of peoples suffering (Bartlett et al. 2017).

By framing abjection, death, dependency within the social imaginary of the fourth age, Gilleard and Higgs suggest that the driving force behind this pursuit is societies ‘moral imperative of care’ (Higgs and Gilleard 2016d). They argue that is this has seen the aged and infirm become the ‘objects of this imperative’ (Higgs and Gilleard 2016d). They describe that how, even through multiple scandals, crises of funding and market failures, this moral imperative has remained ‘largely unchallenged, losing none of its social nor political value’ (Higgs and Gilleard 2016e). In this way the moral imperative becomes what has been termed ‘protected discourse’ (Dahler-Larsen 2013b), something that might be considered virtually sacred and is therefore left unquestioned by societies dominant forces. More so, they describe how personhood, dignity and perhaps now newer terms such as ‘compassion’ and their increasing centrality to care narratives has reinforced this moral imperative as the driving force behind the improvement of the practical aspects of care, but also people’s ability and right to equal access.

I argue that the moral imperative to care helps reinforce the position of dementia’s orientating theoretical frameworks towards the preservation of all that is of form, positively feeding back to create a practice that is seen as a universal force for good, a universal truth that has become impossible to criticise or break free from. Yet my findings challenge the nature and orientation of this moral imperative. By inhabiting the empty spaces that surround what is empirically observable, I suggest an approach that tends to the darkest aspects of life, its infirmities, indignities and the relentless ambivalence to which life seems to pass by without so much of a moments concern for them. This approach incorporates the non-form and opens new possibilities for how we accommodate not just value and meaning, but its inextricable links to absence, loss and all that might appear as meaningless⁷.

To understand this further, the world of the form might be seen to be composed of ideals. Whilst holding an ideal is certainly a thing of great value, it has the ability to awaken a passion

⁷ This concept is discussed as a central theme throughout this chapter. It is diagrammatically conveyed in [figure seven](#) and [figure eight](#) and will be revisited in more detail at varying intervals.

and urgency that brings out the best in people, they also create an unending pursuit for perfection. When humans become vulnerable, the ideal, or the perfect image we have of our being, begins to fall away. Human addiction to the pursuit of perfection affords little patience for being vulnerable, let alone the near complete dependency associated with advanced states of dementia. Yet at the same time, this is also the very nature of what it means to be human, born into a body that is inherently susceptible to accident, illness or injury.

Form, non-form and the ideal type

In my description of ‘ideal care’ ([Chapter Five, page 126](#)), and the organizing ideals of the form, I am in essence classifying in generalisable terms an approach to care that I have uncovered from within my empirical data. To better define what I mean by this I will draw on Max Weber’s construction of the ideal type (Buiger 1976). I will discuss how my ideas on what constitutes the form bear resemblance to this theoretical construct and its epistemological and methodological foundations. This discussion is designed to add conceptual clarity, providing reference to a platform through which my ideas might be better understood as typologies upon which people can elaborate and draw meaningful conclusions.

The ideal type is a mental construct used to approximate reality by selecting and accentuating certain elements of a given phenomena (Psathas 2005). The ideal type is seen to overcome some of the limitations associated with broad ranging, organizational concepts that, whilst analytically useful, might struggle to balance out generalisability with the preservation of unique facets of the phenomenon under investigation (Hekman 1983; Swedberg 2018). In this sense, an ideal type is not a description of reality, nor is it a hypothesis (Weber 1963). Instead, it is an attempt to create some order from otherwise heterogeneous set of events by paying greater attention to, or accentuating its homogeneous attributes (Hendricks and Breckinridge Peters 1973). Sidestepping the critique that ideal types become functionally lost somewhere between definition and theory, analysts instead point to their use, not in their existence per se, but in what becomes visible when juxtaposed alongside empirically reality (Hekman 1983). It is this comparative process that brings discovery and the possibility of causal explanation to empirically observable patterns of interest (Swedberg 2018; Hendricks and Breckinridge Peters 1973).

The construction of an ideal type is described as embedded within a distinctive process of selection and synthesis which sets it apart from other conceptual categories (Hekman 1983; Psathas 2005). This includes empirical facts or observations being constructed alongside their

cultural significance, i.e. via the meaning that social actors associate with their actions, and also acknowledging the relationship with meaning that is compatible with the theoretic interest of the investigation (Hekman 1983). Where the creation of an ideal type is embedded within a different epistemological paradigm to the knowledge desired from its operationalisation, its analytical use and the subsequent theoretical constructs might become impaired.

My description of ideals, and the more detailed description of the ‘aesthetic ideal of care’ (chapter five) operates in a similar way to an ideal type. At the same time, whilst the concepts of form and non-form have not been developed in accordance with an ideal type sociological analysis (Swedberg 2018), my description of their function and methodological development bears significant overlap. In this way, form, and its organising ideals, are not generalisable entities holding a discrete analytical function, indeed the reality of care is much more than just my description of its idealising principles. Instead, their use comes through their comparison with reality and elements of the non-form. For example, my description of ideal care, when held in relation to my empirical account of the social lives of people with advanced dementia, allows us to see how care can become rooted in paradox and contradiction. When considered alongside the moral imperative that supports the implementation of our ideals, it becomes clear that such a model can conceal the value held within all that is non-form meaning the general approach to care becomes rooted in a closed loop cycle. This is problematic at many levels, but especially when trying to create an organizing conceptual framework that might allow people to progress from living well, to dying well with dementia.

As a model, my description of the form, its organising ideals, and the non-form might work to achieve heuristic and analytic purposes whilst also serving to orient further empirical study in this area. Understanding them through the lens of an ideal type might ultimately offer a more nuanced discussion on the use of form and non-form as organising concepts through which we might conceptualise interactions, test causal relationships or explain specific actions.

Form, non-form and the social imaginary

Whilst my use of the word ‘ideal’ alludes to a categorizing phenomena by which we organise and orient an approach to care, I am also using it with another, perhaps broader meaning. Within this second approach I am trying to encapsulate the essence of an ideal and the power it holds in encouraging us to reach beyond our existing limitations to a realm where something surprising or

new may emerge. In this way, an ideal is something that is fundamental to how any functioning society survives and operates.

Over the last couple of centuries there has been a line of analysis that seeks to generalise an encompassing spirit that can characterise a period, people or phase of life (James 2019). In, 'the social imaginary in theory and practice', Paul James traces what he sees as a coalescing of ideas around a dominant 'spirit' or singular essence and how this has evolved under the influence of secular social theory from a universalising cosmology to a constructivist approach whereby humans create the spirit that is the subject of enquiry. Such a discourse has led to the conception of a social imaginary, and with it a series of questions that sought to understand the commonalities of such a construction (James 2019).

Whilst there have been various orientations of the social imaginary, my intention is to focus on those posed by Charles Taylor and Manfred Steger (Steger 2008; Taylor 2007). Charles Taylor defines the social imaginary as 'the ways we are able to think or imagine the whole of society' (Taylor 2007). Here the imaginary is not the specific ideas of belief patterns held by a set of people, but the convocation of those ideas or experiences into a larger social frame. Importantly, although it can be analysed by academics and theorists, it is not designed to be an intellectual framework. Instead, it is a more generalising sensibility that reflects the lived experience of people. Significantly, it is not a totalising phenomenon, but instead a cultural dominant which might be layered or interwoven with prior and emerging imaginaries (James 2019).

There are significant parallels between my description of the form and non-form and the ideas conveyed in Taylor's social imaginary. They are an attempt to describe the basic processes by which humans might come to know themselves, both as a whole and in relation to others whilst offering a much broader description of what constitutes meaning and value in the context of profound dependency and death. If indeed there is use in understanding my findings through the lens of a social imaginary, it follows that there is potential in its use to help understand and orientate layers of social meaning within the world. This paves the way for further analysis and also offers scope for it being adopted as a novel approach to care at the end-of-life.

However, despite crossover, and the analytical potential this offers, there are also significant differences. My description of a moral imperatives and its operation alongside the more metaphysical components to the non-form point to an understanding of ourselves that is not exclusively social, indeed in the context of advanced dementia the social realm is deconstructed to the point where it is barely recognisable. As I have discussed, the pursuit of meaning and

value that might be associated with progress can become futile and therefore disorientating when operating at the extreme ends of life. Here, progress, meaning and value are perhaps not the ends we think they are, whilst the pursuit of such things can ultimately reinforce a way of thinking that conceals what is bestowed through all that is non-form.

Operating in such spaces necessitates an ontological, and subsequent epistemological shift, something that I have outlined in detail in chapter four. It is here where the significant differences between my work and the concept of a social imaginary lie. Whether this means form and non-form can be understood as something beyond a tool for ‘meaning formation’, something that is not just another ‘cultural dominant’ through which to understand progress, but something that questions the nature of what we understand by success from a position beyond the social realm.

The true position of my work within the constellation of organizing concepts is perhaps yet to be determined and is likely to require further empirical testing and analysis. How form and non-form lie alongside, entwined or layered upon other ideas, ideologies, imaginaries and ontologies, what the specific practices associated with reproducing them are, and how they might combine to create and orientate comprehensive belief systems in the social world and beyond, are avenues for further development. However, in a world that is predominantly oriented to all that is of form, where meaning and value are to be objectively defined, understood and therefore measured, accommodating all that is of non-form might offer a more integrative approach to care at the end-of-life.

Form, non-form in the context of organization, evaluation and institution

In the preceding section I discuss how organizing concepts such as ideal types or social imaginaries offer an analytically useful approach that might help define and orient the pursuit of meaning, offering a set of progressive ideals in the process. Yet, as I have described, at the very end-of-life, or states of advanced dementia which might about this juncture, these words and their meaning become difficult to define thus calling into question their use as points on which to build a response. Here, in the emptiness that exists beyond our outermost limitations, our ideals fail us, or we are a failure to our ideals, the sense of meaningless can be as disorientating as it is profound ([see chapter four – reflexive considerations for more detail](#)). Where people strive to define and imagine the light through which we might find progress, other areas become neglected and fall into shadow, with this follows an almost relentless pursuit for progress that

can deny what is found in the darkness itself. This can be seen in the approach to dementia. Where death and dependency cannot be remedied, the ideal of care and the ideal death are constructed as the points on which to focus efforts and build a response ([see chapter five, the aesthetic ideal of care, page 126](#) & [chapter one, advancing the idea of a good death, page 17](#)). Whilst this has brought ‘progress’ on some fronts, it has brought profound moral and existential distress on others ([see chapter five](#)). Yet we remain wedded to this cycle as a result of the ethically binding and unquestionable moral imperative to care. Here our undeniable, virtuous ideals create a moral imperative to care which brings us ever closer to achieving the success associated with the realisation of our initial ideal, and away from failures associated with all that conspires to destroy them. The closer we get to the ideal, the more the idea of progress becomes paradoxical. Seemingly within, but always and forever out of reach, the pursuit becomes less of a linear progressive trajectory and more of a recurring cycle. This is the unending paradox of working within and towards the orientating ideals of the form. As I identified throughout chapter one, two, three and to a large extent through chapter four, this approach does not accommodate the dark, empty planes where meaning is as present and yet as evasive as trying to clutch at running water.

This notion, and its broader implications, might be understood in relation to the discussion on the spread of organization and evaluation as a means of learning and social betterment (Dahler-Larsen 2013b; Mark, Henry, and Julnes 2000; Mark 2008). In his book, ‘The Evaluation Society’, Dahler Larsen positions the ‘wave of evaluation’ as a central feature of organisational and institutional practice that has come to generate and define progress and development. Viewed from within the wave itself, evaluation leads to learning, social betterment, increased efficiency, better management, more public information and many other forces for good. Reminiscent of my description of the moral imperative to care, opposition to evaluation exists only as an entity to be overcome, often revolving around discovering the correct methods with which to achieve this whilst the self-defined success of evaluation creates a positive feedback loop.

Larson goes on to use a rational, learned and institutional approach to organisational theory to illustrate this point further. A rational approach, he argues, aims to provide maximum predictability towards a set of pre-defined objectives or ideals, this produces a paradigm whereby best practice is defined by procedures that can organise actions to carry out a central idea in the best way possible. The critique being that there is always a risk that the instrument, and it’s now legitimate, unquestionable procedures become a form that is maintained for its own sake at the expense of other emerging and substantive values. In this way, the organisational structure uses

evaluation to create and then impose a preferred world view at the expense of emerging complexities, further acknowledgement and understanding of which might lead to genuine progress (Dahler-Larsen 2013d).

The limitations of a rational model are largely described as being overcome by a learning model of organisation. This acknowledges not all decisions are made rationally or can be evaluated according to set goals, but instead adjustments happen mostly at the margins. Here, learning and evaluation become synonymous through the integration of feedback which leads to action and subsequent cycles of learning and re-evaluation (Dahler-Larsen 2013c). Unlike rational organisation, the learning model is quicker, more flexible, adaptable and offers positive connotations in the direction of the individual and collective, progressive development (Dahler-Larsen 2013c). Yet the approach remains orientated towards progressive betterment or optimisation, without addressing the central issue of defining the ideas and imaginaries that characterise a society driven by the mechanics of evaluation. Put simply, to what end do we pursue progress, and how is progress even understood or imagined? Without such an imaginary it is argued that either a rational or a learned approach to organisation and evaluation risks neglecting what is important to know in the first instance.

A third and final perspective is put forward as institutional organisation theory. A fundamental difference is introduced, that humans cannot ever fully understand themselves. Instead, there is another dimension. Something that is not amenable to rational calculation or can be discovered through reflection and continued cycles of learning and practice. More so that not everything is reducible to purpose, meaning or function. Institutional constructions such as ritual, myth, culture, language, typologies, norms, habits and values become so ingrained they appear as givens, ultimately becoming a reality in and of themselves. From here institutions can develop their own logic independent of the people within them. In this way the rational aspects of organisation and evaluation, of knowledge and the very concept of betterment are themselves an expression of ritualised myth that has become legitimised by expectations in organizational environments (Dahler-Larsen 2013b).

The book argues that many of the norms, values and expectations that evaluation brings to our society are poorly understood. Yet faith in evaluation runs deep due to its positively reinforcing nature that has become set within institutional beliefs and values, constantly adapting and evolving into new forms whilst each time allowing its orientating principles or imaginaries pass through unexamined. The implication being that an underlying imaginary on which to base

practice, the pursuit of betterment, can inadvertently exclude what might be important to know and understand in the first instance. In this way, the history of evaluation and organisation is not necessarily a story of increasing perfection, of a linear path to some ideal state. Instead, each phase has brought its own limitations and tensions (Dahler-Larsen 2013a).

Discussing the theoretical approach to organisation and evaluation in this way draws attention to and reinforces the limitations of working with all that is of form at the end-of-life. Whether a rational, learned or organisation approach is adopted there is a clear and reproducible pattern evolving. That being structure can drive a type of progress that is self-defined, meaning it can work to conceal its own limitations. This is replicated in my description of the ideals that contribute to the form and the moral imperative that drives them. Working with the non-form I have evidenced how, at the outermost limitations of human capacity and understanding, at the point of loss to which there is no possibility of return, to talk of success, failure of evaluation and progress, offers only an ephemeral sense of value or meaning. Indeed, human existence and its meaning and value does not gather anywhere, it is part of a constant cycle of passing and becoming that defines the unmappable, boundless and open-ended realm that is the non-form. Here value resides as much in our dying as it does in our living and whilst we come to move towards the non-form realm, our perception of all that was once familiar, ordered and structured becomes bent, warped and alien. Whilst this is greeted with profound discomfort, grief and unknowing, I have also provided evidence to suggest it is also the route towards healing ([chapter five, creating into space as a means of healing, page 148](#)), where we might become literate in loss, learning to trust in its transformational presence and value, that exists not *despite* the darkness but *because* this is how it exists, forever entwined and inseparable from all that is broken, damaged and soiled. This is the unique message and learning that has been made available by the increasing presence of advanced dementia and the fourth age, indeed the presence of abjection, suffering and darkness that it has come to symbolise.

Summary: form, non-form as organizing concepts

I have summarised my discussion on the relevance and implications of my work to dementia theory in the two figures below. They are referenced throughout the preceding text, and I encourage the reader to reflect back on this section with these images in mind. Figure seven describes how progress is understood when considered from the perspective of all that is form. Rather than a progressive linear trajectory it takes the shape of a closed loop cycle. This is representative of how, at the point of our outermost limitations, the point at which we abut the

perimeter of the fourth age and the unavoidable and inescapable realm of loss, progress can be illusory and the applications of any formulated structure applied to generate meaning, to define success, ends up creating a false paradox, an unending quest for a point on which meaning and value might collectively gather. By discussing the analysis and generation of broad organising concepts such as the ideal type and social imaginaries I hope to have provided a platform to understanding my work through a similar lens. Whilst this might help bring conceptual clarity, I also recognise the potential for further analytical development.

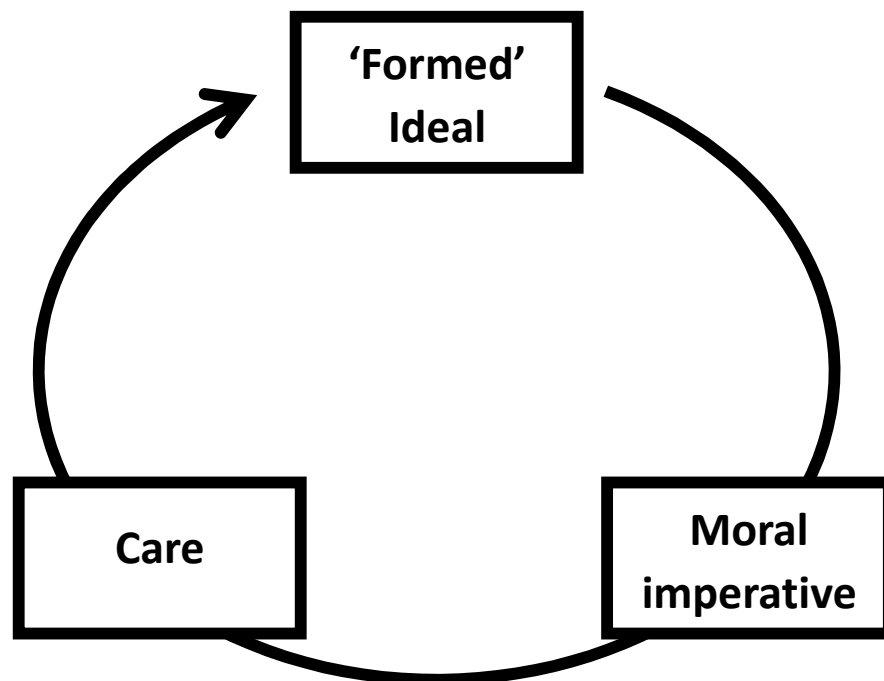


Figure 7: The closed loop cycle of the form

Figure eight describes how all that is of form might originate from all that is non-form before ultimately returning to this state. This relationship is aptly described in the autobiographical memoir 'Speak, Memory' by the novelist Vladimir Nabokov (Nabokov 1951) but can be found expressed across many disciplines and cultures ranging from physics and metaphysics, theology and philosophy to name but a few.

"The cradle rocks above an abyss, and common sense tells us that our existence is but a brief crack of light between two eternities of darkness. Although the two are identical twins, man (sic), as a rule, views the prenatal abyss with more calm than the one he is heading for..."

Integrating the non-form into dementia theory breaks the closed loop cycle of the form, unlocking the practice and orientation of care from its moral imperative and orientating it towards the transformational potential held within the non-form. Here our ideals, that define our very nature are recognised as originating from the unbounded and unstructured realm of the non-form. In what is a clear and definite break from the perfectionism of all things form, these ideals offer hospitality towards our inherent vulnerability, towards woundedness, failure, absence, loss and all things imperfect. Within this there is an implicit and explicit recognition that beauty, and all things of value originate from, and exist alongside all that is fractured soiled and broken. This is the beauty of the ‘true ideal’, from which we can formulate the structures of care that are necessary to bring action, to realise what is best, and reach beyond our limitations up unto the point of our outermost limitations. This point, the transition back towards all that is formless, can be mediated by the practices of care. Rather than being orientated and defined by what is of form these are orientated towards the absence and transformational presence of the non-form.

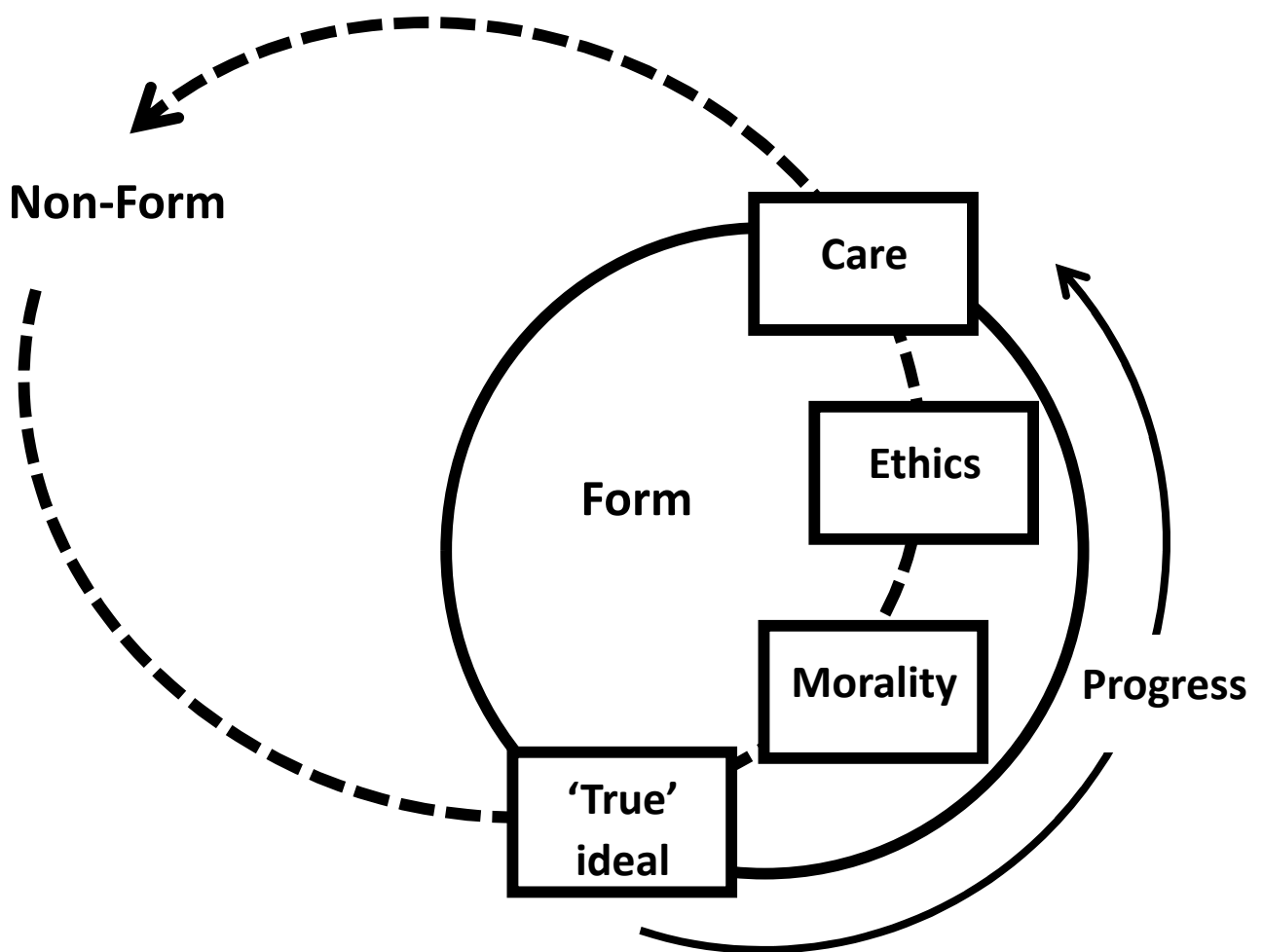


Figure 8: Form and its relationship to the non-form

I recognise figure eight also appears cyclical and therefore might appear to deny the importance of ‘progress’ and how form and non-form can work together to achieve this ([see chapter five: integrated not opposing worlds, page 160](#)). Progress, in its most literal sense, is a signature feature of the form. Indeed, it is structure, order and meaning that moves the world. Yet I have argued the very notion of progress can become paradoxical when viewed through its own lens. Instead, it is perhaps an appreciation of the non-form that might allow true progress, to be achieved through the apparatus of all that is form. In this sense it is not a closed loop cycle, the non-form gives rise to new beginnings and iteratively developed progress in what is representative of their integrated rather than opposing nature. Figure nine offers this same information but from slightly differ perspective. Depending on your interpretation of the images one may help to illustrate this point more than the other.

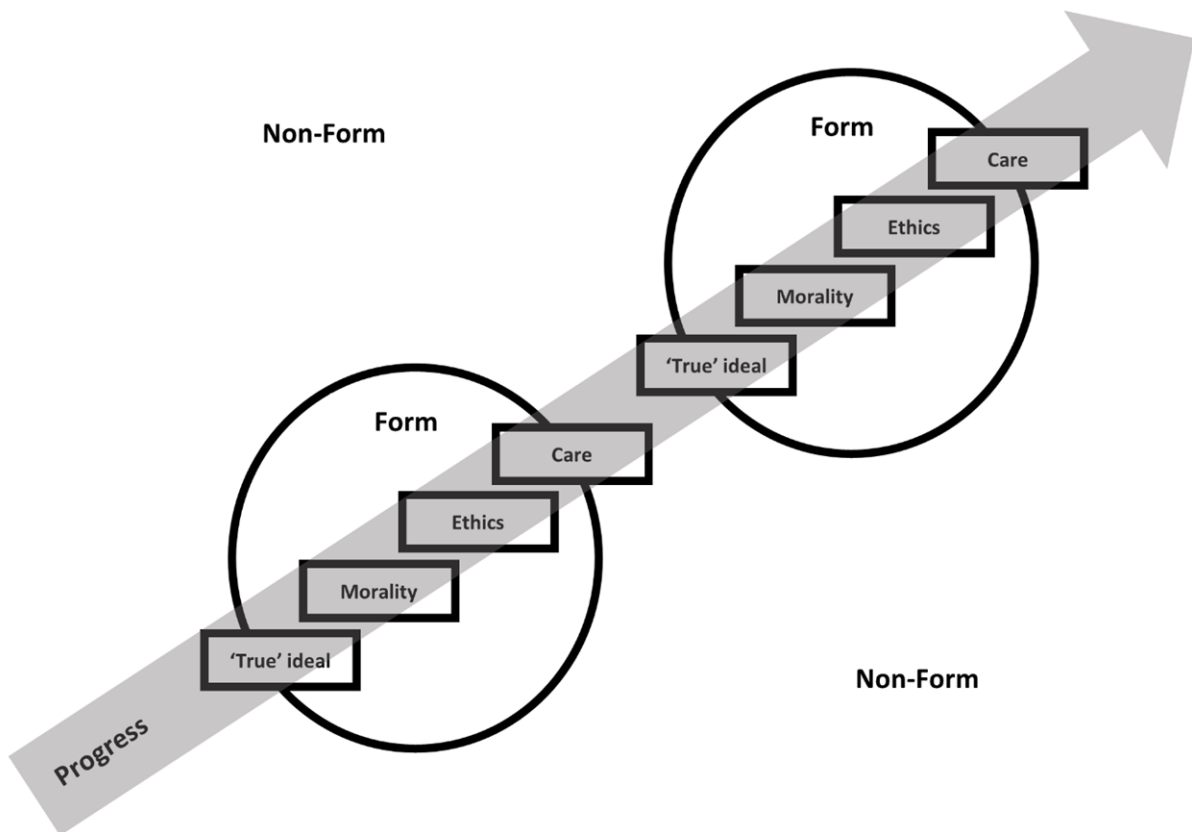


Figure 9: Form, non-form and an integrate approach to progress

Whilst I have discussed and evidenced the potential of working with the non-form, I have also guarded against seeking out, or arriving within it as some sort of positive outcome or endpoint. Rather I am at pains to describe how neither a reframing of our ideals, a restructuring of our theoretical approach to death and dementia nor seeking to heal, progress or ‘succeed’ at

dementia care are end points in themselves. So, if none of these are suitable points at which to draw a conclusion to this journey, then what is?

An integrative approach to dementia theory: accommodating loss by forming a kinship with the non-form

Through the data I have presented, I argue that people with dementia address us from the realm of the non-form, a place that exists beyond the complex collection of structures and ideals, a strange alien world but one that is nevertheless one to which we are intimately bound through a deep sense of belonging. I have discussed how when such people are addressed through the realm of the form, they become the objects of societies moral imperative to care (Higgs and Gilleard 2016e). This is the unquestionable force that drives the processes of care that feeds our progress-oriented ideals ([figure seven](#)). Addressed from the realm of the non-form, people with advanced dementia are the educators, imparting gifts of transformational value from this alternate realm to which we are bound through a deep and true sense of belonging. This is perhaps a difficult step for the rational mind to make, it sounds fanciful. Yet I would argue this response comes from an almost instinctive desire to interpret any given phenomena through the lens of form, to separate out experiences as either positive or negative, rational or irrational. The step becomes somewhat easier when processed through the heart. Here, there is a recognition that the sense making apparatus of the form has a limited bearing, instead what is required is to reflect on your own experiences of reading the empirical data, seeking to accommodate the sadness and deep despair that has been conveyed alongside moments of great tenderness and profoundly felt meaning. Embracing the feeling this invokes or awakens within you, rather than focussing on what can be rationalised out, is the pathway by which we might recognise and accommodate the potential within the non-form.

