Oldest-old partner’s experiences of providing end-of-life care: a narrative study

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For Nick, my love

Declaration

This dissertation comprises work conducted by Tessa Morgan for the Degree of Doctor of Philosophy from the University of Cambridge. This thesis is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the preface and specified in the text. It is not substantially the same as any work that has already been submitted before for any degree or other qualification except as declared in the preface and specified in the text. It does not exceed the prescribed word limit for the Schools of Clinical Medicine and Veterinary Medicine Degree Committee. Submission date: 29.06. 2021.

Abstract

Title

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Background

Population ageing has rapidly increased the number of people requiring end-of-life care across the globe. Governments have responded by promoting end-of-life in the community. Partly as a consequence, older partners are frequently providing for their partner's end-of-life care at home, despite potentially facing their own health issues. Little is known about people aged 75 and over who are providing end-of-life care. In order to prepare our health and social care systems for rapidly ageing populations, we need to understand more about this group's experiences of end-of-life care.

Aim

To explore the experiences of oldest-old partners looking after their partner approaching end-of-life care.

Method

First, I conducted a systematic review of the extant literature published since 1985 on the topic. Second, I conducted a longitudinal narrative interview study with 17 couples (19 participants in total).

Findings

A systematic review of the literature identified a small and only medium quality evidence-base with important empirical and theoretical gaps that require further research. Drawing on interview data, the first key finding was that older partners navigated the carer identity in relation to external and internal factors with not all subsequently embracing the carer identity for themselves. A second key finding is that older partners are actively engaged in integrating care in their capacity as home-keepers, networkers and vigilant visitors. A third key finding highlights the creative ways in which older partners engaged with a pill organizer called a dosette box to make their daily end-of-life caring and medical management bearable.

Conclusions

The overarching contributions of this thesis challenge notions of the fourth age as merely comprising “decline, passivity and frailty” by emphasizing the activity and creativity of older partners providing end-of-life care. Second, by thinking about oldest-old partners needs and experiences as interconnected, I suggest that policy-makers and health and social care providers will be able to more effectively design services that meet the needs of both oldest-old partners.

Publications and Conference Proceedings

Publications presented in this thesis

Morgan, T., Duschinsky, R., Gott, M., Barclay, S. (2021) Problematising carer identification: A narrative study with older partner's providing end-of-life care SSM Qualitative Research in Health (Chapter 4)

Morgan T, Bharmal A, Duschinsky R, Barclay S (2020) Experiences of oldest-old caregivers whose partner is approaching end-of- life: A mixed-method systematic review and narrative synthesis. PLoS ONE 15(6): e0232401. https://doi.org/10.1371/journal.pone.0232401 (Chapter 2)

Morgan, T. Duschinsky R., Barclay S. (2021) Maintenance Art: Paul Stenner's liminality and the case of older caregiving spouses in Wagnor, B., Zittoun, T., eds., Experience on the Edge: Theorizing Liminality Springer: New York, pp. 121-35. (Appendix 15).

Publications during PhD without overlap with the doctoral thesis

Bentley, A., **Morgan, T.,** Salifu, Y., Walshe, C. (2021) Exploring the experiences of living with Lewy body dementia: An integrative review Journal of Advanced Nursing – in pre-production

Tessa Morgan, Janine Wiles, Lisa Williams & Merryn Gott (2021): COVID-19 and the portrayal of older people in New Zealand news media, Journal of the Royal Society of New Zealand, DOI: 10.1080/03036758.2021.1884098

Tessa Morgan, Melissa Carey, Merryn Gott, Lisa Williams, Victoria Egli & Natalie Anderson (2021): More than mortality data: a news media analysis of COVID-19 deaths in Aotearoa, New Zealand, Kōtuitui: New Zealand Journal of Social Sciences Online, doi: 10.1080/1177083X.2021.1905006

Gott, M., **Morgan, T**., Williams, L. (2020) Gender and palliative care: a call to arms *Palliative care and Social Practice* 14: 1-15

Hopkins, SA., Lovick, R., Polak, L., Bowers, B., **Morgan, T**., Kelly, MP., Barclay, S. (2020) Reassessing advance care planning in the light of covid-19 BMJ;369:1927

Clare Gardiner; Jackie Robinson; Michael Connolly; Claire Hulme; Kristy Kang; Christine Rowland; Phil Larkin; David Meads; **Tessa Morgan**; Merryn Gott (2020) Equity and the financial costs of informal caregiving in palliative care: a critical debate *BMC Palliative Care* 19 (71): 1-7.

Morgan, T., Wiles, J., Moeke-Maxwell, T., Black, S., Dewes, O., Park, H-J., Williams, L., Gott, M. (2019) Social connectedness: what matters to older people? *Ageing and Society* 41(5): 1-15 https://doi.org/10.1017/S0144686X1900165X

Morgan, T., Wiles, J., Moeke-Maxwell, T., Black, S., Dewes, O., Park, H-J., Williams, L., Gott, M. (2020) People haven't got that close connection': meanings of loneliness and social isolation to culturally diverse older people *Ageing & Mental Health* 24(10): 1627-1635

Wiles, J., **Morgan, T.**, Moeke-Maxwell, T., Black, S., Dewes, O., Park, H-J., Williams, L., Gott, M. (2019)Befriending Services for Culturally Diverse Older People *Journal of Gerontological Social Work* 62(8): 1-18.

Bharmal, A**., Morgan, T**., Kuhn, I., Wee, B., Barclay, S. (2019) Palliative and end-of-life care and junior doctors': a systematic review and narrative synthesis *BMJ Palliative and Supportive* Care. doi:10.1136/bmjspcare-2019-001954.

Park, H-J., **Morgan, T**., Wiles, J., Gott, M. (2018) Lonely ageing in a foreign land: Social isolation and loneliness among older Asian migrants in New Zealand *Health & Social Care in the Community* 27(3):740-747. doi: 10.1111/hsc.12690

Blog posts:

https://tearairesearchgroup.org/2020/03/06/palliative-care-is-a-feminist-issue/

https://tearairesearchgroup.wordpress.com/2020/07/16/experiences-of-oldest-old-caregivers-at-end-of-life/

Presentations:

Key note for International Women's Day event at King's College London (Appendix 17).

Lucy Cavendish College Graduate Research Seminar: "Nobody cares about the carer": Older spouses' experiences of looking after their partner at end-of-life

Lucy Cavendish College Student Research Conference presentation: Do older caregiving spouses see themselves as ‘carers’?

EAPC 2019 (Oral): Experiences of oldest-old carers whose partner is approaching end-of-life: a systematic review and narrative synthesis

APM 2019 (Oral): Experiences of oldest-old carers whose partner is approaching end-of-life: a systematic review and narrative synthesis

Dumfries Graduate Student Conference (2016): Very old end of life spousal carers: Are they ‘hiding’ or are we looking in the wrong place?

Awards:

Best Junior Researcher, UK Association for Palliative Medicine 2019 conference

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Prologue: “Love is the best medicine”

Over strong-shot espressos, 89 year-old Guilia, a slight woman with big white curls, seethed when recounting her husband’s end-of-life diagnosis. She explained that three years ago she and her husband Arvind had returned home from visiting family in Italy when she noticed that he seemed especially tired and lacking energy. To save both of them trying to get up the stairs, she set him up on the velvet settee in the living room and she slept in the adjacent armchair. In the morning she rang the ambulance to assist her in taking him upstairs to their bedroom. Instead Guilia explained that the ambulance staff took Arvind to hospital where he remained for the following six weeks. Guilia slept at his side in the hospital every night in a flimsy metal chair. During discharging procedures, Guilia described how she was abruptly informed that Arvind had only two months to live and was to go home, without any formal rehabilitation support, to die. She was completely blindsided by this pronouncement and even years later scoffed with piercing malice “who does the doctor think she is, she is trying to play god?”. When I asked “what did they think was wrong with him?” Guilia saw the problem as relating to her care:

> *R: No they say it’s me who has been taking too much care of him. And then what I said, there is a way how to make people to live eh if it’s me, what have I done take care of him. Treating him with love like life was normal I talk to him like he is normal. And that he is another three years needs I feed him. I give food I help him in anything I do.*
>
> ***I: Yeah.***
>
> *R: And they says if was someone else I’m sure he would have died ah yes the person would decide when to die. The doctor dares two months. Well he is something really disgusting what I do I do normal things normal with the love not just keeping him in one corner now I do my business. I don’t care about never that…if you treat with love yes everybody must die but is different that is my policy love is the best medicine in the world. (int 1)*

It was only an hour into the interview that Guilia explained that Arvind (now also aged 89) had advanced Lewy Body Dementia which contributed to his bed-bound state. Guilia, who was also house-bound due to her unsteadiness on her feet, gave little time to their diagnoses. Rather, she focused on how she felt penalised by medical professionals for caring “too much”. On the other hand, she was clearly proud that through doing “normal things, normal with love”, such as talking to him, feeding, bathing and toileting she perceived she had succeeded in keeping her husband alive in spite of his prognosis. Guilia’s story offers a window into the complexity of providing end-of-life care whilst also being in advanced old age.

Chapter 1: Introduction

Ageing and Dying in the United Kingdom

Mirroring international trends (United Nations, 2017), the United Kingdom (UK) has a rapidly ageing population (Office for National Statistics., 2018). At present there are nearly 12 million people aged 65 and above in the UK, of whom 5.4 million people are aged 75+ and 1.6 million are aged 85+ (Age UK., 2019). Current projections forecast the number of people aged 85 and over living in the UK will double over the next 25 years to 3.2 million people (Office for National Statistics., 2016). Mortality trends have also dramatically changed with people now generally dying in advanced old age. ONS mortality data for 2018 found that of the 539,738 deaths in 2018 in England and Wales, 40% (216,781) were people aged 85+ and 68% (368,703) people aged 75+ (Office for National Statistics., 2018).

Based on developments in medical technology and successful public health initiatives, such dramatic demographic changes across the 20th century have been heralded as one of resource-rich nations' most significant achievements (Payne, 2010; World Health Organisation., 2013). Viewed in this way, caring for the oldest-old has been referred to as "the price of affluence" (MacAuley, 2007, p. 546). Caring for the oldest-old has also been viewed therefore as one of the biggest challenges facing health and social care systems globally (Fine, 2012; Oliver, 2014). For example, while the NHS was initially set-up to provide episodic treatment for acute illness, the growing population of older people has resulted in vastly changing illness trajectories and patterns of need that challenge standard models of care (Charles, 2020; NHS England., 2014b).

Changing palliative care models

Palliative care is for people living with a terminal illness where a cure is no longer possible (Marie Curie, 2014). The palliative care approach seeks to improve patients and their families quality of life whilst managing problems associated with a life-threatening illness, by holistically considering their "physical, psychosocial and spiritual needs" (World Health Organisation, 2018c). Ageing populations are directly linked to the increase of palliative need (Etkind et al., 2017). Older people's profiles and needs have in turn prompted changes to existing palliative care models (Davies, 2004). Initially designed for patients with cancer with relatively determinable dying trajectories, palliative care has recently expanded to include other terminal conditions such as Dementia, Chronic Obstructive Pulmonary Disease (COPD) and Heart Failure to reflect changing dying trends attributed to population ageing (Marie Curie., 2015). For the “average” General Practitioner (GP) with a patient list of 2000 patients, it is estimated that there will be an average of 20 deaths per year of which almost half (8/20) are likely to be patients with “Frailty/Comorbidity/Dementia” compared to 5 with Cancer and 5-6 with Organ Failure (Royal College of General Practitioners., 2011).

Palliative care models have had to adapt to oldest-old people’s protracted trajectories which make it difficult to determine when really sick becomes dying (Cardona-Morrell et al., 2017; World Health Organisation., 2011). Dementia, for example, is a condition that is considered terminal upon diagnosis, yet it is usually only in the later stages of the illness that people exhibit signs and symptoms of their end-of-life, such as eating and talking less and sleeping more (Alzheimer’s Society., 2019). Compounding matters, oldest-old people’s higher rates of multi-morbidity present a challenge to single-diagnosis models. An extensive Scottish primary care cross-sectional study found that 23% of all patients were multimorbid, with a prevalence rising to 65% in the 65-84 age group (Barnett, 2012).

Consequently, the definition of end-of-life has expanded in UK-based clinical practice and policy from the last 3-months of life to the “last year of life” (Department of Health., 2008; NICE., 2004; Royal College of General Practitioners., 2011). Scholars have further expanded end-of-life to the chronologically indefinite part of life when patients and their caregivers encounter the implications (e.g., symptoms, practical support needs) of an advanced chronic or progressive life-limiting illness (Gaertner et al., 2017; Lorenz et al., 2005). The expansion of the end-of-life period fits with the broader shift towards personalised palliative care based on individual’s identity characteristics, symptomology, support and care needs and living situation (Leadership Alliance for the Care of Dying People., 2014; National Palliative and End of Life Care Partnership., 2015).

Evidence suggests that these definitional re-conceptualisations have not been fully realized in practice. For example, a UK based study found that 80% of people with one or more advanced non-malignant illnesses died before being identified for generalist or specialist palliative care (Harrison, 2012). Pollock and Seymour (2018) contend that formal palliative care continues to elude “the majority of frail, older patients with the greatest need” (p. 329).They attribute this to a range of factors, including lack of funding for both palliative and geriatric care, confusion about the responsibilities of specialist and generalist providers, and the “continuing push to shift responsibility for older people’s health and social care from the NHS to the care home sector and family carers” (p. 329).

Rise of care in the community

An ageing population has also coincided with changes to where palliative care is delivered. A 2003 UK Government White Paper first outlined a shift towards "home-based" dying in the UK (Department of Health., 2003). This continues to feature in end-of-life care policies (Department of Health., 2008; NHS England., 2014b). These home- and community-centered policies are in line with the broader trends across the 20th century to shift care from hospital to the community; incentivised by changing population health profiles and government objectives to scale back health spending (Heaton, 1999). The rise of community care has been hailed by some as a return to the good old days of end-of-life care before the medicalisation of death and dying (Kellenhear, 2007). 'Home as best' policies have been lauded for better reflecting people's preferences for where they want to die (Gomes & Higginson, 2006). This shift reflects the principles of broader "ageing well" policies, which advocate "ageing in place", on the assumption it enables older people to maintain their autonomy and connection with family and friends as well as presenting an cost-effective alternative to institutional care (Wiles et al., 2012).

Recent scholarship has problematised the shift to providing care in the community (Gott et al., 2018; Sutherland et al., 2016). Hoare (2015) queried the empirical basis for the assumption that everyone wants to die at home by demonstrating that reported preferences for place of death often exclude the views of those who are undecided or not asked, thus providing an inaccurate picture of people's preferences. Robinson and colleagues (2015) highlighted important benefits to receiving end-of-life care in hospital such as improved feelings of safety. Other studies have also drawn attention to the way 'home as best' policies presupposes the existence of a family culture in which members are willing to give and receive care from one another (Gott & Ingleton, 2011; Payne, 2010). Such policies have also been critiqued for disproportionately relying on women to provide such care, thus entrenching gender inequities (Gott et al., 2020; Morgan et al., 2016). Other studies have raised concerns about the inequitable access to specialist palliative care services designed to support family caregiving in the community (Dixon et al., 2015; Tobin, 2021).

