How do partners of people with dementia decide whether to tell family and friends about the diagnosis?: a thematic analysis

Doug Hobson

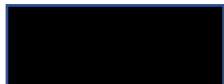**D.Clin.Psy thesis (Volume 1), 2021**

University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this 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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Date: 24/06/2021

Impact statement

Within academia, the thesis highlighted the flexible nature of qualitative research and how an inductive approach could follow the data in analysis, to find things that were not anticipated within the original research question. This allowed the results to remain close to the participants' accounts, and give an authentic representation of how they did (or did not) make disclosure decisions. The research also gave a voice to a stigmatised and under-represented group, and followed guidance to put people with dementia, or their caregivers, at the heart of the research process. This was also the first piece of research to specifically investigate how spousal family caregivers made disclosure decisions in relation to their partner's dementia diagnosis, and added knowledge to an under-researched area.

The thesis offers insight into many areas for future research when considering decision-making as an aspect of spousal caregiver burden. It highlighted how people may inadvertently avoid decision-making altogether, the things that people consider important when making disclosure decisions, and the internal dilemmas they face, which capture the heart of decision-making as an aspect of caregiver burden. The thesis also adds to the wider field of work in relation to 'disclosure and dementia'. A summary of the key findings and conclusions are available on the University College London Unit for Stigma Research (UCLUS) research website. They can be found here:

https://www.ucl.ac.uk/pals/research-dementia-stigma-and-disclosure

I also plan to publish the research in a relevant journal following submission of the thesis.

Practically, the research findings have the potential to inform interventions for spousal caregivers of people with dementia, to aid in their consideration of diagnostic disclosure

decisions. The topic was promoted and discussed as part of targeted recruitment efforts for the research via a 'Twitter Live', with a popular dementia account that has over 10,000 followers. The finding that spouses sometimes do not perceive themselves as having a decision to make, or struggle to articulate how they make this decision, may influence practical advice to help support spousal caregivers with this decision, which could enable them to be proactive and facilitate a greater sense of control. The findings from the research also highlight the dilemmas that spousal caregivers face; an acknowledgement of these from the outset, and their potential burden, may be helpful in facilitating adjustment to a caregiving role. Ultimately, the research may help influence the provision of practical support around disclosure itself, which could have a positive impact on the wellbeing of both the person with dementia and the spousal caregiver, as they are able to adjust to, and accept, their newly formed identities.

Overview

UK government policy over the past decade has championed earlier dementia diagnosis, alongside an ageing population. This has increased the number of spousal family caregiver(s) (FCG), at an earlier stage in their partner's illness, where symptoms may be more easily concealable. These FCGs are at a greater risk of a host of negative physical and psychological outcomes. Telling others about their partner's diagnosis may enable practical and emotional support to mitigate against these, but this may go against their partner's wishes, shift long-standing privacy boundaries, or create anxiety around stigma. This thesis aims to understand the factors that influence a FCG's decision-making process on whether to disclose or conceal their partner's dementia diagnosis.

Part one comprises a conceptual introduction to decision-making, as an aspect of spousal dementia caregiver burden, in particular the decision to tell others about their partner's diagnosis. Theories of privacy communication management and disclosure of stigmatised identities are brought together in a conceptual synthesis of areas relevant to spousal caregiver disclosure decision-making, and their utility and limitations considered. It concludes further qualitative investigation of spousal FCG decision-making processes is required.

Part two is a qualitative study exploring how partners of people with dementia make diagnosis disclosure decisions, through an inductive, reflexive thematic analysis of interviews. The findings include themes around how spouses may avoid decision-making, decisional influences that are pertinent, and the ongoing dilemmas they face. These decisional dilemmas capture how the decision to disclose or conceal a partners' dementia diagnosis can be an

aspect of caregiver burden. These are discussed in relation to existing theory, and implications of the research are outlined, alongside suggestions for future areas of research.

Part three is a critical appraisal of the key points of reflection I encountered during the research process. Topics discussed include: my personal relationship with the research topic and attempts to 'bracket' this, methodological dilemmas, my occupation of different identities, the research context, and the use of personal disclosure.

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Acknowledgements

I would like to thank my supervisor, Georgina Charlesworth, who has always been available for advice and guidance when I have asked for it. She has also always held me to high-standards and helped to push me to produce a piece of research that I hope does myself, and my participants justice.

To my wife Claire, and my children, Sebastian and Evie, thank you for your support and understanding for those weekends when I have had to stay in and work, rather than go on family outings. I cannot wait to start enjoying more precious family time together again.

To those who participated in the research and shared their stories, thank you for being so open and brave in telling me about your experiences. To all family caregivers out there, thank you for your strength and resilience in relation to the many challenges you face, and a lack of wider systemic support within the care system.

To my Dad, Roger, who is one of the most selfless people I know. And finally, to my Mum Ros, who was diagnosed with dementia in 2015. Thank you for raising me and teaching me how to conduct myself, I will forever be thankful for this.

Part one: Conceptual Introduction

How do spousal carers of people with dementia decide whether to

tell family and friends about the diagnosis: a conceptual

introduction

Abstract

Taking on an increased responsibility for decision-making is an aspect of spousal dementia caregiver burden that is neglected in the current literature. An important decision for spouses to navigate is who to tell about their partner's diagnosis. Their approach is likely to be influenced by their long-standing strategies for decision-making and privacy management, within the, now altered, marital relationship. Currently, little is known about how spouses manage this decision-making process. This is an important omission as it neglects consideration of different disclosure strategies, which may subsequently impact the quality of life for both caregiver and partner. In light of this, four disclosure decision-making models are compared and their utility considered in application to spousal caregivers deciding whether to disclose or conceal their partners' diagnosis. Theories of privacy communication management and disclosure of stigmatised identities are brought together in a conceptual synthesis of areas relevant to spousal caregiver disclosure decision-making, highlighting for the first time, diagnosis disclosure as an aspect of caregiver burden.

Introduction

Dementia: the statistics

Dementia is a global public health priority. In 2015 it was estimated that 46.8 million people had dementia worldwide (Prince et al., 2015). This is expected to reach 115 million by 2050. Currently, there are around 850,000 person(s) with dementia (PwD) living in the UK. As the UK's population is, on average, living longer, the number of PwD is increasing and will continue to do so (Powell & Baker, 2019). By 2051 the projected number of PwD in the UK is over two million (Alzheimer's Society, 2014). Dementia mainly effects people over the age of 65 years, with one person in fourteen diagnosed. It has been referred to as the 'modern epidemic of old age' and the diagnosis most feared by older adults (Bond & Corner, 2001, p.96). The likelihood of developing dementia increases significantly with age, and one in six people over the age of 80 has a diagnosis. There are also around 42,000 people under the age of 65 diagnosed with dementia currently living in the UK (Alzheimer's Society, 2014). There are currently around 540,000 family caregiver(s) (FCG) of PwD in England, and one in three people will care for a PwD during their lifetime (NHS England, 2018). As the population ages, the number of FCGs will continue to increase (Ferri et al., 2005; Livingston et al., 2010). FCGs are considered integral to the quality of life for a PwD (Brodaty & Donkin, 2009), spending on average 36 hours per week caregiving (Alzheimer's Society, 2014), and the emotional well-being of the spouse is likely to have a major impact on the PwD (Burgener & Twigg, 2002).

Current UK dementia policy

The UK government set ambitious targets in relation to diagnosis, treatment and care of dementia (Department of Health, 2015). This included being a world leader in 'fighting'

dementia and providing the best place to live in the world for those diagnosed and their FCGs (Powell & Baker, 2019). As part of this ambition, an emphasis was placed on access to early diagnosis in the hope that it would improve the quality of life for patients and carers (National Institute for Health and Clinical Excellence [NICE], 2018). Key advantages of early diagnosis are viewed as better adjustment, the enablement of forward planning, slowing of disease progression, and economic savings due to prolonged independence, and delayed need for care home or hospital admission (British Psychological Society [BPS], 2014). This mirrors an international consensus based on expert and advocacy groups who support early, and more 'timely', diagnosis (Prince et al., 2015; Robinson et al., 2015). Early diagnosis means a greater number of people living with insight into their dementia diagnosis, and a greater number of partners or spouses are now as classed as FCGs, at a stage when their partner's symptoms are less severe and can be more easily concealed. It has also provided an opportunity for research to look at supporting FCGs in the earlier stages of their partner's illness, and in doing so to try and maximise the quality of life for both the FCG and PwD (Aminzadeh, et al., 2007).

Spousal caregiver burden

A spousal caregiver is defined as a partner of someone with a chronic illness or long-term disability, in this case, a dementia diagnosis. They provide support, and emotional and instrumental care to their partner in light of their condition, and may also take on an active role in treatment decisions (Hagedoorn et al., 2008; Monin et al., 2019). The nature of the spousal relationship means they are likely to have a unique experience of caregiving to that person (Monin et al., 2019). Spousal FCGs of PwD face many demands. The ongoing mourning, and unpredictable nature of the illness, makes caregiving an exceptional situation

(Schoenakers et al., 2010), and spousal FCGs have been termed the 'invisible second patients', as they can face years of managing evolving symptoms whilst making complex decisions (Broadaty & Donkin, 2009, p.217). The caregiver burden literature tells us that spousal FCGs for PwD are vulnerable to substantial physiological, psychological and economic strain, meaning they are at an increased risk for a host of negative outcomes, including developing depression, illness, social isolation and an overall decreased quality of life (see Etters et al., 2008 for a systematic review). An aspect of these demands that has been neglected within the caregiver burden literature, is an increased responsibility for decision-making on behalf of the PwD, across a range of domains (everyday, medical, end of life) (Robinson et al., 2012). This responsibility can increase through the trajectory of the disease, as a PwD's ability to participate in decision-making becomes increasingly compromised (see Bhatt et al., 2020 for a systematic review), and 'ownership' of the diagnosis is more likely to transfer to the FCG as they increasingly manage the interface between personal and public worlds on behalf of the PwD (Benbow, 2009).

Research has repeatedly found that the vast majority of individuals with, or without, cognitive impairment would prefer to be told about their dementia diagnosis (Bamford et al., 2004; Robinson et al., 2011; van den Dungen et al., 2014; Werner et al., 2010), and NICE (2018) guidelines advocate such transparency from health professionals. However, this has not always been the case in practice; in the early 2000s, an estimated 40-50% of PwD were not informed (Bamford, 2010; Carpenter & Dave, 2004) with non-disclosure attributed to medical professionals worrying about diagnostic uncertainty, concerns over PwD insight, lack of effective treatment and the fear of causing trauma to the PwD (Bunn et al., 2012; Keighley & Mitchell, 2004; Koch & Iliffe, 2010; Robinson et al., 2011). FCGs may also express caution about their relative knowing, due to a desire to protect them (Robinson et al., 2011). Research

has also found that only one fifth to one third of people with dementia could recall their diagnostic label accurately (Carpenter et al., 2008). This means that an important aspect of a FCG's decision-making burden, is whether to tell others about their partner's diagnosis as the 'burden of knowledge', often lies with the them as either the PwD is not told, or is unable to retain the information (Holroyd et al., 2002). Decision-making around telling others can be further complicated by the insidious onset of symptoms; in the early stages the diagnosis is often 'invisible', and, as symptoms progress, they become more difficult to conceal (Livingston et al., 2017). This means a FCG may have to revise their decision, or actions, to conceal or disclose the diagnosis over time, and in drawing a parallel with literature on individuals who attempt to conceal their stigmatised identities, to constantly monitor any individual situations to try and determine who is aware of the diagnosis, who may suspect or who does not know (Pachankis, 2007).

Longstanding privacy rules

For spousal FCGs, the increased responsibility for decision-making takes place within the context of the pre-existing marital relationship, where couples may have a longstanding approach to sharing or concealing private information between themselves or with others. According to communication privacy management theory (CPMT; Petronio, 2000; 2002), when two people form a long-term partnership they co-construct a set of privacy rules, and, over time, couples develop distinct ways of managing their private information and privacy boundaries (Petronio, 2002). In applying the theory, one can speculate that the onset of dementia for one half of a couple may disrupt these longstanding patterns of (explicit or tacit) communication. Decision-making may be especially challenging where the PwD absents themselves from decisions that would have previously been made by them, or collaboratively,

or where impairments in cognition are marked by lack of awareness, or deficits in problem-solving or organisation. Research shows that spousal FCGs commonly experience difficulties with the considerable changes in their relationship with the PwD and the increased responsibility associated with the transition to becoming a carer (Robinson et al., 2012).

Couples and families may also have pre-existing patterns of concealment. At the heart of the cycle of concealment model (CCM; Afifi & Steuber, 2010) is the idea that individuals keep sensitive information (such as a dementia diagnosis) private, to protect themselves and other family members from being hurt or shamed, and to preserve existing relationships. An individual may fear a negative reaction from family members due to past disconfirming or aggressive responses. These create expectations of negative reactions, and if they consistently happen, privacy boundaries may become impermeable over time. The principles of this model can be seen when applied to spousal FCGs of PwD; according to the World Alzheimer's report (2019), 35% of FCGs have hidden the diagnosis of a family member from at least one person, and research has found that partners may employ stigma management strategies through 'covering practices', helping to preserve the public face of the PwD and the couple as a 'collective unit' (Alzheimer's Disease International, 2019; MacRae, 1999). Generally, these processes of concealment by the FCG seek to protect both the PwD, and the family reputation (Mackenzie, 2006). Conversely, if individuals feel close to another, and their opinions are accepted, they are more likely to reveal sensitive information, and confirming reactions can enhance self-esteem and reinforce a desire to disclose (Afifi & Caughlin, 2006). Both CPMT and the CCM highlight the background context to decision-making through conceptualising the quality of pre-existing relationships, rules, and previous disclosure experiences. In applying these theories to spousal dementia disclosure, they help us consider why spouses and couples may adopt different disclosure or concealment strategies in

reaction to the same diagnosis, and move away from caregiver literature that tends to group FCGs together, ignoring differences both within and between couples.

In applying CPMT terms, spouse carers have co-ownership of diagnosis information that is akin to guardianship; the responsibility for protecting dissemination to individuals within and outside of the couple, and family, privacy boundaries (Petronio, 2010). Applying CPMT, and parallel research on FCGs of people with a mental health diagnosis, we would anticipate the dialectical tension spousal FCGs may experience when they want to conceal information, (to avoid harm such as stigma or protect the PwD) but simultaneously want to disclose (to seek support) (Karnieli-Miller et al., 2013). Disclosing private information is perceived as leaving one vulnerable (Petronio et al., 2004), but FCGs may have to alter privacy boundaries to attain the level of care and support needed for both themselves and the PwD. This may mean renegotiating privacy rules with the PwD as the illness progresses, or taking sole responsibility for privacy management (Petronio, 2010). CPMT research has found that healthcare and family privacy intersect to bring about boundary shifts to meet the needs of the person who is ill, as boundary protection is seen often as secondary to health concerns (Petronio et al., 2004). Applying this theory to dementia FCGs, this may result in them extending or violating traditional privacy boundaries for more support, at the risk of compromising their relationship or embarrassing the PwD. A further dilemma may occur if a PwD requests their diagnosis is kept confidential, as advocating for their own, or the PwD's best interests, may clash with protecting the information in accordance with the owner's wishes (Caughlin & Petronio, 2004). This is not an unlikely scenario as research has shown that many PwD, in the early stages of the disease, experience anxiety about others' reactions, and may hide their diagnosis, experience shame and withdraw from social situations (Riley et al.,2014; Robinson et al., 2011). In applying CPMT to understanding the communication-

privacy dilemmas faced by FCGs of PwD, it highlights the complex and potentially stressful nature of communication-privacy decisions, and suggests the need for a greater understanding of how spousal FCGs negotiate them.

Why disclose a dementia diagnosis?

Much disclosure research assumes that individuals will disclose for a cathartic effect (Greene, 2015). The decision to disclose a partner's diagnosis, under the right circumstances, could have a range of psychological and practical benefits for both the PwD and FCG that could mitigate wider aspects of caregiver burden. This includes increased family cohesion and teamwork in making difficult decisions, an opportunity to develop coping skills, a sense of relief, better scope for future planning, and increased access to support services (Bamford et al., 2004; Biernacki, 2003; Connell et al., 2004; Livingston et al., 2010). Disclosure may enable wider family and social support networks, and these have been linked with better coping and lowered levels of depression in spousal FCGs (Beinart et al., 2012). Disclosure has also been viewed as important for expressing feelings of loss for FCGs in relation to their partner's dementia (Derksen et al., 2006).

Research into dementia diagnosis disclosure has largely been undertaken from the perspective of the professional who needs to 'break the bad news', and has focused on reasons for disclosure or concealment, rather than what underlies the decision-making processes itself (Greene, 2015). To this author's knowledge, no research has looked at the decision-making processes that spousal FCGs go through when disclosing or concealing their partner's diagnosis to wider family or social networks. This is an important omission, as informing others about the diagnosis is a critical aspect of accepting the disease, and forming a new self-narrative for both the PwD and FCG (Weaks et al., 2015).

Models of Disclosure Decision-Making

In light of the gap in the research literature highlighted above, a decision was made to identify, describe, compare, and contrast existing models of disclosure decision-making, to consider their applicability to spousal FCGs, and consider their decision-making processes.

Identifying models

There is a vast field of decision-making literature, and therefore efforts were made to hone in on the potentially most relevant models to spousal FCGs. The models were selected following an initial '*Google Scholar*' search using the terms 'disclosure', 'model', 'privacy', 'stigma' to determine the most commonly cited models potentially relevant to spousal FCGs. From the initial search, further refinement and reading of relevant literature was carried out, alongside discussion with experts in the field of disclosure of stigmatised illnesses, when presenting ideas to the University College London Unit for Stigma Research (UCLUS) group. This resulted in four models being selected. The first is a general framework for studying self-disclosure (Disclosure Decision Model [DMM]; Omarzu, 2000). The second is for individuals living with a stigmatised condition or identity (Disclosure Process Model [DPM]; Chaudoir & Fischer, 2010). The third model focuses on decision-making around sharing health conditions or new diagnoses with others (Health Disclosure Decision-Making Model [DD-MM]; Greene, 2009), whilst the fourth considers the psychological impact of hiding a concealable stigmatised identity, and how individuals manage this – suggesting psychological harm can

come from concealment per se (The Cognitive-Affective-Behavioural Model of Stigma Concealment [CAB-SC]; Pachankis, 2007).

*The Disclosure Decision Model* (Omarzu, 2000)

The DDM (Figure 1) provides a framework for studying individuals' self-disclosure decisions across different situations, by evaluating their strategies behind disclosure behaviour. It assumes that individuals manage disclosures to achieve social and personal goals (Omarzu, 2000), and its focus is on explaining the initial disclosure decision. It outlines three stages of decision-making that can lead to different types and levels of disclosure, based on the assumption that disclosure decisions are the product of the careful balancing of risks and rewards, through the consideration of anticipated outcomes (Omarzu, 2000). The model links the purpose of disclosing for an individual to the availability of obtaining one of five potential goals (approval, intimacy, relief, identity, control; Figure 1), and posits that situational cues and individual differences are initially evaluated by an individual to predict the breadth, length and depth of disclosure in a given situation, prior to the three proposed stages.

The first stage, *entering the situation and pursuit of social goal* deems that individuals must perceive that disclosure is both possible and related to a disclosure goal (Omarzu, 2000). Barriers to disclosure at this stage include no clear disclosure goal, or goal conflict.