The here and now is the domain of the rational mind. To discover what exists beyond we must use the eye of the imagination, yet it is the human heart that draws us here. I have discussed how these processes were central to my ethnographic data collection and my attempts to inhabit the void created by dementia and its associated losses ([chapter four, working within the spaces created by dementia, page 103](#)). Within these spaces I found that human presence nor meaning never really gathers in any one final resting place. Even in the way our bodies are structured, hands and arms extendable as if to reach out to some distant point to which our eyes are drawn and our voice projected, we are always drawn to and seeking out what exists beyond. That

ultimately, at the outer reaches of our ideal form, we might be addressed and acknowledge the gifts imparted by those inhabiting a realm of absence and loss has the ability to capture our attention because it resonates with the sense of beyond that exists within us. The gifts bestowed by meeting people within the realm of the non-form, the presence of healing into our grief and the notion of coming home to death ([chapter six non-form: coming home to death, page 199](#)), connects and settles at once with the 'elsewhere' that exists within us. It is as if a part of us has lived in exile, and when it comes to meet us again, we are momentarily whole. This is the sense of beauty ([chapter five: the pathos of beauty, page 138](#)), completion and satisfaction that exist alongside, rather than in spite of all that is broken, soiled and fractured. That we might encounter these moments, and with them a sense of belonging, is the nature of profoundly intimate moments provided by caring for the dying and vulnerable. This is entirely distinct from the rationally derived moral or ethical imperative to care. Instead, it is a felt presence that arrives to us when we are positioned patiently in the disorientating darkness of nothingness.

My aim here is not to describe a utopian state of wholeness as some sort of end point or conclusion to which we should aim, this would entirely contradict my findings and description of the nature of the non-form. The moments of wholeness or beauty I'm trying to describe do not therefore represent some point of enlightenment to which life's journey arrives. Indeed, these moments may or may not occur, whilst when they do, they are not necessarily predictable, existing outside of the structures of time that belong to all that is of form. Where they are absent, hidden or still entangled in the slow process of transformation and transition, struggling to fully emerge at the threshold between form and non-form, is a feature that is representative of the struggle to become literate in the processes of death, decline and loss. This process is central to our ability to accommodate and then create some sort of 'kinship' with loss, so that when it does arrive, we might welcome what it offers.

The notion of kinship that is of particular relevance here is the suggestion of a depth of relationship that extends beyond mere association or fleeting transaction, instead pointing to how we might be bound to loss and non-form in such a way that is comparable to relationships arising from procreation, social construction or through 'mutuality of being' (Sahlins 2011).

What kinship is, its specific quality which separates it from other relationships, is something that has long been debated in anthropology. Anthropological orthodoxy in kinship studies has proposed kinship as a product of procreation, filiation, or descent prenatally or postnatally as a product of culturally appropriate social mediation (Holy 1996). This is in recognition of a well

demonstrated phenomena that whatever kinship systems are created genealogically, they may also be constructed socially (Bamford 2009; Carsten 2000; Franklin and McKinnon 2001).

More recently Kinship has been proposed as ‘mutuality of being’ (Sahlins 2011). Within this idea Sahlins describes ‘people who are intrinsic to one another’s existence’, an expansive domain that includes ‘mutual person(s)’, ‘life itself’ and ‘intersubjective belonging’ (Sahlins 2011). Here kinship is descriptive of a relationship that is intrinsic to one’s identity and existence, something that encompasses procreation, ‘performative’ or ‘made’ kinship but also extends to encapsulate the variety of meaningful attributes beyond the presumed connections of biology or common substance.

To describe the human relationship with loss in terms of a kinship is to position loss, absence and all that is non-form as something that exists as part of us. Indeed, the relationship bears many of the hallmarks of kinship as described by anthropologists, that there might be a shared substance through which a bond is created that ties us to a system within which we are intimately and independently held. Similarly, in the way that orthodox anthropologists would describe kinship as originating from genealogical or biological ties, a kinship might exist with the non-form in the sense that this is where we are from and ultimately the place that we will return to (see (Nabokov 1951)).

A kinship formed with loss, absence and the non-form might therefore be considered a fundamental or elementary unit to a system that holds us in connection with what it means to be human. It is retracing the roots of our being and building an awareness that this is also our destination at the reaching of life’s aim. Framing the association with loss and all that is non-form as a kinship helps to build an awareness that such an association is more than a transactional relationship.

Perhaps one of the most agonising aspects of any potential kinship with the non-form, and the potential this might hold, is the ephemeral nature of the moments of value, presence or beauty it offers. This is aptly described by the poet Manley Hopkins:

*How to keep – is there any, any, is there none such, nowhere
known some, bow or brooch or braid or brace, lace, latch or
catch or key to keep
Back beauty, keep it, beauty, beauty, beauty,...from vanishing
away?*

Yet I have described how engaging with the non-form is not simply another pursuit for a positive way of living with dementia and the losses, grief and abject suffering it brings. In this boundless, unstructured realm there are no constancies of being, no final endpoint at which to arrive. Engaging with the non-form awakens our hearts to new experiences that, although momentary, might also be transformational, or unforgettable, not to the mind, but to our hearts and the sense of connection we form through the eternal movement towards a greater belonging.

Forming a kinship with absence and loss in this way has the potential for dementia theory to lead the way for a more integrative approach to absence, loss and grief. Here dementia does not exist as a standalone topic but is representative of humanities vulnerability to loss and the unique set of values this might hold for human life. Engaging with the non-form might allow us to see that it is not so much absence, but more obstructed or arrested appearance that conceals value in these moments. Within such a paradigm, the point at which my thesis began, the crisis of care brought by dementia (WHO 2012), becomes not a challenge to resolve but an opportunity to realign with the non-form, to exist in a state of waiting without anticipation that accommodates a set of ideals that recognise the beauty of our imperfection and vulnerability.

Implications for Public Health Palliative Care Theory

In chapters two and three, I position new public health approaches to palliative care as a potential solution to the multiple and profound challenges posed by increasing rates of dementia worldwide. Throughout chapter four I describe what I see as a problematic approach when trying to ‘test theory’ in a new context and how this can often be guise for what in reality is a convoluted processes that instead tries to make existing theory fit. I have described how reducing experiences, paradox, tension and enigma into outcomes that either work or don’t work was a process that denied the reality of people’s experiences and what the data was saying when I attempted to remain open ended to the unique becoming’s of people’s lives.

To conclude by offering a theory as to how public health approaches to palliative care, how a Compassionate Community might work for the people with dementia is in essence a denial of all that I have described and experienced. Rather the question becomes, what can we learn from people affected by dementia that might meaningfully impact public health approach to palliative care, and how can these learning points best be integrated into the practices and principles of end-of-life care.

In chapter two I outline and discuss the core philosophical perspectives upon which a public health approach to palliative care is founded. Much of this revolves around understanding caregiving, dying, death and grief as interdependent processes which we engage with as shared social experiences composed of sequences complex drama that are interwoven into the fabric of what it means to be human ([chapter two; philosophical perspectives](#)). Using the metaphor of a shared breath I discuss how authors have characterised death as something beyond just the absence of life and the nihil of nothingness that it might come to represent. I discuss how the absence of life contrasts with new relationships that form and the interpersonal experiences that the process of dying, caring and bereavement can bring which ultimately help to bring a legacy for change.

I find echoes of the non-form in my early writing. The idea that there is presence in the absence, and that there might be an unbounded amalgamation of joy and sadness in many of the experiences that come to pass at the end-of-life. Yet there remains a striking tendency and will to apply form to non-form as a means of resolution. In chapter five I discuss the work of Carlo Rovelli and his discussion on time as a set of approximations designed to bring order and meaning (Rovelli 2019a). Yet as knowledge has progressed, these approximations have been understood for what they are, leading them to slowly disintegrate in use and form. This notion is encapsulated by the thermodynamic properties of entropy, $\Delta S \geq 0$, the change in entropy (S) is always greater than or equal to 0. That is to say, entropy (disorder) always increases or stays the same. In what comes to represent my description of ‘coming home to death’, persistent attempts to apply form to the non-form only ever take us back to the place from which we began, a state of formless disorder that seems to be the natural state of things, the point to which we unravel and arrive home to a world that has somehow always existed within us but concealed through repeated attempts to find rational meaning.

A similar process might be unfolding in how public health palliative care theory is being translated into practice. When absence or disorder appear at the end-of-life, they are considered through the lens of the form. Presence: moments of joy, beauty, intimacy and value are described and linked to the generation of new experiences, the warmth of new relationships and the lightness they afford us in moments of utter darkness and despair. Considering these events through the lens of the form leads to their categorisation as positive experiences that can be distilled and understood through the rational application of responsibility, morality, ethics ([see chapter one; philosophical approaches](#)). An avenue of understanding opens before us, how do networks of people form and congregate around death? How is responsibility defined and how

do these structures work at the interface between professional and lay people? Empowerment, network building and the role of social capital are all discussed in chapter two and their relevance to dementia critically appraised in chapter three. Yet there is something within this quest for good that remains inherently reductionist, neglecting the principle that dementia can take whatever structure is built to help understand and orientate progress, and break it down to all that is non-form. Whilst this might strike somewhat of a nihilistic tone, I have demonstrated in my empirical data how transformational value and purpose exists within the nihil as something beyond the socially constructed ideals associated with a moral imperative of care. Whilst public health palliative care alludes to a similar principle, the presence, which is manufactured and understood, remains orientated to what is of form. This spawns a series of tensions and conundrums as to how best to lead and structure a response that is orientated towards a set of positive outcomes.

This can be seen in the association and development of the ‘death positivity movement’ (Wilson et al. 2022). Here current policy for end-of-life care incorporates the core assumption that encouraging open public discussion around death is likely to increase uptake of advance care planning which in turn will improve access, equity, quality and experiences at the end-of-life fulfilling the ideal of the ‘good death’ (Fleuren et al. 2020; Brinkman-Stoppelenburg, Rietjens, and van der Heide 2014). Public health palliative care promotes a similar narrative, although it is not orientated towards advance care planning and the notion of a good death, instead placing the locus of progress on relationships, how they might grow and translate into an independent and autonomous source of support in themselves (Abel and Kellehear 2022; Abel, Kellehear, and Karapliagou 2018a; Abel et al. 2013b; Horsfall 2018). Viewing such practices through the lens of the form highlights the commonalities in what initially seem to be polarising approaches. They are united in essence by the quest for progress through the application of form to non-form. Such an approach will feed the closed loop ([figure seven](#)), tempting us once more into the relentless pursuit of perfection that only serves to deny the existence of the non-form and the potential it holds in accommodating all that is fractured, empty and broken.

Public health palliative care theory acknowledges many of the principles of the non-form yet its translation into practice is troubled by the pursuit of an ideal, how this might be implemented, measured and objectively evaluated by both its users and the healthcare structures within which it operates poses numerous tensions that threaten to derail its implementation. The question therefore becomes, how can public health palliative care theory and practice accommodate the

non-form and the potential it holds for orientating practice in such a way that allows for a more integrative approach, facilitating the transition from form to non-form.

I conclude my integrative literature review on public health palliative care by suggesting the potential held within the approach lies within its ability to understand value in death and its relationship to the whole ([Chapter two: Conclusion](#)). I suggest that how knowledge progress from this point is of vital importance. I propose two options, one that showcases Compassionate Communities and cities as entities to be implemented, where theory and its relevant points are used to intervene before being subject to evaluation, and another whereby theory is seen as a lens through which people can view their own actions in such a way that communities ebb and flow in response to what is needed.

My findings reinforce this point, emphasising the tension that originates from a perspective that prioritises attention to human suffering and decline, demanding and valuing a framework with which to understand, navigate and value the intricacies of the dying process so that they don't go unmissed or devalued, yet at the same time recognising that such a framework can conceal the appearance of what is of value in the first instance.

How then might public health palliative care better redress the balance between form and non-form, training our eye to points of transition in such a way that allows us to remain open to the presence and potential the non-form holds. In chapter four, five and six I suggest that inhabiting the non-form is to detach oneself from the polarising notions of success and failure and instead hospitably accommodate the pathos of beauty as a route towards what might exist beyond the form and within the nothingness. This is what public health approaches to palliative care stand to learn from people with dementia, that an approach to loss cannot be constructed or formulated towards a positive outcome without denying the reality of death's value. Perhaps then there is a need for the movement to adapt or even break from academic structures to achieve its full potential and accommodate people with dementia and the lessons they may impart.

Implications for a systems-based approach to end-of-life care

I have used the effects of dementia, old age and frailty as a looking glass through which to understand the nature of humanities relationship with absence, loss and its associated suffering. This I believe paves the way for a more integrative and inclusive approach that transcends diagnosis and disease. It also means that much of what I have identified has much broader implications than just caring for people affected by dementia.

The story of death and loss in the 21st century is addressed by the recent Lancet Commission on the Value of Death (Sallnow et al. 2022). Here the authors join a growing list of people who have highlighted how conflict, corruption, mistrust, inequity, have contributed to contradiction and a growing imbalance that limits humanities ability to integrate the value of death into life (Sallnow et al. 2022; Becker 1973; Illich 1975b; Kaufman 2015c; Gawande 2014). Rebalancing the relationship between individuals and the state, the position of lay and indigenous knowledge in relation to professional services and the meaning and role of community relative to large scale institutional care and global health is seen as a priority that underpins many of the challenges faced by end-of-life care practice and policy.

The commission acknowledges that the context to these challenges extends beyond healthcare systems. In an attempt to broaden the debate, they analyse recognised challenges through the lens of the ‘death system’. They suggest that bringing balance here can lead to a more integrative approach to death and dying, offering it as perhaps a foundation to on which to gather and restore a sense of equilibrium to a disparate and fragmented field.

Death systems as opposed to healthcare systems

Robert Kastenbaum first described the idea of a death system as ‘interpersonal, socio-physical and symbolic networks through which an individual’s relationship to mortality is mediated by society’ (Kastenbaum 1977). It is argued that these systems are the means by which death and dying are understood, regulated and managed, ultimately shaping how people behave and the multiple practices that unfold at the time of death. Components of a death system are varied and unique to the social, cultural, religious, economic and political contexts at any given time.

Examples of what might form part of a death system include, but are not limited to, people, places, times, objects, symbols and images. The functions of a death system are equally broad, ranging from the prediction and prevention of death to caring for dying people, disposing of the dead, social consolidation and the finding of meaning and value (Kastenbaum 1977).

Many have advocated for a systems approach to understanding profound complexity or so called ‘wicked problems’ (Head and Alford 2015), arguing that more reductionist methods achieve little other than adding to the complexity through part analysis and understanding. The obvious question is therefore, what does the concept of form and non-form offer to the idea of a death system, and what is the potential in such a relationship?

Philosophical and religious underpinnings

Many of the world's varied philosophies and religions describe death as part of a cycle of birth, life, death and rebirth. This gives rise to a description of transitional states which are often shrouded in ritual. Others describe the existence of the afterlife and resurrection whilst Western philosophy describes death as a point to which we arrive, a final destination. Here value in death can be described in consequentialist terms, that it is almost some sort of homeostatic mechanism that allows for the evolution of and renewal of life and all that it contains. Yet others have described how death also holds value within itself (Jacobsen 2022). Here, authors present death as a unique 'gift' that arrives to all regardless of any cultural or religious webbing (O'Donohue 2003a). Regardless of the specific religious, philosophical or spiritual perspective, these ideas are widely regarded as fundamental in informing the assumptions, values and behaviours that define death systems (Sallnow et al. 2022; Walter 1996).

There are certainly similar characteristics in my description of the non-form and that of a spiritual domain. The intangibility of all that is non-form, the presence that is found in absence, and the transformational capacity of working in the spaces that surround what is empirically observable. Yet at the same time there is significant difference. This revolves around how meaning and value are interpreted, how the human mind searches to distinguish between a positive experience and a negative experience neglects the fundamental and defining feature of the non-form, that it is not possible to separate out these entities. It becomes fanciful to speak of joy, beauty and value that resides in death without careful acknowledgement of its close association to all that is broken, tormented and soiled. Whilst many spiritual and theological writings allude to this notion it is as if the cognitive interpretation of this cannot help but apply form and structure. To rationalise out meaning in suffering and death is an impossible task, any structure designed to do so, be that religious or otherwise, keeps people embedded in the closed loop cycle of the form ([figure seven](#)). In this way, the non-form would suggest there is value in the emptiness death brings. Here there are parallels with an approach that sees value as inherent within the relationship with death and loss itself, rather than being derived from what follows as a consequence (Levinas 1999; Mauss 2000; Sallnow et al. 2022). Levinas describes a 'gratuitous movement of presence' (Levinas 1999), Mannix describes the 'gift' of care at the deathbed (Cooke 2020), O'Donohue writes of 'departure becoming transforming presence' (O'Donohue 2003b), and Walter discusses an 'absent presence' (Walter 2017). My description of the non-form goes perhaps one step further, arguing that neither value or meaning are separable from their pathos, and as such do not represent their own end. That the death system might seek some final

resolution to the multiple and profound challenges brought by death, dying and loss is a road that leads to all that is form. Instead, when death systems are viewed through the lens of the non-form it might be surprising how much more is visible whilst re-orientating the objective from the pursuit of identifying meaning and value to firstly accommodating, and then forming some sort of kinship with loss so that we might be receptive to the gifts it may impart.

Social and structural underpinnings

In chapter one I reference Illich and Kauffman and their work in describing how medicine, embedded within a chain of associated institutional healthcare drivers, have combined to shape our experiences and organise our judgements in relation to absence and loss associated with death in such a way that they are normalised and embedded within a set of moral and ethical binding imperatives (Illich 1975b; Kaufman 2015c). Indeed, there are many such structures, social and otherwise, that influence how we feel and act in the face of loss (Walter 1996; Walter 2007). I argue this process underpins the concept of a good death. In chapter five I describe how it might work in creating the concept of ‘ideal care’ whilst developing my arguments as to how these structures might serve to conceal the presence found in the absences associated with dementia. Considered from a systems perspective, the idea of all that is form describes how the structural components of death systems are not benign entities. Indeed, as the Lancet commission describes in detail, death systems ‘can replicate and reinforce discrimination and inequity. Power resides within these systems and often maintains the interests of those holding power’ (Sallnow et al. 2022).

The reality of power and its widespread effects is an uncomfortable truth for those studying death systems. There is widely available data that shows inequity across the life course and particular at the end-of-life. From race (Abbasi 2020; Umberson et al. 2017; Petersen et al. 2019), gender (Mackinnon 2009; Gott, Morgan, and Williams 2020; Crenshaw 1989), social class (Payne 2010; Henry et al. 2017; Kessler et al. 2005), age (Applewhite 2016; Burge et al. 2008), illness group (Chen 2019; Walshe et al. 2009; La Frenais et al. 2021), and sexual orientation (Cloyes, Hull, and Davis 2018).

Using the lens of power offers interesting insights when examining the concept of form and non-form. Goffman popularised the notion of “total institutions” like hospitals where behaviour is controlled and people are treated alike (Goffman 1961) whilst Freidson demonstrated medical paternalism and power (Freidson 1970) and Foucault documented how power operated in

institutions, showing how the doctor's knowledge of the patient's body can operate as a basis for medical power (Foucault 2012). Power, although invisible, is therefore intimately associated with systems and their associated structures yet its effects, although not explicitly looked for, were largely found to be absent in the realm of the non-form. The power held within the systems and their structuring processes can breed and maintain inequality and is recognised as a significant barrier to change (Sallnow et al. 2022). In a similar way power is a by-product of applying form to non-form, keeping practice orientated towards a set of norms that maintain existing power imbalances whilst concealing the potential of what might be found in the non-form (Dahler-Larsen 2013d). My analysis and description of the non-form has been made possible by the presence of dementia. A condition that systematically denies any form of structuring process, crumbling it to dust and leaving people searching for any fragment of meaning that might rekindle the preservation and maintenance of form. Yet I have also described how all that is of form ultimately unravels into non-form, and the potential held in embracing this process. It follows that a greater attention to all that is non-form has the potential to break down power structures that breed inequity.

Grounding the movement to decolonise death systems, death studies, death practices and end-of-life care in general within the non-form might allow us to recognise that justice, beauty, value and equity are not necessarily end points in themselves, instead they are by-products to the process of accommodating and forming a kinship with all that is absent, all that is formless. What this might look like and how this might be achieved are beyond the scope of my work but remain important question for the those that come next.

Endings: The importance of their existence and absence

Ultimately the challenges associated with end-of-life care in dementia are embedded within the much broader issues of how we face up to the challenges of death, dying and loss on a global scale. That we might learn from people affected by dementia and their lived experience of loss is the point on which this chapter is founded. An approach that focusses on disease specific scenarios does little to put forward a more integrative approach where the effects of dementia, or any illness, might be understood as being representative of the fragility and vulnerability of human life. Whilst the lessons this brings has important repercussions on how we orientate not only services but the entire approach to the darker side of human existence. The idea of form and non-form that I have identified as being implicit in the effects of dementia therefore has implications far beyond this field alone.

Current approaches to death mean that the continued drive to progress and develop a systems-based approach to its management is likely to result in health systems becoming overwhelmed. This has been visible throughout the COVID-19 pandemic. The emerging and sustained pursuit for immortality, the progressive calls for assisted dying to be adopted as a universal component of healthcare, the challenges associated with the climate crisis, how we orientate the goals and objectives of healthcare and medicine in the face of an ageing population faced with increasingly complex medical problems are all challenges that can benefit from being re-examined through the lens of form and non-form.

The Lancet commission into the value of death concludes that ‘profound, rather than incremental change’ is required to meet the current and future challenges brought by death and dying. My work supports this notion, arguing that current perspectives have created a set of operational structures that neglect an entire perspective through which we might find a set of orientating practices to identify and accommodate not just a consequentialist argument of value, but one where death has implicit value in and of itself. In what has already become a reference point for systems change and the generation of a new and radically different future, the Lancet commission identifies what they term a ‘realistic utopia’ as a platform for reimagining death and dying through a systems-based approach rather than a healthcare approach. In their vision they outline five principles; that the social determinants of death, dying and grieving are tackled; that dying is understood as a relational and spiritual process; that networks of care lead support; that conversations and stories about everyday death become common, and that death is recognised as having value (Sallnow et al. 2022).

To remain true to the orientating framework of my thesis, the questions is not necessarily how such a realistic eutopia might accommodate the experiences of people affected by dementia, but how it can be shaped by their experiences to make it more relevant and applicable in the first instance. Much of the report acknowledges that the story of dying is rooted in paradox. That understanding and conveying meaning and value in amongst suffering, much of which is avoidable, can at best be contradictory and at worse seem supercilious. There is clearly much that needs to be done to improve care for people at the end-of-life. Yet at the same time I have argued that the constant pursuit for betterment can prove circular and ultimately reinforce a way of thinking that conceals the values bestowed through the unknown. The creation of any form of structure, be that values, ideals or principles immediately takes us into the realm of the form. This per se, is not a bad thing. Indeed, I have described in detail the merits and necessities associated with working with what is of form as a means of delivering progress. Broadly

speaking, working with these types of interventions set us on a pathway of change which is orientated to a proposed endpoint, an outcome which is better than what we currently have. The non-form teaches us that there is perhaps no outcome or ending that provides such a resolution, that success and failure, progress and decline do not exist as polarities on a binary scale, rather they exist together representing the part of us that originates from and will ultimately return to all that is formless.

The creation of policy recommendations, or the objective of system reformation and how these policies play out at the end-of-life is ultimately representative of how form meets non-form. Having some awareness of these domains, their inherent values and the language with which we can navigate, acknowledge and accommodate them to reveal their value and potential is an important part to the overall approach of what makes us whole.

In this way, the outcomes and influence of my theory on form and non-form on systems thinking and policy recommendation is to suggest that all that is of form allows us to navigate towards the outermost point of humanities rational capacity, at this point of not just the unknown, but the unknowable unknown, there is no marker on which to orientate best practice. Regardless of human technological, spiritual or scientific progress this point will always exist. Travelling towards it through the structured processes associated with the form can help dispel unnecessary suffering, drive equity and justice and provide value. These are representative of perceived endpoints, of positive outcomes. Yet at the same time this approach does not prepare us for what happens next, what happens when we meet an impenetrable wall of unknowing. Relentlessly travelling to this point without preparing for what happens when we meet it will ultimately return us to the place from which we began. I have described this with empirical data using the example of applying form in the face of the emptiness that dementia brings. I have characterised how such a pursuit creates yet another trajectory which in turn brings further layers of complexity, contradiction and self-imposed paradox. Beyond this, in the non-form, the point to which any theory of 'betterment' is ultimately guiding us, there is no sense in categorising the positive and the negative, to do so is to conceal the gifts imparted from all that is unknowable. This, in essence, is what forming some sort of kinship with the non-form can provide. It may not solve the 'problem' of dementia and care at the end-of-life, yet it will impart gifts and allows us to see things not previously visible or acknowledged. This is perhaps a reference point for any attempt at complex and profound systems change that are necessary to re-imagine the future.

Implications for research in the field of dementia and end-of-life care

Whilst chapter four contains a detailed account of the methodological approach to my research, I also acknowledge that within it I raise important questions and describe important findings. I aim to discuss these in more detail here, describing their implications for academic structures, how knowledge might be generated and how we might measure success when working with topics such as advanced dementia and the end-of-life where social norms and structures become warped beyond empirical recognition and to such an extent that they have no reliable existence.

In chapter four I discuss the origins of my initial research question and protocol (see [Appendix One](#) for original funding application). In retrospect I can see how my chosen approach fits within the orientating aims and frameworks of healthcare research in general. It makes sense that my research proposal was funded as it meets the broad objectives of healthcare research, those being to lengthen healthy life and reduce the period of ill health or suffering at the end-of-life (Sallnow et al. 2022).

I have already discussed how such healthcare structures are embedded within a moral and ethically binding framework that defines this as nothing but a virtuous endeavour. Yet my description of the non-form fundamentally challenges this, demonstrating with empirical evidence that there are transformational values inherent within our relationship with the nihil that is so commonly equated with what it means to suffer.

Ignoring this notion, and the potential inherent within our ability to engage with the non-form, has serious implications for the field of academic research at the end-of-life, if not beyond. This can be seen through an analysis of the predicted ‘compression of morbidity’ (Fries 1980). In 1980 Fries predicted that the time spent with chronic illness at the end-of-life would be reduced, paving the way for an increase in time between birth and first infirmity before a rapid deterioration in closer proximity to the point of death. This concept has been highly influential in dictating the focus of health care research and treatment (Fries, Bruce, and Chakravarty 2011). Yet evaluating it has provided mixed results with debate centring on what measures of health are used and how the word is interpreted in the first instance. In 2010 a detailed review of compression of morbidity in the USA concluded that the length of life with disease has increased leading authors to state ‘the compression of morbidity may be as illusory as immortality’ and ‘We do not appear to be moving to a world where we die without experiencing disease, functioning

loss, and disability' (Crimmins and Beltrán-Sánchez 2011). Despite this, the underlying principle, to lengthen healthy life and reduce periods of ill health or suffering, remains central to the role of healthcare and the academic structures designed to support it (WHO 2023). The non-form would suggest that health and illness are not binary or opposed entities. I am reminded of the many participants who described in no uncertain terms their friend or relative with dementia as existing in a state of 'good health'. Betty told me on more than one occasion 'he is the most healthy of all of us!' when describing her husband, John. In a similar but unrelated anecdote, a friend and colleague was admitted to hospital with a heart attack. He ended up forming a connection with his neighbour on the ward, the relationship sparked joy and a profound re-evaluation of how and what he considered to be 'health', intuitively he told me that in the days following his heart attack, during his time in hospital, he felt himself in a state of absolute health, the like of which he had never experienced before. This suggest that orientating academic practice within all that is form neglects an entire world within which we might come to better understand some of the limitations to our current approach.

Much has been written and said about the disparity between the universality of death and its associated sufferings, and the amount of research that has been invested in and produced in response. In the USA dedicated federal funding for palliative care research has been described as 'critically low' (Buehler et al. 2023), in the UK there have also been repeated calls to address a demonstrated lack of investment (Sleeman, Gomes, and Higginson 2012; Sleeman et al. 2019). In the field of dementia, end-of-life care remains a neglect area of research and intervention (van der Steen and Goodman 2015; Sampson et al. 2020), representing only 4.9% of collective funding from across the G7 countries (Canada, France, Germany, Italy, the UK, and the USA; data unavailable for Japan) for the year 2016 (Pickett and Brayne 2019). Many authors have used such data to add weight to their calls for more funding and more research (Sleeman, Gomes, and Higginson 2012; Sallnow et al. 2022). Yet my findings detailed in chapter four call into question whether there is a bigger issue at stake here, whether the orientating practices of orthodox academic research can allow us to see what is essential and necessary to see when facing out into all that us unknown and unknowable.

Regardless of the epistemological or ontological stance, orthodox academic practice is orientated to bring certainty to uncertainty, control to disorder, logic and understanding to all that is meaningless. Yet, just as a flowing river shifts, bends and changes over time and distance travelled to ultimately flow out into the disorientating depths of the ocean where its intricacies, temperament, character and form become lost to all means of recognition, so too does our own

existence unravel into a formless state, unrecognisable and unknowable. This is also the nature of entropy ($\Delta S \geq 0$), that all things in life move from and back to a state of disorder.