Reliance on Family Carers

With this shift to care in the community, families are being increasingly relied upon to provide care for older dying family members at home (Funk et al., 2010; Grande & Ewing, 2019; Pickard et al., 2000). In the UK, there is an estimated 7.6 million family carers aged 16 and over, 67% of whom are caring for an older relative (Petrie, 2018). Family members providing end-of-life care have been identified as providing high levels of end-of-life care often for prolonged periods of time (Exley, 2007; Rowland et al., 2017). The most recent State of Caring survey conducted with 7525 self-identifying UK carers (albeit not strictly providing end-of-life care) found that 46% of respondents reported providing 90 or more hours of care every week (Carers UK., 2019). A range of UK-based studies outline how providing end-of-life care involves a high degree of direct hands-on care (like toileting) and administrative and organizational work (attending medical appointments) (Ewing et al., 2018; Grande & Ewing, 2019; Lowson et al., 2013; Rowland et al., 2017). Some family members, for example, are involved in arranging their older family member's health care assistants by liaising with care agencies and the local council in order to access personalised budgets in order to fund care (NHS England., 2021; Ungerson, 2005). While the UK welfare state means hospital-based care is free of charge as are medications for anyone over 65 years old, families are still expected to meet many of the financial costs of this care including some equipment and transportation (Gardiner et al., 2020).

Concerningly, evidence indicates that UK family members providing end-of-life care are currently insufficiently supported in their caring roles (Carduff, 2014; Ventura, 2014). Qualitative interviews with family members of end-of-life patients have found that their needs and circumstances were insufficiently considered in discharge planning (Ewing et al., 2018). Carers of patients with a range of terminal conditions, such and Motor Neurone Disease and Chronic Obstructive Pulmonary Disease have been found to not have their needs (both physical and psycho-social) sufficiently met by formal health care providers over the course of their long-term caring responsibilities (Ewing et al., 2020; Farquhar, 2018; Micklewright & Farquhar, 2020). A mixed-methods study comparing the UK to four other European countries concluded that countries offered formal palliative care as a one-off event without institutionalised support structures (Ateş et al., 2018). This meant that family carers did not receive proactive care nor adequate access to supportive resources (Ateş et al., 2018). There are at present few evidence-based strategies for effectively improving the outcomes of family carers providing end-of-life care (Gomes et al., 2013; Turner et al., 2016). This means that even basic questions such as whether using the term "carer" is the best way of identifying and supporting people in caring roles still require further clarification (Molyneaux, 2011).

Impact of Providing End-of-life Care on Family Carers

There is a strong body of research linking end-of-life caregiving with increased rates of depression (Braun et al., 2007), emotional distress (Hoerger & Cullen, 2017), physical ill health (Pinquart & Sörensen, 2003) and even some evidence that it increases mortality (Schulz & Beach, 1999; Schulz & Eden, 2016). Studies have found that family members providing end-of-life care have particularly poor health and psychological outcomes. For example, family members have been found to be emotionally and physically unprepared for caring for their dying relative (Jack, 2014). Quantitative evidence suggests that family carers show a greater prevalence of anxiety and depression than end-of-life patients themselves (Braun et al., 2007; Gotze, 2014). A recent UK-based survey found that across all age group psychological morbidity scores were 5–7 times higher amongst end-of-life cancer carers than the general population (Grande et al., 2018).

Notably there have been calls in the scholarship to move beyond the burden of care discourse (Schulz et al., 2018). Studies have since considered the positive aspects of end-of-life caring, such as the degree of personal development and coping skills gained and increased feelings of closeness with their dying family member (Bangerter et al., 2018; Henwood, 2017; Roth et al., 2015). It is now perceived that there is a relatively strong evidence base around midlife family carers – predominantly of people with cancer. Scholars have urged that future research should focus on under-researched carers to ensure the generalizability and efficacy of any further interventions (Grande et al., 2009; Hudson, 2011).

Older Family Carers

Older family carers have received increased scholarly attention over the last thirty years. Landmark studies in the 1990s were the first to draw attention to the wide range of caring activities in which older people, particularly spouses, were engaged (Arber, 1991; Navon, 1996; Wenger, 1990). Wegner contends that the emergence of "older carers" marked a significant conceptual shift from earlier caregiving studies, which perpetuated the image of a carer of an older person as:

> "a middle-aged woman caught between the generations, beset by role conflict as parent, wife and daughter as she strives to meet the needs of aged parent(s), unsupportive husband and demanding adolescent children"(Wenger, 1990, p. 211).

Fundamental to this stereotype is that carers are necessarily physically able women, which helped to entrench the notion of care in these earlier studies as the unidirectional relationship in which an active and independent caregiver provides care to a passive, dependent, often burdensome care-receiver (Finch, 1980; Graham, 1983; Qureshi, 1989). Since the 1990s, studies have applied more sophisticated analyses of care as an inter-relational, processual and context-dependent process involving both a disposition and an activity (Sevenhuijsen, 1998; Tronto, 1993; Williams, 2018). These analyses, enrichened by feminist ethic of care scholarship and disabilities studies, have highlighted the active contributions older people make to their own care and the care of others (Barnes, 2006; Chattoo, 2008; Wiles & Jayasinha, 2013). Studies are also likely enriched by the growing body of scholarship about grandparents providing care for their grandchildren (Minkler, 1999). More recent studies have attested to the way that even within the context of severe physical or cognitive disability, people can reciprocate care and retain some independence, for example, through continuing to do simple tasks such as daily food preparation as a form of reciprocity (Atta-Konadu, 2011; Buch, 2018; Hellstrom, 2015).

Increased scholarly attention in the last decade has come with the growing recognition of the number of older people in caring roles. The Social Market Foundation (2018) estimates that there are currently two million carers aged 65 and over, 417,000 of whom are aged 80 and over. Carers UK reported that the total number of carers has risen by approximately 11% since 2001 with the number of older carers increasing three-fold (35%) (Carers UK., 2015). Amongst those aged 85 or older, there has been a 128% increase over the last decade (Carers Trust., 2015). Concerns have been raised by the charity sector that older people have had to take up caring roles as a result of inadequate informal and formal care. The charity Age UK put it starkly in a 2017 headline: “Older carers left to fill the gap while our social care systems crumbles”(Age UK., 2017). The rise of older carers dovetails with concerns about the wider crisis of care in late-modern societies. Older populations are set to outpace the growth of younger populations the world over (United Nations, 2017), which alongside the increasing participation of mid-life women in the labour force, has culminated in the dwindling supply of family carers (Schulz et al., 2018; vanGroenou, 2016). Despite this increased attention older carers have remained relatively invisible in policy until very recently (Henwood, 2017). Their inclusion into the NHS Long-term Plan, which should be seen as a culmination of these efforts, promises far greater acknowledgement of their circumstances in the future (NHS England., 2019).

Drawing attention specifically to older carers’ needs is important as their circumstances and health outcomes differ from other caring populations. Compared with other carers, older carers are more likely to live with the person they care for (Petrie, 2018), to care for someone with who they have a long-term relationship (Henwood, 2017) and to have their own health problems and multi-morbidity

(Gott & Ingleton, 2011; Ventura, 2014). The Carers Trust reports that older carers have a high level of psychological morbidity whilst caring compared to younger carers, with 69% of older respondents (ranging in age from 60-94 in this study) indicating that being a carer has harmed their mental health (Carers Trust., 2015). Older carers are also more likely to be caring for someone with dementia and attendant changes in behaviour and communication that make caring more complex (Milne, 2003; Wadham, 2016b).

Older people are also more likely to be providing partner care which is a factor associated with comparatively poorer health outcomes (Wenger, 1990). Spouse caregivers report more depression symptoms, greater financial and physical burden and lower levels of psychological well-being than any other caring group (Pinquart & Sörensen, 2011). These worse outcomes are ascribed to older spouses spending comparatively more time caring (Ory, 1985; Pinquart & Sörensen, 2011). One of the reasons for this is that older spouses have been identified as providing care largely unaided by community services or other family members (Joyce et al., 2014; Ornstein, 2019). Low levels of support have been identified as reasons for poor self-reported physical health amongst carers of all ages, but particularly so for older people (Mitchell, 2020). Underpinning the intensity of spousal caring appears to be cultural expectations associated with marriages in Western societies that require partners to each be responsible for the other's health and social concerns, and continue to care at any cost (Gopinath, 2018; Henwood, 2017).

Oldest-old carers

While there has been some epidemiological and experiential research focused specifically on older carers' needs, this has largely been restricted to young-old (sometimes referred to as "third age") carers aged between 60–75 (Milligan et al., 2016; Robine, 2007; Venkatasalu et al., 2014). Those in oldest-old age group (sometimes referred to as the "fourth age"), who for the purposes of this project are defined as those 75 and over (Greenwood & Smith, 2016), have higher incidences of falls, dementia, declining social networks and as outlined above, high rates of multi-morbidity (Hallberg, 2004). They are also the age group with the the largest variability in function (Liang, 2003). All these factors are likely to shape caring experiences, indicating that this group needs to be considered separately. UK census data also suggests that most carers aged over 80 spend more than 50 hours a week caring, with married men in this age group providing a higher number of hours caring than married women (Dahlberg, 2007; Del Bono, 2009). Oldest-old carers thus offer an opportunity to understand unique gendered practices with much-understudied groups of carers such as spouses and men (Larkin et al., 2018).

Very little research has been conducted with oldest-old caregivers, with a 2016 systematic review identifying only 18 published studies on the topic; most of the reviewed studies were of early-stage dementia caregiving (Greenwood & Smith, 2016). This review identified similarities to the third-age carer literature, including ambivalence for asking for help. This review also identified unique qualities to this group, including increased difficultly leaving the house and concerns about what would happen if they died, particularly prominent for those caring for children with disabilities. Greenwood and colleagues (2019) subsequently conducted a qualitative focus group study with 44 oldest-old participants which highlighted that loneliness and isolation were prominent aspects of their daily caring experiences. For health and social care practice to keep up with the rapidly ageing population, more research is required about oldest-old caregivers, particularly those who are providing end-of-life care, as even less is known about these final stages of caring.

Rethinking care and the fourth age

Exploring the experiences of oldest-old people in caring roles grants an opportunity to deepen our understanding of what sociological and gerontological studies refer to as the "fourth age". The fourth age was popularised by gerontologists Baltes (2006) and Laslett (1996) to identify when chronic illness and frailty mark a terminal phase in the life course that is separate from the third age (65-75). Higgs and Gilleard have expanded this theory contending that the bifurcation of later life into third and fourth age is a feature of late modernity fueled by consumptive practices dedicated to delaying ageing (Gilleard & Higgs, 2007; Higgs & Gilleard, 2015). Whereas third age is characterised by "autonomy, choice and leisure", the fourth age features as the site of "real" old age, including decline, frailty and passivity and the inability to "sustain first-person narratives"(Gilleard & Higgs, 2010) (p. 475).

Drawing directly on the views and perspectives of the oldest-old (Archibald, 2020; Hallberg, 2004; Sharp et al., 2013) and informed by new models of ageing that privilege resilience and 'capability' approaches (Stephens, 2017; Wiles et al., 2012), studies have helped to complicate the association of fourth age as being merely absent of status or agency. For example, qualitative studies have explored how oldest-old people navigate the challenges of declining physical and/or cognitive health by adopting a series of strategies, including narratively avoiding discussions of frailty (Breheny, 2012; Nicholson, 2012; Wiles et al., 2018). Scholars have also begun to consider the ambivalent place care occupies within the fourth age as to be cared-for both necessitates some form of dependency and presents the opportunity for one's personhood to be recognized and upheld (de Sao Jose, 2020; Higgs & Gilleard, 2016; Pocock, 2020). Most of the research relating to care and the fourth age has centered on interactions between fourth-aged people reliant on formal care for at least some of their daily activities of living (Buch, 2015a; Cleeve, 2020; de Sao Jose, 2020). Through serial interviews with frail, older patients, Lloyd and colleagues (2016) demonstrated their participants attempted to counter feelings of dependency by reciprocating care through emotional or financial means. Focusing on the ways fourth-aged partners navigate caring for their fourth-aged partners provides a fruitful avenue to explore this new strengths-based approach to care and the fourth age.

Research objective of the study

The core objective of this thesis is to:

- Explore the experiences of oldest-old partners looking after their partner approaching end-of-life

To achieve this, each chapter explores a different aspect of experience by considering the following aims:

- Chapter 2: To undertake a systematic review and narrative synthesis of the qualitative and quantitative literature published since 1985 concerning the experiences of oldest-old carers whose partner is approaching end-of-life.
- Chapter 4: To understand the carer identification practices of older partners providing end-of-life care
- Chapter 5: What roles do older partners play in integrating formal care in the context caring for their partner who is approaching end-of-life?
- Chapter 6: How does the dosette box, a pill organiser, mediate older partner's experiences of providing daily care for their partner who is approaching their end-of-life?

Locating the study

Building on research that enables older participants to express their own views and experiences about their daily caregiving and policies that concern them, this thesis comprises a longitudinal narrative interview study conducted in two field-sites in England. Twigg (2006) contends that a narrative approach usefully “wrestles the account of old age out of the hands of experts” and places older people actively in conversation with the policies and issues that impact them (p. 53). Narrative methods also have the potential to counter the over-reliance of end-of-life caregiving studies on cross-sectional qualitative data and thematic analytic methods, which often fail to capture the complexity and fluctuation of caring (Funk et al., 2010; Henwood, 2017; Larkin et al., 2018). Attending closely to the ways participants described their end-of-life caregiving, I noticed early on that death and dying featured surprisingly little in interview talk. Aulino, (2019), who conducted an ethnography on end-of-life family caregiving in Thailand, details a similar conceptual flip during her fieldwork away from death and dying to focus on the daily karmic caring rituals orientated towards sustaining life.

Guided by older partner’s attempts to sustain life, the empirical chapters of this thesis are organised around three key policy topics: carer self-identification, care integration and carer’s provision of daily medications. These topics emerged as important to participant’s experiences of daily caring. These policies are discussed as they broadly relate to health and social care, as few participants were receiving specialist palliative care services. I return specifically to the implications of these findings for palliative and end-of-life care in the discussion.

Introducing myself as researcher

This thesis takes a transdisciplinary approach, recognizing that “boundary production between disciplines is itself a material-discursive practice” (Barad, 2007, p. 90). Taking a transdisciplinary approach suits my researcher journey and sensibilities. Having completed my undergrad BA in History and Politics, I was fortunate to be offered an internship at the University of Auckland School of Nursing in a Palliative and End-of-Life Care research group which introduced me to new concepts such as qualitative research and systematic reviews. Having the experience to conduct interviews and analysis qualitative data prior to my PhD instilled in me the importance of letting your data guide your analysis. This formative experience also helped me to understand how productive it can be to bring ideas from critical theory to bear on health service research, as I previously found from applying a gendered view of palliative care practices (Gott et al., 2020; Morgan et al., 2016).