Stage 2 of the model is defined as *strategy selection and target search* - if both a situation and goal are accessible, an individual decides whether disclosure is an appropriate strategy. At this stage alternative strategies may be considered.

Figure 1

The Disclosure Decision Model (Omarzu, 2000)
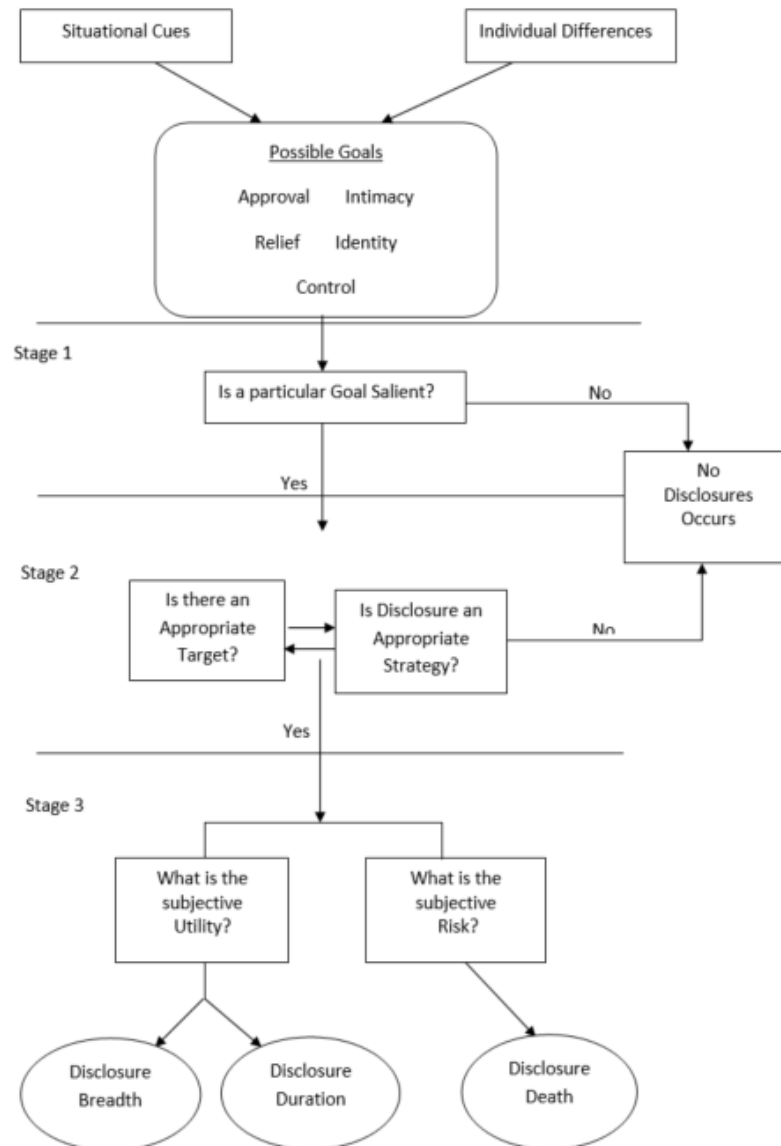
The third stage of the DDM is, once disclosure and a recipient have been selected, an individual considers the breadth, length and depth of disclosure. *Subjective utility* is the perceived value of the social goal, with *subjective risk* the perceived adverse effects of disclosure such as social rejection. The model proposes that the *subjective utility* of disclosing decreases breadth and increases duration of disclosure. Conversely, perceived *subjective risk*

decreases depth of disclosure and could result in disclosure of surface level information (Omarzu, 2000).

The Disclosure Process Model (Chaudoir & Fisher, 2010)

The DPM (Figure 2) is designed for individuals living with a stigmatised condition or identity, to understand disclosure decisions, and the impact of these on their wellbeing. It is based on the assumption that disclosing a concealable stigmatised identity is a complex process that can result in benefits and harm (Chaudoir et al., 2011). The model characterises the disclosure process through three main interrelated components: *decision-making, disclosure event*, and *outcomes.*

The decision-making component highlights how individuals consider the outcome of disclosure based on an approach or avoidance motivational goal system. Approach goals involve the pursuit of positive outcomes such as educating others or strengthening relationships, whilst avoidance goals are motivated by preventing negative outcomes such as social rejection or conflict (Chaudoir & Fischer, 2010).

The DPM also considers disclosure outcomes in relation to goal motivation. Individuals with approach goals pay closer attention to positive stimuli and approach-focused coping, and therefore may experience better outcomes compared to those with avoidance goals, as they are likely to communicate in ways that contain optimal levels of depth, breadth, duration, and emotional content (Chaudoir et al., 2011).

Figure 2

The Disclosure Process Model (Chaudoir & Fischer, 2010)
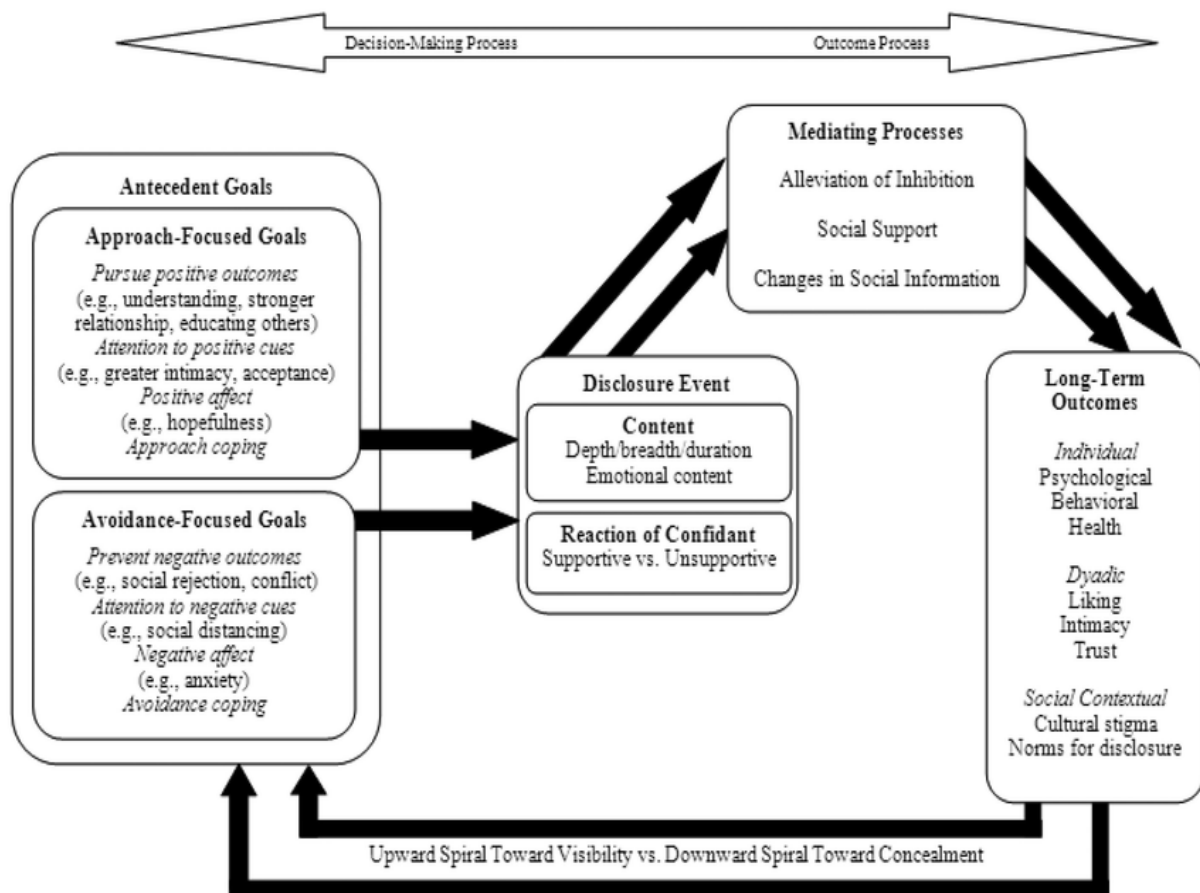
The *Disclosure Event* is the second stage, and considers disclosure content and confidant reaction. The DPM outlines the outcome of disclosure decisions at three levels. Individual outcomes refer to psychological or physical consequences of concealment or disclosure. Dyadic refers to interpersonal outcomes - a disclosure may help build or damage social relationships depending on the response. Individual disclosures can also affect the broader *social context* in which the discloser lives, and can facilitate discussion that may shape wider societal beliefs (Chaudoir et al., 2011). The 'feedback loop' describes how the outcomes of single disclosure events influence future decision making (Chaudoir et al., 2011).

*The (Health) Disclosure Decision-Making Model (Greene, 2009)*

The DD-MM (Figure 3) focuses specifically on health-related disclosure decisions, and how individuals balance the potential risks and benefits of disclosure (Greene et al., 2006). The model assumes that decisions occur in relation to an individual, are planned, and based on two main factors: *diagnosis*, *potential confidant*, that feed into an individual's *disclosure efficacy* (Greene et al., 2012). Assessment is at an individual (the diagnosis), and relational (potential confidant) level which leads to preferences and candidates for disclosure (Pahwa et al., 2017).

Assessing information about the diagnosis is broken down into five potentially overlapping factors: stigma, prognosis, symptoms, preparation, and relevance. Consideration of these factors demonstrates why there may be many different responses to disclosing the same diagnosis, and each aspect may or may not be relevant depending on their perceived importance to the individual (Greene, 2015). According to the model, perceptions of *stigma* associated with the diagnosis decrease intention to disclose, as perceived risk is elevated, though this may be mediated by the anticipated reactions and perceived effectiveness of disclosure (Greene, 2009).

The second factor is an *analysis of the potential confidant* by the quality of existing relationship and anticipated reaction; the model is suited to decisions where a personal relationship exists (Greene, 2015). This consideration of relational issues recognises that disclosure occurs in the context of social relationships, through active decisions that consider individual preferences (Pahwa et al., 2017). Individuals generally disclose to others they feel close to and trust (Greene, 2009), as they expect a more positive response (Petronio, 2002).

Figure 3

The (Health) Disclosure Decision Making model (Greene, 2009)
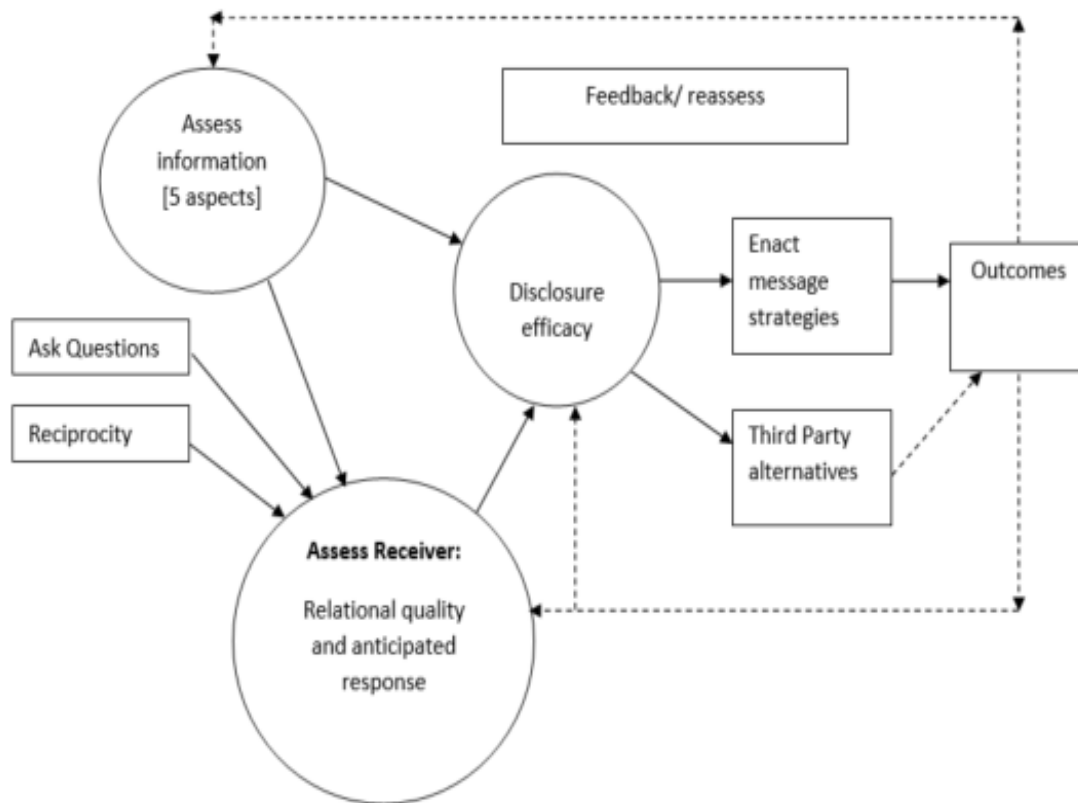
Disclosure efficacy is an individual's self-perceived ability to disclose a diagnosis and produce a desirable outcome (Bhatt et al., 2020). If they perceive adequate efficacy, and the other assessments indicate disclosure, they will enact the message which includes planning the setting, timing, medium and message features (Greene, 2015). Another alternative is the use of a third-party discloser. However, little research has considered this component of the model (Greene, 2015), and third-parties are seen as unable to truly 'disclose' because the information does not 'belong' to them (Greene, 2015).

The DD-MM conceptualises the disclosure process as non-linear and offers exit points in relation to decision-making. *Questions* from others can bring about, or force a disclosure.

Reciprocity is a potential reason for disclosure, and people generally share an equivalent disclosure (Greene et al., 2003).

The psychological implications of concealing a stigma: A cognitive-affective-behavioural model of stigma concealment (Pachankis, 2007)

The CAB-SC (Figure 4) was conceived to integrate research on people with concealable stigmas and consider the challenges they face, including disclosure decisions, worrying about discovery, isolation, and being detached from oneself (Pachankis, 2007). Specifically, it aims to understand the cognitive–affective–behavioural processes and psychological implications of concealing a stigma, noting their interrelated and bidirectional nature, akin to Beckian (1979) cognitive theory (Beck et al., 1979). The model considers the cycle common to all individuals when concealing a stigma. Essentially, doing so, activates a set of negative cognitive and affective internal reactions that influence eventual behaviour. *Self-evaluative* implications refer to the individual monitoring their interpersonal environment. The model suggests all four components are interrelated and play a role in perpetuating problematic psychological outcomes; the negative psychological impact of a concealable stigma is primarily around the challenges of concealing, per se (Pachankis, 2007).

Figure 4

The Cognitive-Affective-Behavioural Model of Stigma Concealment (Pachankis, 2007)
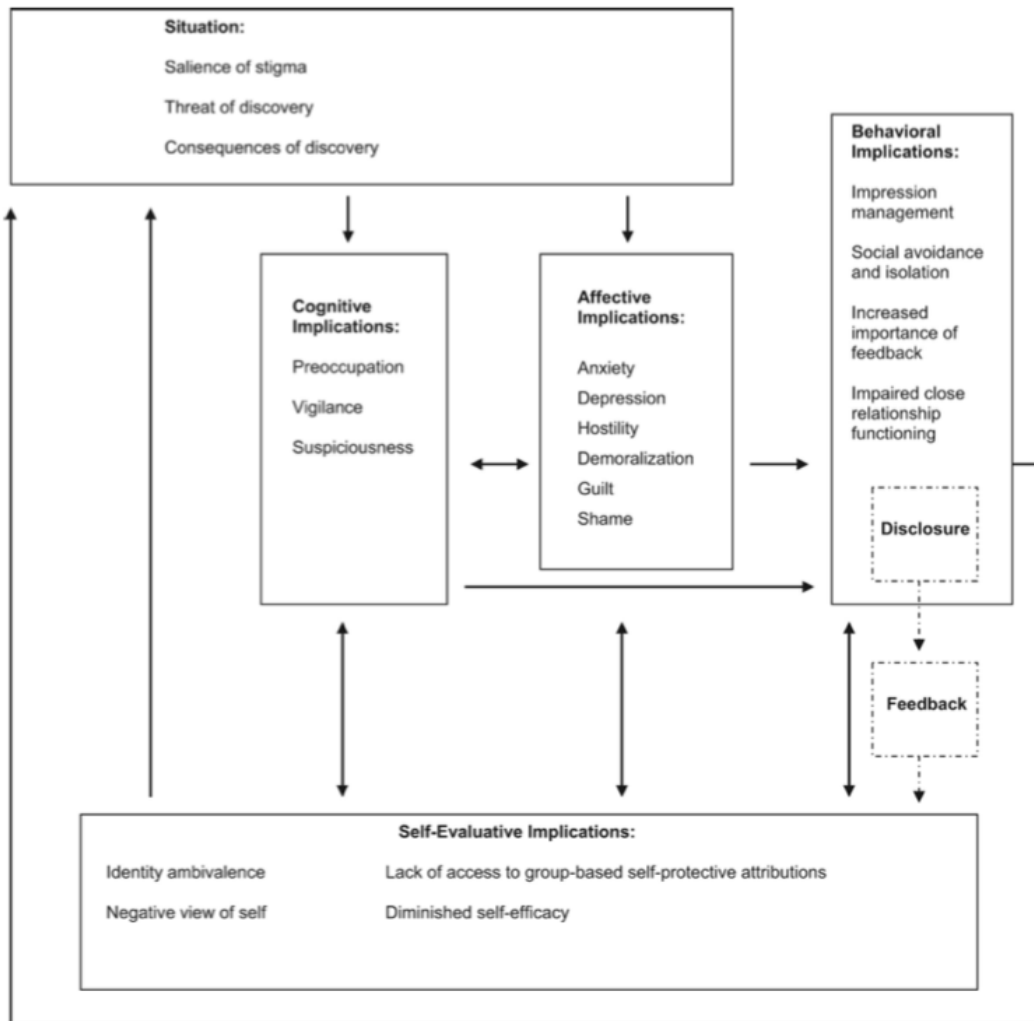
The model considers three situational influences an individual may internally struggle with when concealing. Cognitive, affective and behavioural implications are prompted by these (Figure 4). *Preoccupation* refers to rumination over active concealment, *Vigilance,* the monitoring of social interactions and *Suspiciousness* concealing a stigma in difficult situations where they may suspect discovery. These cognitive aspects foster (six) negative affective

states, which feed back into negative cognitions and perpetuate a cycle of concealment for a stigmatised individual.

The model proposes that individuals balance the stress of concealment, versus the potential stress of being devalued. Behavioural Implications, mainly focus on how concealing a stigma can disrupt interpersonal interactions. *Impression management* requires effort, is not guaranteed to work and is associated with distress (Pachankis, 2007). *Social avoidance* may prevent an individual from challenging their beliefs about how others may react (Miller & Rubin, 2007) and miss out on social support; facing challenges in close relationships.

The final part of the model outlines the damaging self-evaluative implications that concealment can generate. *Identity ambivalence* refers to an inconsistent view of one's core self. Concealing also prevents access to group-based self-protective attributions; an individual may view negative feedback as a personal deficiency rather than it being part of a stigmatised group (Crocker & Major, 1989), and consequently may not receive or internalise the normalisation and support identifying as a carer may engender.