Whilst orthodox academia is considered to be ‘standing on the shoulders of giants’, to look out into the beyond and imagine a state of progress, our inability to recognise humanities outermost limitations may inadvertently have caused a shift in gaze. Could it be that, at the periphery of human capabilities we have now come full circle, so that we are now looking back in, holding onto the successes of what has come before, what is of form, without realising that we have become trapped within an illusionary reality where ‘progress’ has become either static or paradoxical ([figure seven](#)).

I would argue the data I present in chapter four adds weight to this argument. From the formation of a research question to the selection of a specific research methodology, the focus is narrowed to what is of form at the expense of seeing value in what lies in the spaces surrounding this. The proliferation of the systematic review and the invariably observed outcome that ‘more research is needed’ (Ioannidis 2016), the protocolisation and standardisation of research methods (Braun and Clarke 2012; Wong et al. 2016; Tong, Sainsbury, and Craig 2007) and the reduction of research ethics into what is objectifiably measured and detected (Arteaga and Llewellyn 2022; Balkin et al. 2023) reduces our innate sensibility to detect and explore the unknown in the ways of our academic ancestors.

Such a notion is further reinforced by recently identified trends that demonstrate how research is becoming less disruptive (Park, Leahey, and Funk 2023). Whilst the volume of literature being produced continues to grow exponentially, it is not shifting the trajectory of thinking (Park, Leahey, and Funk 2023). Could it be that the academic structures designed to progress knowledge here are acting to conceal what is of value in the first instance? This, I suggest, is a topic of significant relevance to the field of end-of-life care that needs to be acknowledged and discussed alongside the demonstrated lack of funding.

In chapter four I describe the limitations of a realist programme theory in allowing me to address the challenges brought by my data. That essentially, I was making the data fit into a structure that did not fully accommodate it. Ultimately what I am proposing here is this is representative of a more fundamental problem, that the quest for new, better knowledge, for discovery, innovation and progress becomes meaningless at the extremities of human existence. Indeed, the question of what matters, what represents progress and what defines meaning and value in the face of all that is absent is so profound that it transcends the ability of any formulated structure applied to

evaluate it. All that is left is to form some sort of kinship with the absence, trusting that this in essence is what makes us whole, what returns us home, and that somehow, within this process we might greet and accommodate the transformational presence of all that is non-form.

Summary

In this chapter I have positioned my findings as organisational concepts that might recalibrate the theoretical approach to dementia, public health palliative care and the organisational structures that hold them. My discussion on sociological theory relating to ideal types, social imaginaries and an approach to evaluation and organisation brings conceptual clarity to key terms which I have found to be necessary basis of my scientific analysis whilst also allowing me to demonstrate reproducible patterns that are summarised in figures seven and eight. I have discussed the future avenues through which my work may be developed to help orientate a more integrative theoretical and practical approach to end-of-life care, not just in dementia, but beyond.

Chapter Eight

The value & function of an ontological zero

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Introduction

The concept of absence, of nothingness, has a long history of being overlooked across various disciplines and cultures (Nieder 2016; Seife 2000; Rotman 1987). After all, ‘zero’ has no use in the operative functions of daily life. Yet the discovery of the numerical zero is described as one of the greatest single achievements of the human race (Dantzig and Mazur 1954). Enumerating an entity happens because it has a tangible presence, zero does not operate in the same way. As a numerical concept, zero requires abstract thinking, we have to move away from the empirical world to understand that zero is still something, even when it is nothing. Perhaps more than this, it *needs* to be something. The absence of empirically observable presence needs to become a category in its own right, a mathematical object. If it does not, the structures we intuitively rely on begin to fall away, to disintegrate into ambiguity. Take the use and function of zero in the numerical positional notation system. Here, without 0, the numbers 2 and 5 may represent any one of several numbers, 25, 250, 205 etc. there is therefore a need for ‘nothing’ to have a distinct categorical value and function. In mathematics, the number zero, whilst an abstract concept, is still something that has presence we can interact with, whilst its discovery has given rise to calculations that are now fundamental to the functional order of the world.

In many ways my description of the non-form is trying to provide something of an ontological equivalent, it is a metaphorical symbol for a lived experience of zero. Loss and absence, the nothingness associated with the disintegration of our social, rational and biological form needs to be categorised as something that in itself has a distinct value and functionality. Without this it becomes difficult to bring meaningful order, to define progress and to orientate our actions. In this way, the non-form does not do any work in and of itself, yet without it, without an abstract conceptual picture of nothing as something, all that is of form begins to turn in on itself, descending into ambiguity and self-imposed paradox. This leads me to my central concluding point. Regardless of how my findings come to be interpreted or used either as organizing concepts, a heuristic, a social imaginary, as new theory or perhaps as an emerging dialectic between theory and experience, its function lies in how actions and interventions are calibrated against it. Without any attempt to do so, it is likely the intervention will remain limited in its scope and, whilst it may bring some form of objective success, it is also likely to create corresponding shadows of failure.

With this in mind, I will now present some of the practical implications of this central idea. I will frame these in the specific context of dementia and public health palliative care before

summarizing the importance of a closer, more intimate relationship between form and non-form.

Practical implications of working with form and non-form

Dementia: Reimagining an approach to risk

During the writing of my research, I sent a short summary of my description of the form and non-form to research participants. Some of them replied to me with their thoughts and reflections. Below is an email from one participant whose mother, although not a subject of my research, also has dementia and is cared for at home by the participant's sister.

Oh my goodness, Joe.

This is fascinating. Would it be okay if I give it to my sister to read, as long as I ask her not to send it to anyone else? She is my mum's primary carer and she lives with my mum. I think she might find this very helpful.

In particular, I think she would really value your remarks about the current concept of "ideal care" that we are encouraged to accept, and your questioning of it. She sometimes says that she feels that the care she provides is not up to the mark because she isn't doing those things you listed. Mum has recently developed a pressure sore – I'm hoping we can manage it through to healing, but (anonymised) feels terrible about it, because she lets Mum sit for long periods at a time.

The rest of us encourage her, but I think we still buy in to the "ideal". It is interesting to think that what's going on for mum on the non-form front may be far more important than any lack of "ideal care"...

This led me to consider in greater detail the practical implications of my work, how it might be used in a meaningful way to help meet the specific practical challenges of care that I discuss in chapter one. Much of this revolves around how we understand and orientate an approach to risk. I begin to develop my ideas around risk in chapter six ([The architecture of place: risk and safety, page 192](#)), describing how, when considered through the lens of the form, safety, and the risks that threaten it, are 'understood in relation to the preservation of structures that enable us to find and utilise control'. I identify the approach to risk as a driving force behind interventions relating to place of care. Here I aim to position this approach to risk more broadly before discussing how

it becomes a central driving force to the practical tasks of care. I will then discuss how risk works when viewed through the lens of the non-form and the implications for this in shaping an approach to the practical tasks of care.

In chapter six I discuss how risk is often identified around activities that have the potential to exacerbate a functional, physical, cognitive or social decline towards death (Alaszewski et al. 2000; Alaszewski and Manthorpe 1991, 2000; Clarke et al. 2009). In a wide literature on the topic, there is acknowledgment that there are benefits to taking risks, that each individual's risk appetite is variable, and that the degree of risk is often shaped by cultural perceptions and meanings which can change over time (Adams 2001; Beck 2000; Lupton 2013). There is also discussion on the discrepancy between how risk is viewed between professionals and lay people (Adams 2001). Professionals are described as relating risk to the presenting diagnosis (i.e. a deficit centred approach) as opposed to the capacity and abilities of the individual (i.e. a capacity centred approach) (Carr 2011). Much of the literature relating to risk focusses on this polarity and as such bears significant resemblance to my description of the false dichotomy that arises when dementia theory is categorised as either deficit or capacity led.

Here, the medical approach might be seen to disregard the positives, reducing the capacity of professionals to be sensitive to the needs and preferences of the individual (Adams 2001; Alaszewski and Manthorpe 2000), whilst creating fertile ground for the miscalculation of risk where a focus on diagnosis and disease processes can reduce pro-active problem solving and risk taking (Green 2007). Lay people have been found to focus more on the interpersonal domain as opposed to the physical (Adams 2001), whilst people with dementia have been described as having a more nuanced perspective, experiencing risk through the lens of emotion, balancing activities of daily living alongside mental health issues and the issue of loss of identity (Robinson et al. 2007; Stevenson, Savage, and Taylor 2019).

For all these descriptions, the locus of risk is centred on the loss and decline of what I have identified as components of the form. In this sense, separating out risk based on the professional deficit or disease-based approach, or on a relational or person-centred approach is again representative of a false dichotomy. Both approaches are unified in the orientation to risk as a point upon which loss might be experienced. Be that a biological, functional loss, or a social, personal and emotional loss. Framing the debate as to which approach to risk is better or worse, or concluding that there can be no single applicable approach to risk (Dickins et al. 2018) therefore fails to question what is meant by risk when we exist at the outermost point of our

empirical existence, at a place where what lies beyond is no longer of form. Here the very notion of risk becomes lost and therefore a disorientating and emotionally challenging point upon which to orientate a practice of care.

This can be seen in the current approach to commonly encountered issues whilst caring for someone with advanced dementia. For example, towards the end-of-life there is a naturally increased and inherently unavoidable risk of developing a pressure sore. The development of such an event is often a complex combination of factors that range from changes to skin integrity and physiology, changes in dietary and nutritional balance, changes in fluid balance, reduced mobility, weight loss, or indeed weight gain and reduced movement (Jaul et al. 2018). Pressure sores can be painful, are prone to infection and although they develop for complex reasons beyond just physical processes, have become synonymous with poor quality care meaning they can be stigmatising for institutions and carers, both lay and professional (Moss and La Puma 1991; Reuler and Cooney 1981). The practice of care therefore becomes orientated towards the prevention and management of pressure ulcers, reducing the risk becomes a component of high-quality care that is driven by the unquestionable moral imperative of care ([figure seven](#)). Where practice is highly structured and oriented towards outcomes that are clearly defined and exist as either positive or negative, there is little room to accept the fact that progress in one domain can mean regression in another. In the example of the pressure sore, regular turning can prevent the sore but cause agitation for the person with dementia whilst generating an ideal of care that is both impractical and unmanageable for the carer. When a pressure sore does eventually appear, the feeling of guilt and neglect might be irreconcilable, creating a moral and existential distress which might feel impossible to settle.

I have discussed how these processes unfold through a series of interventions and the associated moral imperative that is driven by a focus on what is of form. In essence, when the theoretical approach is orientated to the form, these same orientating practices filter down to the practical tasks of care and shape people's experiences in the ways I have described. Whilst I have chosen to describe this phenomenon using the example of pressure sores, the approach can be broken down in the same way when considering other challenges faced by people with dementia. This includes a greater dependency on others for basic care, an inability to communicate or convey one's needs, double incontinence, problems with mobility (including becoming bedbound), weight loss, poor nutrition and dehydration, swallowing difficulties and the increased risk of aspiration and other infections. If the nature of risk is orientated to what is of form, our practice

will always be orientated away from the point to which we are aiming for, that being a return to all that is formless ([figure eight](#)).

What happens then when we orientate the practical tasks of care to the non-form? Where we move away from the polarities of success and failure and understand them as existing in an unbounded state, inseparable in how they are experienced. Here the quest for success and progress might seem enigmatic or even futile. Below is part of my response to the initial email I presented above:

I'm sorry your mother has developed a sore, caring for people is such a complicated business and because of this I find it hard to imagine what success looks like sometimes, but it is definitely more than just good skin! I'm sure (anonymised) is bringing many treasures in her role as primary carer and it is important these are not eclipsed by things like the sore....'

Here I am suggesting that that the issue itself is not necessarily how we might approach risk through the lens of the non-form. But rather how we approach the broader concept of care as a whole. The very concept of risk is alien to the non-form. It is a way of working with structure, of creating ideals, outcomes and endpoints that can be rationally interpreted. As such it serves to eclipse the other components of care that are positioned in such a way that accommodates our eventual return to the non-form, our structured existence unravelling into the nothingness of loss and death. This is a process fraught with moments of pain and suffering but also a process within which we might encounter a transformational presence, awakening within us the part of our being that is also non-form and returning us home ([chapter six, coming home to death, page 199](#)). The arrival of a pressure sore may give rise to a sense of guilt and despair, yet it is important to understand where these feelings originate from, a response to our failure to uphold an ideal that is rooted in perfectionism and therefore unattuned to the values and beauty brought by our own vulnerabilities and imperfections.

Building a kinship with the non-form enables us to accommodate loss, enigma, pain, unavoidable suffering and paradox as entities with which we dwell as part of human nature. Here, orientating the practice of care towards risk serves only to build momentary relief from the disorienting emptiness associated with loss. The product of orientating an approach to risk in this way creates a set of outcomes that bring only temporary resolution before another set of problems of a similar nature arise, trapping us within the progress orientated closed loop of the form ([figure seven](#)).

Guarding against futility and nihilism

Engaging with the non-form in such a way that gives us overall direction and an ability to accommodate loss and the darker elements of human existence must however guard against the feeling of futility and nihilism. In simple terms, accepting decline and dependency as part of human nature does not mean nothing should be done to prevent pressure sores and that people should be left to decline without appropriate care. Indeed, I would argue that my descriptions of engaging with the non-form and the implications for this at a theoretical and practical level are fundamentally different to what would be produced by nihilism. Yet at the same time, I recognise they are not immune to being misinterpreted in this way.

Nihilism has historically been associated with a discourse that opposes the predominant ideologies of the time. Despite it being a popular term with a commonly understood meaning, nihilism has a particularly complex meaning as well as a disparate number of associations (Toribio Vazquez 2021). Despite the extreme disparity of contexts and a lack of academic consensus regarding its use and meaning, it has become progressively linked to ‘moral, religious, and political anarchism, usually grounded in a loss of belief in God’ (Carr 1992). This is the rather elusive ideology of the *nihil* or nothingness, where there is perhaps extreme scepticism or a negation of values and ideals that help shape society, a tendency to negate the existence of a concrete idea, belief or ideological assumption. Such a dominant approach to the word is the one I will choose to focus on rather than that the more nuanced discussions proposed by Nietzsche, Heidegger or others (Nietzsche 1989; Heidegger 1958; Toribio Vazquez 2021).

I have consistently evidenced and argued for the ‘nothingness’ that might be seen to define an advanced state of dementia, as existing as a realm that contains presence, meaning and value. Whilst I acknowledge that this is particularly difficult to rationalise out, I also qualify this by suggesting the mind is the tool of the here and now, any move ‘beyond’, into the nothingness, is dependent on the imagination and the heart (Sharmer and Senge 2016; O'Donohue 2003b). In this way the structuring processes and ideals that compromise the form are the tools that take us to the outer limits of human possibility. Here at the frontier of life and death and its ultimate absence, we might look out and forward rather than returning to a set of tools that offer nothing more than the comfort of a partial reality to which we no longer belong. In this way the role and function of the form exists as integrated rather than in opposition to all that is non-form ([chapter five: integrated not opposing worlds](#)). That we might move into and accommodate the space of the non-form to realise its potential is as a consequence of all things form, rather than in

spite of it. Whilst we might strive to find a way of bettering the care of people with dementia or those in advanced old age through our ideals and values, we might also be hospitable to their failures and fall backs. It is this that allows us to remain open to what lies beyond, and the transformational impact that comes with findings presence in absence. In the case of the pressure sore, or any other complicating factor of advanced dementia, the presence of grief or failure is a route to the non-form and the healing that comes with engaging with it.

Public health palliative care

My aim now is to describe what the theoretical implications discussed in chapter seven mean for the practical development of Compassionate Communities and other interventions performed under the banner of public health palliative care. In essence this is a call to guard against the impulsive, consistent and reductive application of form to non-form. I will cite examples of where this relationship can be of help, and where there is a need to apply caution, before guarding against the evaluation of such programmes in terms of outcomes that categorise people's experiences into binaries.

Moving from non-form to form and vice versa: implications and challenges in the formation of Compassionate Communities

The limitations to the current approaches to end-of-life care are well documented and evidenced (Abel and Kellehear 2016) (see also chapter one). Through inequity, injustice and all that is challenging in the current approach, comes the light brought by new ideas on how to build more sustainable and effective models of care. Yet at the same time death, absence and loss will forever remain, a permanent reminder of the ultimate vulnerability that accompanies our every move.

Moving from a service led model of palliative care towards a socially constructed response is representative of how form is born out of the non-form and can be used to guide us towards new ideas and the potential they hold ([figure eight](#)). What is of form within public health palliative care is important in bringing progress, yet a preoccupation with this can also lead to the limitations associated with a neglect of the non-form ([figure seven](#)). Recognising and anticipating how to orientate practice can be helpful in the application of practice methods as well as the guiding theoretical principles of the movement.

At a practical level, new public health measures can be used to demonstrate the value held within relationships. Much of the theoretical underpinnings of this approach arise from what I would consider to be the non-form. Here relationships might be understood as independent entities, invisible, intangible and also subject to the paradox of love. As the Australian musician Nick Cave writes in his book 'Faith, Hope and Carnage' (Cave and O'Hagan 2022):

"If you have been fortunate enough to have been truly loved in this world, you will also cause extraordinary pain to others when you leave it. That's the covenant of life and death, and the terrible beauty of grief"

This notion gives rise to a new set of structures and processes. That we might somehow capture the essence of what is of value in this by applying form to non-form. New public health approaches seek to operationalise the varying components of these relationships as a means to demonstrate progress and build a platform for more accessible, equitable and meaningful care. Much has already been done to demonstrate a set of outcomes that are of great significance to the field of health and social care (Horsfall 2018; Noonan 2018; Noonan et al. 2016; Barnes et al. 2005; Gott et al. 2018). Yet the shadows that accompany such successes are never far away.

During my research I was asked to assist and advise a local hospice in their plans to implement the Compassionate Community Charter ([Appendix Six](#)). I attended several meetings and events which sought to facilitate the generation of community-based networks. Meetings were co-ordinated by someone employed by the hospice to establish networks and demonstrate their value. These gatherings were initially well attended, yet many people began to express concern at the time commitments required. This culminated in the hospice-based lead for the initiative telling to me that it would soon 'fall apart' if he were to leave post. The meetings, composed largely of charities and other non-profit organisations with an interest in health and social care, began to dwindle and the lead for the project became disillusioned, reflecting on an increase in responsibility to co-ordinate meetings and the unsustainability of the work that was being generated. During the meetings people also expressed concern that they would be taking on problems that were beyond their responsibility to manage, many attendees also cited issues relating to data protection, the need for an accountable body and the checks they might require

such as applying for disclosure and barring service (DBS) checks⁸ for volunteers and community members.

Whilst there is clear and robust evidence for the potential within social networks to infer benefit, it would seem the pathway to implementation is vulnerable to the operating structures of the form which can conspire to conceal the values present within all that is non-form. This relationship seems to exist in proportion to the scale of the intervention and the time within which it is delivered ([figure ten](#)). That being the larger the scale of the intervention, the increased reliance on what is of form. Whilst I do not have empirical evidence to support this proposition, the implications for this notion are significant when considered from a public health palliative care perspective that by definition is operating at large scale and under increasing pressure to deliver desirable outcomes within what is becoming a very short time window (Etkind et al. 2017). Whether or not there is a way of integrating ideas on form and non-form within large scale interventions is a pertinent question that I would suggest is fundamental to what might come next.

⁸ DBS: The Disclosure and Barring Service (DBS) helps employers make safer recruitment decisions each year by processing and issuing DBS checks for England, Wales, the Channel Islands and the Isle of Man. DBS also maintains the Adults' and Children's Barred Lists, and makes considered decisions as to whether an individual should be included on one or both of these lists and barred from engaging in regulated activity. <https://www.gov.uk/government/organisations/disclosure-and-barring-service/about>

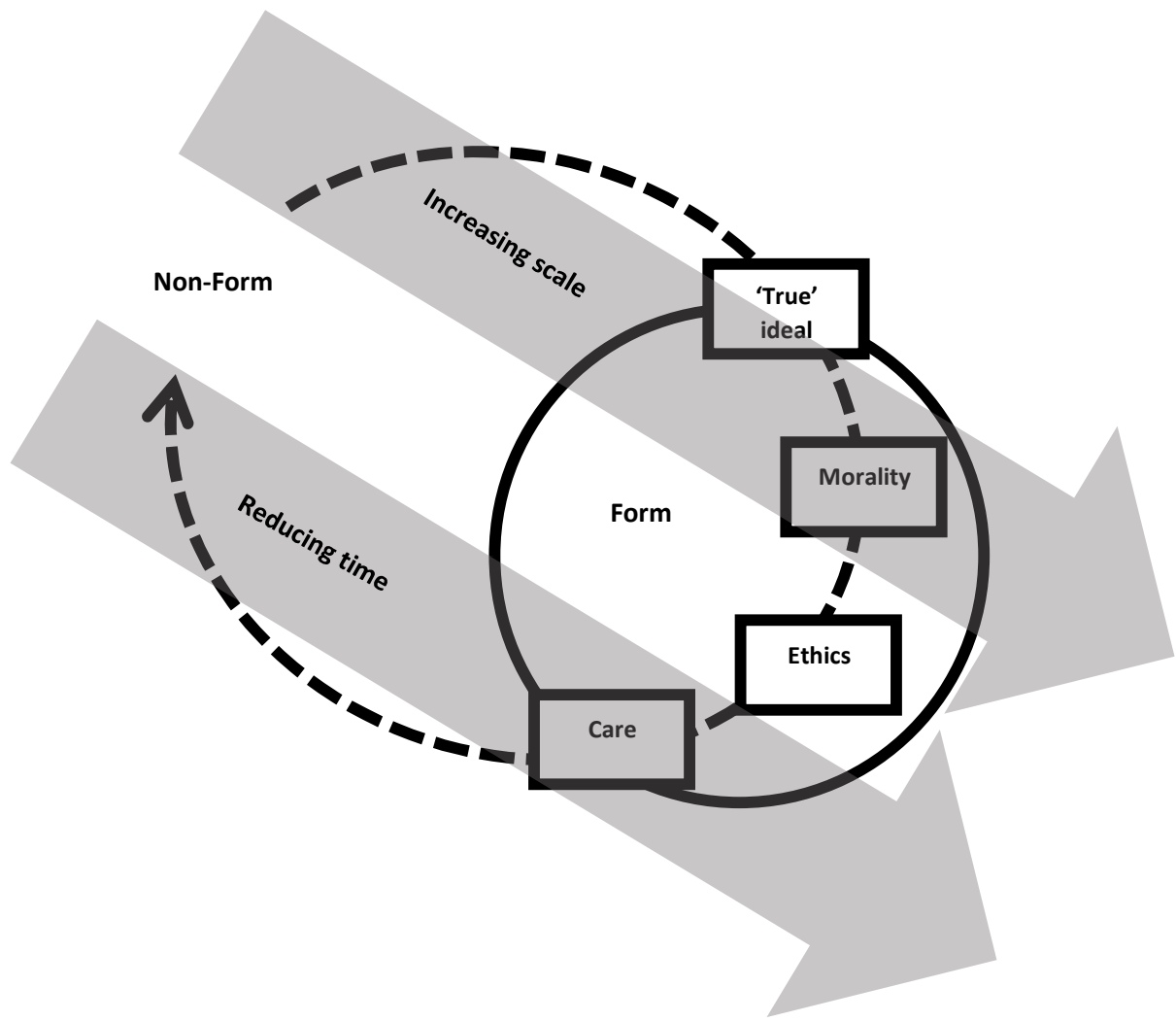


Figure 10: The balance between form and non-form in relation to scale and time of an intervention

Part of the issue here is the almost instinctive desire to orientate practice towards a specific and desired outcome and away from what is perceived as undesirable. When performed at scale, there is a need to reduce complexity and harness popular support by demonstrating effective and achievable outcomes. Such an approach is a hallmark of the form and an ultimately pathological desire to strive for perfection. That complexity can be evaluated, and delineated into component parts denies a core feature of the non-form, that beauty and value is intimately and inextricably linked to its pathos ([chapter five: the pathos of beauty](#)). In the context of social networks, the love and protection brought through supportive and caring relationships will always exist alongside the pain and suffering that accompanies it. As I have described, the non-form is not a utopic destination at which we arrive. In the same way, a Compassionate Community cannot, and will never be, a eutopia. A system that seeks to capture and distil the positive elements of life, death and suffering is ethereal in nature, visible to the ideals of our rational mind's eye yet

when pursued into reality serves to conceal what is of true value whilst putting people under great strain.

Balancing the necessity of form to achieve what is best and reach beyond our limitations whilst also accommodating the reality of our outermost limitations is a major challenge for the public health palliative care movement. This is also the frontier at which efforts must be focussed if Compassionate Communities, or any other such intervention from the field of public health palliative care, are to accommodate people affected by dementia.

Much like my description of risk in the context of either form and non-form, public health palliative care seems to be plagued by the expected need for a set of demonstrable and deliverable outcomes. Yet the non-form fundamentally resists these structuring processes. Whilst they have been helpful in alerting people of a need to break with tradition and remain open to the possibility of new ways of working, the creation of a unifying ideal solution to end-of-life care by extracting and distilling notions of control and autonomy, beauty and joy from a process that is inextricably linked to uncertainty, dependency, suffering and profound sadness is unjustified by the evidence I have presented. Instead, the purpose of the form is to take us to the point of its own outermost limitations. As I have discussed in relation to the concept of ‘the evaluation society’, at this point, there is a need to return back to the non-form rather than entangle ourselves with further structures that conceal what might emerge from the emptiness (Dahler-Larsen 2013b). Engaging with the non-form in this way means letting go of the orientating practices to which we have become so strongly adhered so as to accommodate the value inherent within the absence. In the context of Compassionate Communities, the structures of social capital, network building, empowerment and community are vital in shifting the narrative and trajectory yet, as I have observed in dementia, can conceal beauty’s pathos, and with this, an understanding of the transformational value death holds for life. In this way, many of the tensions I outline in chapter two do not exist to be resolved, but rather they are to be embraced as part of an open-hearted kinship towards woundedness, weakness, failure and all that makes us vulnerable.

Concluding remarks

My thesis begins with an image of dementia, old age and frailty that presents a set of unique challenges to which we might endeavour to understand and respond to in such a way that might come to define best practice. Positioning the components of the research in this way creates an

image that is familiar to us. That in the anticipated face of darkness, the generation of knowledge combined with human will and endeavour, will flow forward in a cumulative progress orientated direction to create a reality that is ever closer to a 'now' that fulfils our ideals.

This is representative of a packaged approximation of reality, where the past is fixed and the future remains open to possibility. Here, reality flows through from past to the present and on towards the future whilst the evolution of all things between is intrinsically asymmetrical. This, we assume, is the basic structure of the world and the point at which we might understand and measure progress, betterment or success.

Yet this familiar picture has fallen apart. By positioning existing theory and knowledge alongside the loss and emptiness associated with dementia, advanced old age and death, I have repeatedly shown that progress-oriented frameworks that facilitate the transition from living to dying only offer an approximation to a reality that is only ever partially reifiable.

To this end, offering a set of concluding remarks that conform to this structure, that seek to reimagine the future and offer an aspirational ideal of how we might get there, is to contradict what I have learnt from the people I have been privileged to accompany over the course of my research. Instead, I am inclined to focus on the notion that justice, beauty, value, equity and the relief of suffering are perhaps not the end points we think they are, but part of the process of accommodating and forming a kinship with all that is absent, all that is formless, an 'ontological zero'. Perhaps more than accommodating the non-form, I have suggested that we might recognise human association with the non-form as more of a kinship. Framing the relationship in these terms recognises that death, absence and loss exist within us as a unitary and elemental constant that can hold us in connection with what it means to be human.

This is not to deny the vital importance of endings. I do not wish to convey scepticism that negates the values and ideals that help shape our formed reality. More that the importance lies not just in endings per se, but also the absence of them. From this perspective, what is essential to know and understand, and the implications and influence this holds for the future, is only part of the story. The other, lesser acknowledged issue relating to knowledge and its material form, is what is its role and function at the outermost limitations of rational existence, where progress is simply and unavoidably paradoxical in and of itself. This is the nature of reality in the face of loss and why, in these concluding remarks, I do not simply ask, where do we go now? but also, what is there to do when we arrive? Here, at the perceived point of destination, I have suggested that

knowledge, progress, light and beauty are not ends in themselves but ephemeral moments that exist as part of an endless cycle of passings and becomings.

To distil what I consider to be the essence of this body of work is to move beyond what might be considered by an ‘ending’, to challenge what we perhaps take for granted as the basic structure of the world. From the perspective of the form, I have shown how our futures are open to the imagined possibilities of our ideals and it is this that drives progress and moves us from a stationary formless state of being. This is what we stand to gain from working with the form, states of order, structure and control. This notion is reflected across many different disciplines, however the parallels with physics and the laws of thermodynamics are particularly applicable and can help us to understand this abstract concept more rationally. As Carlo Rovelli writes:

“What makes the world go round are not sources of energy but sources of low entropy”⁹. Without low entropy, energy would dilute into uniform heat and the world would go to sleep in a state of thermal equilibrium – there would no longer be any distinction between past and future, and nothing would happen’. (Rovelli 2019b)

Understood from the perspective of form and non-form, form is required to drive progress, it is what moves the world. The non-form is of a different nature entirely. Here progress is abstract, enigmatic and paradoxical because the natural order is orientated towards disorder and an equilibrium that does not move things in any one direction, existing instead in a state unbounded by polarities such as success and failure.