This doctoral study was also importantly shaped by an eight-month period of patient and public involvement (PPI) (Appendix 1, page v of document). As a New Zealander I was an outsider to the UK health and social care system. As someone who had not previously provided end-of-life care, I was also studying an experience outside of my own, although this changed during the course of my PhD, which is something I reflect on in Chapter 6. To ensure that it was meaningful and relevant to family members providing end-of-life care in the UK, I consulted with 31 caregivers and eight formal care providers specifically about my study. This process led to me to move away from a central focus on gender (which a PPI group of 5 former carers did not see as the reason for differential treatment) to focus centrally on the oldest-old. That said, given that identity is shaped “not by a single axis of social division (such as gender, race, class)… but by many axes that work together and influence each other” (Hill-Collins, 2016, p. 2), certainly age, gender and other aspects such as disability status were interwoven in the analysis (Anthias, 2013a; Krekula, 2007). Family members and service providers identified this oldest-old age group as a particularly vulnerable group yet were unsure how to best support them. Such inklings that research was required in this area were further reinforced through two days of shadowing with two palliative care teams which introduced me first-hand to the questions including what happens in older couples when the carer can no longer cope and whether patients should be discharged home if the carer at home also has a significant illness?

My outsider positionalities, as a researcher from New Zealand in my mid-20s also prompted particular interactions that helped make the fieldwork both personally enjoyable and empirically rich. Participants frequently drew analogies between myself and their granddaughters due to my age and gender. This made for a comfortable interview dynamic where participants positioned themselves as friendly experts willing to impart knowledge and instil life lessons. A similar dynamic has been acknowledged by another younger woman interviewing older women (Jen, 2020).

Outline of thesis

In Chapter 1 I have introduced my research topic and myself as a researcher. I have highlighted the importance and overall aims of this research and mapped the structure of this thesis.

In Chapter 2, I report from a systematic review of the existing empirical evidence about the experiences of caregiving partners aged 75 and over whose partner is approaching end-of-life. This review synthesised the limited existing research in the area and outlined a range of potential lines of inquiry for future research, including a need to further clarify whether the term "carer" was an appropriate label for this age groups and reasons for the under-utilisation of services. I also identified a clear need for studies to have greater theoretical engagement in order to deepen the quality of analysis on this topic. This systemic review has been published in *PLOS ONE*.

Chapter 3 outlines the narrative methodology and chronicles it's application in the data collection and analysis process. In total 41 interviews were conducted using in-depth, longitudinal narratives with 17 couples (19 participants in total).

Chapter 4 explores whether older partners use the 'carer' identity to describe and understand their caring practices. Exploring this question is important given that policy and service provision across health and social care remain heavily dependent on carer self-identification. This chapter introduces "carering" to conceptualise carer identification as a discursive practice. Through the narratives of Mary and Paul, Charles and Dolores, and John and Betty, I demonstrate the range of engagement with "carering". Given that not all older partners will embrace the carer identity, I conclude that interventions designed to support them should not depend upon carer self-identification initiatives. I suggest that the older couple, as a pair, ought to be placed at the heart of alternative identification strategies.

Chapter 5 addresses the timely second issue: what role do family caregivers play in integrating care? This question is important as Integrated Care Systems (ICS) have been pitched as a "new service model for the 21st century"(NHS England, 2019). Yet remarkably little consideration has been given to the role family members currently play in providing care nor how their roles may change in the new ICSs. Chapter 4 compares and contrasts the multiple ways Donald and Rita, Evelyn and Rupert and Carol and Charles attempt to integrate care by networking, home-keeping and vigilant visiting. This chapter highlights the variability of formal support older couples were receiving and concludes that as older partners are already serving as care-integrators, policy-makers and health and social care professionals would benefit from including their views and experiences into conceptualisations and the implementation of new ICSs.

Chapter 6 engages with a broader sociological question: how can people maintain lives in environments that deplete them? This chapter explores how one medical technology – the dosette box – provides an unexpected companion and "weapon of the weak", making life manageable for older partners. This chapter traces the relationships and interplay of Radhika and Rahul, Helen and Barry, Joan and Richard with their respective dosette boxes in their pursuit of keeping care at home. This chapter provides contributions to thinking about "agency" in both family care and the fourth age as well as considering how "technologies of the bearable" such as the dosette box can be used more broadly to navigate and endure in depleting environments such as caring for a partner at the end-of-life.

In Chapter 7 I summarise and integrate the key findings from across this thesis. I reflect on the strengths and weaknesses of my thesis, and the implications of my findings for practice, policy and future research. I explicitly highlight the contributions these findings have for palliative care. I conclude by reflexively returning to consider my role in the research process.

Chapter 2: Experiences of oldest-old caregivers whose partner is approaching end-of-life: A mixed- method systematic review and narrative synthesis

Preamble

What does the existing evidence tell us about the oldest-old spousal end-of-life caregiving? As outlined in Chapter 1, there has been a growing body of research since the 1990s about older carers, yet most of this research has been of people aged between 60-75+, with less research conducted amongst the oldest-old age group. The purpose of this review is to identify all the published studies since 1985 published on the topic, critically analyse the quality of the evidence and narratively synthesis the findings. Through identifying gaps in this current evidence base, this review helped to guide the remit and methodology of the narrative study presented in Chapters 3-6. This paper has been published in PLOS ONE: Morgan T, Bharmal A, Duschinsky R, Barclay S (2020) Experiences of oldest-old caregivers whose partner is approaching end-of- life: A mixed-method systematic review and narrative synthesis. *PLoS ONE* 15(6): e0232401. https://doi.org/10.1371/journal.pone.0232401

Background

Rapidly ageing populations across the world present significant challenges to traditional health and social care models (MacAuley, 2007; Oliver, 2014), in no small part because people have more protracted end-of-life phases (Gott & Ingleton, 2011). There has been a rapid rise of chronic diseases, including cardiovascular diseases, cancers, and respiratory disease, which continue to be the leading causes of death internationally (World Health Organisation, 2018b). Despite the fact that the majority of deaths internationally now occur amongst the over-65s, there remains relatively little policy concerning their needs and care preferences towards end-of-life (World Health Organisation, 2011). This paucity of policy and research is starker still when considering the oldest-old (Ernsth-Bravell, 2010; Fleming et al., 2016; Hallberg, 2004), who are now the fastest growing age-group in developed countries (Christensen, 2009).

Many governments are advocating the importance of providing end-of-life care in the community (Venkatasalu et al., 2014; World Health Organisation, 2018a). This policy directive is informed by resource-limitations across health care sectors as well as more apparently empowerment-focused agendas of “personalized care” and “ageing in place” (World Health Organisation, 2011, 2015). Scholars working with family caregivers have voiced concerns that the “care in the community” approach relies on family members to take on intense, often 24/7 care for indefinite periods of time (Ewing et al., 2018; Exley, 2007) with input from professionals often only late in the end-of-life phase (Phillips & Reed, 2009) if ever (Dixon et al., 2015). Alongside this care they are expected to manage their own feelings about the impending death of their relation (Henwood, 2017).

While there is some evidence that end-of-life caregiving can bring family members closer and catalyze caregiver’s personal growth (Bangerter et al., 2018; Roth et al., 2015) other research suggests that family caregivers feel emotionally and physically unprepared for caring for their dying relative (Jack, 2014) and struggle with the financial consequences (Gardiner et al., 2013). Marked associations have been identified linking caregiving with increased rates of depression (Braun et al., 2007), physical ill health (Pinquart & Sörensen, 2003) and mortality (Schulz & Beach, 1999; Schulz & Eden, 2016). Additional evidence suggests these costs are disproportionately borne by women, who often spend more time caring and are engaged in more intense care tasks (Navaie-Waliser, 2002; World Health Organization, 2015). Consequently women family caregivers have been identified at increased risk of psychiatric morbidity whilst caring (Morgan et al., 2016; Yee & Schulz, 2000).

There is now a growing recognition in policy and research that family caregivers are often older themselves and living with complex and multiple long-term conditions (Gott & Ingleton, 2011; Grande et al., 2009; NHS England, 2019; Ventura, 2014). The emergent evidence on older caregivers of older care recipients indicates they are an at-risk population, being more likely to experience feelings of “powerlessness” (Milberg, 2004) and have increased likelihood of caregiver breakdown (Morris et al., 2015). Research to date has predominantly examined the experience of ‘third’ age caregivers aged between 60-75 (Costello, 1999; Milligan et al., 2016; Robine, 2007; Strang, 2001; Venkatasalu et al., 2014), or includes caregivers aged 65 and above without differentiating further (Jack, 2014), despite evidence that there are important variations between being aged 65 to 75 let alone aged 65 to 90+ (Thome, 2004).

Comparatively little is known about oldest-old caregivers who are over-75 years old. This is particularly concerning given that people in this age-group have a higher incidence of falls, dementia and declining social networks (Baltes, 2006; Hallberg, 2004; Twigg, 2003): all factors likely to shape caregiving needs and experiences. There are also indications of unique gendered patterns of caregiving in this age group; UK census data suggests that married men are more likely to be providing 50 hours or more of care per week than married women (Dahlberg, 2007; Del Bono, 2009). This suggests there may be a different distribution of physical and psychological impacts and indeed meanings of caregiving amongst the very old. Greenwood and Smith's (2016) systematic review of oldest-old caregiving identified 18 published studies, of which most focused on early-stage dementia caregiving. They did not conduct a formal quality assessment of these studies, so the quality of the evidence remains unclear: nor did they examine the experience of providing end-of-life care specifically.

In order to gain an in-depth understanding oldest-old end-of-life caregiving, I decided to look specifically at spousal care. Oldest-old spouse caregivers have been identified as a particularly at-risk group when compared with non-spousal caregivers as they tend to provide more care per week (National Alliance for Caregiving & AARP Public Policy, 2015), live with the person they are caring (Henwood, 2017), provide more care as they age (Princess Royal Trust for Carers, 2011) and care without the support of other secondary carers (Tennstedt, 1989) or formal services (Feld, 2010; Joyce et al., 2014). Research also indicates that older spousal caregivers are at greater risk of lower self-esteem (Chappell et al., 2015), physical burden (Kang, 2016) and social isolation than adult-child carers (Montgomery & Kosloski, 1994; Ory, 1985). These disproportionately adverse impacts may be linked to the normative demands associated with living as a couple (Pistrang, 1995; Wadham, 2016a).

Aim

To undertake a systematic review and narrative synthesis of the qualitative and quantitative literature published since 1985 concerning the experiences of oldest-old carers whose partner is approaching end-of-life.

Research Design and Methods

Outlining the search

Spousal caregivers were partners (whether married or not) who were "in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management" (NICE., 2004). Participants were required to be community-dwelling rather than living in an institution to align with our own as well as policy-makers interest in end-of-life care in the home. Though various parameters have been used in the literature (Cohen-Mansfield, 2013), this review defined oldest-old (or the 'fourth age') as aged 75 and above, in acknowledgement of differences in mean age at death across the world (age 74 in East Asia and age 80 and above in Western Europe) (World Health Organisation, 2015). My approach mirrors that taken by Greenwood and Smith (2016) who included papers where the mean age of caregivers was 75 years and over. When caregivers' age-ranges might have a mean of 75 or over, full-text papers were read for clarification.

There are difficulties with the prognostication of end-of-life amongst the oldest-old, given protracted trajectories and difficulty surrounding when really sick becomes dying (Cardona-Morrell et al., 2017; Kafetz, 2002; World Health Organisation, 2011, p. 3). As such, a more holistic definition was used in this review: "end-of-life" refers to the chronologically indefinite part of life when patients and their caregivers are encountering the implications such as symptoms and practical support needs of an advanced chronic or progressive life-limiting illness (Gaertner et al., 2017; Lorenz et al., 2005). Consequently, studies focusing on dementia were only included if they reported on moderate to severe stages of the illness. Papers focusing on diagnosis, early-stage or mild to moderate dementia exclusively were excluded.

Search strategy

The review protocol and search strategy was developed through discussion with my supervisors and a professional Medical Librarian. The wider search process was guided by the PRISMA checklist (Appendix 4)(Moher, 2009) and the research question was organised within the PICOS framework (participants, interventions, comparisons, outcomes, and study design). Search terms were initially developed in relation to the key search areas and subsequently refined through a pilot Medline search (Appendix 5). Recognising the definitional complexity of the term "experience"(Scott, 1991), we followed a critical interpretative approach by not specifying predefined understandings of the concept in advance of the synthesis (Dixon-Woods et al., 2006; Rodríguez-Prat, 2017).

The inclusion and exclusion criteria are outlined in Table 1. To maintain the focus on partners as primary caregivers, included studies were restricted to home or retirement home settings, recognising the significant amount of independent living in the latter (Reeve, 2016). Hospitals, hospices and nursing homes were excluded as in these contexts health and social care professionals become the primary caregivers (Robinson, 2013). Included studies were peer-reviewed with substantively new empirical data. There was no restriction on methods and or country of origin. Papers were restricted to English language only as I had no resources for translation. My search commenced in 1985 to align with "informal care" and "family carer" entering bibliographic databases (Heaton, 1999) as a result of reduced public spending in many countries and a shift of responsibility for care of the elderly from the state to families and the voluntary sector (Daly & Lewis, 2000). A protocol has been registered with protocols.io: dx.doi.org/10.17504/protocols.io.bdm8i49w.

Table 1. Inclusion and exclusion criteria

Inclusion	Exclusion
• Carer/ supporter/ helper of someone with life-limiting end-of-life condition • Home, retirement village, Aged residential care facility • Carer 75 and above (mean of paper) • Search parameters: human, English-only, research, 1985- • Peer-reviewed, published empirical research • All research methods • No restriction on country of publication	• Perspective of person who is dying (primary focus) • Person being cared for does not have an end-of-life condition (only a chronic illness e.g. arthritis) • Formal or paid health care professionals or volunteers. • Friends, adult-child, neighbours. • Hospital, hospice or inpatient unit at a retirement village • Mean of paper under 75 (unless case made for specific cultural relevance of oldest old in a particular sample) • Unpublished manuscripts, conference abstracts, posters and other empirical work not published in full Opinion pieces, guidelines, papers with no new empirical data • Grey literature

	• Interventions

Conducting the search

In April 2018 I searched six databases: Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, Sociological Abstracts and Social Service Abstracts. Between May-July 2018 and again in May 2019 I independently screened titles to ensure the most up-to-date search. The title screening was done by one reviewer as is considered acceptable by Cochrane guidelines (Higgins, 2019). A research colleague Aamena Bharmal (AB) was a second reviewer through the abstract screening, full-text screening and analysis process. She was selected because she was not a content expert and thus did not have pre-formed opinions that can bias the assessment of the relevance and validity of articles. In line with advice from the medical librarian and Cochrane guidelines, Aamena reviewed a randomised selection of 10% of abstracts and a randomised selection of a third of full-text papers. Aamena and I read and confirmed all of the included studies ahead of quality appraising all of these studies independently.

The transparency of the screening process was enhanced through the use of Rayyan a web application designed for collaborative citation screening and full-text selection (Ouzzani et al., 2016). Using Rayyan, Aamena and I independently documented their inclusion or exclusion decisions by attaching a justificatory label to each paper (for example a frequent label was ‘excluded because of wrong age-range’). We subsequently conferred findings to ensure the consistency of screened studies. On the few occasions disagreements arose, the team (also involving my two supervisors) transparently resolved them by reference to reasoning recorded in Rayyan. I then undertook reference searching of included papers, citation searching using Google scholar, and reference chaining to support robustness of the review.

Data analysis

Included studies were analysed using a narrative synthesis approach in order to coherently and systematically integrate findings from studies using heterogeneous methodologies found in the included qualitative and quantitative studies (Popay et al., 2006). This approach is suited to nascent fields as it provides a structured way to generate a “trustworthy story” about the evidence base where little is currently known (Popay et al., 2006). As oldest-old carers are an under-researched group this method was considered the most appropriate.