Table 1

Comparison table of disclosure decision-making models

	Scope of model	Motivation behind disclosure	Consideration of feedback	Stance on desirability of disclosure'	How model was generated	Strengths	Limitations
DDM	Initial disclosure decision. Non-population specific self-disclosure. Breadth, depth and duration of disclosure.	Strategic and goal orientated (social and personal), based on balancing risk and reward to self.	Anticipated outcomes only	Neutral – considers when disclosure helpful/unhelpful	Theoretical model that requires empirical testing	-Specific goals/goal conflict -Alternative strategies -Non-disclosure exits	-Only considers initial disclosure decision -does not consider wider cultural context
DPM	Individuals living with stigmatised identity (self-disclosure). Disclosure as process including decision, event and outcome. Breadth/depth of disclosure.	Goal oriented - approach versus avoidance motivation, related to goal type. Ego-centric.	Disclosure outcomes (at 3 levels) and feedback loop to future decisions	Neutral – looking at when and why disclosure will be beneficial	Conceptual framework drawn from existing literature to be tested in future research	-Goal approach related to outcome -Dyadic and Societal outcomes -Process and feedback loop	-does not consider wider cultural context in decision-making
DD-MM	Initial decision around health related (self) disclosure. Considers diagnosis, confidant and value of disclosing. Also considers questions and reciprocity as interruptions to planned disclosure.	Balance of risk and benefits at individual and relational level. Considers self-perceived efficacy of individual to produce desired outcome.	Anticipated outcome through existing relationship. Feedback of outcomes to future decision making	Neutral	Proposed theoretical framework to predict decisions to disclose. Integrates existing research, proposes areas to test in future research.	-Detailed information assessment of diagnosis in decision-making -Disclosure efficacy -Different mediums of disclosure -Interruptions	-groups all health conditions together
CAB-SC	Individuals with concealable stigmas, and the negative cycle that can become self-perpetuating if one conceals.	To break negative cycle of concealment and disrupt unhelpful thoughts/behaviours to improve overall wellbeing	Cognitive monitoring/vigilance when concealing. Responses influence future disclosure.	Concealment negative, per se	Theoretical model to guide interpretation of literature and suggest future directions for research	-Considers consequences of concealment and benefits of disclosure -Identity ambivalence	-overly negative on concealing -lacks specific consideration of decision-making process

Synthesis: comparison of models and consideration of their applicability to dementia spousal family caregivers

Table 1 summarises some of the key aspects of the four models. These will be discussed below, alongside their applicability to spousal FCGs.

Scope of model

A central aspect of all models is their focus on self-disclosure, which in itself highlights a gap in the current literature in relation to a model specifically for FCGs, or anyone disclosing another person's information. Indeed, the DD-MM is the only model that mentions third-parties, in a manner not relevant to their decision-making.

There are also no disclosure models that consider a decision over dementia, per se. Whereas the DDM is non-population specific, the DPM is designed for individuals living with a stigmatised identity; caring for someone with dementia would only loosely fit under this umbrella. The DD-MM is currently the only model specific to health-related disclosure, albeit from perspective of the person with the condition (Greene et al., 2012), whereas the CAB-SC model specifically relates to concealable stigmas, an umbrella under which dementia can fit (Herrmann et al., 2018). However, the model assumes an individual is concealing an identity from the outset, which does not factor in the multitude of disclosure decisions a FCG may enact.

The information assessment component to the initial disclosure decision in the DD-MM, is broken down into more detail than the other models, and specifically focuses on the diagnosis, to form a complex conceptualisation of health information (Greene et al., 2012). *Prognosis, relevance* and *symptoms* are all directly relevant to dementia decision-making. For example, FCGs may consider a poor prognosis as a reason for disclosure to those close to the

PwD; so they can 'make the most' of time left, or before further cognitive deterioration. Similarly, symptoms of dementia are fluctuating, unpredictable and present in many different ways (Livingston et al., 2017). Some behaviours such as swearing or shouting, are likely to be perceived by FCG as more stigmatised, in comparison with those such as word finding difficulties. However, the latter are also likely to be more concealable. It is unclear how specific symptoms may influence a disclosure decision, but a PwD's symptoms generally become more difficult to conceal as the disease progresses, which may be a factor in telling others as it is perceived there is no alternative.

Whereas the DDM and DD-MM both mainly focus on the initial disclosure decision, an advantage of the DPM is it offers a more comprehensive and interrelated overview of disclosure decisions through describing the disclosure process from decision-making, and event, through to outcomes. Disclosure is conceptualised as an ongoing process that has significance across several domains, influences subsequent disclosures, and has repercussions at the societal level that can continue beyond the initial disclosure event (Chaudoir & Fischer, 2010). An example of this in relation to spousal dementia FCGs, is actress Barbara Windsor's husband, Scott Mitchell, publicly disclosing her diagnosis of Alzheimer's disease, and the subsequent coverage this has received, which has increased awareness of both the impact of dementia and caring responsibilities (BBC News, 2020). According to the model, if an individual is motivated with approach goals, such as educating others or de-stigmatising dementia, then such societal outcomes may influence future decision-making for the individual, if they see a positive outcome in relation to this goal. This is highlighted in Mr Mitchell's frequent interviews and media appearances up until her death. In relation to decision-making, this helps highlight the on-going process that FCGs may go through during the trajectory of their partner's illness. Similarly, the concept of

disclosure efficacy from the DD-MM is a highly relevant consideration for FCGs, and adds

the other models by encapsulating how an individuals' personality traits, past experience of

disclosing, and new disclosure experiences, impact an individual's self-perceived ability to

disclose. This helps demonstrate why a FCG's disclosure decisions can change over time and

how decision-making is influenced in a way independent from the disclosure content.

Another aspect unique to the DD-MM is *interruptions* in regards to *questions* and

reciprocity which are an advantage of this model in considering how the traditional decision-

making process may be bypassed due to situational opportunities or conversational acts that

may unexpectedly arise. These both are important considerations in relation to spousal FCGs

where the symptoms of the PwD may create impromptu opportunities for disclosure through,

for example, others questioning unusual behaviour or absences from social occasions. There

is also an increased prevalence of dementia and earlier diagnosis in older populations, making

it likely that there may be similar others in a FCGs social network where reciprocal disclosures

may occur. Similarly, the DDM is helpful in considering why individuals may choose non-

disclosure; if an individual can obtain their goals without disclosing (for example, FCGs may

perceive that *relief from stress* can occur through exercise rather than telling others), which

help move away from the prevalent narrative within the literature that tell us disclosure is

helpful or necessary, per se (Greene, 2015).

In terms of individual model components, the importance of identity is considered in

both the CAB-SC and DDM, and this is likely to be important in relation to FCG decision-

making, in regard to the transition to a FCG role and loss of previous identity (Robinson et al.,

2012). Concealing a family member's dementia diagnosis may help preserve a sense of

previous identity for a spousal FCG, because they may anticipate others will continue treat

them in the same way. However, they may also perceive efforts to conceal as a source of

unnecessary distress, especially when trying to merge existing roles alongside caring duties, and may view disclosure as a way of establishing and then accepting their new identity.

An important component outside of the scope of the models is the PwD's reaction to their diagnosis and its subsequent influence on FCG decision-making. Research has shown that many PwD, when in the early stages of the disease, experience anxiety about how others may respond to them and contemporary and prospective loss in relation to their identity, self-esteem and functioning (Robinson et al., 2011). This may result in hiding their diagnosis and withdrawing from social situations, leading to overdependence on family members (Riley et al., 2014).

All four models were developed to integrate and organise lines of research, and are mainly theoretical in nature.

Motivation behind disclosure

A theme running through the DDM, DPM and DD-MM is the idea of balancing risk and reward, with decision-making conceptualised through an ego-centric lens; an individual's focus is on managing their self-image whilst avoiding harm (Derlega et al., 2004). In relation to spousal FCGs this highlights an important point of interest that cannot be accounted for in the models – whether disclosure goals are ego-centric or based on the best interests of the PwD. This alone highlights an additional decision-making burden in terms of whose interests to privilege. For example, a desire to preserve a pre-dementia identity may be communicated to spouses who then must decide whether to respect their partner's wishes and not tell others, negotiate who can be told, or violate these wishes in regard to their own, or the PwD's perceived best interests (Bunn et al., 2012). The DPM's conceptualisation of approach and avoidance, in relation to goals, offers a more nuanced approach, and allows a wider range of

goal consideration under the over-arching theme of motivation. It also suggests when FCG disclosure may be more successful, based on the factors that underlie the decision and moves away from the simplistic notion that disclosure will always lead to positive outcomes. Indeed, a criticism of the CAB-SC it that it oversimplifies outcomes with the notion that concealment is 'bad' and disclosing is 'good'. We know this is untrue in the dementia field as stigma may result in the exclusion of the PwD and their FCGs by others (Herrmann et al, 2018). Dementia severity is linked with social distance toward a PwD and PwD and FCGs have reported losing friends due to a lack of understanding and a fear of 'contagion' (Devlin et al., 2007; Werner, 2005). The model's author acknowledges that concealment can be adaptive in difficult environments, and individuals may choose a realistic placement of boundaries along a disclosure-concealment continuum (Pachankis, 2007).

The DD-MM and DDM both allude to stigma or social approval in relation to goals, which is a highly relevant consideration for spousal FCGs, as fear of judgement could be a powerful reason for concealment (Bunn et al., 2012), and dementia related stigma is globally pervasive, and universally impacts help-seeking, and the quality of life for both the PwD and their FCG (Herrmann et al., 2018). Indeed, 'courtesy stigma' has been reported by FCGs of PwD. This refers to a tendency for stigma to 'spread' from the individual with the stigmatised identity to their close connections, which may be relevant to spousal FCGs making disclosure decisions (MacRae, 1999). Similarly, *relief from stress* in the DDM may be a pertinent disclosure goal, due to FCG vulnerability to poorer mental and physical health (Etters et al., 2008). The notion of goals in the DDM and DPM (and goal conflict in the DDM) are also relevant as disclosure may be pre-planned in nature (Bhatt et al., 2020). It is likely that disclosure goals may change over the course of the PwD's illness, where they may require different kinds of help or support depending on the severity of the condition. For example,

early on, FCGs might be keen to have a confidant for emotional support. Later, they might need 'micro-respite' or tangible support for themselves and the involvement of others to maximise the wellbeing of the PwD. This suggests that stage of the illness is an important factor to consider in the disclosure decision-making process.

Consideration of feedback or anticipated response

A limitation of the DDM is that it does not consider the confidant's reaction (anticipated or actual), or how wider disclosure outcomes may influence future disclosure decision-making (Derlega et al, 2004). The DPM considers the outcome of disclosure decisions at an individual, dyadic, and social contextual level, including confidant reaction. The consideration of dyadic outcomes in particular, are likely to be relevant for FCGs, as they may influence future disclosure behaviour (Derlega et al., 2004). In terms of decision-making, outcomes within the DPM are important only in terms of how they influence future disclosure decisions. This is demonstrated through the inclusion of the feedback loop. A theme running across the DPM, DD-MM, and CAB-SC is the notion that positive responses from others increase efficacy and the likelihood of future disclosure, and research shows that expressing supressed thoughts or receiving a supportive response through disclosure can be beneficial for spousal FCGs (Bhatt et al., 2020). Anticipated response, outlined in the DD-MM, is a helpful component of the decision-making process as it considers the FCG's interpersonal relationship with the potential confidant. It is supported by dementia research that found people often begin by assessing their social network in terms of who to tell, with disclosure selective and purposeful (Bhatt et al., 2020). This is an aspect unique to an individual FCG in terms of what they perceive the anticipated outcome will be and is supported by CPMT; if an individual feels close

to someone, they may anticipate them to be accepting and supportive, and their privacy boundaries may become more permeable as they view less disclosure risk (Petronio, 2000).

Stance on desirability of disclosure

Another aspect of the models to consider in the way they frame decision-making, is their stance on the desirability of disclosure. The DDM, DPM and DD-MM all take a neutral stance through consideration of the factors that individuals weigh-up. For example, the DDM seeks to understand what prevents people from disclosing when potentially helpful, or revealing too much and then regretting it (Omarzu, 2000). The CAB-SC in contrast, views concealment of stigmatised identities in a negative light. When considering applicability to spousal FCGs, a neutral stance is more relevant as this considers the range and complexity of disclosure decisions. However, the proposed negative cognitive and behavioural consequences of concealment within the CAB-SC illuminate the difficult decision-making process a FCG may face, and potential stress if concealing. Parallel research on concealment of sexual orientation has been referred to as a 'private hell' for the concealer (Smart & Wegner, 2000, p.222). This may be particularly relevant if a FCG is engaged in extensive 'covering practices' in relation to their partner's diagnosis. The model also specifically captures the uniqueness of decision-making when an illness is concealable, which can apply to dementia, depending on the nature of symptoms, stage of illness and concealment efforts made. I*mpression management, social avoidance* and *ongoing vigilance* could all influence a decision over-time, as, for example, they become too burdensome. The CAB-SC also helps conceptualise how an FCG may be unable to challenge their negative beliefs concerning disclosure in the decision-making process, as they cannot discover whether the perceived negative consequences come true (Pachankis, 2007).

Disclosure strategy

The DDM and DPM consider a disclosure approach in terms of breadth, depth and duration of disclosure. The notion of deciding a disclosure strategy is an important component in decision-making as an individual may be comfortable with a certain approach. Disclosure has been conceptualised as existing on a continuum, in relation to mental illness (Corrigan et al., 2011). Herman (1993) described a hierarchy of approaches that range from *social avoidance* – telling no one and avoiding exposure, to *broadcast experience* – where a person actively educates others through experience sharing. In-between are three stages. *Secrecy* involves keeping the illness a secret but not avoiding situations, *selective disclosure* involves a discriminant approach to what and with whom one discloses, *indiscriminate disclosure* means the illness is not actively concealed from anyone. *Secrecy* and *social avoidance* would be concealment strategies for FCGs. The idea of disclosure on a continuum is helpful in the consideration of how a disclosure approach may change as the FCG and PwD engage in an ongoing process of assimilation, adaptation and adjustment (Cheston, 2013). Disclosure is not an 'all or nothing' process, but a more nuanced decision that can be refined over time and employed differently amongst a FCGs social network; decisions are not one-off events, and may potentially occur with every new situation or person that is encountered (Derlega et al, 2004). This is particularly relevant to health disclosure decisions that can be ongoing; as the dementia progresses, disclosure decisions may be constantly reassessed – especially with those who are not informed (Greene, 2015).

Conclusion

Longstanding communication-privacy rules and societal attitudes towards dementia (stigma) provide the context within which spousal carers make disclosure decisions to wider family

and friends. There are no theoretical models of disclosure decision-making by spouses of a PwD, however, based on models of personal disclosure of health conditions or stigmatised identities, we may anticipate that factors that influence decision-making are: the weighing-up of, sometimes conflicting, goals; the anticipated response from the potential confidant; perceptions of stigma associated with a dementia diagnosis; past disclosure experience and, the situational circumstances a FCG may find themselves in. It is also likely that the PwD's symptoms, and the progression of these over time may influence a decision to disclose, through a potential need for increased support for the FCG or PwD, or to help contextualise increasingly obvious symptoms. The models selected predominantly emphasise rational, information processing theories of decision-making. Other theories assert that emotions are the dominant driver of the most meaningful decisions in life (see Keltner & Lerner 2010 for a review). This may be highly relevant to spousal FCGs given the potentially emotive circumstances and the nature of disclosure decisions. The lack of integration of emotion focused decision-making theory highlights a limitation of current disclosure decision-making models. The above synthesis has highlighted that individual components of existing models of disclosure decision-making have some applicability to FCGs of PwD, but there are also significant limitations in their applicability, especially in relation to the unique context of a dementia diagnosis (fluctuating concealability), making disclosure decisions on behalf of someone else, the influence of courtesy stigma (MacRae, 1999), the role of emotions, and third-party influences from the PwD on the FCG disclosure decision. This highlights the gap in the literature for qualitative investigation to understand the disclosure decision-making process negotiated by the spousal FCGs of PwD.

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Part 2: Empirical Paper

How do partners of people with dementia decide whether to tell

family and friends about the diagnosis?: A thematic analysis

Abstract

Background: Family caregiver(s) (FCG) disclosure of a person(s) with dementia's (PwD) diagnosis to their wider family and social network has risks and potential benefits.

Aims: To explore the factors that influence a FCG's decision-making process on whether to disclose or conceal their partner's dementia diagnosis.

Method: Individual semi-structured interviews were carried out with 12 current or former spousal FCGs of a PwD, using a topic guide. Recruitment took place via social media and word of mouth. Audio-recordings were transcribed and analysed using reflexive thematic analysis, following the stages outlined by Braun and Clarke (2021). A constant comparison approach was used to evolve codes and emerging themes.

Results: Analysis identified three overarching themes: 'Decisional absence', 'Decisional influences', and 'Decisional dilemmas'.

Conclusions: This research has increased our knowledge of how spousal FCGs make decisions in telling others about their partner's diagnosis, looking at how they may avoid decision-making, key decisional influences, and the ongoing dilemmas they face. The implications for these findings are discussed alongside areas for future research.

Introduction

UK government policy over the past decade has championed earlier dementia diagnosis, alongside an ageing population (National Institute for Health and Care Excellence [NICE], 2018). This has increased the number of spousal FCGs, at an earlier stage in their partner's illness, where symptoms may more easily concealable (Livingston et al., 2017). Spousal FCGs are at risk of a host of negative physical and psychological outcomes (Etters et al., 2008). Telling others about their partner's diagnosis may enable practical and emotional support to mitigate against negative outcomes. However, this may go against their partner's wishes, move long-standing privacy boundaries, or create anxiety around stigma, and result in the loss of friendships and social demotion (Devlin et al., 2007; Harman & Clare, 2006; Werner, 2005; Werner et al., 2010). Thus, decision-making over whether to conceal or reveal a partner's dementia diagnosis to wider family and social networks is a complex process for spousal FCGs. It is also significant, as the task of conveying information about the diagnosis to other people within their social networks represents a crucial aspect of coming to terms with the illness, and developing a new self-narrative, for both the FCG and PwD (Weaks et al., 2015). In order to support FCGs struggling with the decision to disclose, it is important to understand their experience and what factors influence disclosure (Eaton et al, 2017). As shown in the Conceptual Introduction (CI) to this thesis, existing models of disclosure decision-making have some applicability to spousal FCGs of PwD, but also limitations in being able to consider this unique context for decision-making.

This research

Due to the nature of the topic, a qualitative approach was adopted, as they are oriented towards understanding meanings and experiences of individuals, through rich descriptions within their local contexts (Castleberry & Nolen, 2018). Spousal FCGs were interviewed to understand how they make decisions over whether to tell their family and wider social network about their partner's dementia diagnosis.

The research focus is on spouses, as the spousal relationship provides a unique context for decision-making, due to the longstanding nature of partnerships and privacy boundaries (Petronio, 2010). Spouses are faced with disclosure decisions whilst also navigating the loss of partnership, emotional closeness, and sense of self and identity (Robinson et al., 2011). They are the most common family member taking on the primary caregiver role, and those most likely to have poor health outcomes (La Fontaine et al., 2016; Martin et al, 2006; Schoenmakers et al., 2010). Research has shown that kinship differences may influence the perception and impact of stigma associated with a dementia diagnosis, alongside the unique context of a spousal relationship, making it important to focus on spouses alone within the remit of this research (Hong & Kim, 2008; MacRae, 1999).