In the context of the fourth age and the end-of-life, a perception of reality where the past is fixed and a future is open to our own agency and will, can make progress seem enigmatic. This means that the rational, carefully formulated approach to progress cannot be the point on which to orientate and define our actions when considering care at the end-of-life. Instead, we might ask what captures the essence of my description of all that is non-form and how can we accommodate the implications and potential within its existence.

I have argued in chapter four that the rational processes associated with any given ontological and epistemological approach to knowledge can conspire to limit the part of our being which belongs to all that is non-form. This is also the part of us that is awakened and receptive to the

⁹ Entropy being a measure of disorder. According to the laws of thermodynamics $\Delta S \geq 0$, the change in entropy (S) is always greater than or equal to 0, that is to say entropy (disorder) always increases or stays the same

gifts imparted by those in a state of dependency, vulnerability and decline associated with the end-of-life. To truly accommodate the potential held by all that is non-form, it is therefore not sufficient to engage with this material through rational processes alone, this will only take you so far. Rather it is the totality of the human response that observes the undercurrent to each chapter of this thesis. Forming an open-hearted kinship with the non-form, not that we might understand it, map its terrain and navigate a forward path, but that we might position ourselves in such a way that we remain open to the ephemeral moments of beauty and value that it might impart is all that I can justifiably conclude.

Non-form and the source of all that is form

My outward journey from all that is form to all that is non-form has led me to understand that there is no end point at which academic knowledge can present us with in the context of loss. No final resting place of meaning or value, no universally utopic point of success at which to rest. I have described how the rhythm to the form is in part determined by a set of ideals and their accompanying moral and ethical frameworks that define progress as an unquestionable virtuous endeavour. Yet, at the outermost limitations of our rational existence, I also describe how following this path can lead to paradox and existential distress.

Engaging with the non-form provides a home for these feelings, recognising that there is, and always will be, an inseparability of light and dark in the events and actions that occur in the face of profound dependency, decline and death. At this point, and in the events and processes leading up to it, there is very little that resembles form or bears any of the hallmarks of its operating, progress orientated structures. There is also no variation of what is of form that might successfully accommodate the notion of progress or success. Indeed, there is no separating out meaning, value beauty or joy from all that is broken, damaged, stunted or soiled. More so there is no separating out presence from absence or absence from presence. This means that possibility and promise remain, embedded within the sense of waiting, of waiting without anticipation within the constancies of life's passings and becomings.

I have described my attempts to position myself at and within all that is non-form, and the potential for my findings to reorientate the point of focus, so that the ephemeral moments of transformational beauty arise through our hospitality towards woundedness, infirmity, weakness and failure rather than in spite of them. Yet a question remains, what of the return journey, from non-form to form?

That it is through the non-form that our ideals might emerge, to create structure so that we ourselves have a role to play in driving progress ([figure eight](#)) suggests that the directionality of progress is real but also perspectival. At the extremes of human existence, at the frontiers of death, loss and absence we might recognise that disorder, imperfection and vulnerability exist within us as part of our innate belonging to all that is non-form. And it is from this domain which our 'true ideals' are created.

Much of this theory is evidenced by my data, other sections are plausible whilst parts remain that are simply attempts to understand the emptiness beyond our formed reality, recognising that it is essentially and fundamentally unknowable. Is there still scope to drive progress, to shift through the gears of our carefully formulated structures and bring light over dark? I believe so, but the route to this end might be through inhabiting all that is non-form, being open, humble and graciously accommodating both the pain and gifts this may impart. Regardless of how we view and achieve progress, this is not an end in itself. And therefore, there is no grand finale, whilst there is perhaps importance and value in its performance, there is also great value within the absence and the change brought by a continued cycle of constant passing and becoming.

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Bibliography

- Abbasi, J. 2020. 'Taking a Closer Look at COVID-19, Health Inequities, and Racism', *Jama-Journal of the American Medical Association*, 324: 427-29.
- Abbott, S. 2009. 'Social capital and health: The problematic roles of social networks and social surveys', *Health Sociology Review*, 18: 297-306.
- Abel, J. 2018. 'Compassionate communities and end-of-life care', *Clin Med (Lond)*, 18: 6-8.
- Abel, J., and A. Kellehear. 2016. 'Palliative care reimagined: a needed shift', *BMJ Support Palliat Care*, 6: 21-6.
- . 2018. 'Palliative Curriculum Re-imagined: A Critical Evaluation of the UK Palliative Medicine Syllabus', *Palliat Care*, 11: 1178224218780375.
- . 2022. *Oxford textbook of public health palliative care* (Oxford University Press).
- Abel, J., A. Kellehear, and A. Karapliagou. 2018a. 'Palliative care-the new essentials', *Ann Palliat Med*, 7: S3-S14.
- Abel, J., A. Kellehear, and A. Karapliagou. 2018b. 'Palliative care-the new essentials', *Annals of palliative medicine*, 7: S3-S14.
- Abel, J., H. Kingston, A. Scally, J. Hartnoll, G. Hannam, A. Thomson-Moore, and A. Kellehear. 2018. 'Reducing emergency hospital admissions: a population health complex intervention of an enhanced model of primary care and compassionate communities', *Br J Gen Pract*, 68: e803-e10.
- Abel, J., T. Walter, L. B. Carey, J. Rosenberg, K. Noonan, D. Horsfall, R. Leonard, B. Rumbold, and D. Morris. 2013a. 'Circles of care: should community development redefine the practice of palliative care?', *BMJ supportive & palliative care*, 3: 383-88.
- Abel, J., T. Walter, L. B. Carey, J. Rosenberg, K. Noonan, D. Horsfall, R. Leonard, B. Rumbold, and D. Morris. 2013b. 'Circles of care: should community development redefine the practice of palliative care?', *BMJ Support Palliat Care*, 3: 383-8.
- Abreu, W., D. Tolson, G. A. Jackson, and N. Costa. 2020. 'A cross-sectional study of family caregiver burden and psychological distress linked to frailty and functional dependency of a relative with advanced dementia', *Dementia (London)*, 19: 301-18.
- Adams, T. 2001. 'The social construction of risk by community psychiatric nurses and family carers for people with dementia', *Health Risk & Society*, 3: 307-19.
- Alaszewski, A., H. P. Alaszewski, S. Ayer, and J. Manthorpe. 2000. *Managing risk in community practice: nursing, risk and decision making* (Baillière Tindall).
- Alaszewski, A., and J. Manthorpe. 1991. 'Literature review: Measuring and managing risk in social welfare', *The British Journal of Social Work*, 21: 277-90.
- . 2000. 'Finding the balance: older people, nurses and risk', *Education and Ageing*, 15: 195-209.
- Alliance, W. P. C., and W. H. Organisation. 2014. "Global Atlas of Palliative Care at the End of Life." In.
- Aoun, S. M., L. J. Breen, I. White, B. Rumbold, and A. Kellehear. 2018. 'What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach', *Palliat Med*, 32: 1378-88.
- Applewhite, A. 2016. *This Chair Rocks: A manifesto against ageism* (Networked Books, Inc.).
- Ariès, P. 1974. 'The reversal of death: changes in attitudes toward death in Western societies', *American Quarterly*, 26: 536-60.
- Arteaga, I., and H. Llewellyn. 2022. 'Cultivating Ethnographic Sensibilities in Ethnographies of Dying People', *Ethos*, 50: 353-71.
- Bakelants, H., F. Van Droogenbroeck, K. Chambaere, S. Vanderstichelen, L. De Donder, L. Deliens, S. De Gieter, D. De Moortel, J. Cohen, and S. Dury. 2023. 'A compassionate university for serious illness, death, and bereavement: Qualitative study of student and staff experiences and support needs', *Death Stud*: 1-12.
- Bakelants, H., S. Vanderstichelen, K. Chambaere, F. Van Droogenbroeck, L. De Donder, L. Deliens, S. Dury, and J. Cohen. 2023. 'Researching Compassionate Communities: Identifying theoretical frameworks to evaluate the complex processes behind public health palliative care initiatives', *Palliat Med*, 37: 291-301.

- Balkin, E. J., M. G. Kollerup, I. G. Kymre, B. Martinsen, and M. Gronkjaer. 2023. 'Ethics and the impossibility of the consent form: Ethnography in a Danish nursing home', *J Aging Stud*, 64: 101110.
- Balouch, S., A. Zaidi, N. Farina, and R. Willis. 2021. 'Dementia awareness, beliefs and barriers among family caregivers in Pakistan', *Dementia*, 20: 899-918.
- Bamford, S. 2009. 'Family trees' among the Kamea of Papua New Guinea: a non-genealogical approach to imagining relatedness.' in S. Bamford and J. Leach (eds.), *Kinship and beyond: the genealogical model reconsidered*.
- Barnes, S., M. Gott, S. Payne, C. Parker, D. Seemark, S. Gariballa, and N. Small. 2005. 'Recruiting older people into a large, community-based study of heart failure', *Chronic illness*, 1: 321-29.
- Barrado-Martín, Y., P. Nair, K. Anantapong, N. Aker, K. J. Moore, C. H. Smith, G. Rait, E. L. Sampson, J. Manthorpe, and N. Davies. 2021. 'Family caregivers' and professionals' experiences of supporting people living with dementia's nutrition and hydration needs towards the end of life', *Health & Social Care in the Community*, n/a.
- Bartlett, R., R. Milne, and R. Croucher. 2019. 'Strategies to improve recruitment of people with dementia to research studies', *Dementia (London)*, 18: 2494-504.
- Bartlett, R., and D. O'Connor. 2007. 'From personhood to citizenship: Broadening the lens for dementia practice and research', *Journal of aging studies*, 21: 107-18.
- Bartlett, R., and D. O'Connor. 2010a. *Broadening the dementia debate: Towards social citizenship* (Policy press).
- . 2010b. 'Setting the context for broadening the debate.' in, *Broadening the dementia debate: towards social citizenship* (Bristol University Press; Policy Press).
- Bartlett, R., D. O'Connor, and J. Mann. 2010. *Broadening the dementia debate: Towards social citizenship*.
- Bartlett, R., L. Windemuth-Wolfson, K. Oliver, and T. Dening. 2017. 'Suffering with dementia: the other side of "living well"', *Int Psychogeriatr*, 29: 177-79.
- Bauernfreund, Y., M. Butler, S. Ragavan, and E. L. Sampson. 2018. 'TIME to think about delirium: improving detection and management on the acute medical unit', *BMJ open quality*, 7: e000200.
- Baum, F. 2008. *The new public health* (Oxford University Press: South Melbourne).
- Bauman, Z. 1992. *Mortality, immortality and other life strategies* (Stanford University Press).
- Beck, U. 2000. 'Risk society revisited: theory, politics and research programmes.' in B. Adam, U. Beck and J. Van Loon (eds.), *The risk society and beyond: Critical issues for social theory* (SAGE: London).
- Becker, E. 1973. 'The denial of death, New York (The Free Press) 1973'.
- Benbow, S. M., and D. Jolley. 2012. 'Dementia: stigma and its effects', *Neurodegenerative Disease Management*, 2: 165-72.
- Bhaskar, R. 1978. *A Realist Theory of Science* (Routledge).
- . 2008a. *A Realist Theory Of Science* (Routledge: London and New York).
- . 2008b. 'A Realist Thoery of Science.' in (Routledge: London & New York).
- Biehl, J., and P. Lock. 2017. 'Introduction: Ethnographic Sensorium.' in, *Unfinished: The Anthropology of Becoming* (Duke Univserity Press: London).
- Birch, D., and J. Draper. 2008. 'A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia', *J Clin Nurs*, 17: 1144-63.
- Blandin, K., and R. Pepin. 2017. 'Dementia grief: A theoretical model of a unique grief experience', *Dementia (London)*, 16: 67-78.
- Borgatti, S. P., M. G. Everett, and L. C. Freeman. 2002a. 'Ucinet for Windows: Software for social network analysis', *Harvard, MA: analytic technologies*, 6: 12-15.
- . 2002b. 'Ucinet for Windows: Software for social network analysis'.
- Borgatti, S. P. E., Martin G; Johnson, Jeffrey C. 2018. *Analysing Social Networks* (SAGE: London).
- Bozzola, F. G., P. B. Gorelick, and S. Freels. 1992. 'Personality changes in Alzheimer's disease', *Arch Neurol*, 49: 297-300.
- Braun, V., and V. Clarke. 2006. 'Using thematic analysis in psychology', *Qualitative research in psychology*, 3: 77-101.
- . 2012. *Thematic analysis* (American Psychological Association).
- . 2020. 'One size fits all? What counts as quality practice in (reflexive) thematic analysis?', *Qualitative research in psychology*: 1-25.
- Bressan, V., C. Visintini, and A. Palese. 2020. 'What do family caregivers of people with dementia need? A mixed-method systematic review', *Health & social care in the community*, 28: 1942-60.

- Brinkman-Stoppelenburg, A., J. A. Rietjens, and A. van der Heide. 2014. 'The effects of advance care planning on end-of-life care: a systematic review', *Palliat Med*, 28: 1000-25.
- Brodady, H., and M. Donkin. 2022. 'Family caregivers of people with dementia', *Dialogues in clinical neuroscience*.
- Browne, B., N. Kupeli, K. J. Moore, E. L. Sampson, and N. Davies. 2021. 'Defining end of life in dementia: A systematic review', *Palliat Med*, 35: 1733-46.
- Buckley, J. 2002. 'Holism and a health-promoting approach to palliative care', *Int J Palliat Nurs*, 8: 505-8.
- Buehler, N. J., J. L. Frydman, R. S. Morrison, and L. P. Gelfman. 2023. 'An Update: National Institutes of Health Research Funding for Palliative Medicine 2016-2020', *J Palliat Med*, 26: 509-16.
- Buiger, T. 1976. *Max Weber's Theory of Concept Formation* (Duke University Press: Durham, North Carolina).
- Bunce, A. 2018. 'Developing a Compassionate Community Compassionate Inverclyde', *International Journal of Integrated Care*, 18: 1-2.
- Bunn, F., C. Goodman, K. Sworn, G. Rait, C. Brayne, L. Robinson, E. McNeilly, and S. Iliffe. 2012. 'Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies', *PLOS medicine*, 9: e1001331.
- Bunn, F., J. Lynch, C. Goodman, R. Sharpe, C. Walshe, N. Preston, and K. Froggatt. 2018. 'Improving living and dying for people with advanced dementia living in care homes: a realist review of Namaste Care and other multisensory interventions', *BMC Geriatr*, 18: 303.
- Burge, F. I., B. J. Lawson, G. M. Johnston, and E. Grunfeld. 2008. 'A population-based study of age inequalities in access to palliative care among cancer patients', *Med Care*, 46: 1203-11.
- Butler, R. N. 1969. 'Age-ism . Another Form of Bigotry', *Gerontologist*, 9: 243-&.
- Byock, I., K. Norris, J. R. Curtis, and D. L. Patrick. 2001. 'Improving end-of-life experience and care in the community: a conceptual framework', *J Pain Symptom Manage*, 22: 759-72.
- Care, D. o. H. a. S. 2020. "Prime Minister's Challenge on dementia 2020." In, edited by D. o. H. a. S. Care.
- Carr, K. L. 1992. *The banalization of nihilism: Twentieth-century responses to meaninglessness* (SUNY Press).
- Carr, S. 2011. 'Enabling risk and ensuring safety: self-directed support and personal budgets', *Journal of Adult Protection*, 13: 122-36.
- Carsten, J. 2000. *Cultures of relatedness: New approaches to the study of kinship* (Cambridge University Press).
- Cave, N., and S. O'Hagan. 2022. *Faith, Hope and Carnage* (Canongate Books: Edinburgh).
- Chan, D., G. Livingston, L. Jones, and E. L. Sampson. 2013. 'Grief reactions in dementia carers: a systematic review', *Int J Geriatr Psychiatry*, 28: 1-17.
- Chen, M. L. 2019. 'Inequity of Palliative Care for Non-Cancer Patients', *J Nurs Res*, 27: 1-2.
- Cheston, R., and M. Bender. 1999. *Understanding Dementia: The Man with the Worried Eyes* (Jessica Kingsley Publishers Ltd: London).
- Clark, A., S. Campbell, J. Keady, A. Kullberg, K. Manji, K. Rummery, and R. Ward. 2020. 'Neighbourhoods as relational places for people living with dementia', *Social Science & Medicine*, 252: 112927.
- Clarke, C. L., C. E. Gibb, J. Keady, A. Luce, H. Wilkinson, L. Williams, and A. Cook. 2009. 'Risk management dilemmas in dementia care: an organizational survey in three UK countries', *Int J Older People Nurs*, 4: 89-96.
- Clarke, D. L. R. 2020. *Dear Life: A Doctor's Story of Love and Loss* (Thomas Dunne Books).
- Cloyes, K. G., W. Hull, and A. Davis. 2018. "Palliative and end-of-life care for lesbian, gay, bisexual, and transgender (LGBT) cancer patients and their caregivers." In *Seminars in Oncology Nursing*, 60-71. Elsevier.
- Cohen, D., and C. Eisdorfer. 2001. *The loss of self: A family resource for the care of Alzheimer's disease and related disorders* (WW Norton & Company).
- Coldwell, M. 2019. 'Reconsidering context: Six underlying features of context to improve learning from evaluation', *Evaluation*, 25: 99-117.
- Collaborators, G. D. F. 2022. 'Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019', *The Lancet Public Health*.
- Collier, A., and M. Chapman. 2023. 'Matters of care and the good death - rhetoric or reality?', *Current Opinion in Supportive and Palliative Care*, 17: 208-13.

- Collins, A., J. E. Brown, J. Mills, and J. Philip. 2020. 'The impact of public health palliative care interventions on health system outcomes: A systematic review', *Palliative medicine*, 0269216320981722.
- Connidis, I. 2009. "Family ties and aging. 2nd Thousand Oaks." In.: CA: Sage.
- Conway, S. 2008. 'Public health and palliative care: principles into practice?', *Critical Public Health*, 18: 405-15.
- Cooke, R. 2020. 'Is there a better way to die? ', *The Guardian*.
- Crenshaw, K. 1989. 'Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics', *u. Chi. Legal f.*: 139.
- Crimmins, E. M., and H. Beltrán-Sánchez. 2011. 'Mortality and morbidity trends: is there compression of morbidity?', *The Journals of Gerontology: Series B*, 66: 75-86.
- Crowe, J. A. 2007. 'In search of a happy medium: How the structure of interorganizational networks influence community economic development strategies', *Social networks*, 29: 469-88.
- Cuijpers, P. 2005. 'Depressive disorders in caregivers of dementia patients: a systematic review', *Aging Ment Health*, 9: 325-30.
- Curelaru, A., S. J. Marzolf, J. K. G. Provost, and H. H. H. Zeon. 2021. 'Social Isolation in Dementia: The Effects of COVID-19', *J Nurse Pract*, 17: 950-53.
- D'Eer, L., B. Quintiens, L. Van den Block, S. Dury, L. Deliens, K. Chambaere, T. Smets, and J. Cohen. 2022. 'Civic engagement in serious illness, death, and loss: A systematic mixed-methods review', *Palliat Med*, 36: 625-51.
- Dahler-Larsen, P. 2013a. 'Epilogue: Perspectives for Evaluation.' in, *An Organisational Analysis of Evaluation* (Stanford Univeristy Press: California).
- . 2013b. *The Evaluation Society* (Stanford University Press: California).
- . 2013c. 'The Learning Organization.' in, *An Organisational Analysis of Evaluation* (Stanford University Press: California).
- . 2013d. 'Rational Organization.' in, *An Organisational Analysis of Evaluation* (Stanford Univerity Press: California).
- Daly, M., and H. Silver. 2008. 'Social exclusion and social capital: A comparison and critique', *Theory and society*, 37: 537-66.
- Danermark, B., M. Ekstrom, and L. Jakobsen. 2005. *Explaining society: An introduction to critical realism in the social sciences* (Routledge: London).
- Dantzig, T., and J. Mazur. 1954. *Number: The language of science* (Penguin).
- Davies, C. A. 1998. *Reflexive Ethnography* (Routledge: London & New York).
- Davies, J., and D. Gregory. 2007. 'Entering the dialogue: Marriage biographies and dementia care', *Dementia*, 6: 481-88.
- Davies, N., T. De Souza, G. Rait, J. Meehan, and E. L. Sampson. 2021. 'Developing an applied model for making decisions towards the end of life about care for someone with dementia', *PloS one*, 16: e0252464.
- Davies, N., L. Maio, G. Rait, and S. Iliffe. 2014. 'Quality end-of-life care for dementia: What have family carers told us so far? A narrative synthesis', *Palliative Medicine*, 28: 919-30.
- Davies, N., L. Maio, K. Vedavanam, J. Manthorpe, M. Vernooij-Dassen, S. Iliffe, and I. R. Team. 2014. 'Barriers to the provision of high-quality palliative care for people with dementia in England: a qualitative study of professionals' experiences', *Health & social care in the community*, 22: 386-94.
- Davis, J. 2020a. 'The Devalued Status of Old Age ' in J. David and P. Scherz (eds.), *The Evening of Life: The Challenges of Aging and Dying Well* (University of Notre Dame Press: United States of America).
- Davis, J. E. 2020b. 'The Devalued Status of Old Age.' in J. E. Davis and P. Scherz (eds.), *The Evening of Life: The Challenges Of Ageing and Dying Well* (University of Notre Dame Press: USA).
- Davis, J. E., and P. Scherz. 2020. *The Evening of Life: The challenges of aging and dying well* (Univeristy of Notre Dame: United States of America).
- de Boer, M. E., C. M. Hertogh, R. M. Droes, Riphagen, II, C. Jonker, and J. A. Eefsting. 2007. 'Suffering from dementia - the patient's perspective: a review of the literature', *Int Psychogeriatr*, 19: 1021-39.
- Dees, M., M. Vernooij-Dassen, W. Dekkers, and C. van Weel. 2010. 'Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review', *Psychooncology*, 19: 339-52.

- Dempers, C., and M. Gott. 2016. 'Which public health approach to palliative care? An integrative literature review', *Progress in palliative care*, 25: 1-10.
- Dempers, C., and M. Gott. 2017. 'The status of a public health approach to palliative care at New Zealand hospices', *Progress in palliative care*, 25: 75-81.
- Dening, K. H., L. Jones, and E. L. Sampson. 2011. 'Advance care planning for people with dementia: a review', *International Psychogeriatrics*, 23: 1535-51.
- Dickens, A. P., S. H. Richards, C. J. Greaves, and J. L. Campbell. 2011. 'Interventions targeting social isolation in older people: a systematic review', *BMC public health*, 11: 647.
- Dickins, M., D. Goeman, F. O'Keefe, S. Iliffe, and D. Pond. 2018. 'Understanding the conceptualisation of risk in the context of community dementia care', *Soc Sci Med*, 208: 72-79.
- Diehl-Schmid, J., R. Jox, S. Gauthier, S. Belleville, E. Racine, C. Schüle, G. Turecki, and S. Richard-Devantoy. 2017. 'Suicide and assisted dying in dementia: what we know and what we need to know. A narrative literature review', *International Psychogeriatrics*, 29: 1247-59.
- Doka, K. J. 2010. 'Grief, multiple loss and dementia', *Bereavement Care*, 29: 15-20.
- Dowd, J. J. 1975. 'Aging as exchange: A preface to theory', *Journal of gerontology*, 30: 584-94.
- Downs, M., A. Blighe, R. Carpenter, A. Feast, K. Froggatt, S. Gordon, R. Hunter, L. Jones, N. Lago, and B. McCormack. 2021. 'A complex intervention to reduce avoidable hospital admissions in nursing homes: a research programme including the BHiRCH-NH pilot cluster RCT'.
- Droes, R. M., R. Chattat, A. Diaz, D. Gove, M. Graff, K. Murphy, H. Verbeek, M. Vernooij-Dassen, L. Clare, A. Johannessen, M. Roes, F. Verhey, K. Charras, and I. s. H. Taskforce. 2017. 'Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice', *Ageing Ment Health*, 21: 4-17.
- Duggan, S., T. Blackman, A. Martyr, and P. Van Schaik. 2008. 'The impact of early dementia on outdoor life: Ashrinking world?', *Dementia*, 7: 191-204.
- Dupuis, S. L., J. Gillies, J. Carson, C. Whyte, R. Genoe, L. Loiselle, and L. Sadler. 2012. 'Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services', *Dementia*, 11: 427-52.
- Egdell, V. 2013. 'Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care', *Ageing & Society*, 33: 888-907.
- Erel, M., E.-L. Marcus, and F. Dekeyser-Ganz. 2017. 'Barriers to palliative care for advanced dementia: a scoping review', *Annals of Palliative Medicine*, 6: 365-79.
- Etkind, S. N., A. E. Bone, B. Gomes, N. Lovell, C. J. Evans, I. J. Higginson, and F. Murtagh. 2017. 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', *BMC medicine*, 15: 1-10.
- Excellence, N. I. f. H. a. C. 2014. "Developing NICE guidelines: the manual." In, 237. National Institute for Health and Care Excellence.
- Faes, K., J. Cohen, and L. Annemans. 2018. 'Resource Use During the Last 6 Months of Life of Individuals Dying with and of Alzheimer's Disease', *J Am Geriatr Soc*, 66: 879-85.
- Farah, M. J., and A. S. Heberlein. 2007. 'Personhood and neuroscience: naturalizing or nihilating?', *Am J Bioeth*, 7: 37-48.
- Field, B., G. Mountain, J. Burgess, L. Di Bona, D. Kelleher, J. Mundy, and J. Wenborn. 2019. 'Recruiting hard to reach populations to studies: breaking the silence: an example from a study that recruited people with dementia', *BMJ open*, 9: e030829.
- Finch, J., and J. Mason. 2008. 'Filial Obligations and Kin Support for Elderly People', *Ageing and Society*, 10: 151-75.
- Fletcher, A. J. 2017. 'Applying critical realism in qualitative research: methodology meets method', *International Journal of Social Research Methodology*, 20: 181-94.
- Fletcher, J. R. 2020a. 'Mythical dementia and Alzheimerised senility: discrepant and intersecting representations of cognitive decline in later life', *Social Theory & Health*, 18: 50-65.
- . 2020b. 'Renegotiating relationships: Theorising shared experiences of dementia within the dyadic career', *Dementia-International Journal of Social Research and Practice*, 19: 708-20.
- Fleuren, N., M. Depla, D. J. A. Janssen, M. Huisman, and C. Hertogh. 2020. 'Underlying goals of advance care planning (ACP): a qualitative analysis of the literature', *BMC Palliat Care*, 19: 27.
- Fook, J., and A. Kellehear. 2010. 'Using critical reflection to support health promotion goals in palliative care', *J Palliat Care*, 26: 295-302.

- Foucault, M. 2012. *The birth of the clinic* (Routledge).
- Franklin, S., and S. McKinnon. 2001. *Relative values: reconfiguring kinship studies* (Duke University Press).
- Freidson, E. 1970. *Professional Dominance: The Social Structure of Medical Care* (Atherton Press).
- Fries, J. F. 1980. 'Aging, natural death, and the compression of morbidity', *N Engl J Med*, 303: 130-5.
- Fries, J. F., B. Bruce, and E. Chakravarty. 2011. 'Compression of morbidity 1980-2011: a focused review of paradigms and progress', *J Aging Res*, 2011: 261702.
- Garner, I. W., C. Walshe, L. Dunleavy, A. Bradshaw, N. Preston, L. K. Fraser, F. E. Murtagh, A. O. Oluyase, K. E. Sleeman, and M. Hocaoglu. 2022. 'Charitably funded hospices and the challenges associated with the COVID-19 pandemic: a mixed-methods study (CovPall)', *BMC Palliative Care*, 21: 1-9.
- Gawande, A. 2014. *Being mortal: Medicine and what matters in the end* (Metropolitan Books).
- Gigliani, G. 2017. 'The Hidden Life of Matter: Techniques for Prolonging Life in the Writings of Francis Bacon 1.' in, *Francis Bacon and the refiguring of early modern thought* (Routledge).
- Gilleard, C. 2021. 'Bearable and unbearable suffering in later life', *Journal of Population Ageing*, 14: 343-55.
- Gilleard, C., and P. Higgs. 2005. 'Community and the Nature of Belonging.' in, *Contexts of Ageing: Class, Cohort and Community* (Polity Press: Cambridge).
- Gilleard, C., and P. Higgs. 2010a. 'Aging without agency: theorizing the fourth age', *Aging Ment Health*, 14: 121-8.
- . 2010b. 'Aging without agency: Theorizing the fourth age', *Aging & mental health*, 14: 121-28.
- Goffman, E. 1961. *Asylums: Essays on the social situation of mental patients and other inmates* (AldineTransaction).
- Gott, M., T. Morgan, and L. Williams. 2020. 'Gender and palliative care: a call to arms', *Palliat Care Soc Pract*, 14: 2632352420957997.
- Gott, M., J. Wiles, T. Moeke-Maxwell, S. Black, L. Williams, N. Kerse, and G. Trussardi. 2018. 'What is the role of community at the end of life for people dying in advanced age? A qualitative study with bereaved family carers', *Palliative Medicine*, 32: 268-75.
- Granovetter, M. S. 1973. 'The Strength of Weak Ties', *American journal of sociology*, 78: 1360-80.
- Granovetter, M. S. 1977. 'The strength of weak ties.' in, *Social networks* (Elsevier).
- Green, D. 2007. 'Risk and social work practice', *Australian Social Work*, 60: 395-409.
- Green, J. 2015. 'The public health profession and the community', *Critical Public Health*, 25: 123-24.
- Greenhalgh, J., and A. Manzano. 2022. 'Understanding 'context'in realist evaluation and synthesis', *International Journal of Social Research Methodology*, 25: 583-95.
- Guerchet, M., and M. Prince. 2020. "Numbers of people with dementia around the world." In, 2. *Alzheimer's Disease International*.
- Haeusermann, T. 2019. 'Forced continuity: Explorations of biographical narratives in dementia care', *J Aging Stud*, 49: 1-8.
- Hamnett, C. 2003. 'Gentrification and the middle-class remaking of inner London, 1961-2001', *Urban studies*, 40: 2401-26.
- Handley, M., F. Bunn, and C. Goodman. 2015. 'Interventions that support the creation of dementia friendly environments in health care: protocol for a realist review', *Systematic reviews*, 4: 180.
- . 2017. 'Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review', *BMJ Open*, 7: e015257.
- Harrison Dening, K., E. L. Sampson, and K. De Vries. 2019. 'Advance care planning in dementia: recommendations for healthcare professionals', *Palliat Care*, 12: 1178224219826579.
- Hauge, S., and M. Kirkevold. 2012. 'Variations in older persons' descriptions of the burden of loneliness', *Scand J Caring Sci*, 26: 553-60.
- Hayashi, A. 2021. *Social Presencing Theater: The Art of Making a True Move* (PI Press: Cambridge, Massachusetts).
- Hayashi, M. 2017. 'The Dementia Friends initiative – supporting people with dementia and their carers: reflections from Japan', *International Journal of Care and Caring*, 1: 281-87.
- Hazelwood, M. A., and R. M. Patterson. 2018. 'Scotland's public health palliative care alliance', *Ann Palliat Med*, 7: S99-S108.
- Head, B. W., and J. Alford. 2015. 'Wicked Problems: Implications for Public Policy and Management', *Administration & society*, 47: 711-39.