This narrative synthesis intertwined three main elements of Popay's approach (Popay et al., 2006): developing a preliminary synthesis, exploring relationships within the data and assessing the robustness of the synthesis. Our adapted version of the narrative synthesis approach is presented in a supplementary table (Appendix 6). Notable adjustments include conducting a critical appraisal of the data before the production of themes to ensure that the themes were not heavily weighted towards low quality studies or towards unique studies that had more than one paper included in the review.

Aamena and I weighted each paper independently using Gough's "Weight of Evidence", a widely used tool suitable for qualitative and quantitative studies. This process involved rating studies 'high', 'medium' or 'low' weight in relation to the three categories: A) generic quality of each studies, B) their specific appropriateness to the review, and C) their utility (Gough, 2007). The overall weight of evidence "D" of each study was awarded on the basis of the average of the individual scores (if two highs and a medium study was marked high) (Appendix 7). Aamena and I then compared their independently ascribed weightings of each study: we did not need to adjust the overall quality score ('D' rating) of any study indicating consistency in the evidence appraisal between the two assessors

Informed by evidence that end-of-life caregiving is a heavily gendered process (Dahlberg, 2007; Morgan et al., 2016; Sutherland et al., 2016), I subsequently conducted a feminist quality appraisal of the evidence. In line with a appraisal tool I have previous developed I considered how issues of power, gender and inequity (including those pertaining to intersecting identities of race, class and age) were handled in the aims, study design, data collection and analysis, discussion and recommendations for change section of each included study (Morgan et al., 2017). The studies were scored and the quality attributed through the same process outlined for Gough's tool. These are presented in the characteristics table (Appendix 7).

I conducted a thematic analysis that focused on the "main, recurrent and/or most important (based on the review question) themes and/or concepts across multiple studies" (Popay et al., 2006, p. 18). Through this process I identified three overarching themes, which are presented below. To further protect against bias, a modified version of the vote-counting process was used to determine whether each theme was supported, negated or irrelevant to each included study in turn (Popay et al., 2006). Relevant insights from this process, particularly the cases of conflicting findings, were subsequently incorporated into the synthesis. Themes were frequently discussed between myself as the lead researcher, Aamena and my two supervisors to aid transparency and reliably of their production.

Results

Search results are summarised in the adapted Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flowchart (Appendix 8) (Moher, 2009) and the characteristics are displayed in Appendix 7. A total of 19 papers were included from 16 unique studies, of which ten used qualitative methods and nine quantitative methods. It was striking that ten of the papers included were published in recent years (between 2016-2019) and none were published before 1993 (Tennstedt et al., 1993).

Based on Gough's "Weight of Evidence" all but one of the included papers were of at least medium weight. Four papers drew from large longitudinal observational cohort studies covering two, three, seven and eight time points (Dassel, 2016, 2017; Potier, Degryse, Bihin, et al., 2018; Tennstedt et al., 1993) and one study (Sampson et al., 2016) included a retrospective longitudinal analysis of general practice records (median time 3 years). Three qualitative studies conducted serial interviews (Black, 2008; Sanders & Power, 2009) including an ethnography lasting 13 months (McGhan et al., 2013). The feminist quality of included papers was low despite the frequent focus on the differences between genders: only six studies engaged with the gendered construction of care (Poysti, 2012; Sanders & Power, 2009; Shavit et al., 2019; Siriopoulos, 1999) and only two did so to a high standard (Russell, 2001; Williams et al., 2017).

Of the nine papers providing mean ages of caregivers, the collated mean age was 76.9 years (Dassel et al., 2017; Dassel, 2016; Edwards & Noller, 1998; McGhan et al., 2013; Perry, 2002; Poysti, 2012; Sampson et al., 2016; Sanders & Power, 2009; Tennstedt et al., 1993) (note this only includes the ages of dementia carers in Dassel studies). Of the five studies reporting age ranges, all but one included at least one caregiver aged over 90 (Black, 2008; Russell, 2001; Siriopoulos, 1999; Turner et al., 2016; Williams et al., 2017). Studies were conducted exclusively in western contexts and reported findings predominantly about white and heterosexual populations. Thirteen studies reported, at least initially, on current caregivers, three studies focused on bereaved carers and three studies combined both groups.

Most studies identified their caregiver-participants via their partners' condition with only four studies requiring participants to self-identify as carers or caregivers (Dassel et al., 2017; Dassel, 2016; Edwards & Noller, 1998; Sanders & Power, 2009). Only four studies provided a definition of caregiving, with three definitions focused on supporting another person in their activities of daily living (Perry, 2002; Sanders & Power, 2009; Tennstedt et al., 1993). One study required caregivers to be registered for the government-funded carers' allowance scheme (Edwards & Noller, 1998). One study that identified caregivers by virtue of co-habitation with a person at their end-of-life reported that only 6.9% of this sample had been formally identified as a caregiver by their GP (Sampson et al., 2016).

Participants were caring for spouses with a range of end-of-life conditions. Six studies focused exclusively on care-recipients with end-stage dementia (Black, 2008; Perry, 2002; Poysti, 2012; Russell, 2001; Shavit et al., 2019; Siriopoulos, 1999), six on advanced frailty (Edwards & Noller, 1998; Potier, Degryse, Aubouy, et al., 2018; Potier, Degryse, Bihin, et al., 2018; Potier, Degryse, Henrard, et al., 2018; Sanders & Power, 2009; Tennstedt et al., 1993), and the rest focusing on care-recipients who had died. Both the age of the care recipient and the length of care were inconsistently reported with eight and ten studies respectively not providing this information.

Narrative synthesis of content

This section presents a narrative synthesis of the overarching themes identified across the included studies. The three themes were the embodied impact of care, caregiving spouse's conceptualisation of their role, and learning to care.

Embodied impact of care

Studies highlighted the "double jeopardy" (McGhan et al., 2013) associated with caring for a spouse whilst managing one's own poor health. Studies reported caregivers with multiple chronic comorbidities, frailty, respiratory problems and, in one study, cancer (Dassel et al., 2017; Dassel, 2016; Edwards & Noller, 1998; McGhan et al., 2013; Poysti, 2012; Sampson et al., 2016; Turner et al., 2016). In three quantitative studies, caregiving increased the risk of frailty (Dassel, 2016; Potier, Degryse, Bihin, et al., 2018), with one study indicating that caregivers were six times more likely to be frail than non-caring peers when controlling for other factors (Potier, Degryse, Aubouy, et al., 2018). Two studies reported carers to have been admitted to hospital with their own poor physical health, which they had neglected in order to continue caring for their partner (McGhan et al., 2013; Turner et al., 2016).

Caring was linked with high levels of emotional stress (Black, 2008; Russell, 2001; Siriopoulos, 1999) and psychological strain (Dassel, 2017; Edwards & Noller, 1998; Poysti, 2012; Sampson et al., 2016). Qualitative studies depicted end-of-life care as an exhausting 24/7 role, and both qualitative and quantitative studies highlighted the socially isolating nature of care (Dassel, 2017; McGhan et al., 2013; Potier, Degryse, Aubouy, et al., 2018; Siriopoulos, 1999; Thomas, 2018; Turner et al., 2016). Having cared for one's spouse at end-of-life continued to negatively impact the health of caregivers years after caregiving had ceased following bereavement. Bereaved older caregivers had increased prescriptions for antidepressant and antianxiety medication and more GP consultations than non-carers (Sampson et al., 2016) and caregivers of those with dementia were found to be particularly at risk of their own cognitive decline (Dassel, 2017). Whereas one longitudinal observational cohort study concluded that having cared for a partner increased the risk of mortality (Dassel, 2017), another longitudinal review of GP records did not find a significant correlation (Sampson et al., 2016). Notably, however, caregivers who had severe health problems, such as dementia or depression, were excluded from studies either explicitly (Dassel, 2016, 2017; Edwards & Noller, 1998) or implicitly due to requirements around capacity to consent, raising question about whether health impacts of providing care may currently be under-reported. Conversely, some qualitative studies conclude that spouses viewed their caregiving as "life-sustaining" and the reason for their own longevity (Black, 2008; Sanders & Power, 2009).

Caregiver's conceptualisations of their role

Caregiving was seen as a new chapter of the spousal relationship, which was undertaken out of a combination of their love for their partner and/or an obligation associated with their marital vows (Black, 2008; Edwards & Noller, 1998; McGhan et al., 2013; Perry, 2002; Sanders & Power, 2009; Shavit et al., 2019; Siriopoulos, 1999; Turner et al., 2016). Caregiving spouses strived to maintain familiar aspects of the couple's daily interactions and routines predating the on-set of their partner's illness. Central to this was caring for their partner at home (Black, 2008; Perry, 2002; Sanders & Power, 2009; Turner et al., 2016), which they often did with little formal or informal support (Black, 2008; Poysti, 2012; Russell, 2001; Siriopoulos, 1999; Tennstedt et al., 1993). Nevertheless, as their partner's approached end-of-life, caregiving spouse's found it difficult to maintain aspects of their self and marriage identities (Black, 2008; Perry, 2002; Shavit et al., 2019; Siriopoulos, 1999; Turner et al., 2016). On a practical level, caregivers had to perform more care and modify their house and social life in unfamiliar ways (Black, 2008; Perry, 2002). They also often had to grapple with the losses associated with declining communication and sexual intimacy with their spouse (Dassel, 2016, 2017; Perry, 2002; Russell, 2001; Sanders & Power, 2009; Shavit et al., 2019; Siriopoulos, 1999; Thomas, 2018). One study explicitly identified such loss of intimacy as a trigger for anticipatory grief (Siriopoulos, 1999).

For dementia caregivers this also involved taking on new roles such as protector of their spouse's dignity and personhood (Black, 2008; Perry, 2002; Sanders & Power, 2009; Shavit et al., 2019). Caregiving spouses also struggled when they felt they could not share negative aspects of the caregiving with their partner (Edwards & Noller, 1998; Siriopoulos, 1999) including their fears and anticipatory grief associated with their partner's imminent death (Black, 2008; Sanders & Power, 2009; Siriopoulos, 1999). Caring could be particularly difficult where relationships had been strained prior to illness (Edwards & Noller, 1998; Perry, 2002; Shavit et al., 2019).

Caregiving appears to be conceptualised and experienced differently across genders. Given cultural discourses around women's innate caring nature (Shavit et al., 2019; Williams et al., 2017) and their history of having provided care to other family members (Perry, 2002), wives largely took it for granted that they would care for their husbands at end-of-life. Studies reported that women were more willing to sacrifice their own health and social needs to their partners (McGhan et al., 2013; Perry, 2002; Sanders & Power, 2009; Williams et al., 2017). Studies indicate that husbands tended to initially struggle with the repetitive and thankless nature of caring and household tasks but were able to subsequently incorporate their care into their masculine identities, by reframing nurturing within their pre-existing management skills (Poysti, 2012; Russell, 2001; Siriopoulos, 1999).

Learning to care

Studies highlighted that partners had to learn to provide end-of-life care for their spouse. They had to become experts on their partner's condition and coordinators for their care. This often involved navigating multiple care systems and dealing with a variety of health care professionals inside and outside of the home (Edwards & Noller, 1998; McGhan et al., 2013; Perry, 2002; Russell, 2001; Siriopoulos, 1999; Turner et al., 2016). Many older caregivers tended to provide most of their partner's care themselves, especially when their partner had a non-malignant condition, which meant they received less specialised support (Dassel, 2017; Turner et al., 2016). Sampson (Sampson et al., 2016), however, found that GP surgeries offered similar levels of support to caregivers, regardless of their partners' condition, provided they were both registered at the same practice.

Caregivers tended to take on new forms of hands-on care. They had to learn to provide for their partner's personal care (McGhan et al., 2013; Poysti, 2012; Sanders & Power, 2009; Turner et al., 2016) or had to organise for outside services to do so, a strategy more commonly adopted by men (Russell, 2001; Siriopoulos, 1999; Tennstedt et al., 1993). Caregivers frequently had to make practical changes to their homes including bells and call systems (Perry, 2002; Turner et al., 2016).

Husbands and wives often reported taking on new aspects of household management and maintenance that their spouse had previously performed. Men reported learning new tasks such as food preparation, cleaning and organising social activities (Black, 2008; Russell, 2001; Sanders & Power, 2009; Siriopoulos, 1999), women reported becoming independent decision makers and financial managers (McGhan et al., 2013; Perry, 2002).

Oldest-old caregivers also had to learn coping strategies to persevere with caring. Studies acknowledged a range of emotional coping strategies caregivers utilised such as reminding oneself of the purpose of caring when frustrated (Black, 2008; Perry, 2002; Russell, 2001; Siriopoulos, 1999), drawing on humour (Turner et al., 2016) and instrumental support to overcome particularly difficult tasks (Poysti, 2012; Russell, 2001; Turner et al., 2016). Caregivers were forced to sharpen their decision-making skills and crisis-management capacity (McGhan et al., 2013; Turner et al., 2016).

Part of coping also entailed the caregiver identifying their limits. Three studies found that caregivers were more likely to use formal carers for personal care and make use of respite services when their partners were closer to the end-of-life (Russell, 2001; Siriopoulos, 1999; Turner et al., 2016). Nevertheless, one study found co-resident caregivers used less formal services than those not living with the partner irrespective of the patient's condition (Tennstedt et al., 1993). Dementia caregivers often discussed their plans for moving their spouse into residential care. Studies reported some caregivers who did so when they could no longer cope though these studies also stressed that these caregivers made sure to remain involved in their spouse's care (Perry, 2002; Russell, 2001; Sanders & Power, 2009; Siriopoulos, 1999).

Discussion and Implications for Research, Policy and Practice

This is the first literature review to systematically collate, narratively synthesise and quality appraise the extant literature on oldest-old spouses providing end-of-life care. I identified an increase of research published in recent years, attesting to the growing interest in the academic community of putting oldest-old spousal caregivers on the policy agenda (Dassel, 2017; Potier, Degryse, Bihin, et al., 2018). Indeed, the fact no study was published before 1993 may also indicate that end-of-life caring amongst the very old is more common in the present-day where people are increasingly reaching their end-of-life in advanced age and are increasingly being cared for at home rather than in an institution.

The evidence presented in this review is of medium weight on Gough's Weight of Evidence, which is perhaps higher than expected for a nascent sub-field. Researchers have seemingly heeded calls in the caregiving literature for more longitudinal research that captures the important temporal aspects of caregiving over the development of an illness and life-cycle (Forbat, 2009; Grande et al., 2009). A further explanation is that a notable proportion of these studies are secondary analyses of high-quality ageing cohort studies. However, because these oldest-old caregivers were an unanticipated finding of these studies definitions of 'caring' and 'carer'/ 'caregiver' may not have been as sufficiently outlined to make them high quality studies in light of this review's focus.

On the other hand, the feminist quality of these studies is low and leaves many questions unresolved. This potentially reflects a similar lack of gendered analysis in end-of-life care research which is where a high proportion of these studies originated (Morgan et al., 2016). As such, the incidence of men or women providing end-of-life care in this age group requires further attention; particularly in settings other than the UK. This review has been unable to corroborate or deny earlier findings that men in this very old age group provide more care (Dahlberg, 2007). The physical and psychological impact of caregiving as analysed by gender also requires further attention. Nonetheless, studies described a degree of improvisation in the way these caregivers 'do' gender, challenging assumptions that they necessarily follow 'traditional' gendered scripts because they are members of the stoic post-World War II generation (Calasanti, 2004). These findings suggest we have far more to learn about how this group's advanced age, gender and other aspects of identity characteristics intersect to shape their caregiving experience (Williams et al., 2017).