Disclosure behaviour in relation to mental illness has been linked with a host of individual level factors, such as gender (Brohan et al., 2012), but no research has considered these in relation to disclosure of a partner's dementia diagnosis. Gender is important to consider; a recent systematic review of the literature found that women are more likely to suffer from depression and report greater caregiver burden as a result of caregiving (Xiong et al., 2020). Disclosure could be a possible barrier to this through enabling further support, though research found that gender differences also influence coping strategies, with females more likely to share information with others (La Fontaine et al., 2016) - suggesting that they may disclose for social support. Men are more likely to stigmatise dementia (Herrmann et al.,

2018) which may be internalised and therefore impact their disclosure decisions. In regards to ethnicity, stigma may be particularly strong among ethnic minorities whose belief systems explain dementia in non-medical terms. For example, in Hispanic-American and Chinese-American communities, research has found that FCGs were concerned about how others may react to a family member's diagnosis, the former noting that the literal translation for dementia was 'crazy' (Vickrey et al., 2007, p.238). The euro-American or western view of dementia is generally through the lens of the medical model, which can lessen stigma through its externalisation as any other medical condition (Herrmann et al., 2018). Although FCGs from ethnic minority backgrounds may believe a diagnosis should not be shared outside the immediate family, they may also see caregiving in a more positive light (Doris, et al., 2018; Waite et al., 2004). This may impact both the decision to disclose and the perceived potential benefits or disadvantages of doing so within these populations. A recent systematic review found that Afro-American spousal dementia caregivers had better psychological well-being than their white counterparts. It was speculated this may be due to a network of family member support beyond the dyad (Lui et al., 2020). This implies that disclosure among Afro-Americans helped to reduce caregiver burden through eliciting support.

Another important factor to consider in decision-making may be the amount of time passed since the PwD was diagnosed. This provides an indication of the duration of 'official' caregiving for a spouse. This may impact a spouse's disclosure or concealment decision, as it could be assumed that someone is more likely to have disclosed over time, as they have adapted to their role as a carer. Similarly, the PwD's symptoms may have become more prominent or more difficult to conceal over this time, which may have necessitated disclosure. This is significant as a PwD's higher care needs are related to higher caregiver depression, and a failure to adapt to progressive decline increases caregiver burden

(Papstavrou et al., 2007; Schoenmakers et al., 2010). A FCG's perception of the ability of the PwD to participate in decision-making is an important factor in their own decision-making process (Caron et al., 2006). Therefore it may be that in early stages of the illness they may delegate decision-making to them, as they perceive they are still able to do so. Those who have been caring for longer may have also changed their initial disclosure decision, which offers the possibility for exploration of factors that have directly influenced this. On the basis of this existing literature, it is likely that certain demographic and partnership differences might yield different views and influences on disclosure. Therefore it is important to have a sampling frame that will try and capture the diversity of views and influences that impact decision-making, through representation of different genders, ethnicities and time since a diagnosis was received.

Research Question

The central question of this research is to understand the factors involved in the decision-making process that spousal dementia FCGs go through when making a disclosure decision.

Method

Approach

Reflexive thematic analysis (TA; Braun & Clarke, 2020) was the analytic method used to report patterns across the interviews. As TA is frequently misunderstood as one set of procedures, and poorly demarcated (Braun & Clarke, 2006; 2018), it is important to define a reflexive approach, alongside outlining the accompanying epistemological and ontological positions taken, to show how the methods and central question are in alignment (Braun & Clarke,

2019a; Willig, 2013). Reflexive TA defines themes as patterns of shared meaning underpinned by a central organising concept. In this approach, themes cannot exist independently from the researcher, who actively constructs them via their unique personal lens in order to make sense of the data, and tell its story in relation to the central question (Braun & Clarke, 2015; 2019a; 2021). In this sense reflexive TA exemplifies a 'Big Q' qualitative approach (Kidder & fine, 1987), acknowledging researcher subjectivity, and an organic and recursive coding process (Braun & Clarke, 2013; 2019a).

The central research question was approached in a critical realist, inductive, and (mainly) semantic manner. One of the most important tenets of critical realism (Guba & Lincoln, 1994) is that ontology (i.e. the nature of reality) is not reducible to epistemology (i.e., our knowledge of reality). In this sense human knowledge captures only a small part of a deeper and vaster reality. The inductive approach facilitated understanding of decision-making influences as the participants described them. This allowed the researcher to remain close to the participants' meanings, and report an assumed reality, whilst acknowledging that this does not mirror reality, and that responses are being viewed through a particular interpretative lens through which meaning is then made (Smith & Shinebourn, 2012). A semantic approach focuses on the surface level meaning of the data in the interpretation, with a unidirectional relationship was assumed between meaning, experience and language, and the data providing the bedrock for identifying and interpreting meaning (Terry et al., 2017). This was opposed to latent one which goes beyond the semantic context of the data to identify or examine the underlying ideas or assumptions (Braun & Clarke, 2006).

Reflexive TA was preferred to other qualitative analytical methods as it provides a robust and systematic framework for coding and analysis in relation to the research question (Braun & Clarke, 2014). As the research questions was seeking to understand processes as

the participants described them, considered more appropriate than analytic methods that examine the interaction of speech, such as Conversation Analysis (i.e. Madill et al,. 2001). Similarly, it was used instead of Interpretive Phenomenological Analysis (IPA) due to the latter's greater analytic depth, focusing on language (such as the meaning of pauses or laughter), which was not considered helpful in addressing the central question (Braun & Clarke, 2021). IPA also uses an ideographic approach and focuses on each individual prior to developing themes across cases. The central question of this research necessitated that patterns were identified across the dataset. Reflexive TA was preferred to Grounded Theory (GT) so that coding could focus on the central question, rather than a line-by-line approach. There was no prior intention to develop a grounded theory from the dataset.

Reflexive TA was also preferred to 'little q' (Kidder & fine, 1987) approaches to TA, or more rigorous systematic approaches such as content analysis. These approaches are seen as attempts to bridge the qualitative-quantitative divide, through, for example, focusing on 'reliable' coding. However, the focus in this research was on meaning, and meaning-making, which is always context bound (Braun & Clarke, 2019a). This process of coding data, without trying to fit it into a pre-existing coding framework, was congruent with a critical realist epistemological stance to gain an understanding of the meanings that FCGs placed on the disclosure process, and their lived experience of this (Castleberry & Nolen, 2018). This inductive approach was deemed appropriate as participants' views on the topic were not well known, and followed guidance that recommends placing the perspectives and experiences of people with suspected cognitive difficulties, and *their families*, at the centre of the research process (British Psychological Society [BPS], 2014).

Study and Ethical Approval

The protocol for the research was internally reviewed and approved by member of the academic staff within clinical psychology doctoral programme.

Ethical approval was obtained from the University College London Research Ethics Committee (Project ID: 16961/001; Appendix A). During the research design it was noted that some of the conversations with the interviewees had the potential to be upsetting, and that it may be more difficult to respond to these in an online interview. Therefore measures were taken to negate possible distress. The researcher built rapport with participants before the interviews to get a sense of how they felt about the topic, and 'checked-in' and offered appropriate breaks during the interview, as required. The researcher was also a clinical psychology doctoral trainee who had clinical experience of online therapy, covering sensitive topics, and therefore felt they would be able to pick up on cues to judge levels of participant comfort or distress. They followed the latest BPS (2020) guidelines on remote work.

Development of study materials

The topic guide (see Table 1) was devised following extensive reading of other diagnosis or stigmatised identity disclosure research, with adaptation of the questions for spousal FCGs. An initial list of questions were discussed with the research supervisor that were narrowed down to avoid repetition and aid focus on the research question. During the design phase of the study a presentation was also made to the University College London Unit for Stigma Research (UCLUS) to get feedback on the participant information sheet (PIS; Appendix B), topic guide and study title in regards to comprehensiveness, clarity and relevance. Feedback was sought from a spousal FCG who had expressed an initial interest the research, but

decided not to take part. Some of the wording of questions on the topic guide were adjusted in light of this to make them easier to understand.

Recruitment

Inclusion criteria

Participants were currently or formerly in a longstanding (spousal) partnership with someone with a dementia diagnosis, and were willing to talk about their experience in an audio-recorded online or telephone interview in English.

Recruitment procedure

A sampling frame was used to try and ensure maximum diversity of gender, ethnicity, and 'time since diagnosis' to try and elicit a diversity of experiences in relation to spousal FCG disclosure. Purposive and theoretical sampling were used in relation to this, with the characteristics of early participants compared to the sampling frame, and the recruitment activities amended accordingly. For example, as early participants were predominantly white-British, additional recruitment activities were introduced through the researcher taking part in a Twitter Live with @DiversAlzheimers that was a Twitter account created specifically for non-white dementia FCGs.

Participants were recruited through self-identifying in response to local advertising, word of mouth and social media publicity, and recruitment literature (Appendix C) was disseminated widely through these networks. It was intended for recruitment to continue until 'data saturation' was reached (Fusch & Ness, 2015).

Consent procedure

Individuals who expressed an interest in participating were sent the PIS in order to help them make an informed decision on whether to take part in the study. If they wanted to go ahead they were then sent a consent form (Appendix D) and demographic information sheet (Appendix E) which they were able to sign and return electronically. Participants were also asked on the consent form whether they would like to be sent a preliminary summary of the results once initial analysis had taken place (to participate in a respondent validation exercise). The option of posting a hard copy of the form to participants for them to sign and return was also given to participants, but none took up this offer. Participants were assigned a unique ID number which was put on their demographic information, consent form and interview transcript. A linking document matching participant IDs and names was stored separately. All participant information was kept securely on a University College London server via a password protected account.

Interview procedure

The majority of interviews took place online via *Microsoft Teams* due to the COVID-19 pandemic, and these were audio recorded. The interviewer went through the PIS with the participant at the beginning of each interview and double-checked consent orally. Guidance was provided on how to use and access *Microsoft Teams* for those who requested it. Telephone interviews were used with two participants who stated that this was their preference.

The researcher asked 'open' questions from the topic guide, rather than a fixed set of questions that limits participants to pre-defined response options. Open questions allowed the participants to describe situations, motivations and experiences in their own words, unconstrained by the researcher's preconceptions. This also allowed for supplementary questions to follow-up on areas of interest, and the revision of the topic guide between interviews as areas of interest were identified through analysis. The researcher sought to build rapport with interviewees, and conduct the interview in a conversational style.

Participants were given the option of receiving a gift voucher after the interview which was sent to them via their email address. They were also sent a debriefing document (Appendix F). One participant asked for a donation to be made to the Alzheimer's Society instead, and this was done anonymously on their behalf.

A reflective journal was kept after each interview to ensure that reflections were accurately recorded. This was used to expand on the researcher's initial impressions of the interaction with more considered comments and perceptions (Halcomb & Davidson, 2006).

Table 1

Topic Guide

Topic Guide

Please note the following in relation to the topic guide:
a) Early in the interview the interviewer will establish the terminology preferred by the interviewee (dementia, Alzheimer's, memory problems, etc)
(b) The content of the questions is flexible to cover whichever form of disclosure (or non-disclosure) was used be the individual participant
c) The ordering of the questions is flexible to facilitate a natural flow to conversation during the interviews.

1. Since your partner was told they had dementia, what kinds of conversations do the two of you have about the diagnosis, between yourselves?

2. Have you told other people about your partner's diagnosis?
   Can you tell me a bit more about this?

3. Have you ever decided not to tell others about your partner's illness? Can you tell me a bit more about this?
   - When in the company of others, is there anything you (or your partner) do to 'cover up' or hide your partner's diagnosis of dementia? Why?

4. What has influenced your decision to tell others/not tell others about your partner's dementia?
   Prompts: Who to tell? How to tell them? When to tell them?
   [cover all forms of disclosure as influencing factors may differ]
   -What was your partner's view on this?
   - Why did you decide to tell others about your partner's dementia ?

5. What was your experience with telling other people about your partner's dementia?
   [cover all forms of disclosure as concerns and reactions may differ]
   - What concerns did you have?
   - What reactions have you had from others?
     a) Did their response differ from what you were expecting?

6. How has telling others affected your own wellbeing?
   -How has telling others affected your partner's wellbeing?

7. How has your decision to tell others changed over time?

Transcription and analysis

All interviews were transcribed by the researcher within one week of the recording taking place, and the original recording destroyed after the transcript was re-read and checked against it. This was in accordance with guidance that the researcher should both interview and transcribe data to facilitate a holistic overview of the research process and enable a reliable interpretation of the data (Easton et al., 2000). Transcriptions were done without the use of transcription software, in order to begin data immersion, and this was part of the first stage of data analysis as opposed to a clerical task (Halcomb & Davidson, 2006). Transcription conventions were followed as outlined by Bailey (2008) who notes that the aims and methodological assumptions of a project will determine the form and content of transcripts. As the study adopted a critical realist approach it focused on transcribing verbal data accurately, as it was spoken, with an indication of brief pauses and laughter. It omitted intonation or longer pauses, which may have been more helpful in an approach focusing on deconstructing interactions and language. Transcribed talk that was faltering and inarticulate (i.e. repetitions/false starts) was also omitted to avoid cluttering the text; striking a balance between readability and accuracy (Bailey, 2008).

The different phases of coding and identifying themes were followed, as outlined by Braun & Clarke (2021; Table 2). Although these phases are sequential, analysis was a recursive process, with movement back and forth between different phases.

Table 2

Stages of Reflexive Thematic Analysis (Braun & Clarke, 2021)

1. **Familiarisation with the data** - each interview was transcribed as stated above, in line with Bailey's (2008) conventions. Transcripts were re-read several times to help data immersion and familiarity with content. Preliminary observations about areas of interest were noted.

2. **Coding -** this began alongside data collection, with initial codes relevant to the central question established. After three interviews initial codings were discussed with the research supervisor in reference to the central question. Codes with similar content were clustered together to create an ongoing coding framework which was re-worked and revisited in a 'constant comparison' approach as further interviews were undertaken and analysed. Repeating codes across the dataset identified and refined (see Appendix G for illustrative extract).

3. **Generating initial themes –** this involved examining the codes to identify significant broader patterns of meaning. Initial themes and subthemes were mapped and the process of refining these in relation to the dataset began.

4. **Reviewing themes -** this involved checking candidate themes against the dataset, to determine if they tell a convincing and accurate story of the data, that answered the research question. A list of themes and subthemes, definitions, and supporting extracts were discussed with the research supervisor and reviewed in relation to the coded data, dataset and central question (Vaismoradi et al., 2013). Themes and subthemes were refined, which involved some being combined or discarded.

5. **Defining and naming themes -** this involved working out the scope and focus of each theme and determining the 'story' of each. It also involved deciding on an informative name for each theme. Preliminary findings were sent to participants to comment on.

6. **Writing up -** This involved weaving together the analytic narrative and data extracts, and contextualising the analysis in relation to existing literature.

In line with qualitative research guidelines (e.g. Yardley, 2008), credibility checks were conducted. Lincoln & Guba (1985) suggest that respondent validation is a crucial technique for establishing and enhancing the credibility of research findings. Participants were asked on the consent form whether they would like to be sent a preliminary lay summary of the themes/subthemes, illustrative quotes and definitions once initial analysis had taken place (Langdridge, 2007). They were sent this summary and asked to contact the researcher if they wanted to comment further on the findings (See Appendix H).

Researcher Perspective

Within reflexive TA, a researcher's subjectivity is seen as an analytic resource which requires reflexive engagement (Braun & Clarke, 2020), and reflexive TA acknowledges that an inductive approach is on a continuum due to the inevitability of a researcher bringing their prior experiences and knowledge to the data (Braun & Clarke, 2019a). In accordance with this, and good practice guidelines, I will outline some of my personal characteristics and prior experience of the topic, to aid the reader in evaluating the conclusions of the research (Barker & Pistrang, 2005). In terms of my personal characteristics, I am white-British, middle-class male, and I am a trainee clinical psychologist, with professional experience of working in an older adult memory service. I have personal experience of supporting my Mum who has a diagnosis of dementia.

One perspective I held was the view that it would be important for the PwD to be aware of their diagnosis, if they could be told at a stage where they are able to understand this. This was because my Mum was never told about her diagnosis, something I disagreed with, but accepted. I was therefore conscious of trying to remain impartial in any responses

given in relation to this, and in looking at its impact on the central question. I also held the view it would be helpful for spouses to share their partner's diagnosis, in order to obtain support. Again this was influenced by my Dad whom I felt had not accessed sufficient support, and I was aware I may be intrigued by hearing about instances of support, which could influence my focus within questioning and data analysis. I was also eager to learn more about peoples' experiences of caregiving as I thought these may be able to help myself and increase my knowledge from a personal perspective, again I was mindful to try and focus on the central question as I may be tempted to explore and analyse areas that were of personal interest, but not relevant. Of particular importance, I tried to be aware of how early or immediate interpretations of data may influence subsequent analysis, and how assumptions may influence data collection (Willig, 2013).

Advice was sought from the UCLUS research group on how I could bracket my own position, and views on disclosure of personal experience as part of the research interview. Bracketing methods and personal reflections are discussed further in Chapter Three, and aimed to facilitate awareness of how my personal characteristics and prior experience may influence the collection and interpretation of data. These included keeping a reflective journal throughout the process, recording personal reflections after each interview, and taking part in three bracketing interviews throughout the research process (see Appendix I for illustrative extract). This was especially important alongside the data-led analysis of an inductive orientation, and in the context of reflexive TA where the researcher cannot or would not want to, free themselves of their theoretical and epistemological commitments (Braun & Clarke, 2006; Terry et al., 2017).

Results

Participant characteristics

A total of 12 participants took part in the study (see Table 3). Nine of the participants were female, three male. All were caring for someone of the opposite sex, and in a heterosexual partnership. Despite targeted efforts, ethnic diversity in recruitment was not achieved. All participants were white-British with the exception of one who was white-Irish; all PwD were the same ethnicity as their partner. Dementia type was not specifically asked, but one participant's husband had Korsakoff's dementia. Three PwD had received a diagnosis before the age of 65 years and would be classed as early-onset. The amount of time spent caring (since the diagnosis was given) across the sample was between one and ten years with the average overall time spent being 4.9 years. The youngest FCG interviewed was 59 and the oldest was 90. Interviews ranged from 44 minutes to 75 minutes, with the average length of 59 minutes.

Table 3

Characteristics of Study Participants

Participant ID	Age	Kinship of carer to PwD	Age of PwD	Caring time (years)
01	63	Wife	65*	4.5
02	63	Wife	79	5
03	76	Husband	76	2
04	71	Wife	90	3.5
05	59	Wife	60*	10
06	63	Wife	68*	5.5
07	76	Husband	72	5
08	90	Husband	82	5
09	73	Wife	75	5
10	62	Wife	67	1
11	77	Wife	82	10
12	86	Wife	88	2 (deceased)

*Indicates those who received a diagnosis of dementia before the age of 65

Table 4

Summary of Themes and Subthemes

Theme	Subtheme	Definition
1. Decisional absence – this theme captures situations where a FCG did not consider the choice of telling others about their partner's diagnosis.	**1.1 Concealability** ('*covering up for themselves*')	The PwD's symptoms were still concealable which meant the question of whether or not to tell others was not a focus.
	1.2 'I think it's quite obvious'	The PwD's symptoms were considered so obvious, the FCG assumed others would know and there was no need to mention it.
	1.3 The PwD made the decision ('*[My partner] felt they [other people] should know*')	The PwD was able to take a lead on the decision to tell, or not tell others, so the FCG was guided by this.
2. Decisional influences - This theme captured the influences behind decision-making around whether to tell others.	**2.1 'It's just a fact'**	The way the FCG viewed dementia influenced whether they were likely to tell other people about their partner's diagnosis.
	2.2 'Spreading the word'	A desire to educate others or advocate, influenced the disclosure decision
	2.3 A Desire to Protect ('*why stir up anxieties when it's not necessary*')	The FCG was aware that they, or their partner may be judged because of the dementia diagnosis, and they wanted to protect against this.
	2.4 Others' responses ('*I can't think of a situation where people weren't helpful and kind*')	The responses the FCG received from other people who were made aware of the diagnosis, influenced their decision to tell or not tell others.