- Hebert, C. A., and K. Scales. 2019. 'Dementia friendly initiatives: A state of the science review', *Dementia (London)*, 18: 1858-95.
- Heidegger, M. 1958. *The question of being* (Rowman & Littlefield).
- Hekman, S. J. 1983. 'Weber's ideal type: a contemporary reassessment', *Polity*, 16: 119-37.
- Henderson, J. 2001. 'He's not my carer—he's my husband': Personal and policy constructions of care in mental health', *Journal of Social Work Practice*, 15: 149-59.
- Hendricks, J., and C. Breckinridge Peters. 1973. 'The ideal type and sociological theory', *Acta Sociologica*, 16: 31-40.
- Henry, B., N. Dosani, L. Huynh, and N. Amirault. 2017. 'Palliative care as a public health issue: understanding disparities in access to palliative care for the homeless population living in Toronto, based on a policy analysis', *Current Oncology*, 24: 187-91.
- Henwood, M., and J. Neuberger. 1999. *The future of health and care of older people: the best is yet to come* (Age Concern England).
- Hertogh, C. M., M. E. De Boer, R.-M. Dröes, and J. A. Eefsting. 2007. 'Would we rather lose our life than lose our self? Lessons from the Dutch debate on euthanasia for patients with dementia', *The American Journal of Bioethics*, 7: 48-56.
- Higgs, P. 2012. 'Consuming bodies: Zygmunt Bauman on the difference between fitness and health.' in, *Contemporary Theorists for Medical Sociology* (Routledge).
- Higgs, P., and C. Gilleard. 2016a. 'Agency, identity and personhood in the social sciences.' in, *Personhood, Identity and Care in Advanced Old Age* (Policy Press: Great Britain).
- . 2016b. 'Interrogating personhood.' in, *Personhood, identity and care in advanced old age* (Policy Press: Bristol).
- . 2016c. 'The moral imperative of care.' in, *Personhood, identity and care in advanced old age* (Policy Press: Bristol).
- . 2016d. 'The moral imperative of care.' in, *Personhood, identity and care in advanced old age* (Policy Press: Bristol).
- . 2016e. *Personhood, identity and care in advanced old age* (Policy Press).
- Hillier, R. 1988. 'Palliative medicine', *BMJ*, 297: 874-5.
- Hillman, A., and J. Latimer. 2017. 'Cultural representations of dementia', *PLOS Medicine*, 14: e1002274.
- Holloway, R. 2004a. 'Looking in the distance: The human search for meaning' in (Canongate Books: Edinburgh).
- . 2004b. *Looking in the Distance: The human search for meaning* (Canongate: Edinburgh).
- Holt-Lunstad, J. 2017. 'The potential public health relevance of social isolation and loneliness: Prevalence, epidemiology, and risk factors', *Public Policy & Aging Report*, 27: 127-30.
- Holy, L. 1996. *Anthropological perspectives on kinship* (University of Alberta).
- Horsfall, D. 2018. 'Developing compassionate communities in Australia through collective caregiving: a qualitative study exploring network-centred care and the role of the end of life sector', *Ann Palliat Med*, 7: S42-S51.
- Horsfall, D., R. Leonard, K. Noonan, and J. Rosenberg. 2013. 'Working together-apart: Exploring the relationships between formal and informal care networks for people dying at home', *Progress in palliative care*, 21: 331-36.
- Horsfall, D., K. Noonan, and R. Leonard. 2012. 'Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities', *Health Sociology Review*, 21: 373-82.
- . 2014. 'Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities', *Health Sociology Review*, 21: 373-82.
- Huang, H. Y., K. M. Kuo, I. C. Lu, H. Wu, C. W. Lin, M. T. Hsieh, Y. C. Lin, R. Y. Huang, I. T. Liu, and C. H. Huang. 2019. 'The impact of health literacy on knowledge, Attitude and decision towards hospice care among community-dwelling seniors', *Health & social care in the community*, 27: E724-E33.
- Huang, S. J., C. Y. Huang, L. C. Woung, O. K. Lee, D. C. Chu, T. C. Huang, A. Kitazawa, and J. R. Curtis. 2019. 'The 2018 Taipei Declaration for Ultimate Integration of Palliative Care', *J Palliat Med*, 22: 476-77.
- Illich, I. 1975a. *Limits to Medicine. Medical Nemesis: The Expropriation of health* (Marion Boyars Publishers: London).

- . 1975b. *Medical Nemesis: The Expropriation of Health* (Calder & Boyars: London).
- International, A. D. 2016. "Dementia Friendly Communities: global developments, 2nd edition." In London.
- Ioannidis, J. P. 2016. 'The Mass Production of Redundant, Misleading, and Conflicted Systematic Reviews and Meta-analyses', *Milbank Q*, 94: 485-514.
- Jackson, T. A., J. R. Gladman, R. H. Harwood, A. M. MacLulich, E. L. Sampson, B. Sheehan, and D. H. Davis. 2017. 'Challenges and opportunities in understanding dementia and delirium in the acute hospital', *PLoS med*, 14: e1002247.
- Jacobsen, M. H. 2022. 'Contemplating a career in death and dying- an interview with Tony Walter', *Mortality*, 27: 228-53.
- Jagosh, J. 2020. 'Retrospective theorizing in Pawson and Tilley's applied scientific realism', *Journal of Critical Realism*, 19: 121-30.
- Jakhar, J., S. Ambreen, and S. Prasad. 2020. 'Right to Life or Right to Die in Advanced Dementia: Physician-Assisted Dying', *Front Psychiatry*, 11: 622446.
- James, P. 2019. 'The social imaginary in theory and practice.' in C. Hudson and E. K. Wilson (eds.), *Revisiting the Global Imaginary: Theories, Ideologies, Subjectivities: Essays in Honor of Manfred Steger* (Palgrave Macmillan: Switzerland).
- Jaul, E., J. Barron, J. P. Rosenzweig, and J. Menczel. 2018. 'An overview of co-morbidities and the development of pressure ulcers among older adults', *BMC geriatrics*, 18: 1-11.
- Jeste, D. V., E. E. Lee, and S. Cacioppo. 2020. 'Battling the Modern Behavioral Epidemic of Loneliness: Suggestions for Research and Interventions', *JAMA psychiatry*, 77: 553-54.
- Johansson, S., R. Leonard, and K. Noonan. 2012. 'Caring and the generation of social capital: Two models for a positive relationship', *International Journal of Social Welfare*, 21: 44-52.
- Kääriäinen, J., and H. Lehtonen. 2006. 'The Variety of Social Capital in Welfare State Regimes – a Comparative Study of 21 Countries', *European Societies*, 8: 27-57.
- Kastenbaum, R. 1977. *Death, society and human experience* (Mosby).
- Katbamna, S., W. Ahmad, P. Bhakta, R. Baker, and G. Parker. 2004. 'Do they look after their own? Informal support for South Asian carers', *Health & social care in the community*, 12: 398-406.
- Kaufman, S. R. 2000. 'In the shadow of "death with dignity": Medicine and cultural quandaries of the vegetative state', *American anthropologist*, 102: 69-83.
- Kaufman, S. R. 2015a. 'The Medical-Industrial Complex II: Access, Industry, and the Clinical Trials Phenomenon.' in, *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line* (Duke University Press).
- . 2015b. 'The Medical Industrial Complex I: Evidence-Based Medicine, the Biomedical Economy, and the Ascendance of Clinical Trials.' in, *Ordinary medicine : extraordinary treatments, longer lives, and where to draw the line* (Duke University Press Durham; London).
- . 2015c. *Ordinary medicine* (Duke University Press).
- . 2015d. *Ordinary medicine: extraordinary treatments, longer lives, and where to draw the line* (Duke University Press: Durham; London).
- Keady, J., S. Campbell, H. Barnes, R. Ward, X. Li, C. Swarbrick, S. Burrow, and R. Elvish. 2012. 'Neighbourhoods and dementia in the health and social care context: a realist review of the literature and implications for UK policy development', *Reviews in Clinical Gerontology*, 22: 150-63.
- Kearney, M. 1992. 'Palliative medicine-just another specialty?', *Palliative Medicine*, 6: 39-46.
- Kellehear, A. 1999. 'Inaugural Victorian State Conference on Palliative Care', *Australian Journal of Primary Health - Interchange*, 5: 7.
- Kellehear, A. 2004. 'Third-wave public health? Compassion, community, and end-of-life care', *International Journal of Applied Psychoanalytic Studies*, 1: 313-23.
- Kellehear, A. 2005. *Compassionate Cities: Public Health and end-of-life care* (Routledge: Oxfordshire).
- . 2007. 'The end of death in late modernity: an emerging public health challenge', *Critical Public Health*, 17: 71-79.
- Kellehear, A. 2012. *Compassionate cities* (Routledge).
- Kellehear, A. 2013a. 'Compassionate communities: end-of-life care as everyone's responsibility', *QJM*, 106: 1071-5.

- Kellehear, A. 2013b. 'Compassionate communities: end-of-life care as everyone's responsibility', *QJM: An International Journal of Medicine*, 106: 1071-75.
- Kellehear, A. 2016. 'Commentary: Public health approaches to palliative care - The progress so far', *Progress in palliative care*, 24: 36-38.
- Kellehear, A. 2019. 'Compassionate Cities: global significance and meaning for palliative care', *Progress in palliative care*.
- Kellehear, A., and D. O'Connor. 2008. 'Health-promoting palliative care: A practice example', *Critical Public Health*, 18: 111-15.
- Kelley, M. L. 2007. 'Developing rural communities' capacity for palliative care: a conceptual model', *J Palliat Care*, 23: 143-53.
- Kelley, M. L., H. Prince, S. Nadin, K. Brazil, M. Crow, G. Hanson, L. Maki, L. Monture, C. J. Mushquash, V. O'Brien, and J. Smith. 2018. 'Developing palliative care programs in Indigenous communities using participatory action research: a Canadian application of the public health approach to palliative care', *Ann Palliat Med*, 7: S52-S72.
- Kempster, S., and K. Perry. 2014. 'Critical realism and grounded theory.' in P. Edwards, J. O'Mahoney and S. Vincent (eds.), *Studying Organisations Using Critical Realism: A Practical Guide* (Oxford University Press: Oxford).
- Kessler, D., T. J. Peters, L. Lee, and S. Parr. 2005. 'Social class and access to specialist palliative care services', *Palliat Med*, 19: 105-10.
- Kitwood, T. 1993. 'Towards a Theory of Dementia Care - the Interpersonal Process', *Ageing and Society*, 13: 51-67.
- . 1997a. *The concept of personhood and its relevance for a new culture of dementia care* (London: Routledge).
- . 1997b. *Dementia reconsidered: The person comes first* (Open university press).
- . 1997c. 'The experience of dementia', *Ageing & mental health*, 1: 13-22.
- Kitwood, T., and K. Bredin. 1992. 'Towards a theory of dementia care: personhood and well-being', *Ageing Soc*, 12: 269-87.
- Kitwood, T. M. 1997d. *Dementia reconsidered: The person comes first* (Open university press: Buckingham).
- Kleinman, A., and J. Kleinman. 1991. 'Suffering and its professional transformation: toward an ethnography of interpersonal experience', *Cult Med Psychiatry*, 15: 275-301.
- Kmietowicz, Z. 2012. "Cameron launches challenge to end “national crisis” of poor dementia care." In.: British Medical Journal Publishing Group.
- Knox, H., M. Savage, and P. Harvey. 2006. 'Social networks and the study of relations: networks as method, metaphor and form', *Economy and society*, 35: 113-40.
- Kontos, P., K.-L. Miller, G. J. Mitchell, and J. Stirling-Twist. 2017. 'Presence redefined: The reciprocal nature of engagement between elder-clowns and persons with dementia', *Dementia*, 16: 46-66.
- Kontos, P., K. L. Miller, and A. P. Kontos. 2017. 'Relational citizenship: supporting embodied selfhood and relationality in dementia care', *Sociol Health Illn*, 39: 182-98.
- Kumar, S. 2013. 'Models of delivering palliative and end-of-life care in India', *Curr Opin Support Palliat Care*, 7: 216-22.
- Kumar, S. K. 2007. 'Kerala, India: a regional community-based palliative care model', *Journal of Pain & Symptom Management*, 33: 623-27.
- Künemund, H., and M. Rein. 1999. 'There is more to receiving than needing: theoretical arguments and empirical explorations of crowding in and crowding out', *Ageing and Society*, 19: 93-121.
- Kurzban, R., and M. R. Leary. 2001. 'Evolutionary origins of stigmatization: the functions of social exclusion', *Psychol Bull*, 127: 187-208.
- La Frenais, F., V. Vickerstaff, C. Cooper, G. Livingston, P. Stone, and E. L. Sampson. 2021. 'Factors influencing prescription and administration of analgesic medication: A longitudinal study of people with dementia living in care homes', *Int J Geriatr Psychiatry*, 36: 1354-61.
- Labonté, R., and G. Laverack. 2008. *Health promotion in action: from local to global empowerment* (Springer).
- Langa, K. M., M. E. Chernew, M. U. Kabeto, A. R. Herzog, M. B. Ofstedal, R. J. Willis, R. B. Wallace, L. M. Mucha, W. L. Straus, and A. M. Fendrick. 2001. 'National estimates of the quantity and cost of informal caregiving for the elderly with dementia', *J Gen Intern Med*, 16: 770-8.
- Lawani, A. 2021. 'Critical realism: what you should know and how to apply it', *Qualitative research journal*, 21: 320-33.

- Lee, R. P., C. Bamford, M. Poole, E. McLellan, C. Exley, and L. Robinson. 2017. 'End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice', *PLoS One*, 12: e0179355.
- Lefever, R. 2011. 'The living death of Alzheimer's', *Daily Mail*.
- Leonard, R., D. Horsfall, and K. Noonan. 2015a. 'Identifying changes in the support networks of end-of-life carers using social network analysis', *BMJ Supportive & Palliative Care*, 5: 153-59.
- Leonard, R., D. Horsfall, and K. Noonan. 2015b. 'Identifying changes in the support networks of end-of-life carers using social network analysis', *BMJ Support Palliat Care*, 5: 153-9.
- Lessard, É., I. Marcoux, S. Daneault, A.-C. Panaite, L. Jean, M. Talbot, D. Weil, G. Rouly, L. Sallnow, and A. Kellehear. 2023. 'How does community engagement evolve in different compassionate community contexts? A longitudinal comparative ethnographic research protocol', *Palliative Care and Social Practice*, 17: 26323524231168426.
- Levinas, E. 1999. *Alterity and transcendence* (Columbia University Press).
- Lewis, F., S. Karlsberg Schaffer, J. Sussex, P. O'Neill, and L. Cockcroft. 2014. 'The trajectory of dementia in the UK-making a difference', *Office of Health Economics Consulting Reports*.
- Lewis, J. M., M. DiGiacomo, T. Luckett, P. M. Davidson, and D. C. Currow. 2013. 'A social capital framework for palliative care: supporting health and well-being for people with life-limiting illness and their carers through social relations and networks', *J Pain Symptom Manage*, 45: 92-103.
- Lind Alliance, J. 2017. "Palliative and end of life care top 10 priorities." In.
- Liu, C.-J., S.-J. Huang, and S. S.-C. Wang. 2022. "Implementation of compassionate communities: the Taipei experience." In *Healthcare*, 177. Multidisciplinary Digital Publishing Institute.
- Lupton, D. 2013. 'Risk and emotion: towards an alternative theoretical perspective', *Health Risk & Society*, 15: 634-47.
- Macdonald, G. 2018a. 'Death in life or life in death? Dementia's ontological challenge', *Death Stud*, 42: 290-97.
- . 2018b. 'Death in life or life in death? Dementia's ontological challenge', *Death Studies*, 42: 290-97.
- Mackenzie, J. 2006. 'Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK', *Dementia*, 5: 233-47.
- Mackinnon, C. J. 2009. 'Applying feminist, multicultural, and social justice theory to diverse women who function as caregivers in end-of-life and palliative home care', *Palliative & supportive care*, 7: 501-12.
- Madden, R. 2017. *Being Ethnographic: A Guide to the Theory and Practice of Ethnography* (SAGE: London).
- Maddock, J., S. Parsons, G. Di Gessa, M. J. Green, E. J. Thompson, A. J. Stevenson, A. S. Kwong, E. McElroy, G. Santorelli, R. J. Silverwood, G. Captur, N. Chaturvedi, C. J. Steves, A. Steptoe, P. Patalay, G. B. Ploubidis, and S. V. Katikireddi. 2022. 'Inequalities in healthcare disruptions during the COVID-19 pandemic: evidence from 12 UK population-based longitudinal studies', *BMJ open*, 12: e064981.
- Mannix, K. 2017. *With the End in Mind: How to live and die well* (William Collins: London).
- . 2021. *Listen: How to Find the Words for Tender Conversations* (William Collins).
- Manthorpe, J., and K. Samsi. 2016. 'Person-centered dementia care: current perspectives', *Clin Interv Aging*, 11: 1733-40.
- Mark, M. M. 2008. 'Building a better evidence base for evaluation theory', *Fundamental issues in evaluation*: 111-34.
- Mark, M. M., G. T. Henry, and G. Julnes. 2000. *Evaluation: An integrated framework for understanding, guiding, and improving policies and programs* (Jossey-Bass).
- Markus, H. R., and S. Kitayama. 1991. 'Culture and the Self - Implications for Cognition, Emotion, and Motivation', *Psychological review*, 98: 224-53.
- Marzetti, E., R. Calvani, M. Tosato, M. Cesari, M. Di Bari, A. Cherubini, M. Broccatelli, G. Saveria, M. D'Elia, M. Pahor, R. Bernabei, F. Landi, and S. Consortium. 2017. 'Physical activity and exercise as countermeasures to physical frailty and sarcopenia', *Aging clinical and experimental research*, 29: 35-42.
- Mauss, M. 2000. *The gift: The form and reason for exchange in archaic societies* (WW Norton & Company).
- Maxwell, J. A. 2012. *Qualitative research design: An interactive approach* (Sage publications).
- McCormack, L., K. Tillock, and B. D. Walmsley. 2017. 'Holding on while letting go: trauma and growth on the pathway of dementia care in families', *Aging & mental health*, 21: 658-67.

- McLoughlin, K., S. McGiloway, R. Lloyd, M. O'Connor, J. Rhatigan, M. Shanahan, M. Richardson, and A. Keevey. 2016. 'Walls, wisdom, worries, and wishes: Engaging communities in discussion about death, dying, loss, and care using Cafe Conversation', *Progress in palliative care*, 24: 9-14.
- McLoughlin, K., S. McGiloway, R. Lloyd, J. Rhatigan, and M. Richardson. 2016. 'EAPC2016: Abstracts', *Palliative Medicine*, 30: NP1-NP401.
- Meier, E. A., J. V. Gallegos, L. P. Thomas, C. A. Depp, S. A. Irwin, and D. V. Jeste. 2016. 'Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue', *Am J Geriatr Psychiatry*, 24: 261-71.
- Meuser, T. M., and S. J. Marwit. 2001. 'A comprehensive, stage-sensitive model of grief in dementia caregiving', *Gerontologist*, 41: 658-70.
- Mills, J., J. P. Rosenberg, G. Bollig, and J. Haberecht. 2020. "Last Aid and Public Health Palliative Care: Towards the development of personal skills and strengthened community action." In: Taylor & Francis.
- Mills, J., J. P. Rosenberg, and F. McInerney. 2015. 'Building community capacity for end of life: an investigation of community capacity and its implications for health-promoting palliative care in the Australian Capital Territory', *Critical Public Health*, 25: 218-30.
- Mills, S., and J. Mills. 2016. 'Future directions for community engagement as a public health approach to palliative care in Australia', *Progress in palliative care*, 24: 15-18.
- Mills, S., J. Rosenberg, and J. Mills. 2015. 'PA13 The arts and end of life conversations: an innovative approach to health promotion in palliative care', *BMJ supportive & palliative care*, 5 Suppl 1: A23.
- Mische, A. 2003. M. Diani and D. McAdam (eds.), *Social movements and networks: Relational approaches to collective action* (Oxford University Press: Oxford).
- Mische, A., and H. White. 1998. 'Between conversation and situation: Public switching dynamics across network domains', *Social research*, 65: 695-724.
- Mitchell, S. L., D. K. Kiely, and M. B. Hamel. 2004. 'Dying with advanced dementia in the nursing home', *Arch Intern Med*, 164: 321-6.
- Moher, D., A. Liberati, J. Tetzlaff, D. G. Altman, and P. Group. 2009. 'Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement', *PLoS med*, 6: e1000097.
- Moore, K. J., and S. Crawley. 2020. 'The challenge of providing a timely and holistic approach to support people with dementia and their caregivers', *International Psychogeriatrics*, 32: 543-46.
- Morin, L., D. L. Vetrano, D. Rizzuto, A. Calderon-Larranaga, J. Fastbom, and K. Johnell. 2017. 'Choosing Wisely? Measuring the Burden of Medications in Older Adults near the End of Life: Nationwide, Longitudinal Cohort Study', *Am J Med*, 130: 927-36 e9.
- Moss, R. J., and J. La Puma. 1991. 'The ethics of pressure sore prevention and treatment in the elderly: a practical approach', *J Am Geriatr Soc*, 39: 905-8.
- Muangpaisan, W., R. Praditsuwat, J. Assanasen, V. Srinonprasert, P. Assantachai, S. Intalapaporn, W. Chatthanawaree, P. Dajpratham, V. Kuptniratsaikul, and D. Pisansalakij. 2010. 'Caregiver burden and needs of dementia caregivers in Thailand: a cross-sectional study', *J Med Assoc Thai*, 93: 601-7.
- Murray, S. A., M. Kendall, K. Boyd, and A. Sheikh. 2005. 'Illness trajectories and palliative care', *BMJ*, 330: 1007-11.
- Murray, S. A., and B. Mason. 2010. 'Palliative Care Looking Towards 2020', *Australasian Medical Journal*, 3: 318-24.
- Nabokov, V. 1951. *Speak, Memory* (Gollancz, Victor: London).
- Nguyen, T., and X. Li. 2020. 'Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature', *Dementia (London)*, 19: 148-81.
- NICE. 2006. "Dementia: supporting people with dementia and their carers in health and social care." In. London: National Institute for Health and Care Excellence.
- Nieder, A. 2016. 'Representing Something Out of Nothing: The Dawning of Zero', *Trends Cogn Sci*, 20: 830-42.
- Nietzsche, F. 1989. *Beyond good & evil: prelude to a philosophy of the future* (Vintage).
- Nolan, M., J. Brown, S. Davies, J. Nolan, and J. Keady. 2006. 'The Senses Framework: improving care for older people through a relationship-centred approach. Getting Research into Practice (GRiP) Report No 2'.
- Noonan, K. 2018. 'Death literacy-developing a tool to measure the social impact of public health initiatives', *Ann Palliat Med*, 7: AB007.

- Noonan, K., D. Horsfall, R. Leonard, and J. Rosenberg. 2016. 'Developing death literacy', *Progress in palliative care*, 24: 31-35.
- Noyes, B. B., R. D. Hill, B. L. Hicken, M. Luptak, R. Rupper, N. K. Dailey, and B. D. Bair. 2010. 'The role of grief in dementia caregiving', *Am J Alzheimers Dis Other Demen*, 25: 9-17.
- O'Donohue, J. 2003a. 'To Help a Person Die: The Most Beautiful Gift.' in, *Divine Beauty: The Invisible Embrace* (Bantam Press: London).
- . 2003b. 'When Departure Becomes Transforming Presence.' in, *Divine Beauty: The Invisible Embrace* (Bantam Press: London).
- . 2003c. 'The White Shadow: Beauty and Death.' in, *Divine Beauty: The invisible embrace* (Bantam Press: London).
- . 2010. 'Divine beauty: The invisible embrace.' in (Random House).
- O'Mara-Eves, A., G. Brunton, G. McDaid, S. Oliver, J. Kavanagh, F. Jamal, T. Matosevic, A. Harden, and J. Thomas. 2013. 'Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis', *Public Health Research*, 1.
- Oakley, B. A. 2013. 'Concepts and implications of altruism bias and pathological altruism', *Proc Natl Acad Sci U S A*, 110 Suppl 2: 10408-15.
- Oliver, C. 2012. 'Critical Realist Grounded Theory: A New Approach for Social Work Research', *British journal of social work*, 42: 371-87.
- ONS. 2020. "Dementia and Alzheimer's disease deaths including comorbidities, England and Wales: 2019 registrations." In, edited by O. o. N. Statistics.
- . 2023. "Monthly mortality analysis, England and Wales: December 2022." In, edited by O. f. N. Statistics. online: UK Government.
- Organization, W. H. 2012. *Dementia: a public health priority* (World Health Organization).
- Paoletti, I. 2002. 'Caring for older people: a gendered practice', *Discourse & Society*, 13: 805-17.
- Park, M., E. Leahy, and R. J. Funk. 2023. 'Papers and patents are becoming less disruptive over time', *Nature*, 613: 138-44.
- Pask, S., C. Pinto, K. Bristowe, L. van Vliet, C. Nicholson, C. J. Evans, R. George, K. Bailey, J. M. Davies, and P. Guo. 2018. 'A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals', *Palliat Med*, 32: 1078-90.
- Pawson, R. 2005. 'Evidence-based policy: a realist perspective.' in, *Making realism work* (Routledge).
- . 2013a. *The Science of Evaluation: Realist Manifesto* (SAGE: London).
- . 2013b. *The Science of Evaluation: A Realist Manifesto* (SAGE Publications Ltd: London).
- Pawson, R., T. Greenhalgh, G. Harvey, and K. Walshe. 2005. 'Realist review--a new method of systematic review designed for complex policy interventions', *J Health Serv Res Policy*, 10 Suppl 1: 21-34.
- Pawson, R., and N. Tilley. 1997. *Realistic Evaluation* (Sage: London ; Thousand Oaks, Calif).
- Pawson, R. G., Trisha; Harvey, Gill; Walshe, Kieran. 2004. "Realist Synthesis: An introduction." In: University of Man.
- Pawson, R. T., Nick. 1997. *Realistic Evaluation* (SAGE: London).
- Payne, M. 2010. 'Inequalities, end-of-life care and social work', *Progress in palliative care*, 18: 221-27.
- Peisah, C., J. Weaver, L. Wong, and J. A. Strukovski. 2014. 'Silent and suffering: a pilot study exploring gaps between theory and practice in pain management for people with severe dementia in residential aged care facilities', *Clinical interventions in aging*, 9: 1767-74.
- Pesut, B., C. A. Robinson, and J. L. Bottorff. 2014. 'Among neighbors: an ethnographic account of responsibilities in rural palliative care', *Palliative & supportive care*, 12: 127-38.
- Petersen, E. E., N. L. Davis, D. Goodman, S. Cox, C. Syverson, K. Seed, C. Shapiro-Mendoza, W. M. Callaghan, and W. Barfield. 2019. 'Racial/Ethnic Disparities in Pregnancy-Related Deaths - United States, 2007-2016', *MMWR Morb Mortal Wkly Rep*, 68: 762-65.
- Pickett, J., C. Bird, C. Ballard, S. Banerjee, C. Brayne, K. Cowan, L. Clare, A. Comas-Herrera, L. Corner, and S. Daley. 2018. 'A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025', *International Journal of Geriatric Psychiatry*, 33: 900-06.
- Pickett, J., and C. Brayne. 2019. 'The scale and profile of global dementia research funding', *Lancet*, 394: 1888-89.
- Pink, S. 2015a. *Doing sensory ethnography* (SAGE: London).
- . 2015b. 'Principles for sensory ethnography: perception, place, knowing, memory and imagination.' in, *Doing sensory ethnography* (SAGE: London).