In line with previous studies, the review found that spousal caregivers aged 75 and over provided a wide-range of care for their partner including administration and advocating, emotional support and hands-on care tasks (Gott et al., 2018; Henwood, 2017; Phillips & Reed, 2009). This review fits with current policy indicating that the high level of care provided by older spousal caregivers continues into the last stages of life (Princess Royal Trust for Carers, 2011). Echoing previously reported findings, included qualitative studies highlighted the centrality of spouses developing a range of coping mechanisms to facilitate their caring with obstacles to care seemingly framed as ‘challenges’ rather than ‘threats’ (Epiphaniou, 2012; Wiles, Miskelly, et al., 2019). From this perspective, a spouse’s active decision to move their partner to a care home could be viewed as a coping tactic employed to sustain rather than stop their caregiving (Perry, 2002; Sanders & Power, 2009). More research is required around the impact of these transitions on the continuity of care provided by spouses and is particularly relevant for this age group whose own competing health issues may increase the likelihood of them either separately or jointly having to move into a care home (Kraijo, 2015; Peacock et al., 2014). It was notable that there was little mention of pain and symptom management, which is commonly the focus of end-of-life care (NICE., 2004). This possibly reflects included studies focus on long-term conditions such as severe dementia and advanced frailty where mood and comfort control are the most relevant to the caregiving experience (Hellström & Hallberg, 2004). Overall, recognising the expertise caregivers gain over the course of their partners illness would serve as a valuable resource for health and social care professionals involved in their spouse’s care and align with wider policy incentives of see caregivers as “co-workers”(Twigg & Atkin, 1994).

Evidence suggests that in most cases oldest-old spouses care out of a mixture of normative expectations to do so and out of love of their partner. Qualitative studies emphasised caregivers’ desire to sustain their self- and marriage-identities built up over their life course and favour their spouse label over their caregiver role (Horsfall et al., 2016; Jack, 2014; Morris et al., 2015). In striving for a coherent form of self in spite of the caregiving responsibilities, included studies suggest a tendency of very old caregiving spouses to privilege *biographical flow* whereby illness is incorporated into on-going life and identity over *biographical disruption* where illness disrupts and dominates one’s sense of self and everyday life (Bury, 1982; Faircloth et al., 2004).

The concept biographical flow also helps to explain why the home and household chores featured so frequently in discussions about care. The home has been found in previous research to offer a familiar anchoring point against the “persistent liminality” accompanying both advanced old age and the end-of-life period (Nicholson, 2012). Moreover, spouses’ attempts to maintain familiar aspects of their everyday lives for as long as possible might explain some couples’ reluctance to utilise formal services despite struggling to provide care alone (Dixon et al., 2015; Joyce et al., 2014; Russell, 2001). Another explanation for their unaided caring may be that their partner is not being offered services because they are lower priority given their age and non-malignant conditions (Dixon et al., 2015). More research is needed in this area, including the views of service providers (Sutherland et al., 2016) as well as from a gendered perspective given wider evidence that indicates men tend to receive more formal and informal support whilst caring than women (Bertogg & Strauss, 2020; Yee & Schulz, 2000).

Where *biographical disruption* was reported, it appeared to be precipitated by actual or expected changes in communication and intimacy between partners rather than the biological or cognitive change of their partner (Bury, 1982; Sabat, 1992). This indicates that health care providers need to be particularly attuned to providing support and strategies to enable spouses to maintain their verbal and non-verbal communication. To do so health care professionals need to 'think couple' when designing support strategies that include both members and facilitate opportunities where couples can be observed together, for example at joint GP visits or community groups for both spouses. In some cases, bereavement support might usefully be brought in earlier to help both spouses to manage anticipatory grief and help the caregiving spouse cultivate strategies for when their caring responsibilities cease (Costello, 1999). Future research is also required to ascertain whether anticipatory grief is more pronounced in this group given their advanced age and the physical impact of caregiving may increase the likelihood they are also approaching their end-of-life whilst caring for their partner (Hallberg, 2004). This could be a reason for very old caregivers' emphasis on biographical flow as a form of *ontological security* which prominent sociological scholar Giddens defines as the "stable mental state derived from a sense of continuity in regard to the events in one's life"(Giddens, 1991).

The substantial physical and psychosocial impact of caregiving on spouses' health reflects how illness impacts the whole family, not just the person approaching their end-of-life (Forbat, 2009). This review also suggests in line with previous research that this is a group who are particularly at risk because of their age and pre-existing conditions (Hallberg, 2004). Indeed, one observational Belgium study found caring was linked with increased rates of mortality (Dassel, 2017), although, another UK retrospective GP-record study reported a non-significant mortality increase (Sampson et al., 2016). Further, preferably multi-centred, research is required to clarify whether observed increases in mortality are context-specific, a result of different methodological choices or a more generalizable phenomenon. Researchers could usefully explore ways in which caring can be experienced positively and investigate the situations where it can be "life-sustaining" to ensure that caregiving is not pathologized ipso facto (Roth, 2015).

Research is also needed to understand the extent to which very old caregivers themselves have end-of-life or terminal conditions. This review provides glimpses of such caregivers – for example those with dementia – however only because they were excluded from such studies. Since age is one of the biggest risk factors for developing dementia the phenomena of the person with dementia being the caregiver may be an urgent area of future research (Baltes, 2006). Including caregivers with mild to moderate dementia via methods such as process consent (Dewing, 2007) would help to ascertain a fuller picture of the psychological and physical experience of caregiving. It may also help clarify the degree to which co-caring occurs between spouses (Horsfall et al., 2016). By viewing caregivers as potential 'co-patients' with their own health and service needs, researchers can contribute to growing recognition that *vulnerable dyads* need to supported before a crisis occurs and one or both are expectantly admitted to hospital, care home, or die (Hoerger & Cullen, 2017; Pickard & Glendinning, 2001).

Finally, it is important to recognise that the insights presented above draw from the experiences of a relatively homogenous population. Like Greenwood and Smith (Greenwood & Smith, 2016), we found the academic literature largely reflects the experiences of white, heterosexual married couple in high income countries. Experiences of those caring in their late 80 and 90s were similarly under-represented. Future research needs to include the experience of diverse caregivers in a range of settings to ensure policies are culturally inclusive and appropriate (Gott et al., 2018; Venkatasalu et al., 2014). Concordant with Grande and colleagues' reflection (2009), I also contend more sociologically and anthropologically informed research is required to provide a theoretical basis for investigating such cultural specificities of caregiving. Oldest-old non-spousal caregivers, including children, friends and neighbours, also need to be studied, given that their caring is likely governed by different social mores than spouses (Ory, 1985), and included other challenges such as transportation if they do not live with the person they care for (Chappell et al., 2015).

Limitations

I recognise that using the mean age of 75 to determine the experiences of oldest-old is an imperfect measure shaped by the realities of inadequate reporting of age in studies and little exclusive focus of the very old. This pragmatic strategy meant I was able to isolate this age group somewhat; although I recognise that some insights reported may very well be shaped by evidence from the young-old (Greenwood & Smith, 2016). In addition, all of the papers identified during reference searching centred on people with severe dementia. In discussion with our medical librarian it was found that these papers were not captured by the database searches because they did not contain the end-of-life terminology (Lorenz et al., 2005). This may reflect an academic and service provision reticence to address dying from dementia (The Lancet, 2018). Inclusion of "severe" or "end stage" dementia would be useful additional search terms when conducting future systematic reviews of this age group. Nonetheless, I am confident that my multi-level search strategy effectively captured all the available evidence pertaining to our review question. A final limitation of this search is that one reviewer conducted the majority of title and abstract screening, primarily because this review was conducted as part my PhD. As outlined above a number of steps were taken to mitigate bias including consulting a medical librarian, drawing on guidance of Cochrane guidelines when deciding how much reviewing a second reviewer ought to do, consulting as a team at every step of the process and using the Rayyan application that enabled a clear audit trail. Finally independent screening and quality appraising of all included full-text papers by two reviewers also enhanced rigour.

Conclusion

This is the first systematic review to synthesise and appraise the published literature concerning oldest-old spouses providing end-of-life care. The small, medium-weight and quality evidence base attests to the range of physical, psychosocial and existential challenges facing oldest-old spouses that result from caring for their dying partner at home. More theoretically-informed research with a more diverse range of spousal caregivers is required to capture the variety of caregiving practices amongst the very old. Service providers and policy makers could usefully "think couple" when designing strategies that support spouses to continue to care for their partners. Finally, researchers and service designers alike need to develop new ways of engaging with oldest-old spousal caregivers who are often at once "co-workers" in their partner's care and "co-patients" with their own health issues.

Chapter Summary

This chapter has presented a clear case for the growing interest and importance of studying end-of-life caring amongst the oldest-old. While the extant evidence basis is small and provides only medium-weight evidence, I identified the need for further theoretically-informed research addressing the caring experiences of the oldest-old. In Chapter 3 I present a narrative methodology designed to respond to some of the deficiencies in the current literature. A goal of Chapters 4-6 is to introduce theory into this end-of-life evidence base.

A prominent theme of the literature to date has been conceptualising caring role, in terms of marital identities and household roles. A clear gap in this current evidence base is the role that “carer” plays in these conceptualisations of self and coupledom. Indeed, little attention has been focused specifically on whether the term “carer” was an appropriate label for this age group. Evidence in this review suggests that it might be a less desirable term as couples try to maintain their “biographical flow”. In Chapter 4 I attempt to address this evidence gap directly focusing on the carer identification practices of older partners providing end-of-life care.

Chapter 3: Methodology

> “We tell ourselves stories in order to live. We look for the sermon in the suicide, for the social or moral lesson in the murder of five.” (Didion, 1979, p. 22)

An introduction to narrative research

Shaping this study is a narrative approach that posits that storytelling is a fundamental “human impulse” through which people make sense of the world, themselves, and others (Kleinman, 1988; Mishler, 1984). The “narrative turn” in the humanities and social sciences made it possible to begin understanding storytelling as the core method through which knowledge is produced rather than merely reflected (Labov, 1972; White, 1980). Much of this early narrative scholarship was championed in literary, psychological and linguistics studies focusing on the ways discourse offers windows onto reality (Kleinman, 1988; Labov, 1972; Mishler, 1984). For some post-structuralists, narrative as the vessel of discourse presents the total sum of reality (Barthes, 1977). Atkinson initiated an important challenge to the straight-forward connection between truth and narrative and for further clarity and specificity around what constitutes narrative (Atkinson, 1997).

Narrative in its contemporary iteration is understood as sites of co-produced talk presenting edited views on the world, or what Sandelowski has termed "factions" (Bury, 2001; Sandelowski, 1991). Narrative's scientific value is found in the broader interviewing process which is a site of social negotiation (Mishler, 1984) that explores "the contradictions of social interaction and self-presentation"(Bury, 2001, p. 283) and consequently helps to illuminate how participants "experience their worlds"(Devault, 2002, p. 76). Recent scholarship has emphasised the dialogical nature of narrative whereby narratives do not simply represent a take on a situation in the past, but through engaging in dialogue, narrators intend their talk to do something (Frank, 2010; Riessman, 2008). Evoking Kermode's (1966) pronouncement, narrators always have a sense of "an end in mind" through their communicative acts (Kermode, 1966).

Narrative approaches have received growing interest in the health and social sciences as part of a broader challenge to positivist claims to a fixed reality (Bury, 2001; Greenlaugh, 2011; Riessman, 2008). The narrative turn in health studies has been informed by patient and consumer health movements and the recognition that patients and their families make sense of illness and caregiving via storytelling (Elliott, 2005; Frank, 1995; Wiles et al., 2005). Narrative as the practice of eliciting, witnessing, and recording oral stories has also been successfully used by scholars interested in social justice to bring to public attention stories that might have otherwise remained "private suffering"(DasGupta & Hurst, 2007, p. 5). In doing so scholars and activists can produce counter-narratives (Mattingly & Garro, 2000; Smith, 1999). As acknowledged in the introduction, this method is particularly well-suited to "wrestle the account of old age out of the hands of experts" by enabling older people to share their accounts of their own situations in their own language and on their own terms (Twigg, 2003). Narrative inquiry has become particularly popular in palliative care and bereavement studies as a means of understanding how the disruptive context of death and dying influences ordinary people's reconstruction of their identities and context (Bingley, 2008; Romanoff, 2006; Thomas, 2009, 2018) as well as wider traumatic or public deaths as Didion's opening quote suggests (Didion, 1979). Health care practitioners and scholars also celebrate the therapeutic quality of narrative inquiry to enable people to tell their stories on their own terms (Bingley, 2008; Greenlaugh, 2011).

As a sub-genre of qualitative research, a narrative approach analyses personal narratives, which comprise a “distinct form of communication” that involves the organisation of “events, objects, feelings or thoughts” and the “connecting and seeing the consequences” of these over time (Chase, 2017, p. 928). Narratives provide a “referential context” through which people are made, known and interpreted by others (Kelly & Dickinson, 1997; Polkinghorne, 1988). Narrative approaches primarily focus on the content, form and context of individual cases (Riessman, 2008; Wiles et al., 2005, p. 5).

Narrative inquiry as a case-based approach differentiates it from other commonly used qualitative approaches such a thematic and content analysis. For example, Maxwell and Chmiel (2014) observe that most qualitative research focuses on similarity-based approaches whereby researchers look for resemblances or common features in their data and then categorise their data along these lines. These categories are commonly produced through a process of coding (a process of segmenting the data from labels generated from the data) or thematic analysis (process of identifying a relationship between concepts or actions). An important criticism of this approach is that in producing new categories data are often detached from its original context (Maxwell & Chmiel, 2014). Although researchers using this approach ultimately attempt to link their codes or themes back into larger patterns, Maxwell and Chmiel (2014) contend that they do so by making connections between categories rather than between segments of data. This results in the contextual relationships of the data remaining unanalysed (p. 26). Intersectional scholar Hill-Collins (2016) amongst others has criticised this approach inhibiting marginalised people from telling their stories on their own terms, if their stories are subsequently “torn apart in analysis” (p. 258). Frank (2010) similarly posits that “[p]eople’s access to narrative resources depends on their social location” and is essential context (p. 13).

Maxwell and Chmiel (2014) identify contiguity as the other approach for qualitative data analysis. Relying on connecting strategies, this approach aims to retain and analyse the segments of data within their specific context, usually by focusing on a single participant’s transcript for example (Maxwell & Chmiel, 2014, p. 27). Centring on narrative analysis, Maxwell and Chmiel (2014) posit that an attentiveness to the sequence of events communicated by the participant and the transitions between statements can illuminate understandings and meanings lost through comparative approaches. However, this approach makes it difficult to make comparisons across a dataset or beyond the context of the particular case (Maxwell & Chmiel, 2014, p. 28). Maxwell and Chmiel

(2014) conclude that integrating categorising and connecting strategies is the best way to respond to the limitations of each approach (p. 30).