2.5 Support needs (*'it lightens the load'*)

The FCG told others because they needed either practical or emotional support to help cope.

3. Decisional Dilemmas -
This theme highlighted the burden of decision-making, through the dilemmas a FCG faced such as balancing out being honest, protecting their partner, getting support, or preserving a pre-dementia identity.

No subthemes were deemed appropriate as there was a myriad of dilemmas that spousal FCGs contended with as part of the disclosure decision-making process (*'I was torn'*).

Themes

The analysis generated three themes with eight underlying subthemes (See Table 4). The central question of the research was to identity influences on spouses' decisions to disclose or conceal their partner's dementia diagnosis to their wider family and social network. However, analysis showed that disclosure decision-making was not a universal aspect of spouses' lived experience, resulting in the first theme; 'Decisional absence'. If disclosure decisions were made, they were influenced by several key 'Decisional influences'. The complexity and evolving nature of decision-making was evidenced through the final theme, 'Decisional dilemmas', highlighting the dilemmas that spouses faced throughout their caregiving as they negotiated the burden of competing imperatives.

1. Decisional absence

The central question focused on determining the influences on disclosure decision-making. One of the implicit assumptions was that people make a choice. The analysis showed that both 'concealability' and 'lack of concealability', allowed spouses to avoid actively doing so. It may be that spouses chose to avoid decision-making (and the burden this may bring), or that it had not even crossed their minds that there was a choice to make. Another aspect was that the PwD made the decision, with responsibility abdicated to them, or that 'advanced discussions' had been held which meant making a decision was not considered. Given the noticeable absence of decision-making, a theme was established to reflect this.

1.1 Concealability

The concealability of their partner's symptoms allowed spouses to avoid active decision-making. This subtheme featured in six interviews; a view that there was no point in telling

others as the diagnosis could remain hidden. Some symptoms were easier to conceal, such as forgetfulness or repetition:

> *he would maybe ask people the same thing again, you know, once or twice, even though they just explained it. But really up until the last year or so you wouldn't know there was anything wrong with him [09]*

For some spouses, their partner was good at hiding their symptoms, making the diagnosis less visible to others:

> *the thing is, with people, especially with early onset Alzheimer's are very good at…covering up for themselves to a degree [01]*

1.2 'I think it's quite obvious'

This subtheme featured in eight interviews and reflected a perception there was no decision to be made around telling others, as their partner's symptoms were 'obvious' abdicating them of decision-making responsibilities. There were two elements within this subtheme; things being obvious to family or close friends due to proximity, and things being 'obvious on the street' or to strangers. For one spouse there was a perception that she now looked like a carer and that strangers would easily be able to pick up on her partner's diagnosis:

> *And when we go out, it's quite clear that he's got something now.. he shuffles along. I'm like his carer when we're out as opposed to his wife. So I think it's quite obvious.*

And so there's not really ever the need for him to say anything or for me to say anything

[05]

Another described how she *assumed* people knew:

I mean, to be fair, the last couple of years, it was pretty obvious that there was something seriously wrong with them. It [people knowing] was easier [06].

In terms of telling close family or friends, proximity could mean they had already picked up on changes or knew about existing concerns:

the rest of the family were kind of there in close proximity over a period of time, and so they had started to notice things also became much more and much more aware of it [10]

I think because they're all clever people, they will they recognise there was a problem [04]

1.3 The PwD made the decision

This subtheme featured across six interviews and highlighted the influence of the PwD on disclosure decisions, which allowed the FCG to follow their lead. Below, no decision was required by the spouse as the PwD did the deciding and the telling:

He felt they [other people] should know, because they would be more supportive… now, he openly tells people if we're out if necessary, I am relieved, because I know that they know. So, they can don't need to judge [05]

One PwD made an informed decision to tell others:

He was prepared to say all my memory is getting worse, I'm having trouble with it at quite an early stage. And then it gradually turned into my Alzheimer's is getting worse [04]

Whilst another PwD was accepting and open, due to a lack of insight into what their diagnosis meant, which alleviated her partner of decision-making responsibilities:

she was going round talking to anybody, she was telling everyone that she had Alzheimer's, it was almost like a badge of honour [08]

2. Decisional influences

This theme captured the influences that drove disclosure decision-making. These were numerous, and have been grouped to reflect the main elements: a stigma-resistant attitude to dementia that saw no shame in disclosing, a desire to advocate and educate others to disrupt dominant cultural narratives, a desire to protect, experience of others' responses, and a need for support.

2.1 'It's just a fact'

An important subtheme (featuring in five interviews) that influenced the decision to tell was spouses' viewing dementia in a matter-of fact way which promoted, stigma-resistance for the FCG. This in turn made disclosure easier:

> *I don't have a problem telling people. To me it's just a fact like saying it's raining today. And I may not want it to rain but it's raining. Take your umbrella. You know it's not something that I have any choice over how people will react to how I'm going to react [11]*

Another expressed similar stigma-resistance, and saw no reason not to be open with others:

> *there's a stigma that I've, never understood that. I mean, everybody knows that some people are unfortunate and get this disease…There's just practical issues of course, but I don't see why that would stop me [telling others] [07]*

Another spouse externalised the dementia, seeing it as akin to any other medical problem, which, for them, made it easier to talk about their partner's diagnosis:

> *I try very hard not to be embarrassed. Because In my view is that it's no different in a way to breaking your leg, it's something wrong [02]*

For one couple, they drew on the pre-existing nature of family privacy boundaries in the way they viewed dementia. This meant that openness to their family members was the default response. The 'we' also captures the influence of their longstanding partnership.

> *We didn't have any inhibitions about telling anybody, especially the family, about any medical problems that we had [including Alzheimer's] [08]*

2.2 'Spreading the word'

This subtheme, featuring in five interviews, captured a more activist stance, with the idea that people *should* be told about their partner's diagnosis. One spouse was prompted to disclose through a desire to educate others about dementia, and challenge stereotypes:

> *it's kind of just about, spreading the word that there is a better way to, like, live with dementia than keeping people, you know, basically in the chair watching mindless stuff on the television [10]*

Disclosure was also seen as important in educating; helping others understand that they could support the PwD:

> *people who maybe can't quite manage something, and they're being educated that, just a bit of support, and they can still do it [04]*

Deciding to telling others was also perceived as a way of disrupting dominant cultural narratives of 'what dementia looks like', or challenging stereotypes. This was especially the case in early-onset cases:

> *we both feel very passionately, it's important to, bring a dementia diagnosis out into the open, when people think of what Alzheimer's looks like, they're definitely not seeing him [09]*

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I think people can deal with something much better if they know the facts rather than have suspicions... they need to know so that they can understand why these things happen and be supportive, instead of judgmental [05]

2.3 A desire to protect

This subtheme featured in eight interviews and highlighted how a desire to protect, often in relation to *expectations* of others' responses impacted decision-making. These were mainly anticipating negative appraisals, and acted protect either themselves, the PwD, or others, and to avoid the subject altogether. This desire to protect led to decisions to both disclose and conceal.

In terms of protecting themselves, some spouses did not want others to think they were behaving unusually, and felt disclosure helped them justify this:

there's no way I could have explained my withdrawal from things without telling people why [04]

(if she hadn't told friends) they would have thought what's the matter with her, and why doesn't she want to go for a drink in the bar? [02]

Similarly, disclosure helped allay fears of judgement due to changes in communication style:

I think it was important that they (friends/neighbours) knew from my personal view, I didn't want them to think I was a nag and a bossy woman [01]

Another spouse feared judgment as their partner had gone into a hospice, and therefore continued to avoid mentioning his diagnosis:

one of the things that worried me more than anything was that he had to go into a nursing home because I thought that they might sort of say I should have kept him at home [09]

The subtheme also involved sensitivity to negative reactions to the PwD which have may reflected an internalisation of stigma associated with dementia. It is likely that certain types of early symptoms (i.e. disinhibition) resulted in some FCGs anticipating negative judgement from others, and they therefore sought to protect PwD from negative attention:

it became necessary that people should know, because of the slightly odd things that she was beginning to do [08].

Spouses of those with early-onset dementia were especially protective, as there was a belief that particular symptoms could be seen as strange or disruptive behaviour because their partner was younger. The 'we' in [06] can be seen to reflect perceived responsibilities as a spouse, with a desire to protect their partner:

(we decided to tell others) straightaway because of the changes…we wanted people to understand what was going on. Because when you're that age, generally people don't expect that you've got Alzheimer's… I wanted people to know, so that nobody ever spoke to him in a way that made me really angry or, didn't treat him right [06]

I think it's important people should know… because they if she ever did anything slightly out of order meeting up… I don't have to worry about them thinking… she's exhibiting some strange behaviour [07]

As part of the desire to protect the PwD, some spouses employed the opposite strategy, and employed covering practices. One spouse did not tell others, in order to help facilitate their partner's continued independence:

(on not telling others) I felt, that he needed to still be able to conduct his conversations. He was able to cover things up really quite a lot [12]

Another aided their partner in covering symptoms such as forgetting names. This appeared to be related to protecting the PwD from negative evaluation:

I would go into sort of female dappy mode, oh [PwD] hasn't explained to you, or would you like to tell me? Because he is likely to forget the names of even long-standing friends [04]

Another aspect of protection was seen through a spouse taking on the PwD's responsibilities for them to avoid potential upset for the PwD:

I have to take all messages for him now. I just play it by ear, but basically, you know, I obviously don't want to upset him [11]

There was also a desire to anticipate any potential offence caused to others by the PwD, and in this sense protect them from negative judgement:

he could easily say something really hurtful. Somebody arrives and he says what are you doing here. They would feel very unwelcome, if they knew he was ill, and that there was some reason for him speaking like that, then they'd have more understanding [11]

It was evident in some spouses descriptions there was an avoidance of speaking about the diagnosis (and therefore telling others). This appeared to stem from a desire to protect the PwD, to avoid stirring up anxiety:

So, there was no point in talking a lot about it. It was just something that happened. Something that we'd got used to [08]

On the day to day basis, why stir up anxieties when it's not necessary… I don't have a conversation about it very often with anybody, I suppose to be honest. Once they know, they know [01]

This extended to letting others come to their own conclusions for uncharacteristic behaviour:

we don't go to a drinks party and tell everybody…last Christmas we went to a house he had never been too…her housekeeper found him wondering around upstairs...

everybody thought it was a scream, thought he'd had too much to drink… I didn't say

anything, just left it [02]

2.4 Others' responses

This subtheme came up in eight interviews; and on the whole, these were supportive. Supportive reactions from others influenced future decision-making choices and made disclosure more likely:

People can't support you, if they don't know, and universally, we've we find that to be

a very, very, very positive experience [10]

In the main, as I say, I can't think of a situation where people weren't helpful and kind

[08].

[Friends] have been absolutely brilliant. They text me every evening…and they do their

best to say funny things to cheer me up…they really did help me and really kept me

going [09].

They were brilliant, and really supportive of both me and [PwD] and always included

him in everything that we were doing. And occasionally even insisting that, that he'd

come along to stuff even when I wanted a break [06]

The impact of supportive responses also extended to disclosure to strangers, where disclosure was used to facilitate understanding in certain situations:

some of the nicest and kindest people…the Waitrose delivery or the dustman. They're

often very intuitive because they spend a lot of time dealing with all sorts of different

people [02]

There were some negative reactions reported, though these tended to be subtler: one participant (06) noted that their partner's family did not become actively involved in any aspects of caring, as they said they could not face it. Another reflected that some people over-promised and underdelivered when it came to practical support (4). Whilst another speculated that they may not have been invited to parties (2), though said they had no proof of this.

Not all spouses anticipated negative judgement, especially when telling those close to them:

[*on circle of friends*] *I think I expected them to understand, and be supportive and really*

that is what has happened [05]

And some evaluated their social network to predict on who may react in a more positive manner:

I think in your life the group of friends that have stayed with you for some years,

I think you're able to assess, how they are going to react, how they're going to

accept it. And the ones that you can just come straight out with it and say

what's happening [12]

2.5 Support needs

Another influence on disclosure which featured in all interviews, was around eliciting support, with disclosure generally seen as important for this. One aspect that prompted disclosure was practical support:

> *If I knew I was going to be out, for more than a couple of hours, I would get a friend that he knew very well to, this was after it had advanced a bit, a friend would come and sit with him for that time [12]*

Spouses also disclosed for emotional support, to get empathy or understanding from others:

> *I think it's partly selfish, isn't it? Because I want people to understand…what I'm having to put up with… I would meet a group of friends on the train, and they would say, go on what's he done this time [04].*

In this sense disclosure was seen as having a cathartic effect:

> *I think that it lightens the load to some extent. If one can share that sort of knowledge and that sort of experience…it surely does help in many ways, as far as family is concerned, or even neighbours [08]*

Disclosure was also a mechanism to enable others to support the PwD to do valued activities:

> *I want him to continue to lead his life as well he can, I said you may need to ask some of your golf buddies to mark your card for you, I'll ask them [10]*

or facilitate adjustments at work:

he would still come and work in big groups... and it meant he could continue and our

members understood why he maybe wasn't interacting as much as he used to [05]

The overall subtheme is summarised in the below quote which encapsulates the opportunities that disclosure is perceived to open up:

It gives the other person a chance to offer something either verbally or physically, to

help and that can be a relief and can be a comfort [11]

3. Decisional Dilemmas

The final theme feature in nine interviews and illustrated the tensions that were an inherent part of decision-making, both within individual participant accounts, and across the dataset. The theme aimed to capture the sense of complexity, conflict and dilemma that spousal caregivers faced, and brings to the fore the burden of the decision-making process. The values of honesty, protection, respecting wishes and maintenance of identity seemed to intersect throughout the decision-making process, and in differing manners.

One spouse struggled with the dilemma of wanting to protect her partner from judgement, but at the same time not wanting to deceive those close to her. This resulted in in relief when she disclosed to close friends:

[when she eventually told others] You think you can shoulder it all. And just reaches a

time when you can't... It was a relief because apart from anything else, you know, you

It's so easy to slip up if you're talking to people [09]

Another highlighted the dilemma between honouring her partner's wishes versus being honest, and prioritised honesty:

> *we absolutely wouldn't be able to get to the other side of Christmas unless we basically told lies, and, and I said, I'm not prepared to do that [10]*

One couple initially agreed to conceal the diagnosis as the PwD could continue conversations as before. The 'we' highlights the aspect of shared decision-making that drew on the couple's long-standing privacy boundaries and dynamics for making decisions:

> *At first we decided not to tell anybody until there was what you felt that it was like significant progress. I don't think we told anybody for a long time… he could put this jolly facade on and when you were still with him, the conversations were still the same [12]*

This initial joint decision then changed, as her partner's illness progressed; there came a point when the need for support for her partner trumped privacy:

> *but it [people knowing] didn't seem to be important anymore, it was important he got the support [12]*

One spouse managed to find a resolution to tension between honesty and protection through taking a middle ground approach:

I don't think I've ever announced it to everybody. But I've also not hidden it either. So when it comes it's quite clear I assume lots of people know. But if they were to talk to me, I say well [PwD] has Alzheimer's [05]

Another spouse spoke of changing priorities after initially concealing, as she wanted to protect her partner from negative judgement:

I guess you just know the time is right. And that you have to tell people… I didn't want them to think not any less of [PwD]...they would recognise there is a problem [01]

For one participant, their partner going into a care home signalled a turning point in tensions around respecting their wishes versus telling others:

it's been easier to tell them [friends] since [PwD] was in a care home. Why was that? I think because it was some kind of finality…I felt there was there was no point in not telling people [03]

Another dilemma was around protecting children, versus being honest with them about their father's condition, this partner also expressing relief when coming to a decision:

I'm not saying they're not resilient, but I think, you know, life in your late 20s and 30s is busy enough without having…well, it is a burden in a way, it's a concern what the future can hold. But I think…it was a relief telling the children, I didn't want them to just suddenly turn around, and say, well, why haven't you told us [01]

One spouse made the decision to disclose to seek support for themselves and in doing so, had to deceive his partner, highlighting the difficult dilemmas that FCGs can be faced with:

> *[Caring organisation] gave me a mentor…this sounds selfish, but sort of shifting the emphasis a little bit towards me, and in the fact that, if I wasn't well, either in body or spirit then I wouldn't be much help to [PwD]…I had to make excuses about why I was going out [03]*

Another dilemma a spouse faced was that of trying to maintain continuity, and the PwD's previous identity in the face of obvious changes:

> *I thought it's not fair to him to pretend everything is the same and then people wonder why he's not coming out or why he doesn't want to do something [11]*

One spouse had not told their partner about their diagnosis and was balancing a desire to not let her find out, versus disclosing to others so they would not mention anything. He decided to disclose in secret to avoid potential upset to his partner, with limited success:

> *There's no way I could tell anyone in front of her... so I had to do it behind her back… I just thought they'd be a bit sympathetic, I was hoping that they wouldn't take any notice…the last thing I wanted was to them to treat her any differently… and in fact, some of them did [07]*

For another spouse, the tensions around protecting their partner and deceiving friends were an ongoing theme they had an internal battle with:

> *as our children say, covering up for him and the alcohol really… trying to protect him, which I've always done, and I've probably done it, without realising it at times as well [09]*

One spouse was particular torn between wanting to maintain some elements of her old life versus the fear of being judged for doing, as maintaining this necessitated telling some people about the diagnosis:

> *I was torn, I suppose really, I didn't want people to think, oh, she's not going to be able to do this. Or, on the other hand, how selfish she is still doing that. I didn't want to either of those situations [12]*

Another spouse highlighted the tension between wanting to conceal and protect their partner versus it becoming obvious they were being dishonest as symptoms worsened:

> *That then, people had noticed and people started asking how he was. And in the end as a family, we decided, well, you know, we're just going to look ridiculous if we keep saying, oh, he's okay. And because it was, going to become obvious that he wasn't [09]*

Another was put in a position where they had to balance a desire to be honest with respecting their partner's wishes, for how they wanted to disclose:

I just feel at first a bit guilty about that [his family not being told], they didn't live locally. But it was his responsibility. And he had the capacity to make those decisions [05]

Some spouses did not want their partner's diagnosis to appear as an excuse for their own performance, and therefore decided not to mention it. Here, they were torn between being honest (and enabling themselves to do things) versus preserving their own sense of pre-dementia identity:

I didn't want them to think that what he had would make me incapable because I was teaching on a Friday evening and I didn't want them to think that it would make my work any less [12]

[If I brought it up], it feels as if I'm making the perfect excuse to my personal failing, I suppose if I if I was being distracted in the class, so... I don't want to make the classes about me [05].