- Portes, A. 1998. 'Social capital: Its origins and applications in modern sociology', *Annual review of sociology*, 24: 1-24.
- Poscia, A., J. Stojanovic, D. I. La Milia, M. Duplaga, M. Grysztar, U. Moscato, G. Onder, A. Collamati, W. Ricciardi, and N. Magnavita. 2018. 'Interventions targeting loneliness and social isolation among the older people: An update systematic review', *Experimental gerontology*, 102: 133-44.
- Post, S. G. 1995. 'Alzheimer-Disease and the 'Then Self'', *Kennedy Institute of Ethics Journal*, 5: 307-21.
- Psathas, G. 2005. 'The Ideal Type in Weber and Schutz.' in M. Endress, G. Psathas and H. Nasu (eds.), *Explorations of the Life-World: Continuing Dialogues with Alfred Schütz* (Springer: Netherlands).
- Pyke, K. D., and V. L. Bengtson. 1996. 'Caring more or less: Individualistic and collectivist systems of family eldercare', *Journal of Marriage and the Family*, 58: 379-92.
- Quintiens, B., L. D'Eer, L. Deliens, L. Van den Block, K. Chambaere, L. De Donder, J. Cohen, and T. Smets. 2022. 'Area-Based Compassionate Communities: A systematic integrative review of existing initiatives worldwide', *Palliat Med*, 36: 422-42.
- Rappaport, J. 1987. 'Terms of empowerment/exemplars of prevention: toward a theory for community psychology', *Am J Community Psychol*, 15: 121-48.
- Read, S., and S. MacBride-Stewart. 2018. 'The 'good death'and reduced capacity: a literature review', *Mortality*, 23: 381-95.
- Rees, C., and M. Gatenby. 2014. 'Critical Realism and Ethnography.' in P. Edwards, J. O'Mahoney and S. Vincent (eds.), *Studying Organisations Using Critical Realism* (Oxford University Press: Oxford).
- Reeves, S., A. Kuper, and B. D. Hodges. 2008. 'Qualitative research methodologies: ethnography', *Bmj*, 337: a1020.
- Relman, A. S. 1980. 'The new medical-industrial complex', *N Engl J Med*, 303: 963-70.
- Reuler, J. B., and T. G. Cooney. 1981. 'The pressure sore: pathophysiology and principles of management', *Ann Intern Med*, 94: 661-6.
- Riles, A. 2000. *The network inside out* (University of Michigan Press).
- Rinpoche, S., P. Gaffney, and A. Harvey. 1992. *The Tibetan book of living and dying* (Rider London).
- Robins, G., P. Pattison, Y. Kalish, and D. Lusher. 2007. 'An introduction to exponential random graph (p*) models for social networks', *Social networks*, 29: 173-91.
- Robinson, L., D. Hutchings, L. Corner, T. Finch, J. Hughes, K. Brittain, and J. Bond. 2007. 'Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia', *Health Risk & Society*, 9: 389-406.
- Rose, H., and E. Bruce. 1995. 'Mutual care but differential esteem: caring between older couples', *Connecting gender and ageing: A sociological approach*: 114-28.
- Rosenberg, J. 2011. 'Whose business is dying?: Death, the home and palliative care', *Cultural Studies Review*, 17: 15-30.
- Rosenberg, J. P., D. Horsfall, R. Leonard, and K. Noonan. 2018. 'Informal care networks' views of palliative care services: Help or hindrance?', *Death Stud*, 42: 362-70.
- Rosenberg, J. P., J. Mills, and B. Rumbold. 2016. 'Putting the 'public' into public health: community engagement in palliative and end of life care', *Progress in palliative care*, 24: 1-3.
- Rotman, B. 1987. *Signifying nothing: The semiotics of zero* (Stanford University Press: California).
- Rovelli, C. 2019a. *The Order Of Time* (Penguin Random House UK: UK).
- . 2019b. 'What Emerges from a Particularity.' in *The Order of Time* (Penguin Random House UK: UK).
- Rumbold, B., and S. Aoun. 2014. 'Bereavement and palliative care: A public health perspective', *Progress in palliative care*, 22: 131-35.
- Ryan, T., C. Gardiner, G. Bellamy, M. Gott, and C. Ingleton. 2012. 'Barriers and facilitators to the receipt of palliative care for people with dementia: the views of medical and nursing staff', *Palliat Med*, 26: 879-86.
- Sahlins, M. 2011. 'What kinship is (part one)', *Journal of the Royal Anthropological Institute*, 17: 2-19.
- Saldaña, J. 2021. 'Provisional coding.' in *The coding manual for qualitative researchers* (SAGE: London).
- Sallnow, L. 2016. 'EAPC2016: Abstracts', *Palliative Medicine*, 30: NP1-NP401.
- . 2017. 'Collective social capital: A study of new public health and end-of-life care', University of Edinburgh.
- Sallnow, L., and S. Paul. 2014. 'Understanding community engagement in end-of-life care: developing conceptual clarity', *Critical Public Health*, 25: 231-38.

- Sallnow, L., and S. Paul. 2015. 'Understanding community engagement in end-of-life care: developing conceptual clarity', *Critical Public Health*, 25: 231-38.
- Sallnow, L., H. Richardson, S. Murray, and A. Kellehear. 2018. '10th World Research Congress of the European Association for Palliative Care (EAPC)', *Palliat Med*, 32: 3-330.
- Sallnow, L., H. Richardson, S. A. Murray, and A. Kellehear. 2016a. 'The impact of a new public health approach to end-of-life care: A systematic review', *Palliat Med*, 30: 200-11.
- Sallnow, L., H. Richardson, S. A. Murray, and A. Kellehear. 2016b. 'The impact of a new public health approach to end-of-life care: A systematic review', *Palliative medicine*, 30: 200-11.
- Sallnow, L., R. Smith, S. H. Ahmedzai, A. Bhadelia, C. Chamberlain, Y. Cong, B. Doble, L. Dullie, R. Durie, E. A. Finkelstein, S. Guglani, M. Hodson, B. S. Husebo, A. Kellehear, C. Kitzinger, F. M. Knaul, S. A. Murray, J. Neuberger, S. O'Mahony, M. R. Rajagopal, S. Russell, E. Sase, K. E. Sleeman, S. Solomon, R. Taylor, M. Tutu van Furth, K. Wyatt, and D. Lancet Commission on the Value of. 2022. 'Report of the Lancet Commission on the Value of Death: bringing death back into life', *Lancet*, 399: 837-84.
- Sallnow, L., C. Tishelman, O. Lindqvist, H. Richardson, and J. Cohen. 2016. 'Research in public health and end-of-life care - Building on the past and developing the new', *Progress in palliative care*, 24: 25-30.
- Sampson, E. L. 2010. 'Palliative care for people with dementia', *Br Med Bull*, 96: 159-74.
- Sampson, E. L., J. E. Anderson, B. Candy, N. Davies, C. Ellis-Smith, A. Gola, R. Harding, C. Kenten, N. Kupeli, and S. Mead. 2020. "Empowering better End-of-Life dementia care (EMBED-Care): a mixed methods protocol to achieve integrated person-centred care across settings." In, 820-32. Wiley Online Library.
- Sampson, E. L., and A. Burns. 2013. "Planning a personalised future with dementia: 'the misleading simplicity of advance directives'." In: Sage Publications Sage UK: London, England.
- Samson, Z. B., M. Parker, C. Dye, and K. Hepburn. 2016. 'Experiences and Learning Needs of African American Family Dementia Caregivers', *Am J Alzheimers Dis Other Demen*, 31: 492-501.
- Sanders, S., C. H. Ott, S. T. Kelber, and P. Noonan. 2008. 'The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia', *Death Stud*, 32: 495-523.
- Saunders, C. 1996a. 'A personal therapeutic journey', *BMJ*, 313: 1599-601.
- . 1996b. 'A personal therapeutic journey', *BMJ (Clinical research ed.)*, 313: 1599-601.
- Sawyer, J. 2018. 'Why do we seek to quantify the unquantifiable?', *European Journal of Palliative Care*, 25: 6-8.
- Sawyer, J. M. 2022. 'Understanding dying as a focal point for defining an integrative approach to health and social care', *Journal of Ayurveda and Integrative Medicine*: 100543.
- Sawyer, J. M., R. Asgr, F. N. Todd Fordham, and J. D. H. Porter. 2018. 'A public health approach to palliative care in the response to drug resistant TB: an ethnographic study in Bengaluru, India', *BMC Palliat Care*, 17: 120.
- Sawyer, J. M., P. Higgs, J. D. H. Porter, and E. L. Sampson. 2021. 'New public health approaches to palliative care, a brave new horizon or an impractical ideal? An Integrative literature review with thematic synthesis', *Palliat Care Soc Pract*, 15: 26323524211032984.
- Sawyer, J. M., L. Sallnow, N. Kupeli, P. Stone, and E. L. Sampson. 2019. 'Social networks, social capital and end-of-life care for people with dementia: a realist review', *BMJ open*, 9: e030703.
- Sayer, A. 2000. *Realism and Social Science* (SAGE: London).
- Schulz, R., and P. R. Sherwood. 2008. 'Physical and mental health effects of family caregiving', *Am J Nurs*, 108: 23-7; quiz 27.
- Seife, C. 2000. *Zero: The biography of a dangerous idea* (Penguin).
- Sellevoid, G. S., V. Egede-Nissen, R. Jakobsen, and V. Sorlie. 2013. 'Quality care for persons experiencing dementia: the significance of relational ethics', *Nurs Ethics*, 20: 263-72.
- Shannon, K., K. Bail, and S. Neville. 2019. 'Dementia-friendly community initiatives: An integrative review', *J Clin Nurs*, 28: 2035-45.
- Sharmer, O., and P. Senge. 2016. 'Presencing.' in, *Theory U: The Social Technology of Presencing* (Berrett-Koehler).
- Shepherd, H., G. Livingston, J. Chan, and A. Sommerlad. 2019. 'Hospitalisation rates and predictors in people with dementia: a systematic review and meta-analysis', *BMC Med*, 17: 130.

- Sims-Schouten, W., and S. Riley. 2014. 'Employing a form of critical realist discourse analysis for identity research: An example from women's talk of motherhood, childcare and employment.' in, *Studying organizations using critical realism: a practical guide* (Oxford University Press).
- Sleeman, K. E., M. de Brito, S. Etkind, K. Nkhoma, P. Guo, I. J. Higginson, B. Gomes, and R. Harding. 2019. 'The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions', *Lancet Glob Health*, 7: e883-e92.
- Sleeman, K. E., B. Gomes, and I. J. Higginson. 2012. 'Research into end-of-life cancer care-investment is needed', *Lancet*, 379: 519-19.
- Smebye, K. L., M. Kirkevold, and K. Engedal. 2015. 'Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study', *BMC health services research*, 16: 1-12.
- Smith, C., and T. Elger. 2014. 'Critical Realism and Interviewing Subjects.' in P. Edwards, S. Vincent and J. O'Mahoney (eds.), *Using critical realism to study organisations* (Oxford University Press: Oxford).
- Smith, R. 2000. "A good death: an important aim for health services and for us all." In.: British Medical Journal Publishing Group.
- Sorabji, R. 2006. *Self: Ancient and Modern Insights about Individuality, Life and Death* (Oxford University Press: New York).
- Stajduhar, K., L. Funk, E. Jakobsson, and J. Ohlen. 2010. 'A critical analysis of health promotion and 'empowerment' in the context of palliative family care-giving', *Nurs Inq*, 17: 221-30.
- Stajduhar, K., L. Funk, E. Jakobsson, and J. Öhlén. 2010. 'A critical analysis of health promotion and 'empowerment' in the context of palliative family care-giving', *Nursing Inquiry*, 17: 221-30.
- Steger, M. B. 2008. *The rise of the global imaginary: Political ideologies from the French revolution to the global war on terror* (OUP Oxford).
- Stevenson, M., B. Savage, and B. J. Taylor. 2019. 'Perception and Communication of Risk in Decision Making by Persons with Dementia', *Dementia (London)*, 18: 1108-27.
- Stjernswärd, J. 2007. 'Palliative care: the public health strategy', *Journal of public health policy*, 28: 42-55.
- Stjernswärd, J., K. M. Foley, and F. D. Ferris. 2007. 'The public health strategy for palliative care', *Journal of pain and symptom management*, 33: 486-93.
- Swedberg, R. 2018. 'How to use Max Weber's ideal type in sociological analysis', *Journal of Classical Sociology*, 18: 181-96.
- Sweeting, H., and M. Gilhooly. 1997. 'Dementia and the phenomenon of social death', *Sociology of Health & Illness*, 19: 93-117.
- Sweeting, H. N., and M. L. Gilhooly. 1990. 'Anticipatory grief: a review', *Soc Sci Med*, 30: 1073-80.
- Swinton, J. 2021. 'Re-imagining personhood: Dementia, culture and citizenship', *Journal of Religion, Spirituality & Aging*, 33: 172-81.
- Taylor, C. 2007. 'The Great Disembedding.' in, *A Secular Age* (Harvard University Press).
- Thomas, C., and C. Milligan. 2018. 'Dementia, disability rights and disablism: understanding the social position of people living with dementia', *Disability & Society*, 33: 115-31.
- Thuné-Boyle, I. C., E. L. Sampson, L. Jones, M. King, D. R. Lee, and M. R. Blanchard. 2010. 'Challenges to improving end of life care of people with advanced dementia in the UK', *Dementia*, 9: 259-84.
- Tolhurst, E., M. Carey, B. Weicht, and P. Kingston. 2019. 'Is living well with dementia a credible aspiration for spousal carers?', *Health Sociology Review*, 28: 54-68.
- Tong, A., P. Sainsbury, and J. Craig. 2007. 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups', *Int J Qual Health Care*, 19: 349-57.
- Tönnies, F. 1957. *Community and Society* (Harper & Row: New York).
- Toribio Vazquez, J. L. 2021. 'Nietzsche's shadow: On the origin and development of the term nihilism', *Philosophy & Social Criticism*, 47: 1199-212.
- Triandis, H. C. 1993. 'Collectivism and individualism as cultural syndromes', *Cross-cultural research*, 27: 155-80.
- Tziraki, C., C. Grimes, F. Ventura, R. O'Caomh, S. Santana, V. Zavagli, S. Varani, D. Tramontano, J. Apóstolo, and B. Geurden. 2020. 'Rethinking palliative care in a public health context: addressing the needs of persons with non-communicable chronic diseases', *Primary health care research & development*, 21.

- Umberson, D., J. S. Olson, R. Crosnoe, H. Liu, T. Pudrovska, and R. Donnelly. 2017. 'Death of family members as an overlooked source of racial disadvantage in the United States', *Proceedings of the National Academy of Sciences of the United States of America*, 114: 915-20.
- UN. 2019. "World Population Prospects 2019: Highlights." In.: Department of Economic and Social Affairs, Population Division.
- van der Steen, J. T., and C. Goodman. 2015. "What research we no longer need in neurodegenerative disease at the end of life: the case of research in dementia." In, 189-92. Sage Publications Sage UK: London, England.
- Van Oorschot, W., and W. Arts. 2005. 'The social capital of European welfare states: the crowding out hypothesis revisited', *Journal of European social policy*, 15: 5-26.
- vanderPloeg, W. 2001. 'Health promotion in palliative care: An occupational perspective', *Australian Occupational Therapy Journal*, 48: 45-48.
- Vanderstichelen, S., S. Dury, S. De Gieter, F. Van Droogenbroeck, D. De Moortel, L. Van Hove, J. Rodeyns, N. Aernouts, H. Bakelants, J. Cohen, K. Chambaere, B. Spruyt, G. Zohar, L. Deliens, and L. De Donder. 2022. 'Researching Compassionate Communities From an Interdisciplinary Perspective: The Case of the Compassionate Communities Center of Expertise', *Gerontologist*, 62: 1392-401.
- Vernooij-Dassen, M., E. Moniz-Cook, and Y. H. Jeon. 2018. 'Social health in dementia care: harnessing an applied research agenda', *Int Psychogeriatr*, 30: 775-78.
- Vijay, D., S. Whitelaw, and D. Clark. 2020. 'Logic Conflicts in Community-Based Palliative Care', *Progress in Palliative Care*: 1-7.
- Vincent, S., and J. O'Mahoney. 2018. 'Critical realism and qualitative research: An introductory overview.' in, *The sage handbook of qualitative business and management research methods*.
- Visser, C., G. Hadley, and B. Wee. 2015. 'Reality of evidence-based practice in palliative care', *Cancer Biol Med*, 12: 193-200.
- Waite, L. 2012. 'Dementia: an international crisis?', *Perspectives in public health*, 132: 154.
- Walker, K. H. 1990. 'The Origins of the History and Physical Examination.' in H. Walker, W. Hall and J. Hurst (eds.), *Clinical Methods: The History, Physical and Laboratory Examinations. 3rd edition* (Butterworths).
- Walker, M. U. 2007. *Moral Understandings: A Feminist Study in Ethics* (Oxford University Press).
- Walmsley, B. D., and L. McCormack. 2021. 'Dementia families: Relinquishing home care to aged care services: Guilt, traumatic loss and growth', *Dementia (London)*, 20: 1814-31.
- Walsh, K., T. Scharf, and N. Keating. 2017. 'Social exclusion of older persons: a scoping review and conceptual framework', *Eur J Ageing*, 14: 81-98.
- Walsh, S. C., E. Murphy, D. Devane, E. L. Sampson, S. Connolly, P. Carney, and E. O'Shea. 2021. 'Palliative care interventions in advanced dementia', *Cochrane Database Syst Rev*, 9: CD011513.
- Walshe, C., C. Todd, A. Caress, and C. Chew-Graham. 2009. 'Patterns of access to community palliative care services: a literature review', *J Pain Symptom Manage*, 37: 884-912.
- Walter, T. 1996. 'Facing death without tradition', *Contemporary issues in the sociology of death, dying and disposal*: 193-204.
- Walter, T. 2007. 'Modern Grief, Postmodern Grief2', *International Review of Sociology-Revue Internationale De Sociologie*, 17: 123-34.
- Walter, T. 2017. 'Pervasive death.' in, *What death means now* (Bristol University Press).
- Wang, H., T. Li, P. Barbarino, S. Gauthier, H. Brodaty, J. L. Molinuevo, H. Xie, Y. Sun, E. Yu, Y. Tang, W. Weidner, and X. Yu. 2020. 'Dementia care during COVID-19', *Lancet*, 395: 1190-91.
- Ward, R., K. Rummery, E. Odzakovic, K. Manji, A. Kullberg, J. Keady, A. Clark, and S. Campbell. 2022. 'Beyond the shrinking world: dementia, localisation and neighbourhood', *Ageing & Society*, 42: 2892-913.
- Wasson, K., and R. J. D. George. 2001. 'Non-cancer palliative care: the ethical argument in non-cancer palliative care.' in I. Higginson and J. Addington-Hall (eds.), *Palliative Care for Non-Cancer Patients* (Oxford University Press: Oxford).
- Wastesson, J. W., L. Morin, E. C. Tan, and K. Johnell. 2018. 'An update on the clinical consequences of polypharmacy in older adults: a narrative review', *Expert opinion on drug safety*, 17: 1185-96.
- Webber, M. 1964. 'Urban place and the nonplace realm.' in, *Explorations into urban structure* (University of Pennsylvania Press: Philadelphia).

- Weber, M. 1963. 'Objectivity in social science and social policy.' in M. Natanson (ed.), *Philosophy of the Social Sciences* (Random House: New York).
- Welsh, T. J. 2019. 'Multimorbidity in people living with dementia', *Case Rep Womens Health*, 23: e00125.
- Wharton, T. C., and B. K. Ford. 2014. 'What is known about dementia care recipient violence and aggression against caregivers?', *Journal of Gerontological Social Work*, 57: 460-77.
- Whitelaw, S., and D. Clark. 2019. 'Palliative care and public health: an asymmetrical relationship?', *Palliat Care*, 12: 1178224218819745.
- Whittemore, R., and K. Knafl. 2005. 'The integrative review: updated methodology', *J Adv Nurs*, 52: 546-53.
- WHO. 2012. *Dementia: a public health priority* (World Health Organization).
- . 2018. "Integrating palliative care and symptom relief into primary care: a WHO guide for planners, implementers and managers." In. Geneva: World Health Organisation.
- . 2023. 'Our values, our DNA', Accessed 05.04.23. <https://www.who.int/about/who-we-are/our-values>.
- WHO, T. 1986. 'Ottawa charter for health promotion', *Health Promotion*, 1: iii-v.
- Wilks, S. E., K. G. Little, H. R. Gough, and W. J. Spurlock. 2011. 'Alzheimer's aggression: influences on caregiver coping and resilience', *J Gerontol Soc Work*, 54: 260-75.
- Williams, A. M., J. A. Eby, V. A. Crooks, K. Stajduhar, M. Giesbrecht, M. Vuksan, S. R. Cohen, K. Brazil, and D. Allan. 2011. 'Canada's Compassionate Care Benefit: is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care?', *BMC public health*, 11: 335.
- Wilson, E., G. Caswell, N. Turner, and K. Pollock. 2022. 'Talking about death and dying: Findings from deliberative discussion groups with members of the public', *Mortality*: 1-17.
- Wimo, A., K. Seeher, R. Cataldi, E. Cyhlarova, J. L. Dielemann, O. Frisell, M. Guerchet, L. Jonsson, A. K. Malaha, E. Nichols, P. Pedroza, M. Prince, M. Knapp, and T. Dua. 2023. 'The worldwide costs of dementia in 2019', *Alzheimers Dement*, 19: 2865-73.
- Wise, J. 2013. 'Polypharmacy: a necessary evil', *BMJ*, 347: f7033.
- Wong, G., G. Westhorp, A. Manzano, J. Greenhalgh, J. Jagosh, and T. Greenhalgh. 2016. 'RAMESES II reporting standards for realist evaluations', *BMC Med*, 14: 96.
- Woolcock, M., and D. Narayan. 2000. 'Social capital: Implications for development theory, research, and policy', *World Bank Research Observer*, 15: 225-49.
- Xiang, X., P. H. L. Lai, L. Bao, Y. Sun, J. Chen, R. E. Dunkle, and D. Maust. 2021. 'Dual Trajectories of Social Isolation and Dementia in Older Adults: A Population-Based Longitudinal Study', *J Aging Health*, 33: 63-74.

Appendices

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Appendix One: Extracts from original funding application

Scientific abstract

Please provide an overview of the aims, methods and expected outcomes of the research.

(249/250 words)

Aims

1. To develop an understanding of how compassionate communities can improve outcomes for people affected by dementia at the end-of-life, and the challenges they face in doing so.
2. To understand the impact of community instigated care at the end-of-life on; (i) identity and agency of a person with dementia; (ii) the care-giving process, as experienced by those involved; (iii) the promotion of self-sufficiency and community development.

Methods

The impact of communities will be subject to realist evaluation methods to understand how change is generated in relation to different configurations of context, mechanism and outcomes. Phase 1 will use third generation social network analysis to identify changes in support networks at the end-of-life. Phase 2 will use ethnographic methods to provide an in-depth explanation of the patterns observed from phase 1. Phase 3 will use realist interviews with key participants to refine the programme theory.

Expected outcomes

This fellowship will produce an innovative, evidenced based model of care, centred on the needs of people affected by dementia, that better co-ordinates health and social care together with community based support. This model will (i) provide a template for robustly developed, theory driven public health interventions; (ii) provide a framework for understanding the social context to 'dementia friends' and 'dementia friendly communities' initiatives, knowledge vital to their success in bringing desired change (iii) promote public dialogue on death and dying in dementia thus helping reduce stigma; (iv) advance scientific understanding in a research nascent area, opening new avenues for research.

Lay abstract

Please provide an overview of the aims, methods and expected outcomes of the research for a lay audience. (250/250 words)

The journey through to the end-of-life can be particularly difficult for people affected by dementia. Despite this, people spend a lot of this time without professional help, relying on their own resources, for example family, friends and other community members. This can be isolating and overwhelming, leading to considerable distress. It may also affect the physical health of those around them.

I want to find out how communities support people affected by dementia towards the end-of-life and the challenges they face in doing this. 'Compassionate Communities' have been shown to improve end-of-life care for people with cancer but there is no research on this for people with dementia. I want to see how this approach could improve end-of-life care for people with dementia.

To do this, I need to understand how communities support people affected by dementia at the end-of-life. Where this is not happening, I want to understand why. I will investigate how social networks change when someone with dementia is dying. I will observe caregiving relationships in a variety of settings. Lastly I will interview people caring for someone with dementia to listen to their experiences.

I will learn how communities currently contribute to end-of-life care for people with dementia and how this can be maximised. This will help to; (i) design interventions that support communities and improve access to end-of-life care; (ii) make end-of-life policy recommendations for people affected by dementia (iii) promote community caregiving, reducing stigma and social isolation (iv) motivate further study in this area.

Lay case for support: Understanding how community networks support end-of-life care for people affected by dementia

1. Introduction to the research area and my project

The Alzheimer's Society, in conjunction with people affected by dementia, have prioritised research that develops new ways of caring for people. These should work alongside existing community-based support systems. This research project aims to support this by understanding how 'compassionate communities' can help people affected by dementia at the end-of-life.

As dementia progresses, social relationships may tail off whilst the practical and emotional challenges of care increase. In the absence of professional support, families may sometimes feel socially isolated and overwhelmed by caring. This can impact on their physical and psychological health. The Alzheimer's Society has tried to address this through the 'dementia friends' initiative and the 'dementia friendly communities' programme. How these programmes may support care at the end-of-life is unknown.

Some people have looked to palliative care professionals to help at the end-of-life. Palliative care is a speciality of medicine that looks after terminally ill people, often in hospices. Most people who have experienced palliative care find it helpful. However, many people with dementia are not referred for their services whilst expert hospice care provision is insufficient to meet need.

To help improve this situation a 'public health approach to palliative care' has been proposed. Public health is about protecting people from threats to their health before they occur. In palliative care, this means not waiting until someone dies before thinking about grief and bereavement. In dementia, it means not waiting until someone can no longer look after themselves before thinking about supporting their care needs. At the end-of-life, this means not waiting until the person is dying before thinking about how, where and who will look after them.

The main methods of a public health approach include: (i) public education, helping people understand what dementia is and how it can affect the whole family; (ii) community development - asking what people can do for one another to provide support; (iii) participatory action - getting those who know the person best to help plan for the future.

Public health programmes in palliative care work under the banner of 'compassionate communities'. Compassionate communities are examples of how naturally occurring supportive networks can be combined with the wealth of community resource found in neighbourhoods, workplaces and other institutions in order to reduce social isolation and

improve access to care.

At the moment, most of the research done on compassionate communities relates to people with cancer. Dementia is a very different illness and it is therefore important to understand how this model can work for those affected by dementia. This is the purpose of my research project.

What do I hope to find out and why?

In order to see how this approach works for people affected by dementia I first need to better understand how communities, made up of non-professionals, work to provide care at the end-of-life. Specifically I want to know how naturally occurring support networks impact on; (i) upholding the identity of a person with dementia, (ii) caregivers experience in providing care (iii) the promotion of self-sufficiency and community development. The research will also seek to better understand the social situations that care happens within and the challenges people face.

The purpose is to create a dementia specific template which can be used to design interventions that assist in the growth of compassionate communities. My idea is the product of a large review of the scientific literature and also discussion with members of the Alzheimer's Society research network who have guided and shaped the proposal.

I believe this work will encourage conversation about death and dying for people with dementia at a community level and also a health policy level. The research will build theory to provide the foundation for the development of social interventions that alter health and social care policy, ultimately improving care for people with dementia at the end-of-life.

Why should the Alzheimer's Society invest in this project? Does it offer value for money?

Compassion is a vital part of the ethical response to someone in need of care. When thinking about new ways to care for people with dementia, better understanding how communities gather collectively around this idea is vitally important from a moral and ethical point of view.

In terms of value for money, a public health approach is about identifying problems before they arise. There are proven cost benefits to this. For example, eating healthily is cheaper and has wider benefits than treating a heart attack. Likewise, empowering communities to support each other with social problems is likely to be cheaper and more effective than paying a doctor to treat these same problems with limited resources.

2. Methods and techniques

Step 1: Investigating how social networks change when someone is dying

I will invite up to 10 people who have been directly involved in the care of someone with dementia to identify members of the main care group they worked within. This may for example include; family, friends or neighbours. Once identified, they will be invited to take part in a group interview. It is anticipated there will therefore be up to 10 separate group interviews containing between 5 and 15 participants. These numbers are based on existing research using similar techniques.

During the group interview, carers will be asked to map their social networks on paper at the point at which their journey started, and again at a time when the person with dementia died. This will be a group exercise so that people can discuss and remind each other of relationships as they are drawn. The entire interview will be audio recorded. This is important as the conversation becomes information which will be used to complement the network maps.

Network maps will be uploaded into computerised form using specialist software. The thickness of lines will give an indication to the strength of the ties. Various measures will look at; (i) the number of people within a network; (ii) the potential number of people that could be included in the network; (iii) the way that people are connecting within a network; (iv) how much carers act as a 'bridge' between other individuals within the network; (v) the unity within a network.