For this project I draw on Riessman's (2008) approach to narrative analysis which focuses on a deep-dive of each participants narrative and then a comparison across the data. Riessman (2008), like Maxwell and Chmiel, contends that rigour is enhanced when analysts compare interpretations of a single case in relation to the other cases examined within a particular research project. She contends that a thematic analysis in this way can act as internal verification as well as helping to build a case about the context/ discourses presented in these particular narratives. Thomas (2010) similarly uses this case-then-theme approach as it helps to situate participants as "social actors operate within real social structures (health structures) that they 1) experience as external and fixed at the same time 2) reconstruct and recreate by their actions" (p. 656).

Data collection

Longitudinal narrative interviews

This study uses longitudinal narrative interviews. There is growing acknowledgement that longitudinal qualitative research is better suited than typical snapshot techniques for addressing questions about how and why people's experience of health care change or transition over time (Calman et al., 2013; Murray, 2009). This method also uniquely offers the ability for individual's narratives to unfold, revealing the complexity of their situations (Lloyd et al., 2016; Murray, 2009; Whiffin et al., 2014). In addition, the interviewer and participant(s) are able to build up a rapport through their extended period of time together, enabling a sense of trust to develop to allow frank conversations about difficult topics such as death and dying (Murray, 2009). However, Calman and colleagues (2013) rightly point out that a potential pitfall of this relationship-orientated approach. The boundaries between research and private time become blurred and it also may result in difficulties of "escaping the field"; even if clear descriptions about the remit of the research are laid out at the beginning of the relationship (Calman et al., 2013). Nevertheless, if managed sensitively this method can produce in-depth evidence around underexplored topics and experiences (Calman et al., 2013).

Few qualitative longitudinal studies have been conducted with family caregivers of people with palliative conditions (Funk et al., 2010). Those that have emphasised the ways caregivers' identities and the relationships between care recipient and provider are constantly changing and developing have important implications for service providers trying to support them (Hellstrom, 2015; Hennings et al., 2013; Thomas, 2009). Scholars have identified that qualitative longitudinal studies are required as Gopinath and colleagues (2018) neatly put it to "understand the possibilities and limits of home, couplehood practices and resources in shaping living together at home until advanced stages"(p. 225).

Timing of the interviews

Studies deploying longitudinal narrative methods use a range of intervals between interview periods (Murray, 2009). To determine intervals between interviews, I weighed up what would count as enough time in which things might change versus trying to limit attrition either due to waning interest or issues with deterioration in health. I also considered my preference for staggered recruitment, so I never had too many participants in the study at one time. Creating this space gave me the capacity to be emotionally attentive to the currently-involved participants and recruiters in the study and a means of ensuring I could process and analyse the data as it came through (Calman et al., 2013). The study was therefore designed to include three semi-structured in-person audio-recorded narrative interviews held approximately a month apart.

In practice, participants broadly fell into two camps concerning changes between interviews. The first group had so many changes it was challenging to keep track of, and the second group was far more stable. Participants in the later category tended to be caring for a partner with a long-standing chronic illness that had entered its final phase. This is something explored in the participant's descriptions provided in Appendix 19. Also explored in Appendix 19 is the way that the quality of talk deepened over the course of the interviews. For example, participants often waiting until the second interview to describe the impact caring for their partner was having on their physical health.

Participants in their second and third interviews also tended to feel more comfortable expressing their complicated feelings about caring such as resentment towards their partners due to the omnipresent nature of care. The third interview was always noticeably shorter than the first interview and often took on more of a social flare where I shared more about myself and spent a lot more of our meeting off tape than on. Two of my final interviews were conducted at cafes as participants wanted an outing. Their decision chimed with Manderson and colleagues (2006) insight that for some participants "the personal can only be told in neutral settings" as the home is sometimes too intimate and raw a setting for discussions about topics such as domestic dissatisfaction (p. 1319). Another participant (Patricia) wanted to meet me at a cafe, but her husband fell down the stairs. Our interview was delayed another two months and was ultimately conducted at their house.

Mid-point telephone calls

Protecting against attrition, I planned a mid-point telephone call (roughly 2 to 3 weeks after each interview) to check-in on participants health and social situation and to schedule a subsequent interview in line with:(Carduff et al., 2015). Over the course of the interview process, I found that some participants preferred texting (participant 4,5,9) and emailing (participants 10,11, 15). I also found that these phone calls tended to be more procedural affairs discussing the practicalities of when they would be free for me to come and visit than a rich source of data collection. These interactions mirrored those between the various health care professionals entering their house. As I reflected in my field notes, participants always had their paper-based diary close to them so they were ready to be scheduled. Only the wife in couple 3 (Betty) who was housebound was particularly taken with talking on the phone. On reflection, ring-fencing participant interactions to face-to-face visits helped me maintain some sense of emotional distance from the field so I was relieved with the brief nature of these scheduling events. I made pithy notes about each telephone call and highlighted anything that would be important to raise at the subsequent interview.

Qualifying for the study

Couple or Carer

There are a range of perspectives as to whether interviewing carers separately or with partners is the best way to elicit their experiences. Those in favour emphasise that only through interviewing couples together can analysts capture the emotional dynamics of the caregiving relationship (Molyneaux et al., 2012; Wadham, 2016b). Others scholars contend that interviewing participants separately allows them to speak candidly about their relationships and ensures that participants get the opportunity to speak without being spoken over by their partners (Navon, 1996; Rose, 1995). This dynamic is something to be acutely aware of when interviewing women caregivers whose husbands may otherwise dominate the interview (Rose, 1995). Ryan and McKeown (2020) similarly observed that during joint interviews participants may subtly self-silence themselves in an attempt to maintain a front of coping and solidarity.

Given my interest in exploring the relational aspects of the caregiving relationship and with the knowledge that the line between carer provider-receiver would not always be clear, I planned to interview participants together at the first interview and then individually at sub-subsequent interviews. This tiered process was also recommended by a community geriatrician who I interviewed as part of my Patient and Public Involvement (PPI). She felt that asking participants to interview separately in the first instance might be seen as a hostile method of verifying their individual stories. This longitudinal approach gave me the flexibility to do this. I thought this would also enhance my understanding of the dynamics between the caregiver and care-recipient as well as their relationship with their families and wider support networks (Kendall et al., 2009).

Above all, however, I planned to be flexible. This was in line with reports from other studies such as Roberts and colleagues (2013) who aimed to separately interview patients with advanced cancer and their carers, unless there was a preference for them to be conducted jointly. Consequently, I opted to advertise my study to partners “looking after someone” whilst giving participants the power to determine when and where the interview took place and whether their partner was involved. I also chose not to use the term ‘carer’ in recruitment material studies suggest older people in caring roles may not identify with the term (Molyneaux, 2011). This approach also left the door open for situations of co-caring.

I selected the phrasing “are you looking after someone?” to communicate current engagement with caring roles. This decision was guided by evidence that retrospective reporting around caregiving results in very different (often far more rose-tinted assessments) of the caregiving process (Addington-Hall & McPherson, 2001). The recruitment phrasing was inspired by phrasing from the British Household Panel Study which incorporates the question: “Do you look after or give special help to anyone who is physically or mentally sick, handicapped, or elderly?”. Other empirical studies have used this phrasing to successfully recruit non-identifying carers providing care (Corden, 2011; Jarvis & Worth, 2005).

Beyond the couple?

Keating and colleagues (Keating et al., 2003) argue that only focusing on caregiving dyads obscures the range of kin and non-kin actors involved in the caregiving for older frail adults. The authors also recognise that older, frailer adults are less likely to have extensive caregiving networks than their young-old and/or healthy peers due to their declining ability to maintain reciprocal relationships (Keating et al., 2003). As such, I initially left it open as to whether I would include additional members of the caregiving relationship. I actively invited participants to have a support person at the interview and was open to speaking with them (I built this into my university ethics application). However, it became clear very early on that few of my participants shared their day-to-day caring with another family member (Participant 12 was the exception). Of the two interviews that were conducted with daughters, one happened to be at the house as she was staying with her parents for a week though she lived 5 hours away. Another daughter interview was conducted over the telephone for reasons explained in Chapter 4. A care coordinator was present at two interviews (a dynamic elaborated on in the gatekeeping section). A range of health care assistants were present at six of the participants' homes. I did not have ethics approval to interview them nor did I feel they would have been at liberty to consent given they were in my participants' homes in the capacity as a representative of the private care companies they worked for. In addition, I felt that it would have been unethical to demand more time from them given they had such limited time slots in the home to toilet, lift, feed patients.

Age

While most participants were aged 75+, as in line with my recruitment material, a few participants in the study fell below this age range. These participants also had physical health concerns that could qualify them as "frail", arguably the key quality associated with the social imagery of the fourth age (Gilleard & Higgs, 2010). More importantly, these participants were included because they clearly had a burning story to tell about caring for their partners who were all in their fourth age. Therefore, their inclusion aligned with the overarching ethical commitment of this thesis of enabling older people to tell their stories. Their inclusion also reflects my belief that age itself is a social construction rather than a biological determinant and therefore, it warrants being slightly flexible to acknowledge the variability of functionality and social circumstances amongst older people (Holstein & Minkler, 2003).

End-of-life-ness

I suspected that the focus on end-of-life might similarly create barriers to recruitment as not everyone was necessarily comfortable with the terminology, especially concerning their own family members or themselves (Etkind et al., 2019). Furthermore, the unpredictability of end-of-life trajectories of this population as previously mentioned is another reason for uncertainty about the eligibility of this ‘end-of-life’ orientated study (Hallberg, 2004). As a compromise, I designed the poster to read: “Are you 75 or older, looking after a spouse or partner with cancer, chronic chest disease, heart disease, dementia or a similar condition?” (Appendix 9). By intentionally leaving open the nature of the condition, a concern was that the study might attract people for someone with a chronic but not life-limiting condition. In practice this only occurred in the case of Participant 1 whose inclusion in the study I justify in Appendix 19.

Sampling

Narrative studies tend to have small sample sizes (including as few as a single participant) as they are intended to produce in-depth analysis of particular phenomenon (Phoenix, 2009). However, given the limited published literature applying a narrative approach to this relatively new group of people, my interest was slightly broader and exploratory in scope. This was also shaped by my concern for how different social locations can impact the caregiving experience, I designed my sampling principle around maximum variation which required a slightly larger than usual sample for a narrative analysis (Williams, 2016).

In my ethics applications (Appendix 1), I set out to interview each member of 15 dyads (a total of 30 individuals) expecting there to be a likely drop-out rate as some participants’ partner’s end-of-life care conditions advance or die. This number aligns with Guest and colleagues (2006) widely-cited paper that saturation is usually achieved around 6-12 participants. However, I have since been convinced by Braun and Clarke (2019) that the term saturation, outside of the specific grounded theory methodology, has become more of a “rhetorical device” that renders data as something that exists and is simply yet to be discovered much in the way positivist view on data (p. 4). The authors contend that researchers should instead make an in-situ decision about the final sample size, shaped by the adequacy (richness, complexity) of the data for addressing the research question (Merriam & Tisdell, 2015). Malterud and colleagues (2016) have come to a similar conclusion using the term “information power” rather than saturation as a measure of quality and conceptual adequacy (Malterud, 2015). This flexible approach to sample size also usefully reflects the messiness and unplannable nature of the research process (Malterud, 2015).

Embodied, practical considerations also shaped the composition of the final sample. After a year of fieldwork, I became emotionally and physically worn out. As a research participant in Dickson-Swift and colleague’s (2009) study aptly put it “it’s not just about saturation of when you don’t get new themes…it’s about your saturation as well”(p. 72). Lawton (2000) bravely chronicled her emotional exhaustion at the end of her five month ethnography in an English hospice witnessing instances of the intense distress patient and family experience when grappling with the last weeks and moments of life. While I never directly witnessed death through my fieldwork (although in two cases, I was informed closely after the fact) I experienced a strong sense of having to be ever-present and available to participants during the recruitment period. For example, one evening at 8pm, a participant texted me to let me know about her husband's death that day. This text instantly snapped me into researcher mode as I needed to respond empathetically and check she had the relevant support. Overall, while I sincerely enjoyed my experience interviewing, I also found it emotionally difficult to repeatedly speak to people in increasingly untenable situations for whom I had no way of making it better. Thus my emotional weariness along with a feeling that the data I had already collected was sufficiently rich and complex to begin my analysis informed my decision to exit the field after a year.

Recruitment strategy

Frequently, snowballing has been used in both quantitative and qualitative research in order to access or map previously understudied populations (Geddes, 2017). Effective snowballing relies on vertical/ deep networking beginning with a few strong ties that commence the chain of referral that as it gains momentum goes deep down into the social connections of a particular group (Geddes, 2017). As snowballing is usually conducted from relatively few entry points, it often offers an intensive sample, which is relatively effective in terms of time and effort to recruit. Snowballing also enables researchers relative clarity when saturation has been reached given the focused nature of the sample (Geddes, 2017).

There are, however, several issues associated with this method (Bryman, 2015). Atkinson and Flint (2001) argue that such "chain referral" obscures isolates who do not have regular contact with the wider group. This method also tends to have an overreliance on certain individuals that may ultimately skew the sample. Several strategies such as respondent-driven sampling, indigenous field worker sampling and facility-based sampling have arisen to mitigate the deficiencies of snowballing, however, all rely on a sufficient pre-knowledge of the kinds of people the interviewer wishes to reach (Atkinson & Flint, 2001). Indeed, despite the recent theorising in this area, effective snowballing ultimately comes back to Berg's (1988) insight drawing from Pierre Bourdieu (1984) that a certain type of insider knowledge, or *social capital* is required to start referral chains (Geddes, 2017). Given my "outsider" status as a non-carer and someone who had recently arrived in the country, I wanted a more flexible recruit approach so that I did not find myself in a situation where the “snowball does not roll”(Geddes, 2017).

Consequently I selected a horizontal sampling method that utilises strong and weak ties as “bridges” into new social networks (Geddes, 2017). This enabled me to co-opt a degree of social capital from my primary supervisor who is a prominent general practitioner with deep connection within a range of local GP surgeries in the Cambridgeshire area as well as exploring a range of other links through my engagement in the carers’ community which developed throughout my fieldwork.

Gatekeepers

Forbat’s argues that we should value ‘gatekeepers’ as contributors to research rather than simply framing them as access points to more valuable accounts (Forbat, 2003; Liamputtong, 2013). I was fortunate to have several gatekeepers who were just as committed to promoting the stories and experiences of older carers.

I had positive interactions with two GPs who helped to recruit participants known to them. This link came through my supervisor. It was important to me to recruit participants who were accessing services as well as those who were not. Therefore I tried to spread my recruitment net wide, including GP surgeries, community support groups, carers charities, and attending different carers events where I distributed my recruitment flyer.

I spent a considerable amount of effort with one recruiter who ended up being a critical link (both directly and indirectly) to my research participants in London. I even visited her in Devon and wrote an article for a carers’ magazine to support the advocacy work she was engaged in since her husband’s death.

I spent a half-day including going to coffee and visiting the home of another gatekeeper who invited me along to her Dementia group where I met two women who participated in my study. In addition, I met another ex-GP at a PPI group who put me in touch with a couple she knew would like the experience of being interviewed.

Another important gatekeeper came from a charity that had recently developed a programme to support older carers whose partner was approaching end-of-life. The care coordinator I liaised with enthusiastically supported the project and introduced me to two participants. He was present at the first interviews of participant 14 and 16 to ensure their security and comfort. I include below a section from my fieldnotes about the dynamic of interviewing participant 14 with her care coordinator present. CC is a pseudonym for the care co-ordinator.