Another spouse had an ongoing internal battle between respecting his partner's wishes versus letting people know. He negotiated this in terms of how close they were to the PwD and whether he perceived them as having a 'right to know':

she was ashamed that she didn't want me to tell anybody… I have to tell her close family or children, which I did, I mean, we've always been a fairly close family. So, you

know, then if they needed to know…I did feel constrained at first because I was…respecting [PwD]'s wishes not to tell people so I felt a little bit constrained that sometimes awkward when I was kind of sidestepping the issue [with neighbours] [03]

Respondent validation

Comments from FCGs involved in the respondent validation exercise agreed that they recognised themselves within the themes/subthemes, that it was helpful and thorough seeing the data presented in this way, and helped them to think about the topic in a light they had not seen before (or even considered).

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Discussion

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This study sought to elicit the perspectives of spousal FCGs in their decision-making around disclosure of their partner's diagnosis of dementia. An inductive thematic analysis, taking a critical realist approach, identified three overarching themes and eight subthemes. These themes were: 'Decisional Absence', 'Decisional Influences' and 'Decisional Dilemmas'. These themes are now discussed in relation to existing literature and the decision-making models introduced in the CI.

'Decisional absence'

The headline of the study is that spousal disclosure decision-making, in relation to concealing or disclosing a partner's dementia diagnosis, is often not an active cognitive process. This is at odds with the assumption implicit in the models of decision-making outlined in the CI, and the wider field of decision-making literature; that disclosure is always actively considered

through a rational process of weighing up pros and cons. For example, the Disclosure Process Model (DPM; Chaudoir & Fischer, 2010) and Disclosure Decision Model (DDM; Omarzu, 2000) outline how an individual may consider a distinct disclosure approach in terms of breadth, depth and duration of disclosure. The former conceptualises the idea of a distinct *Disclosure Event* that suggests the disclosure of important information is preceded by considerable planning. There was little evidence of this in some of the responses, with decisional absence meaning specific goals were sometimes never a consideration, as disclosure did not seem a matter of choice. This highlights the limitation of decision-making models that fundamentally conceptualise decision-making within a cognitive, rational framework.

The theme also highlights the role the PwD played in decisional absence, allowing the FCG to follow their lead. Whereas some spouses described their partner as angry or in denial, others mentioned the complete openness of their partner – with them keen for other people to know, to help ease adjustment. This may have removed some of the decision-making burden as they could default to their partner's decision, and was at odds with research that has found many PwD, in the early stages of the disease, experience anxiety about others' reactions, and hide their diagnosis (Riley et al.,2014; Robinson et al., 2011). It offered partial support for previous research that found shared decision-making between the PwD and their FCG for important decisions (Mariani et al., 2017) but indicated a preference to relinquish decisional responsibilities to the PwD, and overall and highlighted a limitation of decision-making models in not considering the PwD's view. This is significant within itself, as previous research has found up to half PwD are not informed of their diagnosis (Bamford, 2010; Carpenter & Dave, 2004), meaning that the decision to tell was the sole responsibility of the FCG. This was not seen within this sample, with only one PwD not told of their diagnosis, and

this may reflect the sample, or a change in practice of medical professional to be more in line with recommended guidance (NICE, 2018).

One possible explanation is that this 'decisional absence' may have been a way of spouses consciously or unconsciously managing the burden of decision-making through avoiding it, alongside trying to cope with the multiple other aspects of caregiver burden (Etters et al., 2008). This avoidance may be part of the 'collective denial' found in prior research (Bahro et al., 1995). It may also be a way of avoiding the burden of concealment that the Cognitive-Affective-Behavioural Model of Stigma Concealment (CAB-SC; Pachankis, 2007), if applied in relation to spouses, suggests an FCG may experience. In this sense decisional absence, when possible, may be perceived as protective to a FCG. Another consideration is that spousal carers may be responding from a more instinctual place than can be articulated and captured through the explicit cognitive decision-making process outlined within the decision-making models; and those interviewed have never articulated these cognitive influences to themselves. For example, this may be an instinctual desire to protect their partner, or the falling back on longstanding privacy boundaries within the spousal partnership (Petronio, 2002; 2010). This finding created a new take on the scope of the initial research question, and highlights the importance of an inductive, data-led approach when working in an under-researched area.

'Decisional Influences'

The central question was around the key influences in regards to the decision-making process. One notable influence that contributed to disclosure was a stigma-resistant view, that saw dementia as 'any other' medical condition, which made disclosure more straightforward for these spouses. This finding is odds with research that has found dementia related stigma is

universally pervasive, but in alignment with the expected white-British cultural perspective of seeing dementia through a medical lens (Herrmann et al., 2018). There was little overt articulation of FCGs experiencing 'courtesy stigma' (Larson & Corrigan, 2008), with some expressing surprise at this idea. This challenged research that found partners of PwD as apologetic on their behalf due to pervasive generational stigma (MacRae, 1999). However, some fears of social disapproval were implicit behind a desire to protect the PwD and the FCG themselves. The decisional influence that it was important for people to know, to help advocate for the PwD and educate others could be captured within the concept of an 'approach' goal within the DPM (Chaudoir & Fischer, 2010) and would be classified as broadcast experience if applying Herman's (1993) hierarchy of approaches to disclosure.

A desire to protect was evident within the data. Rather than conceal the diagnosis for protection, as would be congruent if applying the Cycle of Concealment Model (Afifi & Steuber, 2010) to spouses, FCGs disclosed to anticipate judgement, protect and offer clarity. This was at odds with research that found concealment of a diagnosis was used to protect both the PwD, and the family reputation (Mackenzie, 2006), and, applying ideas from the CAB-SC, which suggests that an individual may be compelled to conceal if there is a greater salience of stigma related cognitions. Disclosure in anticipation of negative judgement, *is* supported by research that associates disclosure with an increased sense of control for a PwD and their FCGs (Livingston et al., 2010). Many of the spouses were sensitive to how their altered actions may be perceived by others, through appearing to be more controlling or not attending social occasions. This led them to disclose or conceal to protect *themselves*. This highlights an under-researched area, as research has tended to focus on fears of judgement around dementia, rather than changes in routine behaviours and manner, as part of the transition to caregiving.

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The influence of others' responses on future disclosure decision-making supported the idea of the 'feedback loop' in the DPM, and ideas in the Disclosure Decision Making Model (DD-MM; Greene, 2009), and CAB-SC; disclosure experiences impacted future disclosures. Spouses experienced generally positive disclosure experiences, and were then more confident in future disclosures. The positive responses are in contrast with studies that have found spouses have been sidelined or ignored post-disclosure (Devlin et al., 2007; Werner et al., 2010). This may reflect the nature of the sample, cultural differences, or, more promisingly, a reduction in societal stigma. Although there were some more subtle negative reactions reported, these were not substantial enough to alter future disclosure behaviour. There was also a consideration of anticipated response, a component featured in the DD-MM and communication privacy management theory (CPMT; Petronio, 2002), with spouses assessing their social network to try and determine who they may expect a positive response from when deciding who to tell and their privacy boundaries becoming more permeable if they viewed less disclosure risk (Petronio, 2002).

Support needs was a key influence behind disclosing. This is in line with CPMT research that found boundary protection comes secondary to health concerns to meet the needs of the person who is ill (Petronio et al., 2004). It also aligns with the idea of specific disclosure goals such as those outlined in the DDM - clarification of identity, social approval, relief from stress and social control were all evident in terms of support needs associated with disclosure.

'Decisional Dilemmas'

This internal burden of decision-making was evident within the data, and was captured through the competing nature of different influences, with values of honesty, protection, support, and maintenance of identity intersecting. They highlighted the spouse's co-

ownership of the diagnosis (in CPMT terms), with responsibility for protecting dissemination (Petronio, 2010). Some decisional dilemmas resolved due to changes over time, or in circumstances, whilst others remained an ongoing burden. A theme running through the DDM, DPM and DD-MM is the idea individuals balance risk and reward, with decision-making conceptualised through an ego-centric lens (Derlega et al., 2004). This decisional balancing was partly relevant, as was the notion of goal conflict (Omarzu, 2000). However, the nature of these goals were not necessarily ego-centric (as hypothesized in the models), instead a myriad of dilemmas were highlighted in relation to a FCG's values, and whether they privileged themselves, or the PwD, with the choices they made. As seen within the 'decisional absence' theme, these 'decisional dilemmas' were not approached in the individual cost-benefit analysis manner implicit in decision-making models. Again, it likely that decisions were influenced by a complex mix of instinctual responses, couple and family privacy boundaries, past experiences and personality traits. The concept of *disclosure efficacy* from the DD-MM comes closest to capturing these, and accounting for why disclosure decisions may change.

Disclosure may become a more feasible option for FCGs overtime, as their partner's symptoms deteriorate their focus may switch from retaining the PwD's autonomy, to focusing on support for themselves alongside their increased caregiving burden (La Fontaine et al., 2016). Indeed, evidence of revised decision-making was captured within the data – some spouse's desire to conceal for protection of their partner changed as their partner's illness progressed; there came a point when the need for support trumped privacy. This is understandable as evidence that shows FCG stress is associated with greater symptom severity (La Fontaine et al., 2016), and dementia severity is linked with social distance toward a *PwD* (making maintenance of normality harder) (Werner, 2005). A key dilemma was that of being honest versus others factors such as maintenance of identity (for PwD and FCG),

respecting the PwD wishes or eliciting help. It appeared that honesty often trumped other imperatives when tensions resolved, which goes against the idea of the tightly targeted boundaries predicted by CPMT (Petronio, 2010). The data showed how some spouses were torn between wanting to maintain some elements of their old life, versus the fear of being judged for doing so, which led to non-disclosure. This dilemma supports evidence that suggests spouses experience difficulties adjusting to a loss of identity associated with their transition to the role of carer (Robinson et al., 2012).

The finding of 'decisional dilemmas' as a key theme offers support to the limited existing research on FCG decision-making from other fields. A study on disclosure decisions for relatives of a person with a mental health condition recognised the dialectical tension FCGs may experience when they want to conceal information, (to avoid harm such as stigma or protect) but simultaneously want to disclose (to seek support) (Karnieli-Miller et al., 2013). Another study, with the parents of children with Attention Deficit Hyperactivity Disorder found that information was disclosed on a 'need to know' basis and that attempts were made to strike a balance between protecting them from harm, and seeking empathy and support, whilst achieving the best possible outcome for the child (Eaton et al., 2017). Karnieli-Miller et al., (2013) concluded that disclosure decisions contribute to stress, worry, and caregiver burden, and these consequences are evident within this research.

Clinical and research implications

In terms of research implications the study helped to illuminate several areas that would benefit from further insight. Decision-making as an aspect of spousal caregiver burden was highlighted as an under-researched area within the CI. This study has demonstrated this aspect of burden through outlining the many dilemmas in decision-making, pertaining to a

range of issues such as honesty, respecting the PwD, maintaining identity and protection. All these areas would benefit from further exploration. Whereas much research has focused on dementia related stigma, it has neglected the exploration of spousal FCG sensitivity to how *they* may be perceived by others, due to their transition to a caregiving role. This study found the importance of disclosure in trying to clarify this, or conversely how a partner's diagnosis was not disclosed due to a desired retention of pre-caregiving identity as part of their overall image management. This study only focused on spouses, further research on how offspring make decisions would add to the field and provide a useful point of comparison. For example, to determine if the decision-making models would be more applicable to their decision making and to understand that dilemmas that they encounter. The study has also highlighted the absence of a decision-making theory or model to conceptualise the process spousal FCGs go through, and has helped to offer insight for what may be important to include within this.

In regards to clinical implications, the findings around how people approach decision-making are particularly important, as successful adjustment to a diagnosis of dementia is vital to the envisaged health and economic benefits of receiving a diagnosis early (BPS, 2014). Disclosing to others is seen a part of successful adjustment for both PwD and FCG, and creating time and space for FCGs to think about this may be an important part of the conversation when a diagnosis is given (Weaks et al., 2015). Despite the complexity of disclosing a dementia diagnosis, there is limited specific guidance for professionals in how to do so (Poyser & Tickle, 2019). The research suggested that interventions to support decision-making or specific 'decisional aids' (see Davies et al., 2019 for a systematic review of existing aids for PwD, professionals and FCGs that are mainly focused around care and support) may be useful as part of disclosure support interventions, as the topic was sometimes avoided or not considered an option. The deterioration of a PwD's condition corresponds with increased

stress for their spousal FCG (La Fontaine et al., 2016). Therefore, interventions to help increase their wellbeing are vital; and it is likely that the majority of these will necessitate disclosure. Spousal FCGs face complex and fluid situations where they may face a number of disclosure dilemmas including who to tell, at what point and how much information to disclose; creating space and dialogue to consider these is likely to help reduce this burden. This matters, as whilst one cannot influence physiological course of dementia, one can influence the psychological and social factors impacting the FCG and the knock on effect their wellbeing has on the PwD (La Fontaine et al., 2016).

Strengths and Limitations of methodology

Limited research has looked at the needs of caregivers from the caregivers' perspective and this research has privileged the voice of spousal FCGs (Furlong & Wuest, 2008). The exploratory nature of qualitative research was highlighted, through the unanticipated finding of decisional absence, which showed the utility of an inductive data driven approach (Terry et al., 2017). Due to the limited existing research in this area, the findings can be used for hypothesis generation for future research. Whilst not aiming for generalisability in the sense that a quantitative approach would, it is reasonable to assume that information learned from the research will be relevant to other spousal FCGs of PwD, and potentially inform interventions to support them around thinking about and managing disclosure decisions. In this sense the research has made a modest but novel contribution to the existing knowledge base. Considerable efforts were also made to use purposive and theoretical sampling, in line with the sampling frame.

In regard to limitations, the study had little patient and public involvement (PPI). Actively involving patients and informal caregivers in various phases of research projects has become increasingly important in health-related research over the past two decades, as part of the principle that people affected by research should have a right to influence how it is undertaken and contribute towards its quality (Gove et al., 2018; INVOLVE, 2019). On reflection, PPI would have been particularly helpful in relation to the research and material design; beyond one FCGs consultation on the topic guide. PPI was made difficult by the Covid-19 pandemic the initial aim was to recruit via third-sector charity organisations, where it would have been easier to organise informal consultations with FCGs.

The participants interviewed were self-selecting, in that they responded to advertisements to participate. This means that the sample was inherently biased; one could speculate that those willing to participate in research are likely to be more open about their spouse's diagnosis as they are prepared talk about it in an interview, and therefore those who actively conceal their partner's diagnosis or have experienced negative responses to disclosure, may have been less likely to volunteer. Indeed, it may have been difficult for spouses to participate who had not told others (and the PwD) about the diagnosis, as they may have been unable to speak about it in an online interview due to concerns about being overheard or getting caring 'cover' whilst participating in the interview.

Despite purposive and theoretical sampling, and recruitment efforts, all FCGs interviewed were white-British (one White-Irish) and all had partners of the same ethnicity. Whilst the study was not intending to generalise, it is likely the results would been enriched by the inclusion of different cultural perspectives and their influence on decision-making, as had been targeted in the study's methodology. Future research would benefit with a more culturally diverse sample and also including the type of dementia diagnosis, age of onset,

social class and duration of the spousal partnership within the sampling frame, as this would have encouraged more diversity in relation to longstanding dyad privacy rules, family privacy rules, views and understanding of dementia, and could have explored how dementia type (associated with certain symptoms) may impact disclosure decisions. In this case the researcher was keen to only ask for information they deemed absolutely necessary due to the small scale nature of the research and recent changes to general data protection regulation. Despite the sample appearing to be homogenous, the data indicated a diversity of experience and perspectives.

The initial aim of data collection was to reach 'data saturation' (Fusch & Ness, 2015) but on reflection this aim was not appropriate to a reflexive TA (Braun & Clarke, 2019b). The idea of 'saturation' implies that meaning resides within the data and is 'found' by the researcher. A reflexive approach emphasises how meaning is created at the intersection of the data, and the researcher's contextual and theoretically embedded interpretative practices (Braun & Clarke, 2019b). In this sense there are always new insights to be made as long as data is collected and analysed, with 'saturation' considered a fallacy, and it is more important that themes tell a coherent story in relation to the research question.

The study aimed to work at a semantic and latent level with the data through reflexive TA, whilst also trying to leave participants' views and responses intact. The initial focus in analysis was on participants' actual statements and descriptions. However, in retrospect this would have been a key limitation in answering the research question, as participant's were often unable to articulate the cognitive influences on the behaviours they described. Indeed, many participants described behaviours, for example, protecting their partner or doing nothing to hide the diagnosis, but not the reasons *why* they were doing these. This meant that a certain amount of interpretation had to be used in analysis, for example, when creating

the subtheme 'a desire to protect', as this was not specifically stated but was implicit through the actions participants described. Similarly, participants did not explicitly tell me that they had many decisional dilemmas, but this was evident, and could be inferred from the experiences they described. Other approaches such as IPA or GT may have allowed greater interpretation of the influences underlying behaviour, and could have perhaps offered more insight into the data set in relation to the research question.

Conclusion

The lives of spousal FCG are inextricably joined with their partners, and decision-making within this partnership has been a key focus on research, but not in relation to diagnostic disclosure, or as an aspect of caregiver burden (Tyrrell et al., 2006). This research has taken an initial step towards the exploration of this process, and provided an account of aspects of the disclosure journey that spousal FCGs may experience.

The themes outlined in the study capture a diversity of responses whilst also reflecting higher-order patterns. There was not a clear answer to the initial research question; with 'decisional absence' highlighting how spouses often avoid or do not explicitly consider decision-making, perhaps to counter the potential burden associated with this. Decisional influences were difficult to establish directly from the data with the approach taken, as spouses often described behaviours as opposed to cognitive processes. Indeed, decisions may have been more instinctual, related to former patterns of communication, pre-existing privacy boundaries, previous disclosure experiences, or prevailing societal views, as opposed to the rationale calculation or cost-benefit analysis, that the disclosure decision-making

models assumed. The incorporation of emotion focused decision-making theory within disclosure decision-making models may have provided greater relevance and insight into the decision-processes that spousal FCGs navigated. However, it could be inferred that how an FCG saw dementia, a wish to advocate, a desire to protect, the influence of others' responses and support needs were all key factors that appeared to underpin a decision to conceal or disclose. The third finding was the that of disclosure decision-making as an aspect of caregiver burden, through the decisional dilemmas that FCGs are in an internal conflict with as they struggle with competing values and interests. This research is the first of its kind to provide a nuanced understanding of spousal disclosure decision-making, and its findings indicate that this aspect of caregiver burden requires further investigation, in order to support spousal FCGs managing these disclosure decisions.

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Part Three: Critical appraisal

Introduction

This chapter outlines my key reflections on the research process. My personal relationship with the research topic, and attempts to 'bracket' this will be summarised. I will consider methodological dilemmas, including problems inherent in a purely 'inductive' approach, and reflect on these in light of the study's results. I will then discuss a number of other reflections, including my occupation of different identities, the research context, and the use of personal disclosure. The source of the material discussed stems from three bracketing interviews, a research journal and supervision notes.

The purpose of a critical appraisal is captured through the concept of personal reflexivity. This is an awareness of one's contribution to the construction of meaning during research, acknowledging the impossibility of remaining 'outside' of one's subject matter (Willig, 2013). One is therefore encouraged to explore how their values, experiences, beliefs, and identities shape, and interact with their research, and how the research shapes and impacts them (Willig, 2013). Reflexivity is considered particularly important when the researcher has personal experience of the topic, as they may be more like to attend to certain issues, or impose prior assumptions on participants' accounts (Hofmann & Barker, 2016); in inductive thematic analysis, themes do not simply 'emerge' from the data, but are created through the lens in which the researcher perceives the data and the wider world (Braun & Clarke, 2019).