Audio recordings will be written up and used to complement the numerical information. The information gathered will be analysed using a specific method designed to explain how a process works, for whom and in what circumstances. The purpose is to create findings that are applicable across different settings. For example, I may see through the network maps that with time people become isolated. By listening to the audio recording I will try and understand the different contexts in which this happens but also the mechanisms that cause this to happen. It is expected that over the course of the interviews repeating themes will emerge which I will group together to help explain the outcomes. I expect this stage of the project will give me a basic theory which I will build on in steps 2 and 3.

Beyond contributing to the overall theory, this stage of the project will provide a detailed background to the social context of end-of-life caregiving, as well as beginning to identify barriers and facilitators to the development of compassionate communities. I also hope to get evidence that may demonstrate how end-of-life caring has the potential to aid community growth.

Step 2: Listening and observing what happens in real life

I will conduct detailed, systematic observations relating to the interaction between people and their communities in a variety of settings. This step is about observing how the developing theory plays out in the real world.

It is not dependant on numbers but rather the detail and depth of observation. I will therefore recruit a small number of people with whom I will form a close relationship as I join them on their journey through the caregiving process. I will observe as people with dementia move from their homes, into the wider community and into hospitals, day centres and other institutions within their communities. The nature of this work is highly sensitive but necessary in order to better understand the fine details involved in the caregiving process.

Important findings will be recorded in a field diary. This information will be analysed in the same way as step one. Where I conduct these observations will be based on convenience and relevance to the underlying project aims, for example given the project is looking at how communities function it is likely I will need to spend more time here rather than in a nursing home or hospital.

This stage will finish when I feel that I am not uncovering any new information with my observations and themes are starting to repeat themselves. I anticipate this process to last 6 months. I will then look to see how all the information fits into my theory from stage 1. It is likely new findings will alter the theory making it more complete.

Beyond building an overall theory, this stage of the project will investigate how communities support social interaction and inclusion for people with dementia. The ultimate purpose is to identify how communities can be best supported to provide care.

Step 3: Checking the theory with lay people involved in caregiving

I will take the developed theory to a series of interviews. These interviews will be conducted with lay people directly involved in caring for someone with dementia. The purpose of the interviews is to run the theory by those who have the lived experience of how it works. Aspects of the theory are spelled out and people asked for comment and feedback. The interviews will be audio

recorded and all the information analysed in the same way as step 1 and 2. It is expected that between 10 and 20 interviews will be needed. This number is an estimate and may change as new information comes to light.

My proposed methodology has been presented at the Marie Curie Palliative Care Research Department, which will host the project. Senior academics have provided feedback which has been incorporated into this proposal. A full study protocol has also been reviewed and endorsed by two independent experts at Oxford University.

How will I recruit people to take part?

I will recruit participants by advertising at NHS trust sites and through networks of people known to the research team. I will get ethical clearance from the host university to ensure it is conducted to the highest standards and that my role as a researcher does not adversely affect participant's experience. The department in which the study will be based has a lot of experience in conducting such sensitive work to the high standards expected from research ethics committees.

3. Dissemination and implementation

Each stage of the project will lead to new findings. I will publish and present these at national and international conferences. The intention is to influence research and policy on a global platform. I will publicise my work to relevant professionals and lay communities in plain English through the media teams associated with the Alzheimer's Society and Marie Curie Palliative Care Research Department. I will also get help with this from the patient and public advisory group supporting me.

Over the course of the project I will hold regular meetings with Research Network volunteers (monitors). Through short presentations at regular intervals, I will update them on theory development, methodological issues, recruitment and study conduct. The purpose being to support me and the wider research team in maintaining a direction relevant to those the work intends to benefit whilst ensuring participants have a positive experience of the research process.

After this project is complete the next stage of my work will be to design, implement and evaluate a public health intervention in real time. The purpose of this will be to promote the growth of compassionate communities that provide participatory action needed to improve access to care. The work will ultimately lead to evaluating cost effectiveness and impact thus providing powerful evidence on which to influence policy at a government level.

4. Training and educational environment

I will conduct this project in the Marie Curie Palliative Care Research Department that is within the Division of Psychiatry at University College London (UCL). I have been working here since August 2017 and have good working relationships with the team. The department has had many research fellows before me, many of whom have progressed to senior posts where they work on high-impact research.

UCL is one of the world's top universities and has an international reputation for the quality of its research and teaching. My supervisors are all based 'in house' and will therefore be on hand to provide close guidance and support. Dr Elizabeth Sampson has extensive experience in improving care for people with dementia especially at the end-of-life. Her skills include health services research and implementing complex interventions in a range of settings. Paul Higgs is a professor in the sociology of ageing, he is vastly experienced in understanding the social context to dementia and has published several books on this. Paddy Stone is a Professor of palliative

care. He leads the internationally recognised department I will work within and has extensive experience in managing large projects and supervising scientists through to completion of their PhDs.

UCL has already provided support in developing my proposal. I have presented my ideas and received feedback from many senior academics in the department and have also been encouraged to collaborate with external experts. I have forged links with the department's 'qualitative working group' who will also provide support through the course of my project. I have also recruited the support of Dr Geoff Wong at Oxford University. He is a clinician and academic with an international reputation for using my chosen methodology to make sense of complex social interventions. Dr Libby Sallnow has published and presented widely on a public health approach to palliative care will also provide her experience in supporting the project. The independent support of my mentor, Professor John Porter, expert in international public health and ethics, from the London School of Hygiene, provides further opportunity for advice and a wealth of academic contacts.

UCL offers fantastic training opportunities for PhD students. Through the academic careers office there are regular workshops, conferences and events that provide me with networking skills that will assist in publicising my work and generating impact. The department is also linked to the Camden and Islington Community Palliative care team meaning my work will have a direct route to the front line of care provision.

In summary, I am confident that the host institution will provide me with broad and rigorous research training and support. I believe that this will equip me with the skills required to complete the project to a high standard and build a successful career in dementia research.

Scientific case for support: Understanding how networks of community members influence end-of-life care for people affected by dementia: A realist evaluation

Significance of research

The Alzheimer's Society's dementia research roadmap prioritises the understanding of new models of care that help 'co-ordinate health and social care together with community-based support' (Pickett et al. 2018). I seek to address this by asking how a public health approach to end-of-life care can be applied to people affected by dementia in order to reduce social isolation, promote social citizenship and improve access to care.

In the UK there are 850,000 people living with dementia and 700,000 friends and family members caring for someone with dementia (Waite 2012; Lewis et al. 2014). Figures are projected to triple by 2050 (Waite 2012). The need for care, especially at the end of life, is a public health priority (Organization 2012).

Dementia changes close relationships and can put strain on families (Macdonald 2018b). This is particularly so at the end-of-life (Gott et al. 2018). As social networks decline, loneliness and social isolation can follow (Bunn et al. 2012; Gott et al. 2018). In such a context, maintaining a role as both a carer and a family member is a major challenge. Such a challenge can ultimately impact on the physical and psychological health of all those involved (Wilks et al. 2011).

The Alzheimer's Society has played a leading role in addressing stigma and social isolation by seeking to change the way people think, act and talk about dementia. The 'Dementia Friends' initiative and the 'Dementia Friendly Communities' programme have grown exponentially as a

direct result of this (International 2016). However, the knowledge these networks hold, and how this translates into supportive actions at the end-of-life, is largely unknown (Hayashi 2017).

To improve end-of-life for those affected by dementia, many have advocated for better integration of palliative care services. Specialist palliative care professionals have expertise and experience in working with the complexity associated with dementia (Alliance and Organisation 2014; Saunders 1996b; Pask et al. 2018). However, comparatively few people are referred (Mitchell, Kiely, and Hamel 2004). At the same time, hospices have limited capacity whilst cuts to social care mean professional home care is diminishing (Erel, Marcus, and Dekeyser-Ganz 2017; Abel and Kellehear 2016).

‘Compassionate Communities’ are based on a public health approach to palliative care and offer a blueprint for the design of community interventions that translate into supportive actions at the end-of-life (Kellehear 2012, 2004). Similar in principle to dementia friendly communities, a Compassionate Community seeks to build supportive networks of community members that reduce social isolation whilst improving access to care. Whilst an evidence base is building for this approach, it is unclear how aspects of the theory relate to the specific challenges of dementia (Sallnow, Richardson, et al. 2016a; Whitelaw and Clark 2019). Understanding this and identifying barriers to such an approach is key to the expansion of community initiatives that can improve well-being for the thousands of people dying with dementia.

Aims

This study aims to:

3. Develop an understanding of how compassionate communities can improve outcomes for people affected by dementia at the end-of-life, and the challenges they face in doing so.
4. Understand the impact of community instigated care at the end-of-life on; (i) identity and agency of a person with dementia; (ii) the care-giving process, as experienced by those involved; (iii) the promotion of self-sufficiency and community development.
5. Create a template for robustly developed, theory driven community interventions that improve quality-of-life and access to care for those affected by dementia at the end-of-life.

Research Questions

1. What are the important social contexts in which caregiving occurs for people affected by dementia during the end-of-life period?
2. How is the agency and identity of a person with dementia viewed and acted upon within these different contexts, and what are the mechanisms by which this occurs?
3. How do the identified contexts influence caregiving at the end-of-life, and what are the mechanisms by which this occurs?
4. Do identified contexts permit community development to occur through end-of-life caring? What happens in the presence of challenges to community development?
5. In what circumstances, and for who, are the components of a compassionate community effective in (i) promoting the identity of a person with dementia (ii) supporting caregiving at the end-of-life (iii) promoting community growth and self-sufficiency.

Objectives

1. To develop an innovative, evidenced based model of care, centred on the identity and needs of a person with dementia, that better co-ordinates health and social care together with community based support.
2. To use this model to underpin and support the implementation and design of a public health approach to end-of-life care for people with dementia and their families.

Work which has led up to the project

This work draws on established dementia theory such as Bartlett and O'Connor's model of 'social citizenship' (Bartlett, O'Connor, and Mann 2010), Kitwood's ideas on 'personhood' (Kitwood 1997d; Cheston and Bender 1999; Nolan et al. 2006), Gilleard and Higgs theory of the '4th age' (Gilleard and Higgs 2010a) and Kellehear's 'compassionate cities' public health model (Kellehear 2012) (Baum 2008). Within the department this project will complement the **E**mpower **B**etter **E**nd of life **D**ementia care programme (EMBED-Care). A global collaboration, this project will synthesize health and social care policy to develop interventions to improve care over a 5 year period.

My interest in this topic evolved from my previous training in infectious diseases where I published on the role of communities in the management of TB (Sawyer et al. 2018). I learnt that communities are complex social systems, and embracing this complexity is key to better understanding how they work.

In order to address this complexity in my subsequent work with dementia, I have used realist methodology. This is an alternative approach to the classic 'successionist' format of experimental design. Instead of focussing on whether a programme works or doesn't work, the focus is on why it works with specific reference to the underlying social context and mechanisms that combine to give outcomes of interest (Pawson 2013b). This methodological approach is widely regarded as an imperative in evaluating complex social interventions characterised by significant levels of heterogeneity (Pawson 2013b). It is recognised by the National Institute of Health and Care Excellence (NICE) as an essential component to public health guidelines and is used widely in the evaluation of dementia care programmes (Keady et al. 2012; Handley, Bunn, and Goodman 2015, 2017; Excellence 2014; Bunn et al. 2018). As part of my academic clinical fellowship I have taken formal training in realist methodology at the University of Oxford. Following this I conducted a systematic realist review of the relevant literature relating to social capital, communities and end-of-life care in dementia. The programme theory generated from this review has formed the basis of my proposal.

I have written a detailed realist evaluation protocol on which to base this proposal. The protocol has been peer reviewed internally and externally through the London Research Design Service. Based on my proposal I was awarded a grant from the NIHR to conduct patient and public involvement work. Members of the Alzheimer's Society Research Network have shaped the protocol which, along with my review is in the process of being submitted for publication. My work has also been accepted for presentation at this year's European Association of Palliative Care conference. I have also developed a protocol for phase 1 of the study which has already been granted ethical approval from the UCL research ethics committee.

Experimental design and methods

Analytic approach

This study draws on critical realist philosophy (Bhaskar 1978). This approach follows an interpretative, theory driven process of synthesising evidence from quantitative, qualitative and mixed methods research (Pawson and Tilley 1997). The main strength of this approach is to provide findings that explain how and why these processes have the potential to cause change. Findings are described in terms context-mechanism-outcome configurations (CMOCs). Causation is thought to be generative through the release of 'mechanisms' or underlying causal powers of individuals and communities (Pawson and Tilley 1997).

Data will be analysed iteratively throughout the project using a realist framework. NVivo 10 (QSR International) will be used as a platform for analysis. Quantitative measures will be assessed for relevance in relation to the research questions and the overall programme theory. Patterns in the data will be placed into ‘concept boxes’ and refined as the data set emerges as a whole. Transcripts will be analysed in a similar fashion. Where sections of text are deemed relevant to the research questions or programme theory they will be further analysed to see if the data can be interpreted as being context, mechanism or an outcome of relevance. The data will then be re-read to see how different combinations of CMOs relate to each other. This will allow the development of CMO configurations. How configurations relate to the overall programme theory will then be discussed within the research team. This may lead to changes and adaptations to the programme theory. Continually re-visiting the data will be required to build support or refute evolving interpretations.

Phase 1: Theory development

Relating to research questions **1:** What are the social contexts in which caregiving occurs at the end-of-life? **3:** How do these contexts influence caregiving? **4:** Do these contexts permit community development?

Third generation social network analysis will be conducted and changes to the network analysed over time (Leonard, Horsfall, and Noonan 2015a). Third generation network analysis is an innovative methodological technique that seeks a fuller cultural and discursive understanding of social networks beyond individual ties, characteristics and dynamics (Mische and White 1998; Granovetter 1977; Leonard, Horsfall, and Noonan 2015a). Under this methodology networks must always be something constructed by, and recognised by, network members. This approach has been used to demonstrate how end-of-life caring can promote community development for people with cancer but has never been used in the context of dementia (Leonard, Horsfall, and Noonan 2015a).

Social networks will be defined as ‘networks of networks’ or ‘systems of support’ (13). Using a broad definition enables me to explore the multiple functions and limitations of different types of support thus allowing a range of relevant themes and outcomes to emerge.

Up to 10 focus groups will be held from the caring networks of up to 10 people who have died within the last 5 years with a diagnosis of dementia. Carers will be recruited by convenience sampling from the greater London area through letters distributed via a dementia support organisation (The Alzheimer’s Society) to members of its patient expert community. The primary carers will then identify members of the caring network to be invited to participate in a focus group.

Network mapping will begin as a collective exercise. This enables participants to see the results and give interpretive feedback which becomes qualitative data. Using a large sheet of paper, participants will write their names in connection with other members of the network. Two network maps will be drawn, time 1 from the beginning of the care journey to time 2, the point of death of the person with dementia. Participants will discuss the maps and the changes over time. Discussions will be facilitated by the lead researcher who will also audiotape and transcribe the discussion. Network maps will be transcribed into an adjacency matrix using NetDraw 2.117 within UCInet (Borgatti, Everett, and Freeman 2002b). This will be used to measure the following parameters:

- Size: The number of individuals in the networks.^[1]

- **Density:** The number of ties divided by the number of possible ties. An increase in density suggests developing connections and stronger relationships.
- **Transitivity:** This refers to the balance and reciprocity in the relationship among three individuals. High transitivity indicates that people are connecting in egalitarian and cooperative ways.
- **Betweenness value:** This indicates the degree to which the carer acts as a bridge between two other individuals. A decrease in the betweenness value indicates that the person no longer needs to be the sole coordinator of the caring.
- **The principal carer's clustering coefficient:** The clustering coefficient of the principal carer is the density of the carer's close connections and is a measure of cohesion. An increase in the main carer's clustering may indicate that the carer is gaining a stronger inner circle of support.

Quantitative measures will be evaluated between different time points using t-test to look for significant changes to network parameters. Given the exploratory nature of this study and the scarce data on which to base power calculations a pilot study will be conducted in the early stages of the first year in order to better guide recruitment numbers. The innovative approach represents important methodological development in the area of dementia and end-of-life care.

Outputs: (i) Detailed description of the social context to end-of-life care; (ii) Identification of barriers to the implementation of compassionate communities; (iii) Identification of key points for intervention to better support communities. (iii) Develop evidence for the potential of community growth providing a framework for the expansion of dementia friendly communities.

Phase 2: Theory refinement

Relating to research questions **1:** What are the social contexts in which caregiving occurs at the end-of-life? **2:** How is the identity of a person with dementia viewed and acted upon? **3:** How do social contexts influence caregiving?

Ethnographic methods will be used to study social interactions, behaviours, and perceptions that occur within groups, teams, organisations, and communities. The aim is to provide rich, holistic insights into people's views and actions, through the collection of detailed observations and interviews (Reeves, Kuper, and Hodges 2008). Observations and informal interviews will be conducted across a variety of care settings dictated by the flow in care of participants. Observations will be over a period of 6 months. Observations will be recorded in a field diary at the end of each day. The challenges or reflexivity and the influence of researcher perceptions will be taken into account when considering the construction of knowledge to create a more conscious encounter with the multi-faceted aspects of the study site.

In addition to ethnography, realist interviews will be conducted across a sample of health care professionals and members of the lay care network. Due to the nature of a realist approach it is likely that the numbers and type of interviewees may change as data emerge, I envisage holding up to 10 interviews. Participants will be recruited from NHS trust sites by poster advertising. During interviews, developing theories obtained through the analysis of ethnographic and quantitative results will be tested and explored. Interpretations and meaning identified from the data will be discussed. Tentative theories relating to the programme theory are spelled out to interviewees. Comparisons will then be made between participants and observed data. Candidate theories are developed, where there is supportive empirical data to support these theories they will be further developed in phase 3.

Outputs: (i) An evaluation of how community approaches support social interaction and inclusion of people affected by dementia at the end-of-life. (ii) A model of care that identifies how best to support people affected by dementia enabling them to access care services.

Phase 3: Theory consolidation

Relating to research question **5:** In what circumstances, and for who, are compassionate communities effective in improving end-of-life care for people affected by dementia

In order to build explanations an iterative process of data collection is designed. To achieve this there will likely be a need to revisit respondents for repeat interview. The longitudinal element differs from standard qualitative research in that it is not exploring changes over time, but exploring changes to the researcher's theories. The purpose being to pass these theories by those who have 'lived experience' of how social capital works for them. At this stage it is anticipated that there will be a series of CMO configurations that are providing shape to an overall programme theory. Interviews will be conducted with key stake holders identified over the course of the study, the number of interviews will be determined by a theoretical saturation and time constraints. It is anticipated up to 10 interviews will be required based on similar study designs. Data will be subject to the same analytical methods described in phase 1 and 2 but with reference to existing theories that have developed.

Outputs: (i) An innovative, evidenced based model of care that helps to explain how 'compassionate communities' can work with existing community based support to promote the inclusion of people affected by dementia. Key points will be identified for the design of high yield public health interventions.

How will results from this research be used?

Short Term

The project will generate powerful and generalizable results in a research nascent field. These will advance scientific understanding of the nature of social function in relation to end-of-life care in dementia. Understanding this from the perspective of a range of social contexts and generative mechanisms that enable change is crucial when considering public health interventions in complex systems. It is intended that results will be directly applicable to the Alzheimer's Society's 'dementia friends' and 'dementia friendly communities' programme forming a template for how their expansion can translate into supportive actions at the end-of-life. On the front line the results will impact on the way health practitioners view communities in their day to day work, therefore building a force for change.

Medium term

My project will link with the EMBED care programme. This is a 5 year programme that aims to generate a step change in end-of-life care for people with dementia. The programme will give me a platform to disseminate my work with direct links to health and social care policy makers. This will enable me, and other researchers in the field, to help design, implement and evaluate specific public health measures that can impact on end of life care for those people affected by dementia.

Long Term

I believe this body of work will promote community development, helping to create social change that shifts the responsibility in care to the wider social and organisational practices that influence

it. In doing so the effects could be wide ranging, reducing stigma, isolation and guilt whilst improving access to care in a cost effective manner for the increasing number of people affected by dementia.

Involvement of people affected by dementia and other relevant stakeholders

The Alzheimer's Society Research Network (ASRN) have guided and shaped this proposal through face to face meetings and written feedback. The continued involvement of the ASRN, by way of the 'monitors' assigned to this project would be of great value in assisting me, and the wider research team, in maintaining a direction relevant to those the work intends to benefit whilst ensuring participants have a positive experience of the research process. In addition to the monitors put in place by the Alzheimer's society I will have my own patient and public involvement group who will support me on issues such as the emotional burden to study participants and also in the dissemination of plain English summaries that will be disseminated on completion of the study.

Training and educational environment

The Marie Curie Palliative Care research department within the Division of Psychiatry at University College London (UCL) is internationally renowned for research into end-of-life care and dementia. Successful programmes include the COMPASSION programme (**Care Of Memory Problems in the Advanced Stages: Improving Our kNowledge**) which supports interdisciplinary and holistic end of life care for people with dementia, the SEED programme which aims to support professionals to deliver high quality community based end of life care, and the BHiRCH programme, a complex intervention to reduce avoidable hospital admissions in nursing homes. Recently the department, with Dr Elizabeth Sampson as the principal investigator, was awarded a £5 million grant to fund the EMBED care programme. This 5 year programme will create a network of global collaborators with direct links to policy influencers. This will provide me with the ideal platform on which to disseminate my work with maximum impact. I have been working in this department since August 2017 as a clinical academic fellow. This has enabled me to form good working relationships with the team whilst maximising my academic development.

The supervisory team are all based within the department and will therefore be on hand to provide close guidance and support. Dr Elizabeth Sampson has extensive experience in improving care for people with dementia especially at the end-of-life. Paul Higgs is a professor in the sociology of ageing and is vastly experienced in understanding the social context to dementia. Together with Paddy Stone, who leads the department, I have the combined expertise and experience to support my aims for this project. My mentors and collaborators include Dr Sallnow, senior clinical lecturer in new public health approaches to end-of-life care, Dr Wong, international expert in realist methodology at the University of Oxford and Professor Porter, expert in ethics and international public health policy from the London School of Hygiene and Tropical Medicine.

The department has had many research fellows before me, many of whom have gone on to achieve senior posts where they continue to work on high-impact research. The other clinical research PhD fellows will provide an important source of peer support and UCL offers a wealth of training opportunities for PhD students through the academic careers office. Beyond this I have a built a collaborative team of experts external to UCL who will facilitate analysis, expand my own personal research network, and help disseminate my findings across different institutions. The department is also linked to the Camden and Islington Community Palliative care team meaning my work will have a direct route to the front line of care provision.

In summary, I am confident that the host institution will provide me with broad and rigorous research training and support. I believe that this will equip me with the skills required to complete the project to a high standard and build a successful career in dementia research.

Bibliography

1. Pickett J, Bird C, Ballard C, Banerjee S, Brayne C, Cowan K, et al. A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *International journal of geriatric psychiatry*. 2018;33(7):900-6.
2. Waite L. Dementia: an international crisis? *Perspectives in public health*. 2012;132(4):154.
3. Lewis F, Karlsberg Schaffer S, Sussex J, O'Neill P, Cockcroft L. The trajectory of dementia in the UK-making a difference. Office of Health Economics Consulting Reports. 2014.
4. Organization WH. Dementia: a public health priority: World Health Organization; 2012.
5. Macdonald G. Death in life or life in death? Dementia's ontological challenge. *Death Studies*. 2018;42(5):290-7.
6. Gott M, Wiles J, Moeke-Maxwell T, Black S, Williams L, Kerse N, et al. What is the role of community at the end of life for people dying in advanced age? A qualitative study with bereaved family carers. *Palliative medicine*. 2018;32(1):268-75.
7. Bunn F, Goodman C, Sworn K, Rait G, Brayne C, Robinson L, et al. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLoS medicine*. 2012;9(10):e1001331.
8. Wilks SE, Little KG, Gough HR, Spurlock WJ. Alzheimer's aggression: Influences on caregiver coping and resilience. *Journal of Gerontological Social Work*. 2011;54(3):260-75.
9. International AD. Dementia Friendly Communities: global developments, 2nd edition. London; 2016.
10. Hayashi M. The Dementia Friends initiative – supporting people with dementia and their carers: reflections from Japan. *International Journal of Care and Caring*. 2017;1(2):281-7.
11. Alliance WPC, Organisation WH. Global Atlas of Palliative Care at the End of Life. 2014.
12. Saunders C. A personal therapeutic journey. *BMJ (Clinical research ed)*. 1996;313(7072):1599-601.
13. Pask S, Pinto C, Bristowe K, van Vliet L, Nicholson C, Evans CJ, et al. A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals. *Palliative medicine*. 2018;32(6):1078-90.
14. Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. *Archives of internal medicine*. 2004;164(3):321-6.
15. Erel M, Marcus E-L, Dekeyser-Ganz F. Barriers to palliative care for advanced dementia: a scoping review. *Annals of Palliative Medicine*. 2017;6(4):365-79.
16. Abel J, Kellehear A. Palliative care reimagined: a needed shift. *BMJ supportive & palliative care*. 2016;6(1):21-6.
17. Kellehear A. *Compassionate cities*: Routledge; 2012.
18. Kellehear A. Third-wave public health? Compassion, community, and end-of-life care. *International Journal of Applied Psychoanalytic Studies*. 2004;1(4):313-23.
19. Sallnow L, Richardson H, Murray SA, Kellehear A. The impact of a new public health approach to end-of-life care: A systematic review. *Palliative Medicine*. 2016;30(3):200-11.
20. Whitelaw S, Clark D. Palliative care and public health: an asymmetrical relationship? *Palliative Care: Research and Treatment*. 2019;12:1178224218819745.
21. Bartlett R, O'Connor D, Mann J. Broadening the dementia debate: Towards social citizenship 2010. 1-156 p.
22. Kitwood TM. *Dementia reconsidered: The person comes first*. Buckingham: Open university press; 1997.

23. Cheston R, Bender M. *Understanding Dementia: The Man with the Worried Eyes*. London: Jessica Kingsley Publishers Ltd; 1999.
24. Nolan M, Brown J, Davies S, Nolan J, Keady J. *The Senses Framework: improving care for older people through a relationship-centred approach*. Getting Research into Practice (GRiP) Report No 2. 2006.
25. Gilleard C, Higgs P. Aging without agency: theorizing the fourth age. *Aging Ment Health*. 2010;14(2):121-8.
26. Baum F. *The new public health*. South Melbourne: Oxford University Press; 2008.
27. Sawyer JM, Asgr R, Todd Fordham FN, Porter JDH. A public health approach to palliative care in the response to drug resistant TB: an ethnographic study in Bengaluru, India. *BMC Palliat Care*. 2018;17(1):120.
28. Pawson R. *The Science of Evaluation: A Realist Manifesto*. London: SAGE Publications Ltd; 2013.
29. Keady J, Campbell S, Barnes H, Ward R, Li X, Swarbrick C, et al. Neighbourhoods and dementia in the health and social care context: a realist review of the literature and implications for UK policy development. *Reviews in Clinical Gerontology*. 2012;22(2):150-63.
30. Handley M, Bunn F, Goodman C. Interventions that support the creation of dementia friendly environments in health care: protocol for a realist review. *Systematic reviews*. 2015;4(1):180.
31. Handley M, Bunn F, Goodman C. Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review. *BMJ open*. 2017;7(7):e015257.
32. Excellence NIHC. *Developing NICE guidelines: the manual*. National Institute for Health and Care Excellence; 2014.
33. Bunn F, Lynch J, Goodman C, Sharpe R, Walshe C, Preston N, et al. Improving living and dying for people with advanced dementia living in care homes: a realist review of Namaste Care and other multisensory interventions. *BMC geriatrics*. 2018;18(1):303.
34. Bhaskar R. *A Realist Theory of Science*: Routledge; 1978. 284 p.
35. Pawson R, Tilley N. *Realistic Evaluation* Tilley N, editor. London ; Thousand Oaks, Calif: Sage; 1997.
36. Leonard R, Horsfall D, Noonan K. Identifying changes in the support networks of end-of-life carers using social network analysis. *BMJ Supportive & Palliative Care*. 2015;5(2):153-9.
37. Mische A, White H. Between conversation and situation: Public switching dynamics across network domains. *Social Research*. 1998:695-724.
38. Granovetter MS. The strength of weak ties. *Social networks*: Elsevier; 1977. p. 347-67.
39. Borgatti SP, Everett MG, Freeman LC. *Ucinet for Windows: Software for social network analysis*. 2002.
40. Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. *BMJ*. 2008;337:a1020.

Appendix Two: Short Communication

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Short Communication

Understanding dying as a focal point for defining an integrative approach to health and social care

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Global health

ABSTRACT

Long standing and poorly acknowledged tensions underpin what is considered success or failure in the field of health and social care. Such tensions threaten to undermine and limit much needed progress. In this article, I discuss the role of death and the dying process as a foundation upon which we might begin to address these tensions. I argue that through careful acknowledgement and attention to the stillness and silence of death we might better understand the impact the dying process has on the healthcare discourses that surround and orientate themselves to it. Training our eye to the rhythm of the human life course necessitates a greater appreciation of death and its influence in shaping a meaningful response to questions relating to care and the attention to human suffering. With this comes a move beyond a singular focus on the body as life's container, embracing human connections that transcend the physical and social worlds. Here our dependency and vulnerability are as much as what makes us human as our autonomy and rationality. Such an appreciation allows us to move away from values entrenched within notions of success and failure and towards a more integrative approach to health and social care.
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1. Introduction

The health care landscape is laden with conflict. Issues from corruption to mistrust and inequity are juxtaposed alongside a long-standing tension in the relationship between individuals and the state, the position of lay and indigenous knowledge in relation to professional services and the meaning and role of community relative to large scale institutional care and global health. A more integrative approach to health care that establishes what is important to measure and understand, whilst incorporating the notion of healing and whole person care back into medicine is necessary to bring some form of equilibrium to these long-standing tensions.