> *It was my first interview for this study having the referrer of the participant in the room. The wife and husband had been really well briefed by [CC]. that this was an interview for her and she sat by me so I was able to have my back to [CC] and her husband which enabled me to compartmentalise the interview to just us. It helped that the wife was incredibly willing to talk about her situation (she said at the end she spoke so much because she hasn't been able to speak to anyone really). She also felt that "our spirits chimed" so there was an underlying flow to the conversation which also meant that other people's presence didn't matter too much. My observation is that she had told [CC] everything that she was sharing with me before so she did not mind him being there. In fact, a few times she paused her story to tell [CC] something that had come to mind and that she needed help with which reflected their free communication. I think it also helped that he had told them that this hour was for her to talk with me and that he was just going to take a back seat (in the context it was quite literally what he did). He took the time to answer emails. I was aware that I was being observed for the nature of my questions and my questioning style as he was trying to determine whether he would be happy to put me in touch with anyone else in future.*
>
> *Which leads me to the additional point that in no way would I have been able to speak to this couple without [CC] there. First, they her hard-of-hearing means that I wouldn't have been able to contact her by phone. At some points [CC] helped to facilitate the conversation by reiterating what I had said to her (which he did pretty much word for word). They also have security concerns in light of their robberies so I would not have been let into the house without having someone to vouch for me. Interestingly, when I asked if I could come back again she said she would love that but also said that she would like me to go through [CC] to do so. I think this shows that they trust him and therefore trust me. I expect my next visit to them will also be in his company. (Date of notes and interview* 3.5.19).

Some recruitment routes did not result in participants. For example, I attained approval to advertise my study in a local hospice but did not get any recruits this way. I suspect part of the problem was that older people do not tend to utilise hospice services as frequently as other age groups (Dixon et al., 2015).

To increase the diversity of my sample I was referred to the local mosque by a Muslim colleague. Meeting the Imam after the evening prayer we had an hour discussion about care and the Koran. He identified a man at their mosque whose wife had “memory problems”. The Imam approached him but he presumably did not want to participate as he never contacted me.

All in all then, I feel confident that I achieved a range of strong and weak ties with participants coming from a range of recruitment routes. This table provides a shorthand for recruitment routes and the number of participants attain through them.

Recruitment Routes	Number of Participants
Self-selecting into study via study flyer	2
Dementia community groups	5
GP	4
PPI referrals	6
Carers Non-for-profit coordinator	2

Study participation

Fieldwork took place between August 2018-August 2019 with participants living at home with their partner in Cambridgeshire or West London, United Kingdom. To qualify for the study, participants were planned to be 75 or over and looking after their partner who had a diagnosed palliative condition and lived at home with them. All potential participants were first contacted via the telephone to explain the study, to confirm their willingness to take part and arrange in-person meetings. All participants provided written consent at the beginning of each interview (Appendix 10 and 11). For subsequent interviews, participants were always rung to ask if they would like to speak again and before these took place participants signed a new consent form.

In total, 41 interviews were conducted with 19 participants from 17 couples (Appendix 12). Participants were offered the choice to be interviewed either together or on their own (Rose, 1995). Both members of two couples became participants as they were cognitively capable as judged by the health care professional who referred them. For one couple a mid-life daughter also took part. Additionally, twelve severely cognitively-impaired partners were involved in the interviews (Appendix 13). Two participants agreed to interviews but subsequently withdrew from the study, one because he was himself diagnosed with terminal cancer and another because her husband only had days to live.

The high rate of cognitive-impairment in the study shaped the nature of participation in the interviews and accounts for why only two couples jointly participated in interviews. Cognitively-impaired partners who were present in the interview context nonetheless shaped the direction of the interview discussion in both verbal and non-verbal ways. For example, participants often addressed their partner with their thoughts as well as trying to involve their partner in the conversation as much as possible. The most colourful example of this was where Carol sang to Charles which made him open his eyes and nod, the first time he had appeared animated since I had arrived at their home (see Appendix 15).

Unsurprisingly, and in line with the caregiving literature, there was a much higher rate of women than men who participated in this study (Morgan et al., 2016). Four men participants and 15 women participated. This may reflected the disproportionate number of women in caring roles, although as mentioned in the background, there is more equal participation in caring amongst older married couples (Del Bono, 2009). Another reason forwarded for this gender difference is men's aversion to discuss care because it is viewed as a feminine subject and practice (Gott et al., 2020). I noticed that the men who took part were doing well and happy to talk about how they had negotiated their good situations. Narratives of absolute isolation and struggle were only voiced by women participants. Another reason may be my own positionality as a young woman. In line with Jen's (2020) findings, older women were particularly enthusiastic to speak to young woman who were at the other end of their life course. Older men may have been less comfortable speaking to a young girl who was not kin. From my interviewing, however, I found my male participants very talkative and interested in my studies and interests. The disproportionate number of women in the study, as well as the majority white-British sample, limited my ability to conduct an in-depth gender or intersectional analysis (Hill-Collins, 2016). I nonetheless tried to consider intersecting factors in my analysis such as class, cultural factors, gender and disability status.

The narrative interview context

A narrative interview differs from other kinds of talk and it was clear that participants came to the interview with preconceived ideas of what takes place (Ziebland, 2013). Most were comfortable with the idea that I would come around and ask them questions and that they would answer them honestly; attesting to David Silverman's contention that we live in an interview society (Silverman, 1993). This also reflects some important similarities between clinical interviews and qualitative research interviewer techniques such as active supportive listening that involves paraphrasing and probing to develop rapport and encourage discussions about sensitive topics (Birch & Miller, 2000). Furthermore, the researcher's status is akin to the health care professional in as far as the interviewer's authority is based within the pre-text that she has been verified and trained by an established institution. Indeed, by many of my participants referred to me as "the girl from the university".

Narrative interviews differ from other kinds of interviews more commonly found in qualitative research. They focus less on the question and answer format and more on providing an opportunity for participants to narrate their experience for the interviewer (Allen, 2017). The value in this method lies in its ability to illuminate what is most important to respondents by enabling them to draw from their own perspectives and priorities when delivering their response (Ziebland, 2013). As a method it is well-suited to board research questions such as those about experience (Ziebland, 2013).

Rather than asking about more general life events as some narrative interview practices involve (Hollway & Jefferson, 2000), my approach to narrative interviews consisted of unstructured discussion guided around what participants' see as noteworthy in their daily lives of care. This decision was made because my interviews were theoretically interested in care; and ethically because I was aware of not wanting to burden participants by requesting too much of their time. In addition, I was aware they often had very time-consuming caregiving duties and their own health issues.

As such, my interviews consisted of me arriving at my participants' homes, drinking tea and then asking one 'trigger' question: "What's it like looking after your spouse?" and then having the conversation go from there. Sue Ziebland (2013)argues for trigger questions because otherwise narrative interviewing can be too wide-ranging, and participants need to have an inkling of what the interview is about to gauge its purpose. For some degree of consistency across interviews I asked all participants during their first interview:

- "do you see yourself as a carer?"
- "how is your health?"

Some participants were bursting with information and stories as I arrived at the door requiring me to artificially interject in the conversation by insisting that we discuss the consent form before I can record anything. I then had to probe them to repeat what they had said to me again for the tape. For a minority of participants, there was a preference for a more structured interview process. For example, participant 10 (Elizabeth) said as we took our places at her dining room table, “I am looking forward to our guided conversation” (phrasing she had taken directly from my PIS). I, therefore defaulted to the list of interview questions I had produced as a requirement of my ethics application (Appendix 14). Subsequent interviews with her were far more free form once she’d got into the swing of it (see Appendix 19).

At subsequent interviews with participants, I typically begun with a recap of the main thing I took from our previous interview. This did not necessarily set or restrict the tone of the rest of the interview. Participants had clearly been thinking about our interviews in the interim and often shifted the discussion to something they had noticed during the last month that they thought I would find interesting.

My experience has echoes of Twigg and Atkin’s (1994) experiences of interviewing carers. I similarly found participants varied in using the interview situation as an “opportunity to talk with someone new as a way of conceptualising, or coming to terms, with the care-giving arrangement they found themselves in” (p. 40). At other times wanting to “talk about anything other than caring”, relishing the “opportunity to be recognised as something other than carer”(p. 40). Thus while the minimally structured interviews resulted in lengthy conversations that were not necessarily on the topic of care, they helped give context to the people within the care arrangement. This divergence also attests to how life history is an ever-present mode of talk connecting current aspects of people’s lives with prior events and experiences that help to communicate who they are, even if the ‘subject’ is currently under construction (Linde, 1993).

On average, interviews lasted one-and-a-half hours but ranged from 30 minutes to six hours. Second and third interviews tended to be shorter. Participants from 10 couples completed the set of 3 interviews with 4-5 weeks between each interview. Participants from 5 participants completed 2 interviews and 3 participants completed 1 interview. Variation was due to circumstances of their caregiving and is explicitly addressed at the end of each vignette in Appendix 19.

Data analysis

Narrative analysis as a method is widely considered a heuristic guide rather than having 'procedural guidelines' (Creswell, 2017; Frank, 2010) though some scholars have usefully attempted to operationalise the form of analysis (Phoenix, 2009; Riessman, 2008). As outlined above, this narrative analysis is shaped by Reissman's (2008) approach to narrative analysis, which focuses on a deep-dive of each participants narratives and then a comparison across the data. The stages of this analysis a presented below in Figure 1.

Importantly, data analysis began during data collection. After each interview I made fieldnotes and noted emerging ideas. At each subsequent interview, I shared with the participant the main storyline I was hearing from them, which I introduced as so: "What I'm hearing from your last interview was". Discussing observations with participants was designed to support the transparency and trustworthiness of the findings (Lincoln, 1985).

Once data collection was complete, I read through five sets of participants transcripts to begin to create a narrative template that would guide my analysis of the total data set (Appendix 18). At this point, I also returned to three participants (Evelyn, Kathleen, Patricia) to discuss an overview of my findings. All participants agreed with my overall findings and offered suggestions about how to make it better. Some of these suggestions have helped guide my discussion section. This process was also accompanied with a return to the academic literature to help sharpen my conceptual thinking. I completed both these stages to ensure that I was producing a "viable interpretation grounded in the assembled texts" (Hammersley, 2008, p. 484).

Incorporating new insights from participants and the literature, I finalised the narrative analysis template which acted as a general guide rather than a strict framework for conducting my analysis. I then read each participant's full set of transcripts multiple times to get a full sense of their context and what they were trying to communicate and their key storyline. To solidify this I selected a quotation from each transcript that captured the vibe (see Appendix 19). Finally, for each participant, I extracted informative quotations into the narrative template and jotted down ideas and links with other participants' accounts. Once I had completed this process for all participants, I began consolidating my views around the most consistent/ prominent topics and storylines across the sample.

Interestingly, I initially thought I was aiming to uncover generic conventions underpinnings individuals talk such a Tragedy, Comedy, Romance etc. (Aristotle., 2013; Frank, 1995).

Nevertheless, I did not find the consistency of big overarching generic patterns. On reflection this seems to link with Berlant's (2018) insight that:

> Genre flailing is a mode of crisis management that arises after an object, or object world, becomes disturbed in a way that intrudes on one's confidence about how to move in it. We genre flail so that we don't fall through the cracks of heightened affective noise into despair, suicide, or psychosis. We improvise like crazy, where "like crazy" is a little too non-metaphorical. (P. 157)

Instead, what became salient through the analysis was how participants managed "the contradictions of social interaction and self-presentation" in such their accounts (Bury, 2001)(p. 278) against the imminent physical deterioration of their partners as well as their own bodies. The most exciting aspect of the data was the ways participants' emplotted their lives so as to make particular presents and futures "not only plausible but also compelling" (Frank, 2010, p. 10).This is not exactly what I expected given the main focus was end-of-life care.

This revelation helped me arrive at the three topics consistently animating participants talk which are presented in Chapters 4-6 and reflected in the research questions presented in Chapter 1. To further contextualise of participant's concerns and interests, I strove to connect their ideas to wider theoretical discussions. Narrative is a methodology particularly suited to probing theoretical concerns (Hollway & Jefferson, 2000). Theoretical insight has also been identified as something lacking in the current end-of-life care research (Morgan et al., 2020). In each empirical chapter I present three narrative case studies in order to "discover and make sense of the finer differences between apparently similar cases" (Hennings et al., 2013). In each chapter, cases were selected as they reflected a spectrum of experiences across the wider sample in relation to the topic of interest. This was designed to aid the reliability of the findings (Riessman, 2008). To further support the validity of findings participants' quotations and details of their circumstances are presented at length (Lincoln, 1985). My interview questions are included in bold to capture the flow and interactions within interviews (Holstein & Gubrium 2002). Participants are referred to with researcher-selected pseudonyms.

Figure 1: Analysis process

Chapter Summary

In this chapter I have made a case for a narrative research approach and have outlined the design of the methodology with reference to relevant literature. I have then described the nature and outcomes of my year of fieldwork. I then explain how I processed and analysed the data. The following Chapters present the three main findings from this narrative study.

Chapter 4: Problematising carer identification: A narrative study with older partners providing end-of-life care

Preamble

Chapters 4-6 draw from findings of the longitudinal narrative study introduced in Chapter 3. Apart from the methodology which is presented separately, chapters 4-6 are prepared like journal articles to ensure a smooth transition from thesis to publication.

Background

The search for carers is on. Internationally health and social care policies have increasingly promoted carer self-identification as the best way to target and support people in caring roles (Ministry of Social Development., 2019; NHS England., 2019; Victoria State Government., 2018). Carers in the United Kingdom (UK) are widely defined in policy as "lay people in a close and supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management"(NICE., 2004). The carer identity was originally popularised by grassroots UK-based feminist activists and scholars in the 1960-70s to petition for the financial support of mid-life women caring for their older parents (Barnes, 2011; Yeandle, 2016). As a collective identity, it was also designed to foster solidarity amongst those in caring roles irrespective of care recipient's age, disease or disability status (Barnes, 2011). The carer's rights movement has tied into wider contemporary discussions about shifting care for older people from institutions into the community (Heaton, 1999). Since the mid-1990s carer's rights have been increasingly legislated for in the UK (HM Government., 1995, 2004, 2014) and have become a prominent pillar of UK palliative care policy (National Palliative and End of Life Care Partnership., 2015; NICE., 2019).

Despite the widespread promotion of the carer identity by policy-makers, health and social care professionals and grass-roots organisations, there has been remarkably little research concerning how individuals come to adopt this identity (Eifert, 2015; Funk, 2019). A recent review of caregiver identity among adults with chronic disease identified 23 articles presenting a range of explanations for adopting the identity (Eifert, 2015). One explanation is that due to "role engulfment" individual's no longer have capacity to sustain other identities outside of caring and therefore become a carer (Skaff, 1992). Another explanation suggests that the carer identity emerges with the loss of a shared identity, lifestyle and reciprocity within the relationship, typically due to the effects of cognitive impairment (Coeling, 2004; Hayes, 2009; Lennaerts-Kats, 2020). A third explanation suggests that culturally normative expectations placed on families, particularly women, to provide care naturalises the adoption of the identity (Hughes, 2013). Other studies indicate that familial expectations to provide care may impact individual's rejection of the identity. Instead, they may prefer their familial identity as a wife or daughter (Molyneaux, 2011; Turner et al., 2016) or seek to maintain the dignity of their family member and therefore avoid introducing new hierarchies, denoted by carer/cared-for (Henderson, 2001). To this end, Knowles and colleagues (2016) suggest that family and friends supporting people with long term conditions (LTC) did not identify as carers to avoid undermining the independence the their "care recipient", who was attempting to "self-manage" their conditions in line with policy directives.