'Bracketing' is when the researcher details and then 'brackets' their assumptions, while holding them in awareness throughout the process, to mitigate the effects of preconceptions (Ahern, 1999; Fischer, 2009). Personal experience can be an asset, but should be openly acknowledged (Tufford & Newman, 2012). Three bracketing interviews with

someone outside the research were undertaken (See Appendix I for illustrative extract), recorded and transcribed at the beginning, middle and end of the research process, to bring into awareness these preconceptions (Rolls & Relf, 2006). A reflective journal was started prior to defining the research question, and kept throughout research (Ahern, 1999). Another was kept after each interview to expand on initial impressions (Halcomb, & Davidson, 2006; Fasick, 2001).

Why family caregiver disclosure decision making?

Extract from Research Journal: 9th June, 2020 (prior to undertaking interviews):

yesterday I heard that my Mum had a seizure. I only found out because I called my Dad and he was in the hospital. This is a new symptom, and another sign that things are getting worse, and probably towards the latter stages. Dad wanted to avoid taking her to hospital as he was worried she then may not come out, but he had called an ambulance anyway. I heard her distress in the background when I was on the phone. I do wonder how difficult this project is going to be for me personally, when I see my dad as a carer getting such little support. It feels like it is too easy for him to be left to his own devices, and for such a major problem to be hidden away. You would not get this if it was a heart attack. Is it the stigma that is getting in the way? He is trying to protect my Mum because of her fear and confusion. It feels hopeless and like it will be difficult to not bring this to my own interpretations of data.

My engagement with the topic is both historical and alive in parallel to the research. In 2015 my Mum was diagnosed with dementia after about a year of concerted efforts from myself. Although this was around seven years ago, I vividly remember the repeated questions, bumping into things, and burnt lunch being served at 10.30am. Seared even deeper on my mind, are the looks of sadness and confusion on her face, blended with glimpses of awareness that something was not quite right. Perhaps the topic of disclosure appealed to me because my Mum was never told about her dementia diagnosis. Prior to diagnosis, I mentioned my concerns over her 'memory' without ever saying 'dementia'. She shrugged these off as quickly as I'd expressed them, saying it was just low mood. I will never know if she did have any insight, and I suspect internal defensive forces were at work. I also wonder why I was unable to use the term dementia, probably because I knew what this would mean. My Dad made the decision that she must never know, as he believed it would be too painful for her, and her symptoms were already intertwined with a depression that a loss of abilities had induced. After her diagnosis he went on to gradually share the information with the wider family and social network. However, he did so in secret, and stressed the importance of no one mentioning anything in front of her. This created a climate of his own making, where support was difficult to obtain, as, for example, he would be unable to tell her why she was going out with someone else (such as a paid carer). I was left with a narrative of isolation, and a lack of meaningful support for both the PwD and their FCG following diagnosis. Only in the last year or so, since her symptoms have deteriorated and insight reduced considerably, has he finally accepted a small amount of private caring help. It feels like this is a few years too late, and has robbed both of them of their chance to truly 'live with dementia'. We will never know whether it would have helped for her to know. However, it did make me curious about others' stories of concealment and disclosure and how they navigated seemingly impossible

decisions. It made the topic meaningful, and I also viewed it as an opportunity to expand my personal knowledge.

My interaction with the topic was also in a professional capacity. Alongside university teaching on the topic, I spent six months working across an older adult memory service. This included co-facilitating a Cognitive Stimulation Therapy group for people with mild dementia. Here, I saw what 'living with dementia' could be like, and the support that disclosure could enable for PwD in a new stage of their life. I also worked directly with FCGs in a therapeutic role, and gained a further appreciation of their resilience in navigating extremely difficult situations. I did several neuropsychological assessments of people with suspected dementia, and was able to observe how issues of disclosure were navigated by the PwD and their spouse. I was, in a sensitive manner, upfront about the reasons for testing, in line with best practice guidelines (National Institute for Health and Clinical Excellence, 2018). From this extended knowledge I also recognised my Mum's symptoms, and got her specifically re-diagnosed with Posterior Cortical Atrophy (a rare condition, normally caused by Alzheimer's disease). This meant that dementia and disclosure was an area where I was both knowledgeable, and had felt experience of, which I thought could only help in my research and engagement with participants. I was also confident that I would not be unduly emotionally impacted by the research, but conscious that something may come up that could be difficult to hear or catch me by surprise.

Conceptual introduction (CI), topic guide and empirical paper

The biggest methodological and theoretical dilemma I faced was the interaction between the CI and the empirical paper. These were written concurrently, with much of the general

reading for the CI done in advance, and the final version written up and completed before the empirical paper, alongside data analysis. This highlighted a discrepancy between the 'ideal' scenario for a 'bottom-up', inductive, approach to Thematic Analysis (TA), where codes and themes were data driven (Hsieh & Shannon, 2005). It was an impossibility to approach the interviews without having pre-existing ideas and theoretical knowledge of the field, alongside existing personal experience. It must not be uncommon, as a researchers' interest in an area and research proposals necessitate knowledge of literature to highlight a gap in the field, and obtain approval. This is acknowledged by Braun & Clarke (2020) who, in describing reflexive TA, position the inductive-deductive dichotomy on a continuum, and this resulted me in explicitly using this reflexive approach to TA. The researcher inevitably brings their own social position and theoretical lens to the analysis – even when the approach is grounded in the data. This is reflected in their relabelling of the third phase of TA from 'searching for themes' – to 'generating initial themes', to emphasise the active role of the researcher in theme creation (Braun & Clarke, 2020). I noticed this in my initial analysis, when I was inadvertently using 'technical' terms to code the data that were taken directly from the information or disclosure models I had read. It was helpful to move away from a binary definition, and reflect on what prior knowledge I was bringing to the analysis. This also allowed me to reflect on the difference between a semantic and latent approach to TA. Having initially thought I would be adopting a mainly semantic approach, with the idea of leaving my participants' responses untouched, I realised that a reflexive approach to TA would, at times, necessitate looking beyond what the participant said. This involved capturing the interaction between the data and what I brought to It, creating a more interpretative approach to analysis that is evident in themes one and three. It transpired this was pivotal in addressing the research question,

as a purely semantic approach would not have been able to yield the findings, as these required going beyond the semantic meaning of the responses.

An important part of a critical reflection is considering what I may have done differently. On reflection, my topic guide contained some questions that were too broad and invited responses that did not invite focus on the central question. For example, I asked about disclosure outcomes which were only relevant in terms of their impact on future disclosure. I designed the questions for the topic guide it in the early stages of research (to include within the proposal); if I had done them after the CI I would have been armed with information from the four decision-making models. This would have allowed me to have honed the questions towards the central question of factors associated with decision-making. The flexibility of the topic guide gave me scope to pursue areas of interest, but on reflection also to drift. The analysis took a lot of re-working as my supervisor highlighted the initial effort was too broad, I think this reflected a desire to use material out of respect for the participants. Throughout the research process, and especially in the analysis I had to re-read the central question frequently. Ironically, a key theme eventually determined, was the avoidance of decision-making, something not within the direct scope of the central question. I struggled to initially go with this theme, which highlights how preconceptions about what you may find can have on the interpretation of data. However, the ultimate advantage of an inductive approach was that I was able to follow the data, rather than be constrained by a deductive, pre-existing coding framework. Rather than tweak the research question, the first theme was able to show it was limited in scope and create an interesting point for discussion (Terry et al., 2017).

The 'excess' data may be partially accounted for because participants found it easier to speak about what could be considered outcomes, as some of the factors or motivations in decision-making may have been out of their conscious awareness or participants may have

not wished to directly disclose them. In the analysis I tended to find some of this buried within the data. I became more aware of this as the interviews went on, and this may also account for data that did not seem as not relevant to the central question, as I was trying different ways to try to access the information without directly asking the participants why.

Personal reflections from bracketing materials

Beliefs on what I might find

My prior reading led me to expect that participants may disclose on 'a need to know basis', and conceal the diagnosis early on, due to perceived stigma, and a generational mentality of carrying on. I was also aware of potential cultural differences; people in a western culture internalised less stigma, but experienced higher caregiver burden, versus some non-western cultures who experienced higher stigma but provide care within family and experience more positive aspects of caregiving (Doris, et al., 2018; Herrmann et al., 2018; Vickrey et al.,2007; Waite et al., 2004). This highlighted the importance of prior reading in planning the study's sampling frame; the benefits of a culturally diverse sample. I was later able to reflect back on frustrations of lack of diversity, despite concerted efforts to increase recruitment activities, and how white, middle-class females were very much typical of recruitment within this field. I also wonder about the wider issues people may have had without the resources and financial backing of most the participants. Although I did not take a measure of social class in the demographics, it was clear in the transcripts that the majority of participants (all except one) were middle-class and this could have been another important feature of the sampling frame alongside the reflections outlined in the empirical paper regarding future research.

Covid and remote interviews

The wider context to the research setting was the covid pandemic which impacted the research through delays in the ethical approval, and a change of interview format – now everyone has heard of *Microsoft Teams* but few used it back in March 2020. I was curious as to whether the context of lockdown had influenced disclosure decision-making. I was also conscious that the covid restrictions had in all likelihood made things much more difficult for the PwD and their spousal caregivers, due to reduced access to support services, social networks and lack of stimulation. This may have amplified the consequences of concealment or disclosure decisions and led me to question whether doing a research interview would be a priority at this time.

Another major consequence of the pandemic in changing my initial proposal, was the switch of format, from face-to-face, to remote video interviews. I was initially sceptical of this, and suspected I may miss an important part of connecting with interviewees from being in the same room. I also had practical worries about internet lag and access for older participants (something that I was asked to address in my proposal through statistics on older adult internet usage). To my surprise, the format worked well. It expanded my geographical reach and I was able to access participants from around the country and one from Ireland. Video may have helped participants attend, and with the practicalities of travel time, as several had their partner in another room, which meant they did not have to leave them. However, this may have impacted their openness; one participant was interrupted by her husband, which may have made her more conscious of what she was saying. The camera was switched on only before and after the interview in order to initially build rapport and debrief (so the recording file was not too big). It is impossible to know if this impacted responses, but

it helped me concentrate on the words of participants, and perhaps made it easier for them to be more open about things as there was no direct gaze on them.

Being an interviewer not a therapist

I held multiple identities during the research process, and kept in mind the differing aims of a research and clinical interview (Barker et al., 2015). I was reassured by a TA masterclass I attended, which emphasised the use of core counselling skills and letting the person speak, which I naturally erred towards. This was a relief that I did not have to try and push people towards the research question. From a personal perspective, I enjoyed a break from the normal therapist role, a chance to listen and validate in a one-off session. I also spent time building rapport at the start of the interview to try and help elicit truthful answers, and emphasised that there were no right or wrong responses, as I was interested in the interviewee's world view. I was worried about the impact the interview may have on participants, especially when considering generational differences and coping strategies. However, all participants expressed pleasure at taking part in the research, and several mentioned how it had felt cathartic or helpful to speak about their experiences. I found wider therapeutic skills came in useful for one participant who was particularly nervous about opening up due to feeling ashamed, and with another who became quite upset during the interview due as she had lost her partner the previous year. I had to tactfully push one interviewee, as I felt they were avoiding certain key areas around concealment, and again drew on my core skills to so this sensitively. I found my combination of clinical training, blended with personal and professional experience of dementia, was an asset in these situations.

Looking after myself

As part of my preparation for the project I read widely around qualitative research, and became mindful of the potential impact that the research topic may have. I was able to reflect on the discussion with University College London Unit for Stigma Research (UCLUS) group and how this was helpful, in terms of 'talking about talking' and made sure that I paced the interviews out and spoke with people after if needed. Despite my initial worries, I did not notice any particularly strong emotions directly after any of the interviews. One participant was someone who had access to lots of different support via disclosure, I was struck by his positive experience and I noticed wishing my own Dad had access to this. I also noticed how other participants spoke about the quick progression of their partner's illness, which lead to disclosure, and felt some envy that they were not stuck in limbo in the intermediate stages which could last for years for my own family. I felt that undertaking the bracketing interviews allowed me to 'check-in' on my own well-being and gain a sense of clarity through being forced to verbalise thoughts and take a step back from the research. This was also helpful when analysing the data decided to take a more latent approach.

Stated attitudes did not correspond with what participants said they did

The most difficult part of interviewing was trying to explore areas where what people said did not always tally with what they did. Many interviewees claimed to be open in relation to disclosure, but through their descriptions and further responses it was evident that they were actually using some covering practices or avoiding decision-making. This dilemma was linked to the epistemological approach I was taking, which was to take participants' responses at face-value to obtain their understanding of phenomenon, but to acknowledge the level of

interpretation I brought to the data as a researcher. This observation required an extra layer of interpretation in order to draw out themes that created a coherent and meaningful answer to the research question. It may be that interviewees had different definitions of disclosure and concealment, and this framed how they believe they did things. In this sense it was helpful that the analysis could conceptualise higher-order patterns and themes within the data.

Personal disclosure

Prior to interviewing I read about how the use of self-disclosure can help open up conversation, and was in two-minds about how to approach this. Personal experiences may be an asset in building rapport and credibility with the research participants (Barker & Pistrang, 2005). However, shared experience does not mean shared understanding, and disclosure could compromise a level of critical detachment, and lead the participant to falsely assume similarity, thus not fully explaining their perspective (Hofmann & Barker, 2016). 'Insider research' refers to that with populations with which one shares an identity or experience (Dwyer & Buckle, 2009, p.55) and I felt as if I was somewhere on the border between inside and outsider; a son and not a spouse, but with caring experience, whilst at the same time a researcher and psychologist, looking to take a critical stance, perhaps occupying a 'space in between' (Dwyer & Buckle, 2009, p.57).

In light of reflections with the UCLUS research group, I decided not to mention my personal experience at the outset, as the people I were interviewing may have offspring, and this may impact their discussion around them. Indeed, the first interviewee spoke at length about difficulties around telling their children and I noticed myself wondering what my Dad may be thinking about me playing such a big role in the diagnosis, and how this may have

impacted the participant's response if she knew I was in this position. It was a difficult decision as I was also conscious of the age gap between myself and potential participants, and thought this may be able to give me some 'credibility'. As recruitment meant I relied on some *Facebook* groups; I was mindful that people tended to share very personal details on these, and did not want to be perceived as a researcher 'wanting something'. This made it difficult not to disclose as I wanted to 'prove' my legitimacy for being part of this group. I decided to have any personal conversations at the end of the interview, if directly asked about things. One interviewee commented how difficult things may be for my Dad due to my Mum's age at diagnosis, and this did reinforce a belief that it was worse having a diagnosis at a younger age. Another mentioned genetic concerns about getting dementia a younger age, which did provoke some anxiety in myself. I felt compelled to disclose personal experience when one participant questioned if I was aware of the severity of dementia symptoms, after initially being told by them that witnessing dementia whilst working in a memory clinic was not a proper insight. Personal experience also helped with using correct terminology, recognising the stages of the disease, and some knowledge of care homes was also helpful (both my Grandmas are in them). Working in memory clinics meant I could recognise the processes that people were describing and being able to use a similar language or help people remember words clearly helped built rapport and credibility at times.

As part of undertaking the research I had to be much more open about my Mum's diagnosis then I ever had been before; normally only mentioning it if asked or encountering a reciprocal disclosure. I thought about my own reasons for this, and I think it was because I did not want people to feel awkward or not know what to say. I also did not want sympathy. It was also upsetting for myself as it was a reminder of the situation, and it was protective in terms of being out of sight out of mind. During the research I had put the information on the

study website, talked and presented to my colleagues about it, and if asked, discussed it at the end of interviews. In this sense I was making some of the decisions that I had been asking my participants about around disclosure, and found that throughout the process I became more comfortable with talking about my Mum's diagnosis and more open about this.

Conclusion

Overall, I feel both my CI and empirical paper have made a helpful contribution to the field, especially in highlighting areas for further research. In this sense I enjoyed looking into an under-researched area, as it was difficult to anticipate what I may find. I also enjoyed the relational aspect of interviewing alongside the analytical component of making sense of the data. I brought little prior experience of qualitative research, having only done a three interview TA as part of my psychology conversion course around eight years ago. Revisiting the process of conducting research highlighted the lack of 'how to' guides in regards to many parts of the research process (for example, conducting interviews) which meant that I had to draw on my existing therapeutic and analytical skills alongside any technical reading.

Part of a reflexive approach is being able to reflect on how one views a topic differently as a consequence of doing research on it. As stated above, I believe I have become much more comfortable discussing dementia and my own personal experience of this. *Disclosure of perspective* is viewed as a measure of quality for qualitive research (Barker & Pistrang, 2005) in order for the reader to better evaluate conclusions. I feel that my relationship with the topic was an asset, and the research, therapeutic and personal were tightly interwoven due to the nature of my prior experiences, topic choice and work experience. I was personally left with an overwhelming sense of admiration at the interviewees resilience; and felt especially

empathic for people whose partner's had turned violent, or symptoms were in such stark contrast to their pre-morbid traits. My view of poor provision from the social care system have also been extenuated. I also do wonder the impact that dementia has on families who are not white middle-class, and how this can be amplified even more, whether that is due to cultural stigma or lack of financial resources. In many ways, the majority of the people interviewed, and my own parents were fortunate to have financial resources to fall-back on, and supportive and understanding friends and family in relation to the diagnosis. I also found that I got more confident in my relationship with the topic as research progressed; taking part in the Twitter Live as a recruitment activity, and being positioned as a researcher in the area helped me put to use, and reflect on the knowledge I have built up in the area – I can also now say I have made my own modest contribution to the field.

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Appendices

Appendix A: UCL Research committee ethical approval

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

19/08/2020

Dr Georgina Charlesworth
Department of Clinical, Educational and Health Psychology
UCL

Cc: Douglas Stephen Hobson

Dear Dr Charlesworth,

Notification of Ethics Approval with Provisos
Project ID/Title: 16961/001 How do partners of people with dementia tell family and friends about the diagnosis?: A research project to find out what people say and don't say to others about their spouses' diagnosis

Further to your satisfactory responses to the Committee's comments, 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 19/08/2021 with the following provisos:

- Please note that this ethics approval only covers the online- and remote- only methodology. Any in-person methodology must be submitted as an amendment alongside a risk assessment and updated recruitment documentation.
- If you do choose to use third section organisations during recruitment, please provide us with written evidence of collaboration before you do so
- If using TRINT, please ensure this software is in line with GDPR and provide the data sharing agreement to UCL REC, consider seeking advice from the data protection team if it is not recommended by UCL

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

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

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.

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: www.ucl.ac.uk/srs/governance-and-committees/research-governance
- 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
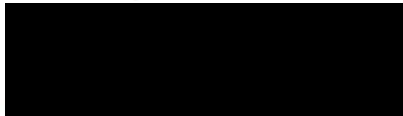
Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix B: Participant recruitment flyer

Participate in our research study

How do partners of people with dementia tell family and friends about the diagnosis?: A research project to find out what people say and don't say to others about their spouses' diagnosis
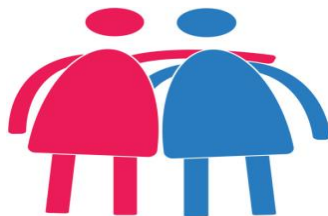
It is estimated that there are currently 540,000 people caring for a family member with dementia in England and that one in three people will care for a person with dementia during their lifetime. One of many dilemmas is who to tell, at what point, and how much information to disclose. We want to understand the factors that influence decisions about whether to tell others' about a partner's dementia diagnosis and to better understand the consequences of this.