Our relationship with death is a neglected foundation on which to collectively gather and work on these issues. Through the attention to human suffering and decline, the field of health and social care is intimately and inextricably linked to matters relating to death and dying. Despite this, there is an absence of any significant framework in which to understand and value the intricacies of

the dying process. This means they are often missed, or worse, systematically devalued to the point of avoidance and ambivalence. The void is filled by a narrative of stabilisation and prevention drawn from the supporting values of autonomy and independence. This has created a Janus-like role for care at the end-of-life and is representative of how the process of dying has become disconnected from what it means to be born into the world, with a body that is inherently vulnerable to illness, accident, and decline. In this article I describe in more detail current western perspectives on dying, before proposing a more integrative approach to death as a foundation upon which health and social care services may evolve.

2. Current perspectives on death

Perspectives on dying develop in ways unique to local culture, tradition, or knowledge systems. In western society, a valued approach to death is often described through the lens of a 'good death' which is cited as an important aim for individuals and health services [1]. The 'good death' describes an ability to 'retain control of what happens, to have control over pain relief and other symptom control and to have choice and control over where death occurs' [1–3]. The notion of a good death has therefore become

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symbolic of a pursuit for the tools that will afford us some sort of control over death, so that when it does come, it occurs on our terms, in line with our individual choice and in a state of relative comfort.

Where this does not occur, death may come to represent failure. Failure of our defence against external forces that could have been avoided through enhanced knowledge, skill, and clinical responsibility. In this way, every 'bad death' is motivation for the generation of services that seek to prevent, reverse, or stabilise the co-morbidities of dying until such a time that death may be interpreted as clinically necessary, namely when a person is in good health and in very old age or where they have reached the limitations of medical sciences.

Palliative care, a sub speciality of the medical sciences devoted to caring for people at the end-of-life, has been instrumental in managing the 'co-morbidities' of dying, whilst shaping and normalising the idea of a good death [4]. Through its holistic response to the challenges posed by the end-of-life, palliative care has helped reacquaint individuals and communities with the processes associated with dying and loss. Here symptom control, frailty, social isolation, and bereavement, are examined from the perspective of such entities being a symbol of impairment that are incompatible with the notion of a 'good death' and therefore necessitate some sort of restorative intervention. At the same time, agency, choice, and individualism is prioritised through advance care planning as a vehicle to achieving a 'good death'. In this way, whilst the speciality fills a much-needed void in care, it does not provide us with a framework upon which to understand, take meaning from and value the darker side of the dying process.

When both society and the medical services do not have a clear conceptualisation of death as a whole, we work against the tide of our inevitable decline harnessing a philosophy that is intimately related to notions of stabilisation and prevention. This clash between culture and reality represents a foundational cause of the discord seen across the health and social care landscape and is continually fuelled by the absence of attention to understanding death as a process that is at the core of what it means to be human.

3. Death from the perspective of 'the whole', an integrative approach

To understand death in a different, more creative way, we can think of it in reference to the general life course and the beauty and struggles contained within it. Beauty is such an attractive, valuable and gracious force precisely because of its close association to the fractured, hollow and painful side of human experience, rather than in spite of it. Beauty dwells in the places most affected by shattered tenderness, with death being no exception. The question is therefore, not how to remove the sense of pain and suffering that death can impart, but how instead can we be faithful to the vacancy of loss, understanding the beauty concealed within its legacy.

Death arrives silently, without fuss or crescendo that might seem fitting to the drama of life that precedes it. Recognizing the choreographed silence and stillness of death is difficult where our eyes are not trained to its rhythm. The imagination, however, has an eye for the invisible and it is here that we might see past the silent departure towards the transforming presence of death. Here, the process of death is one of intense energy where the interpersonal experiences brought by the process of dying, caring and bereavement generate new social interactions, whilst building a source of new knowledge and hope [5]. It is here, in the juxtaposition between the light and the dark that beauty dwells and its transformative effects can be a force to gather around, helping us to build both a local and global resource that is gathered around a sense of

our finitude and the interwoven light and dark that resides within it.

How then can we train our eye to the rhythm of the human life course so that we might better see such beauty? Dying presents us with a series of fundamental unknowns. Rather than waiting for medical sciences to provide the comfort blanket of certainty or calculated risk, perhaps there is a need to embrace the unknown as unknowable and instead focus on the effects that surround it. Drawing on a social imaginary outlined by Gilleard and Higgs, where they liken dying in a state of dependency to a cosmological black hole, perhaps the beauty in death might be 'understood by examining not the experience itself, but its impact on the discourse that surround and orientate themselves to it' [6]. It is here, in the 'event horizon' that we might begin to understand more of what our embodied vulnerability and impermanence means.

Using this analogy, our eyes turn from the body as life's container, towards something far greater. Here in the invisible realm of death, life is held through a series of connections that transcend the physical and social worlds and alludes to what some may describe as a 'soul' [7]. Where human life is understood to be carried by more than just our body, it becomes easier to appreciate the body's impermanence and the painful futility of our efforts to preserve its function in the face of inevitable decline.

The beauty becomes apparent when we shift our focus away from such futility towards the caring human relationships that grow in response to dependency and decline. Accepting dependency as essential to human nature, rather than an unfortunate eventuality, highlights the fundamental importance of caring relationships to 'the whole'. Where relationships develop beyond a transactional nature, they represent a platform where the amalgamation of lightness and dark creates transformative beauty. Recognising the role dying has on social relationships gives weight, value and legitimacy to the roles played out by individuals, families, friends and communities at the end-of-life. This creates recognition that being with someone in a state of dependency can be transformative, not just for the dependent, but also for those who are depended on.

This interdependency allows care to be understood as a moral imperative that is born out through a shared understanding of how we assign, accept and deflect responsibility for health, wellbeing and ultimately death. The importance of the 'transformative presence' of care allows us to move beyond notions of success and failure and towards more thoughtful interventions. For example, in the context of very old age, issues relating to frailty and social isolation might be interpreted as reference points that alert us to the changing pace of life's rhythm. Here the contraction of time around our deteriorating bodies might be understood as necessitating and valuing a deeper connection with the immediate environment instead of a social connectedness no longer appropriate to the roles and identities of very old age. Integrating such an approach transcends the fields of health and social care, harnessing the imagination and creativity of entire communities that is so vital to understanding the invisible realm where concepts are intangible and immeasurable in empirical form.

4. Integration at the interface of professional and lay communities

How services may exist and function as part of such an integrative approach is not straightforward. Where the work of care and the understanding of death is situated in a broader, more creative discourse, there comes a need for responsibility to be shared beyond the confines of professional services. However, where responsibilities are not clearly understood or felt, care can be fragmented and power imbalanced, leading to moral distress [8]. It

follows that for a society trained to develop and foster self-optimisation, independence and autonomy, asking people to embrace an alternative temporality that revolves around vulnerability, dependency and death is a major challenge.

Where we bypass the underlying philosophy and attempt simply to 'empower' people to adopt a transformative presence at the end-of-life, there is potential to isolate those unwilling or unable to do so, whilst at the same time the highly gendered and socially stratified dimensions of caregiving can be accentuated [9,10]. The differing perspectives on how death is conceptualised within professional and lay groups of carers means the negotiation of responsibility can be a fraught process. The notion of shared responsibility therefore needs to be understood beyond that of a cognitive process with clearly demarcated boundaries of 'right and wrong'. Instead, responsibility is cultivated over time so that it is felt within us, compelling us to act in a way that is unique to individual need and context. The fluidity in assuming and deflecting responsibility that might allow people to find their own personal way is traditionally described as a source of burden and distress, yet the sharing of roles may also be perceived as a rewarding and fulfilling process [11]. How we progress knowledge in this area, using death as a lens through which people can view and evaluate their own actions to develop healing capacity in real terms is of vital importance.

5. Conclusion

Whatever the balance between successful and unsuccessful integration of death into our health and social care services that is achieved by a particular generation, each success creates in its shadow new possibilities of failure. Dying people are ever present and their needs ever evolving. How we reach out and meet such a need requires a careful consideration so as not to create divisive practice where death can be characterised as either a success or failure. Rather death is the 'white shadow' [7], the beauty created through the close association of all that is broken, damaged and lost alongside the transformative presence of human love and

compassion. The beauty inherent within the white shadow of death is however not an end in itself, but points to a far greater embrace of belonging that holds everything together as a focal point for the generation of integrative approaches to health and social care.

Source of Funding

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Conflict of interest

The author declares none.

References

- [1] Smith R. A good death: an important aim for health services and for us all. British Medical Journal Publishing Group; 2000.
- [2] Herwood M, Newberger J. The future of health and care of older people: the best is yet to come. Age Concern England; 1999.
- [3] Meier EA, Gallegos JV, Thomas LPM, Depp CA, Irwin SA, Jeste DV. Defining a good death (successful dying): literature review and a call for research and public dialogue. *Am J Geriatr Psychiatry* 2016;24(4):261–71.
- [4] Mannix K. With the end in mind: dying, death and wisdom in an age of denial. London: Harper Collins; 2017.
- [5] Kellehear A. Compassionate Cities: global significance and meaning for palliative care. *Prog Palliat Care* 2020;28(2):115–9.
- [6] Giljeard C, Higgs P. Aging without agency: theorizing the fourth age. *Aging Ment Health* 2010;14(2):121–8.
- [7] O'Donohue J. The white shadow: beauty and death. Divine beauty. London: Transworld Publishers; 2003. p. 193–216.
- [8] Pesut R, Robinson CA, Bottorff JL. Among neighbors: an ethnographic account of responsibilities in rural palliative care. *Palliat Support Care* 2014;12(2):127–38.
- [9] Gardiner C, Robinson J, Connolly M, Hulme C, Kang K, Rowland C, et al. Equity and the financial costs of informal caregiving in palliative care: a critical debate. *BMC Palliat Care* 2020; 19:1–7.
- [10] Gott M, Morgan T, Williams L. Gender and palliative care: a call to arms. *Palliat Care Soc Prac* 2020;14. 2632332420957997.
- [11] Stajduhar K, Funk L, Jakobsson E, Öhlin J. A critical analysis of health promotion and 'empowerment' in the context of palliative family care-giving. *Nurs Inq* 2010; 17(3):221–30.

Appendix Three: Ethics Approval Social Network Analysis

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH



8th March 2019

Dr Elizabeth Sampson
Marie Curie Palliative Care Research Department
Division of Psychiatry
UCL

Dear Dr Sampson

Notification of Ethics Approval with Provisos

Project ID/Title: 14509/001: Identifying changes to social networks and their impact on care for people with dementia at the end-of-life

Further to the review of your re-submitted application at the February meeting of the UCL REC, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until 8th March 2020.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
<http://ethics.grad.ucl.ac.uk/responsibilities.php>

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Office of the Vice Provost Research, 2 Tavton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
<http://ethics.grad.ucl.ac.uk/>

Final Report

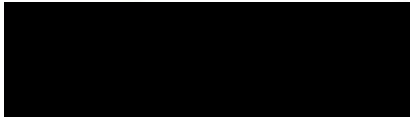
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Cc: Joseph Sawyer

Appendix Four: Ethics Approval Ethnography



**Health Research
Authority**

Yorkshire & The Humber - Leeds West Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

29 September 2021

Dr Joseph Sawyer
Marie Curie Palliative Care Research Department
6th Floor, Maple house,
149 Tottenham Court Road, London
W1T 7NF

Dear Dr Sawyer

| | |
|-------------------------|---|
| Study title: | Understanding how networks of community members support end-of-life care for people affected by dementia: A realist evaluation |
| REC reference: | 21/YH/0184 |
| IRAS project ID: | 281423 |

Thank you for your letter responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005 (England and Wales)

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005 (England and Wales). The committee is satisfied that the requirements of

section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Mental Capacity Act (Northern Ireland) 2016

The Committee approved this research project for the purposes of the Mental Capacity Act (Northern Ireland) 2016. The Committee is satisfied that the requirements of Part 8 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Mental Capacity Act Questions

Relevance of the research to the impairing condition

The Committee agreed the research was connected with an impairing condition affecting persons lacking capacity or with the treatment of the condition.

Justification for including adults lacking capacity to meet the research objectives

The Committee agreed the research could not be carried out as effectively if it was confined to participants able to give consent.

Arrangements for appointing consultees

The Committee considered the arrangements set out in the application for appointing consultees under Section 32 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Section 135 of the Mental Capacity Act (Northern Ireland) 2016) to advise on whether participants lacking capacity should take part and on what their wishes and feelings would have likely to have been if they had capacity.

The Committee was not entirely satisfied with the arrangements to identify and appoint consultees. The Committee agreed that carers and family members should be included as participants and should have separate PIS and ICFs.

The Committee agreed that the research has the potential to benefit participants lacking capacity without imposing a disproportionate burden on them.

The Committee was satisfied that reasonable arrangements would be in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Section 137 of the Mental Capacity Act (Northern Ireland) 2016).

Information for consultees

The Committee considered that the information to be provided to consultees about the proposed research was not adequate for the following reasons:

1. Anyone being asked for information or an opinion should be included as a participant.
2. A PIS and ICF should be created specifically for participants who are healthcare professionals or carers of people with dementia.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

The Committee approved the study however recommended that the easy to read PIS use is monitored for the first few participants as it contains a lot of text.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:

<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at <https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at

<https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|--|---------|-------------------|
| Copies of materials calling attention of potential participants to the research [Poster for interviews] | 1 | 28 June 2021 |
| Copies of materials calling attention of potential participants to the research [Poster for ethnography] | 1 | 28 June 2021 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter of insurance] | 1 | 28 June 2021 |
| GP/consultant information sheets or letters [GP letter] | 1 | 28 June 2021 |
| GP/consultant information sheets or letters [GP information sheet] | 1 | 28 June 2021 |
| IRAS Application Form [IRAS_Form_29062021] | | 29 June 2021 |
| IRAS Application Form XML file [IRAS_Form_29062021] | | 29 June 2021 |
| IRAS Checklist XML [Checklist_02092021] | | 02 September 2021 |
| Letter from funder [Letter from funder] | 1 | |
| Letter from sponsor [Sponsorship confirmation] | 1 | 28 June 2021 |
| Organisation Information Document [OID] | 1 | 28 June 2021 |
| Other [Response to issues raised by committee] | 1 | 02 September 2021 |
| Other [GCP certificate JS] | 1 | 02 September 2021 |
| Participant consent form [Consent form interviews] | 1 | 28 June 2021 |
| Participant consent form [Consultee declaration form] | 1 | 28 June 2021 |
| Participant consent form [Consent form ethnography] | V2 | 02 September 2021 |
| Participant consent form [Easy read consent form ethnography] | 1 | 02 September 2021 |
| Participant information sheet (PIS) [Consultee information sheet] | 1 | 28 June 2021 |
| Participant information sheet (PIS) [PIS ethnography] | V2 | 02 September 2021 |
| Participant information sheet (PIS) [Easy read PIS ethnography] | 1 | 02 September 2021 |
| Participant information sheet (PIS) [PIS interviews] | V2 | 02 September 2021 |
| Referee's report or other scientific critique report [Scientific and lay peer] | 1 | 28 June 2021 |

| | | |
|--|----|--------------|
| review] | | |
| Research protocol or project proposal [Study Protocol] | V2 | 28 June 2021 |
| Schedule of Events or SoECAT [SoECAT form] | 1 | |
| Summary CV for Chief Investigator (CI) [CV JS] | | 28 June 2021 |
| Summary CV for supervisor (student research) [CV ES] | 1 | |
| Summary CV for supervisor (student research) [PH CV] | 1 | |
| Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary diagram] | 1 | 28 June 2021 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

| |
|---|
| IRAS project ID: 281423 Please quote this number on all correspondence |
|---|

With the Committee's best wishes for the success of this project.

Yours sincerely

Rhona Bratt
Chair

Email: leedswest.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: Mr Pushpsen Joshi, Joint Research Office

Lead Nation England: approvals@hra.nhs.uk

Appendix Five: Screen grabs from NVivo

Phase 1 Network Analysis.nvp - NVivo 12 Pro

File Home Import Create Explore Share

Paste Copy Merge Clipboard Properties Open Memo Link Item Add To Set Create As Code Create As Cases Query Visualize Code Auto Code Range Code Undo Case Classification File Classification Detail View Sort By Undock Navigation View List View Find Workspace

Quick Access Files Memos Nodes File Classifications Externals Codes Nodes Methodology Phase 2 Architecture of place Architecture of relationships Context Intersection between professional and la Mechanisms Outcomes Phase 1 Architecture Context Definitions Mechanisms Outcomes random Relationships Relationship Types Cases Notes Memos Methods Phase 1 architecture of intervention Context Form Intersection Non form

Context

| Name | Files | References | Created On | Created By | Modified On | Modified By |
|---|-------|------------|------------|------------------|-------------|------------------|
| individualised networks and the role of character | | 16 | 44 | 30/09/2022 10:54 | JMS | 10/11/2022 14:11 |
| Individualised meaning and relevance | | 2 | 4 | 07/07/2022 11:14 | JMS | 05/10/2022 16:59 |
| integration vs segregation | | 6 | 8 | 29/07/2022 13:10 | JMS | 16/11/2022 17:20 |
| dementia specific | | 2 | 2 | 29/07/2022 14:32 | JMS | 29/07/2022 14:33 |
| isolation | | 3 | 3 | 08/07/2022 14:14 | JMS | 14/10/2022 15:50 |
| Trauma | | 11 | 26 | 05/07/2022 12:55 | JMS | 18/10/2022 14:46 |
| platforms or compassionate spaces+ | | 1 | 2 | 07/10/2022 10:56 | JMS | 07/10/2022 16:31 |
| Proximity | | 1 | 1 | 07/07/2022 10:40 | JMS | 07/07/2022 10:40 |
| shattered yet converging worlds (asteroids) | | 5 | 8 | 14/10/2022 14:20 | JMS | 08/11/2022 20:52 |
| diagnosis or label as validating of a supportive relationship (an example of form and on form | | 3 | 9 | 06/07/2022 16:52 | JMS | 18/10/2022 15:25 |
| negative space (non form) | | 6 | 11 | 22/08/2022 11:53 | JMS | 01/11/2022 10:39 |
| The object of focus, independence, health as fixable (form) | | 3 | 5 | 14/10/2022 12:15 | JMS | 18/10/2022 12:36 |
| The liminal space between worlds | | 4 | 4 | 18/10/2022 12:20 | JMS | 08/11/2022 20:52 |
| Agency | | 6 | 16 | 29/07/2022 14:02 | JMS | 18/10/2022 12:32 |
| existence as demending of moral value | | 2 | 2 | 30/09/2022 13:01 | JMS | 18/10/2022 13:01 |
| money | | 1 | 1 | 01/11/2022 11:14 | JMS | 01/11/2022 11:14 |
| Paradox | | 5 | 7 | 30/09/2022 11:19 | JMS | 21/11/2022 16:18 |
| being happy and healthy with advanced dementia | | 8 | 10 | 08/07/2022 10:09 | JMS | 16/11/2022 15:11 |
| capacity vs spoken will | | 1 | 1 | 14/10/2022 17:11 | JMS | 14/10/2022 17:11 |
| caring as both failure and joy | | 1 | 1 | 18/10/2022 12:02 | JMS | 18/10/2022 12:02 |
| choice as illusionary | | 3 | 3 | 29/09/2022 14:47 | JMS | 01/11/2022 12:36 |
| Illness and risk paradox | | 2 | 2 | 29/07/2022 14:35 | JMS | 22/08/2022 10:54 |
| joy and grey hollows | | 8 | 16 | 08/07/2022 12:01 | JMS | 21/11/2022 16:18 |
| needing help but not knowing what | | 1 | 1 | 14/10/2022 12:42 | JMS | 14/10/2022 12:42 |
| The burden paradox | | 2 | 4 | 28/09/2022 14:19 | JMS | 30/09/2022 15:42 |
| unhelpful help | | 3 | 4 | 30/09/2022 12:37 | JMS | 18/10/2022 12:12 |
| Risk Vs safety | | 3 | 3 | 01/11/2022 13:10 | JMS | 08/12/2022 12:13 |
| Structure and protocol | | 2 | 2 | 01/11/2022 13:02 | JMS | 02/11/2022 10:37 |
| Time | | 13 | 35 | 05/07/2022 13:46 | JMS | 10/11/2022 21:51 |

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Phase 1 Network Analysis.nvp - NVivo 12 Pro

File Home Import Create Explore Share

Paste Cut Copy Merge Clipboard Properties Open Memo Link Item Add To Set Create As Code Create As Cases Query Visualize Code Auto Code Range Code Uncode Case Classification File Classification Detail View Undock List View Sort By Navigation View Find Workspace

Quick Access

- Files
- Memos
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- File Classifications
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- Codes
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 - Architecture of relationships
 - Context
 - Intersection between professional and la
 - Mechanisms
 - Outcomes
 - Phase I
 - Architecture
 - Context
 - Definitions
 - Mechanisms
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Context

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| Name | Files | References | Created On | Created By | Modified On | Modified By |
|--|-------|------------|---------------------|------------|------------------|-------------|
| existing within the intersection between form and non form | | 32 | 73 25/10/2022 14:46 | JMS | 17/01/2023 17:22 | JMS |
| Beyond a completed life (beyond form) | | 9 | 11 10/11/2022 10:25 | JMS | 08/12/2022 14:25 | JMS |
| existing relationships | | 5 | 6 25/11/2022 15:30 | JMS | 09/12/2022 13:43 | JMS |
| New relationships form here | | 6 | 13 14/11/2022 10:32 | JMS | 30/12/2022 10:55 | JMS |
| the role of space and silence | | 5 | 8 22/11/2022 16:26 | JMS | 09/12/2022 10:48 | JMS |
| the role of structure | | 17 | 33 02/11/2022 10:28 | JMS | 30/12/2022 10:55 | JMS |
| the static body | | 11 | 19 08/11/2022 11:48 | JMS | 08/12/2022 11:41 | JMS |
| Time | | 6 | 7 25/11/2022 10:22 | JMS | 30/12/2022 10:55 | JMS |
| Form | | 7 | 8 11/11/2022 10:01 | JMS | 30/12/2022 10:55 | JMS |
| Death and the form | | 1 | 1 25/11/2022 10:08 | JMS | 25/11/2022 10:08 | JMS |
| Loss | | 2 | 3 25/11/2022 10:00 | JMS | 30/12/2022 10:55 | JMS |
| navigating structure | | 8 | 8 23/11/2022 10:42 | JMS | 09/12/2022 16:33 | JMS |
| The rhythm to the form | | 0 | 0 13/12/2022 15:48 | JMS | 13/12/2022 15:48 | JMS |
| ecological rhythm | | 6 | 7 13/12/2022 15:48 | JMS | 09/12/2022 16:28 | JMS |
| time | | 5 | 5 08/11/2022 21:06 | JMS | 25/11/2022 10:21 | JMS |
| work, business, fatigue, anxiety | | 6 | 11 14/11/2022 10:40 | JMS | 17/01/2023 17:22 | JMS |
| Non form | | 18 | 26 11/11/2022 10:01 | JMS | 17/01/2023 17:22 | JMS |
| Grief | | 1 | 1 11/11/2022 15:35 | JMS | 14/11/2022 10:32 | JMS |
| leadership | | 1 | 1 11/11/2022 13:01 | JMS | 11/11/2022 13:06 | JMS |
| lockdown | | 1 | 1 09/12/2022 14:18 | JMS | 09/12/2022 14:21 | JMS |
| paradox | | 11 | 21 08/11/2022 14:34 | JMS | 12/12/2022 20:57 | JMS |
| A present absence | | 2 | 4 10/11/2022 14:25 | JMS | 08/12/2022 11:06 | JMS |
| Joy and sadness co-exist | | 10 | 15 08/11/2022 21:20 | JMS | 08/12/2022 10:44 | JMS |
| Paternalism vs autonomy | | 5 | 5 09/11/2022 12:22 | JMS | 02/12/2022 14:16 | JMS |
| Success and failure | | 2 | 2 14/11/2022 12:04 | JMS | 22/11/2022 15:28 | JMS |
| The rhythm to the non-form | | 6 | 9 01/11/2022 00:14 | JMS | 01/12/2022 13:39 | JMS |
| ecological rhythm | | 6 | 7 11/11/2022 11:21 | JMS | 09/12/2022 16:28 | JMS |
| time | | 5 | 5 13/12/2022 15:49 | JMS | 25/11/2022 10:21 | JMS |
| Unknowable unknowns | | 4 | 4 17/11/2022 09:38 | JMS | 07/12/2022 14:02 | JMS |
| suffering and trauma as part of life | | 16 | 29 14/11/2022 16:43 | JMS | 23/12/2022 12:31 | JMS |

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Appendix Six: Compassionate City Charter



Compassionate
Communities UK

The Compassionate City Charter

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People who live with life-threatening or life limiting illness, their caregivers, and the bereaved are segmented social groups, forced to experience lifestyles that are commonly socially hidden and disenfranchised from the wider society. Outside of the health services that deal specifically with their immediate problems, these populations suffer from a range of other troubles that are separate but linked to their health conditions or social circumstances – loneliness, isolation, job loss, stigma, depression, anxiety and fear, or even suicide. These populations also suffer from a range of other debilitating health problems often caused by their social and psychological troubles - insomnia, cardiac arrhythmias, chronic fatigue and headaches, hypertension, and gastric-intestinal disorders.

THE COMPASSIONATE CITY

- A CHARTER OF ACTIONS -

Compassionate Cities are communities that recognize that all natural cycles of sickness and health, birth and death, and love and loss happen daily within the orbits of its institutions and regular activities. A compassionate city is a community that recognizes that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility.

Compassionate Cities are communities that publicly encourage, facilitate, supports and celebrates care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care. Though local government strives to maintain and strengthen quality services for the most fragile and vulnerable in our midst, those persons are not the limits of our experience of fragility and vulnerability. Serious personal crises of illness, dying, death and loss may visit any of us, at any time during the normal course our lives. A compassionate city is a community that squarely recognizes and addresses this social fact.

REVISED AND APPROVED DECEMBER 2020,
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Through auspices of the Mayor's office a compassionate city will - by public marketing and advertising; by use of the cities' network and influences; by dint of collaboration and co-operation; in partnership with social media and its own offices – develop and support the following 13 social changes to the cities' key institutions and activities.

1. Our **schools** will have annually reviewed policies or guidance documents for dying, death, loss and care
2. Our **workplaces** will have annually reviewed policies or guidance documents for dying, death, loss and care
3. Our **trade unions** will have annually reviewed policies or guidance documents for dying, death, loss and care
4. Our **places of worship** will have at least one dedicated group for end of life care support
5. Our **city's hospices and nursing homes** will have a community development program involving local area citizens in end of life care activities and programs
6. Our city's major **museums and art galleries** will hold annual exhibitions on the experiences of ageing, dying, death, loss or care
7. Our city will host an **annual peacetime memorial parade** representing the major sectors of human loss outside military campaigns – cancer, motor neuron disease, AIDS, child loss, suicide survivors, animal companion loss, widowhood, industrial and vehicle accidents, the loss of emergency workers and all end of life care personnel, etc.
8. Our city will promote **compassionate communities** programmes to engage neighbourhoods and local streets in direct care activities for their local residents living with health crisis, ageing, caregiving, and grief.



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9. Our city will create an **incentives scheme** to celebrate and highlight the most creative compassionate organization, event, and individual/s. The scheme will take the form of an annual award administered by a committee drawn from the end of life care sector. A 'Mayor's Prize' will recognise individual/s for that year those who most exemplify the city's values of compassionate care.
10. Our city will publicly showcase, in **print and in social media**, our **local government policies, services**, funding opportunities, partnerships, and public events that address 'our compassionate concerns' with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring. All end of life care-related services within the city limits will be encouraged to distribute this material or these web links including veterinarians and funeral organizations
11. Our city will work with local social or print media to encourage an **annual city-wide short story or art competition** that helps raise awareness of ageing, dying, death, loss, or caring.
12. All our compassionate policies and services, and in the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how **diversity** shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.
13. We will seek to encourage and to invite evidence that institutions for the **homeless and the imprisoned** have support plans in place for end of life care and loss and bereavement.

Our city will establish and review these targets and goals in the first two years and thereafter will add one more sector annually to our action plans for a compassionate city – e.g. hospitals, further & higher education, charities, community & voluntary organizations, police & emergency services, and so on.



Compassionate Communities UK

This charter represents a commitment by the city to embrace a view of health and wellbeing that embraces social empathy, reminding its inhabitants and all who would view us from beyond its borders that ‘compassion’ means to embrace mutual sharing. A city is not merely a place to work and access services but equally a place to enjoy support in the safety and protection of each other’s company, even to the end of our days.

JULIAN ABEL & ALLAN KELLEHEAR