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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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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 acquaint 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.

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Conflict of interest

The author declares none.

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