We are looking for

- People in an established partnership with someone with a diagnosis of dementia, or former carers of a spouse with dementia

- 18 years old or over

- English speaking in order to attend an interview

Interviews last up to an hour and will take place via an online video call or via telephone. They can be arranged at a time that is convenient for you. They will involve being asked questions about your experience of talking about the dementia diagnosis with your partner and others, whether you have told others about the diagnosis, and the reactions you have encountered from others.

You will be offered a small token of appreciation for your participation in the study if you are chosen to be interviewed.

Please note that we will be asking you for some personal and sensitive information. However, we will store this information in strict accordance with the GDPR (2018). All of your information will be secure and kept confidential

If you are interested in participating the study, please visit:

https://douglashobson100.wixsite.com/website

for more information about taking part, or contact Doug Hobson via douglas.hobson.18@ucl.ac.uk for further information and a consent form.

The study has been reviewed and approved by the UCL Research Ethics Committee [16961/001]. Any information you provide will only be used for this project. For further information about UCL's privacy notice click here.
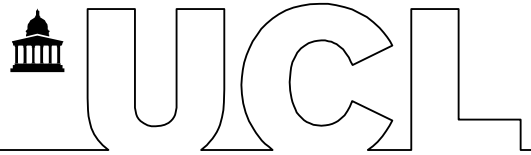
Participant Information Sheet

UCL Research Ethics Committee Approval ID Number: **16961/001**

THIS INFORMATION SHEET IS FOR YOU TO KEEP

Title of Study: How do partners of people with dementia tell family and friends about the diagnosis?: A research project to find out what people say and don't say to others about their spouses' diagnosis

UCL Department: Department of Clinical, Educational and Health Psychology

Name and Contact Details of the Researcher(s):

Doug Hobson, email: douglas.hobson.18@ucl.ac.uk

Gianna Kohl, email: gianna.kohl.19@ucl.ac.uk

Name and Contact Details of the Principal Researcher:

Dr Georgina Charlesworth, email: g.charlesworth@ucl.ac.uk

You are being invited to take part in an interview on the topic of "how did I decide whether to tell other people about my spouse's diagnosis". The interview is part of a research project to better understand attitudes towards dementia and Alzheimer's disease. The project will

be written up within a doctoral thesis. Before you decide to take part, it is important for you to understand why the research is being done and what your participation will involve. Your participation is purely voluntary. Please take time to read the following information carefully and discuss it with others if you wish. Do ask if there is anything that is not clear or if you would like more information. Should you decide to participate you will be provided with a copy of the information sheet and asked to sign a consent form.

Thank you for reading this information sheet and for considering to take part in this research study.

1. What is the project's purpose?

The aim of this study is to better understand how family members decide whether to conceal (hide) or reveal their partner's health status to wider family and social networks. We are also seeking to better understand the consequences of these decisions on the wellbeing of family supporters.

2. Who can take part?

We are seeking to the interview the spouse or partner of a person who has been diagnosed with an illness associated with dementia, such as Alzheimer's disease, vascular dementia, Lewy-body disease, fronto-temporal dementia or any of the rarer forms of dementia. The interviews are carried out in English, so participants need to be confident enough in their English language to hold a conversation about their decisions, views and attitudes.

3. Do I have to take part?

It is up to you to decide whether or not to take part, and participation is entirely voluntary. If you do decide to take part, you will be given this information sheet to keep, and you will

be asked to fill out a consent form. You can withdraw from the study at any time without giving a reason why. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up that point.

4. What will happen to me if I take part?

If you decide to take part you will be asked to sign a consent form, giving your consent to participate in the research. You will then take part in a one-off interview which will last up to an hour. This will take place over a remote online video call via Microsoft Teams in order to comply with Covid-19 regulations. Instructions and advice on accessing and using Microsoft Teams will be provided if required. If conducting the interview online proves difficult, the option of a telephone call will be offered. The researcher will conduct the interview and this will be audio-recorded. You will be asked questions about whether, and how, you have chosen to tell others or hide your partner's diagnosis, and why. Data will also be taken on how recent the diagnosis is, and the age, gender and ethnicity of you and your partner.

At the interview you will be asked whether you would like to receive a preliminary copy of the findings when these are available, and, if so, how you would like to receive this information.

You will be offered a £12 giftcard as a token of appreciation for your time following the interview. This will be sent to you via email as an online voucher code. Alternatively, you can request that this is posted to you.

5. Will I be recorded and how will the recorded media be used?

Your interview will be audio-recorded so that the researcher captures all the detail of what you wish to say. The audio-recording will be typed out ('transcribed'), and the original recording will be deleted. The information that you provide will be used only for the purposes of this project. No other use will be made of it without your written permission, and no one outside the project will be given access to the original recording. Your data will be appropriately anonymised, with care taken to ensure there is no identifying information included in the write-up. Recordings will be kept securely, on a secure UCL server on a password protected account, and will only be kept as long as they are required (likely to be up to two weeks following interview to allow them to be transcribed).

6. What are the possible disadvantages and risks of taking part?

No disadvantages or risks are expected. However, the interviews will include questions about your personal experience of supporting a partner with dementia which can be an emotional topic. Any unexpected discomfort which arises during the interview should be brought to the researcher's attention. You do not have to answer questions if you would rather not, and interviews can be paused, suspended or ended according to your preference. You will be sent a debriefing sheet after your participation.

7. What are the possible benefits of taking part?

Whilst there are no immediate benefits to taking part in the interviews, we hope that the findings will help increase understanding of the experience of family members of people with dementia. Little is currently known about how spouses and other long-term partners choose to reveal or conceal their partner's diagnosis.

8. What if something goes wrong?

Should you wish to make a complaint about any aspect of the research study you can do so

by contacting Dr Georgina Charlesworth via g.charlesworth@ucl.ac.uk

If you feel that this complaint has not been handled to your satisfaction you can contact the

Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

9. Will my taking part in this project be kept confidential?

Yes, all the information that we collect about you during the course of the research will be

kept strictly confidential. Direct quotes from the interviews may be included in reports but

there will not be any identifying information. You are free to talk about your participation in

the study, should you wish.

10. Limits to confidentiality

The only time when confidentiality is breached is if there is evidence of actual or potential

harm to yourself or another. In such cases the University may be obliged to contact relevant

statutory bodies/agencies. If this was the case we would inform you of any decisions that

might limit your confidentiality. Thus, confidentiality will be respected unless there are

compelling and legitimate reasons for this to be breached.

11. What will happen to the results of the research project?

Findings from this research will be written up as part of educational qualifications (doctoral

theses) and will also be submitted for publication in an academic journal(s). A lay summary

of findings will be produced, a final version of which will be made available on the UCLUS

website (www.ucl.ac.uk/pals/research/clinical-educational-and-health-

psychology/research-groups/ucl-unit-stigma-research-uclus).

12. Who is organising and funding the research?

Funding and sponsorship for the research is provided by University College London

Contact for further information

If you require any more information before deciding on whether to participate in the

research please contact:

Doug Hobson

Email: douglas.hobson.18@ucl.ac.uk

Data Protection Privacy Notices

The controller for this project will be University College London (UCL). The UCL Data

Protection Officer provides oversight of UCL activities involving the processing of personal

data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study.

Further information on how UCL uses participant information can be found in our 'general'

privacy notice:

For participants in health and care research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: Name, Address, Age, Gender, Ethnicity

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project and will be held until September 2021. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

CONSENT FORM

Please ensure that you have read the Participant Information Sheet for the study before completing this form.

Title of Study: How do partners of people with dementia tell family and friends about the diagnosis?: A research project to find out what people say and don't say to others about their spouses' diagnosis

Department: Department of Clinical, Educational and Health Psychology

Name and Contact Details of the Researcher(s):

Doug Hobson**,** email – douglas.hobson.18@ucl.ac.uk

Gianna.Kohl, email – gianna.kohl.19@ucl.ac.uk

Name and Contact Details of the Principal Researcher: Dr Georgina Charlesworth, email –

g.charlesworth@ucl.ac.uk

Name and Contact Details of the UCL Data Protection Officer: Alexandra Potts data-protection@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee: Project ID number:

16961/001

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be provided with a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that uninitialed boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Initial Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction. I would like to take part in an individual interview.	

2.	I understand that I will be able to withdraw my data up to March 1st 2021.	
3.	I consent to participate in the study. I understand that my personal information including age, gender, ethnicity and details disclosed in the interview will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing, and, 'research purposes' will be the lawful basis for processing special category data.	
4.	The data I provide will be will be kept securely on a password protected UCL server and will only be kept as long as it is required I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I understand that confidentiality will be maintained as far as possible, unless during communication or interview the researcher hears anything which makes them concerned that someone might be in danger of harm. If this is the case they might have to inform relevant agencies of this. I understand that my data gathered in this study will be stored anonymously and securely. My data will be appropriately anonymised with care taken to ensure there is no identifying information included in the write up.	
5.	I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
6.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without it affecting any benefits to which I am entitled. I understand that if I decide to withdraw, any personal data I have	

	provided up to that point will be deleted unless I agree otherwise. I understand that I will be able to withdraw my interview data up to March 1st 2021.	
7.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
8.	I understand the indirect benefits of participating (to increase knowledge around carers' decisions to disclose and support future carers).	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
11.	I consent to my interview being audio recorded and understand that the recordings will be transcribed and the original recording destroyed within two weeks of the interview taking place. Direct quotes from the interview may be used in the write-up but these will not contain any personally identifiable information.	
12.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher: -I am in a longstanding partnership with someone diagnosed with dementia -I am willing to talk about my experience in an audio-recorded interview in English.	
13.	I am aware of who I should contact if I wish to lodge a complaint.	
14.	I voluntarily agree to take part in this study.	

|			
	15.	I would like to be sent a copy of the preliminary results	
	16.	I understand that my data will be stored and deleted in the following timeframes: Recordings – deleted 2 weeks after they have been taken to allow time for transcription (exact time depends on when data is collected) Transcripts – kept for up to two years after transcription has taken place to allow for thesis corrections and the possibility of publication – data will be anonymised/pseudonymised. Personal data (i.e. name and contact details) – deleted by June 2021 should you decide to see the preliminary results (as indicated above, 16) Application, PIL and Consent forms will be stored electronically on the UCL server (UCL requirements are that data is stored securely for 10 years). There will be no paper records after the project. If you decide you don't want to see these results, your personal data will be deleted after your interview has taken place.	

_____   _____   _____

Name of participant   Date   Signature (you can type name)

_____   _____   _____

Researcher   Date   Signature

Appendix E: Demographic information form
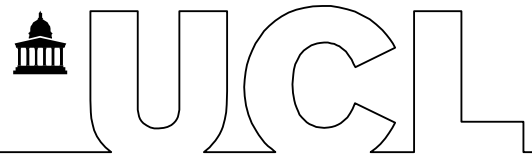
Demographic details' record sheet

How do partners of people with dementia tell family and friends about the diagnosis?: A research project to find out what people say and don't say to others about their spouses' diagnosis

Thank you for expressing an interest in taking part in this study. We need to collect some information from you.

Age: ……………………………………………………………

Gender: male ☐   **female** ☐   **other** ☐   **rather not say** ☐

Ethnicity: white-British ☐   **white other** ☐ **Black British** ☐ **British Asian** ☐

other (please specify) …………………

Relationship to Person with Dementia (PwD) e.g. spouse ……………………………………………….

Age of PwD   ………………………………

Ethnicity of PwD: white-British ☐   **white other** ☐ **Black British** ☐ **British Asian** ☐

other (please specify) …………………

Gender of PwD: male ☐   **female** ☐   **other** ☐   **rather not say** ☐

How long you have been/were you a 'carer' for (to the nearest half year) i.e. 1 and a

half years

………

ID number (for administrative use only): ………………………

The study has been reviewed and approved by the UCL Research Ethics Committee

[16961/001]. Any information you provide will only be used for this project. For further

information about UCL's privacy notice click here.
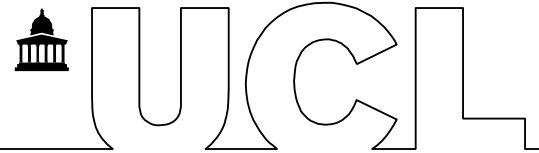
Participant Debriefing

How do partners of people with dementia tell family and friends about the diagnosis?: A research project to find out what people say and don't say to others about their spouses' diagnosis

Thank you for taking part in this research project.

We hope that you have enjoyed taking part in the research interview. There is a possibility it may have got you thinking more about your feelings around the dementia diagnosis and the responses of those around you. If you would like further information or support, the following organisations are able to offer information and advice:

Carer organisations and advice

https://www.alzheimers.org.uk/get-support/help-dementia-care

https://www.nhs.uk/conditions/dementia/carers/

-Alzheimer's Society's National Dementia Helpline on 0300 222 1122

-Age UK's Advice Line on 0800 055 6112 (free)

-Dementia UK Admiral Nurse Dementia helpline on 0800 888 6678 (free)

-Carers Direct helpline on 0300 123 1053 (free)

-Carers UK on 0800 808 7777 (free)

Psychological support

If you are feeling worried or low you can access psychological support through your local

Improving Access to Psychological Therapies (IAPT) "Talking Therapies" service. You can find

your local IAPT service via the link below where you can self-refer online, or, alternatively

you can ask your GP to refer you:

https://www.nhs.uk/service-search/psychological-therapies-(IAPT)/locationsearch/10008

If you have any further questions or concerns following your participation in the study,

please contact Doug Hobson via douglas.hobson.18@ucl.ac.uk or the Principal Researcher,

Dr Georgina Charlesworth at g.charlesworth@ucl.ac.uk

Thanks once again for giving up your time to participate

Appendix G: Extra of initial coding from interview transcript

08: Well, I knew about as much as anybody else that watches television knew. I knew it was an illness of the mind. And then it will get worse. I hadn't perhaps realised the full implications of that. I knew of one or two people who had Alzheimer victims in their families and I've heard from them passing comments about the severity of and the impact it had on the families. So, in a way, I suppose I had some foreknowledge, forewarning of how it might be. But I really hadn't grasped that it was really gonna happen you know I suppose , in a I was hoping it wasn't going to happen. Or if it did, it would happen so slowly, that many years would pass before it became too apparent.

Interviewer: And did you tell your friends about her diagnosis?

08: Yes. Yes, not not as a special announcement, but just in the course of general conversation, as I said earlier, [PwD] was always did make announcement, like practically, about for a while, because it became necessary that people should know, because of the slightly odd things that she was beginning to do. If we went out as a group or a restaurant, I made a point of telling the waitress that my wife had Alzheimer's and that she would need some sort of special care well not care but would she make allowances because some she might be going to the loo every 10 minutes or so for a wee and she might have to have somebody to go with that sort of thing did require a certain amount of explanation called well what the place was we're in where there's a pub or a restaurant or anywhere else

Doug Hobson
Facilitating understanding
Practical support

Interviewer: And how did people respond such as that waitress, for example, when you told them

08: Yeah, everybody the waitress types, and everybody else was very understanding, all expressed great understanding and kindness. And this really has been how it has been all the way through with all sorts of things. Everybody has been as helpful as they are able to, to my face and I don't' know whether behind my back they are saying what a bloody nuisance this is there was no sign of that from anyone else all.

Doug Hobson
Supportive responses

Interviewer: good. And did [PwD] mind you telling people such as the waitress

08: Oh, [PwD] object? Oh, no, no, not at all. There was no reason why she should because we're being frank about our whole thing right from the beginning. And if anything, as I said she was always proud of the fact that she had Alzheimer's I don't know why but that was her attitude or how it came across to some extent.

Doug Hobson
PwD accepting of diagnosis

Interviewer: Okay. And what reactions did you get from your friends when you told them

08: It varied a bit from from one to another , they didn't all react in the same way? Some people perhaps who didn't really understand what was how it was like to go a bit nonchalant and took in their stride others were very sympathetic. And perhaps one of the two mentioned people they knew who had Alzheimer's, but it wasn't. It didn't stay a subject of conversation for very long it was just accepted with one or two comments and then the subject was dropped.

Appendix H: Respondent Validation Email

Dear Research Participant,

I am contacting you in relation the research study that you kindly took part in on the topic of decision-making around whether to tell others about your partner's dementia diagnosis. It was a pleasure to meet you and discuss your experiences.

As part of the interview process, you expressed an interest in seeing a preliminary summary of findings. Attached is a summary of these findings which will then be written up as part of the empirical paper. I would welcome any comment you have on the findings should you wish to make one, there is no obligation to do so. I would appreciate this comment within two weeks of today's date in order to integrate it into the write-up.

When reading the summary findings, it is important for me to emphasise that I collected over 12 hours of interview material and had to focus on reoccurring data that was specific to the central research question. This was, the factors that people weigh-up when deciding to tell others or not tell others about their partner's dementia diagnosis. There were a wide range of views and responses given across the 12 hours of interviews, and I am aware I have not been able to cover everything that has been said. Therefore, please do not be surprised if there are parts you do not recognise or are not in agreement with, as the idea is to get an overall picture of themes across the 12 interviews.

 Thanks,

Doug Hobson

Trainee Clinical Psychologist

Appendix I: Extract from a randomly selected page of one of the bracketing interviews

Interviewer:
And has it been helpful or unhelpful having that personal experience?

Doug (myself):
Yeah, I think it's been helpful because I know, terminology and stages of the disease and common symptoms. And quite often people, I think people have been keen to ask me information, and which, both about other interviews and how they've gone so I think that shows people do care, you know, about how perhaps they've been perceived. But also just being able to demonstrate knowledge around when people have gone to memory clinics, or people have gone into care homes, what that process is like, and when that's happened, so I think it massively helps to know, because it helps you know, the area in more detail.

Interviewer:
It sounds like you've really been able to use it as a resource. And throughout the process, would that be correct?

Doug (myself):
Yeah I've not ever gone in with it. Armed with it in the first place, but I've had it as backup really, something to sit alongside everything.

Interviewer:
Okay, so you've used it to maybe aid with your understanding or to make people feel more at ease, but not like you're saying, sort of as your main tool to help individuals get comfortable in a way?

Doug (myself):
Yes, absolutely.

Interviewer:
And what have you enjoyed the most about this process so far?

Doug (myself):
Yeah, I just enjoy speaking to other people, and hearing their opinion and views, I think it's quite a privilege to actually be able to advertise something and get people to respond to you and give their opinion. So it's definitely been conducting the interviews and arranging them. And yeah, not so much for transcription. But you know, it has it's interesting in its own way, but yeah, just the interviews themselves have been enjoyable.

Interviewer:
And I know, we've discussed this briefly at the beginning. But is there anything else you want to add to how you're finding the process of analysis? Or the process that you started snd that's currently taking a bit of a break from?

Doug (myself):
Yeah, I just think I have to be patient with myself and with the process. And maybe, you know, I'm very much right, I'm gonna do it on word and highlight things and use comments,

but maybe a bit more open to using some software, or post it notes or printing things off or mixing it up a bit, which I really don't fancy doing, especially around software, but I might, I might give it a go or look into it a bit more maybe.