Amidst the range of reasons for adopting or rejecting the carer identity, some consistent qualities have become apparent about the carer identity. First, the carer identity always emerges and is shaped by a range of pre-existing social identities such as relational status, situational identities (worker or retiree) and structural identities such as gender, ethnicity and class (Eifert, 2015). Second, the carer identity does not map directly onto level or type of caring activities. Studies have highlighted how bereaved people may continue to refer to themselves as carers even after the cessation of caring activities (Larkin, 2009). As highlighted above, some people may be involved in physical and/or emotional care tasks yet refuse the identity. Strengthening this point, a recent study with 18 family and friends of people with Mild Cognitive Impairment which found that only three of the 18 participants identified themselves as caregivers (Beatie, 2021). Participants instead overwhelmingly occupied a "liminal" category where they were unsure about the norms associated with the carer identity whilst also feeling that the current needs of their family member/friend were not severe enough yet to warrant seeing themselves as carers (Beatie, 2021). This study among others contributes to the growing scholarly calls to re-consider the prevailing logic that encouraging people to develop the carer identity is the best way to facilitate their support (Funk, 2019). This concern is also supported by evidence that people who identify as carers tend to subordinate their own needs, potentially making it harder to support them (Broady, 2015; Carduff, 2014).

This paradigm shift has important methodological implications for researchers, given that for the most part researchers continue to assign the carer identity to their participants unreflexively. For example, I found through conducting the systematic review in Chapter 2 that 15 of the 19 included studies categorised participants as "carers" on the basis of the care-recipient's condition (Morgan et al., 2020). The remaining four studies required participants to self-identify as carers (Morgan et al., 2020). Utilising the homogeneity offered by the carer identity, researchers have successfully brought to light the adverse psychological and physical impacts of providing care over the last 40 years (Dassel, 2016; Pinquart & Sörensen, 2003; Schulz & Beach, 1999). This research has helped to sustain carers' rights as a political issue (Barnes, 2011; Larkin et al., 2018). Nevertheless, Adams has aptly acknowledged that much of the scholarship on informal care has become overly reliant on the "analyst's accounts" of the carer identity and a focus on "describing carers' inner mental states" (Adams, 2002, p. 251).

The two prevailing theories underpinning caregiver identity development in the current literature are ripe for such critiques. Caregiver Identity Theory, for example, posits that the adoption of the carer identity is a dynamic process that intensifies over time in relation to the demands of their role and is shaped by familial norms (Montgomery & Kosloski, 2009). This theory has been critiqued for presenting the carer identity in an overly deterministic manner which, as acknowledged above, does not fit with empirical findings that indicate that some people never adopt the label (Beatie, 2021; Knowles, 2016).

Positioning Theory has increasingly being used to present a more fluid, situational view of the carer identity by emphasizing that individuals have a repertoire of positions which becomes salient in particular contexts (Harre, 2009; Knowles, 2016; O'Connor, 2007). Based in the intellectual tradition of Speech Act Theory, Positioning Theory hinges on the account of the "knowing subject" whose actions are shaped by discernable intentions (Austin, 1975). Studies using Positioning Theory often re-inscribe an individualistic, cognitive model of carer identification. This is epitomized in the current scholarly definition of carer identity as a "cognitive construction" that serves as an "interpretive frame and sets of standards used by individuals to make sense of personal experiences, actions, and emotions" (Funk, 2019)(p. 14). By centering individual decision-making, this theory has inadvertently contributed to the persistent gap in the literature around the impact of external interactions in shaping the carer identity (Funk, 2019; O'Connor, 2007). Viewing the carer identity as a primarily cognitive process also runs counter to current sociological thinking about identity as no longer a "theory of the knowing subject, but rather a theory of discursive practice" (Foucault, 1977; Hall, 2000)(p. 6).

This chapter aims to further the conceptualisation of the carer identity by offering an account of carer identification as a discursive practice. I have coined the term "*carering"* to denote the co-constructive practices of policy-makers, researchers and broader cultural narratives involved in calling forth the carer identity *and* the unfolding practices of people interacting with the carer identity in relation to their sense of self. For conceptual clarity *caring* is understood in this chapter as "persistent tinkering in a world full of complex ambivalence and shifting tensions" (Mol et al., 2010) (p. 14). To understand carering as a discursive practice, I focus on the process of carer identification, rather than the identity itself. I understand identification as a dual process of subjectification (Greco, 2018). First, identification is based on a process of interpellation whereby discourses and practices always attempt to hail us into place as social subjects of particular discourses (such as the carer self-identification discourse)(Hall, 2000). Identification also always involves what Hall has termed "psychic suturing" whereby individuals themselves must invest to some degree in the subjective self-constitution (Butler, 1992; Hall, 2000). There must be something that appeals to individuals in the identity for them to use it, although people need not be entirely cognizant of such reasons. Butler contends that identification is always constructed in relation to the "other" (Butler, 1995). Identification remains an incomplete process and any identities produced never reflect a "true" proper fit as they are always on some level strategic or positional (Hall, 2000).

In this chapter I explore carering through narrative interviews with older partners providing end-of-life care. This group have been identified as a particularly vulnerable, as they tend to be caring whilst grappling with their own health issues (NHS England., 2019). Paradoxically, they have also been identified as a group who tend to under-utilise existing support services (Princess Royal Trust for Carers, 2011). It is therefore important both from a health service and social theory perspective to clarify the notable ambiguity arising around older people's views and uses of the carer identity (Grande & Ewing, 2019; Larkin et al., 2018). Such ambiguity is captured in Corden and Hirst's study based on a sample of 750 couples from the British Household Panel Survey, which found that partners aged 75 or more were twice as likely than those aged less than 50 years to identify as carers when providing end-of-life care. Nevertheless, only half of respondents aged 75+ identified as a carer. The authors suggest that the disinclination to self-identify as a carer may be due to respondents own health issues, meaning that they may sometimes be the cared-for too (Corden, 2011). The authors concede that further qualitative research is required to unpack these issues further (Corden, 2011).

Aim

- To understand the carer identification practices of older partners providing end-of-life care

Methodology

A full methodology section is outlined in Chapter 3. Direct methodological considerations of this chapter included by role as "necessarily and ineluctably active" in the production of meaning (Holstein & Gubrium 2002)(p. 114). As a researcher I played an important role in the constitution and reproduction of carering. For my recruitment strategy to be as inclusive as possible, recruitment material avoided the term "carer" to avoid forcing this discourse onto participants. This decision was supported through consultation at a Patient and Public Involvement (PPI) meeting with 14 older people with experience of dementia care who felt that many of their peers would not perceive themselves as carers. The recruitment flyer (Appendix 9) read "are you looking after someone with a serious condition". Ultimately, I think it was a successful strategy given some participants did not and likely would never identify as carers. In the discussion of this chapter I reflect on the implications of this on future research and policy.

Results

Engaged carering: "I'm his carer, yeah"

Mary, aged 74 white British, reflected that her husband Paul's diagnosis of early-onset Alzheimer's disease at the age of 64 had left her *"in bed crying, crying, crying"*(int 1). After the initial shock, she thought: "*This isn't doing me any good, I've got to keep well, and I wanted to keep him going. So I toughened up (laughter*)"(int 1). Mary's process of "toughening up" involved seeking out her local dementia carers support group which she and Paul, now aged 74, had remained members of for the past eight years. When asked "what it's like looking after your husband?" Mary directly referred to herself as a carer and linked it with the range of dementia-related organisations and activities she and her husband attended:

> *Hmm, I'm his carer, yeah. And he's fine, he's really good to lots of people. Yeah, but he gets well you can see. [pause] But he is, yeah, we do lots of things, uh huh, we play table tennis, we play short tennis, we go [Dementia singing group] which is a singing group, we*

> *go to choir, we got to the [name of Carer's Organisation] with some friends, we go out for meals, go on holiday, we see our children and our grandchildren. (int 1)*

By forming friendships and a social life through dementia-related connections, Mary hints at the way she has been "hailed" into the carer identity. Through frequent discussions at the carer group, which she refers to as the "best thing", Mary learnt that being a carer is to experience social isolation, chiming with her experience of caring as "*so isolating*", leaving her "*in the same boat*" as other carers. By discussing the issue of isolation in the encompassing second person (you) and first-person plural (we), Mary underlines how she "sutured" the carer identity onto her sense of self:

> *They think it's the best thing ever because you feel so isolated, it's just you and the world and this poor person who we love and it's so isolating and it's such a shell shock to hear but erm, hmm, it's wonderful cos everybody's, oh, we're they're in the same boat and you have a good old chat about the problems that you have and a lot of them are very similar, obviously, with a lot of Alzheimer's are similar and, you know, the different types but there are similarities in them. (int 1)*

While her isolation was directly related to her husband's inability to hold a conversation due to his declining cognition, it was intensified by her decision as a parent not to burden her children who had "*busy lives*". She quipped that "the last thing" her daughter who was a doctor needed "*is a problem from me*". Normative expectations of not burdening other family members responsible for their own nuclear families influenced the conditions of Mary's carering. This was also evident in her subsequent definition of carer in terms of its temporal intensity. This aligned with her perception, gleaned from the carer's group, that for the most part as carers you are "on your own" facing a high level of care responsibilities:

> ***What do you think to being carer means?***
>
> *Being available 24 hours a day to do all the things that need to be done (laughter).*
>
> ***Have you had any problem like adopting that term, or?***
>
> *No, like I'm his wife and that's what wives would do, isn't it? So, it's not, you know, it's not a title, it's just something a wife erm, would help a husband do because, you know, take them on for better, for worse and hopefully he will do the same for me*

> *(laughter).(int 1)*

Mary’s definition also incorporated her view that the carer identity was an inevitable extension of her wifely duties reasoning: “*that’s what wives would do isn’t it?”.* Such wifely tasks had changed throughout the course of her husband’s advancing dementia. While Mary spoke at length about Paul’s generosity as a husband, father and boss, referring to him as “*Mr King-fix-it*”, she also recognised that he now did “nothing” around the house or for himself. Mary and Paul had a traditionally gendered heterosexual relationship where she had been a housewife and he the breadwinner, meaning she had always been responsible for daily household activities. Being in charge of “directing” her husband in all matters of his personal care was a discomforting new experience that changed the relationship’s hierarchies. It also translated into more daily care. Laughing ironically, she exclaimed it “*t[ook] a lot of effort*” to ensure her husband looked so dapperly dressed; something he was known for at the carer group. It was at this point she returned to the narrative she begun with about how to keep caring she had to: “*stay well (laughter)”.* The discursive limits of her “will to health” were laid bare a month after this interview when Mary’s daughter informed us that Mary had had a brain haemorrhage from an aneurysm whilst out at dinner with Paul and two friends. She died in hospital later that evening. Her daughter, who agreed to a brief telephone interview, put Mary’s death down to “the stress of caring”. Mary’s carer identification as a process of “toughening up” had unforeseen consequences, serving as a shell shock for all involved.

Ambivalent carering: “I don’t go around thinking I’m a carer”

Charles, white British 80, had been caring for his wife Dolores, 87, for the last eight years since a severe stroke that left her wheelchair-bound, incontinent and able to communicate only through her facial expressions. Charles, who was one year into his remission from prostate cancer, was supported by a team of three privately-paid for health care assistants (HCA) and two involved step-daughters to care for Dolores at home. While formally registered and recognised as a carer - with the card to prove it - he nevertheless felt that it was an “awkward” fit that did not square with his internal view of self:

> *I have to say because of the circumstances I’m a full time carer I feel quite awkward actually. I am who I am and I’m looking after my wife and the title is not relevant although*

> *it's true it's what I am. And I'm registered as a carer I'm with an organisation in [West London]. And I carry a red card. (int1)*

Underpinning his continued use of the carer identity appeared his hope for improved access to health care for himself and Dolores. Nevertheless, the luke-warm response to his using the term at the G.P. surgery intensified his ambivalent identification:

> *I'm officially a carer. Don't think of myself as that really unless it crops up in conversation and we're very lucky with our medical practice up the road never have to wait too long for an appointment. And I say to them, "am I registered as a carer because I gather if you are you get precedence if necessary", and they said "well I don't know whether you are and anyway you don't get precedence" and I thought you did but again I don't go around thinking I'm a carer (int 1).*

Charles acknowledged that much of his feelings about his carer identity were unconsciously constructed, summarised in his statement that "*I don't go around thinking I'm a carer*" (int 1). On reflection, prompted by the interviewing context, Charles felt that his ambivalence related to his dislike for the way the carer identity redefined his relationship. It hurt Charles to undermine Dolores' position as the care-provider in her household by rendering her the "caree". At seven years her junior, he had always been her "toy boy" and had been "just assumed as an extra plate to fill" when they married later in life. So to avoid affronting her womanhood and her identity as an "intelligent lady", he did not identify as a carer in her presence:

> ***And if you're the carer does that make her the cared-for in terms of the terminology?***
>
> *Is she the caree I don't know I hate to think of her having to accept, it makes me very, very sad because as I said before, for a really intelligent lady who now can't communicate properly, ... you know she used to get really very angry when I used to wipe her mouth after food she now accepts it. And that hurts me for her because she shouldn't have to accept that she should be able to do it herself and it makes me cry…And having somebody to, particularly your husband, to do things which you used to be able to do yourself. (int 1)*

Being a carer also presented challenges to his masculinity, as he was involved in the intimate dirty work of toileting etc. that men do not typically do. Charles shrugged off this cultural baggage describing caring for Dolores as a habitual practice which he had grown competent at due to necessity. He explained that he was frequently met with intrigue or confusion by others, particularly women carers, which he found "strange":

> *I don't know it just happened as I said earlier on I didn't think twice about it, I was going to have to do it, don't enjoy it but it's part of life now the more you do things that are part of life the more you get used to them but as I said before a lot of people seem to think that it's not the man's job "aren't you good for doing it"[mimicking a woman's voice]. I think strange (int 1).*

Charles felt that caring had made him more emotional making him "cry at anything". He felt that his enhanced emotional sensitivity was a key distinguishing factor making his care superior to the female HCAs:

> ***What would being a carer involve?***
>
> *I think what we've been talking about it's physical and emotional both sides of it. But the emotional side is because we're married and the love element comes into it, respect friendship all these elements, but if I was employed as a carer like [HCA's name]… I would probably take a long time to get the emotion, because there's how many patients, clients whatever they're called, service users, are they seeing every day fourteen easily. (int 1)*

This differential in physical and emotional support perhaps links to why he continued to claim the mantle as her "primary carer" so as to indicate that Dolores's care always included the "*love element*", despite the carer identity never thoroughly permeating his sense of self. Ultimately, Charles was content with bending his identity to the circumstances if it meant that he could achieve his goal of "*being carried out of the house in a double coffin*" with his "*intelligent lady*" when their time came.

Disengaged carering: "We're fine"

At their first interview John, white British 85, was referred to the study by a G.P. as being the carer for his wife Betty, 79, whose limited mobility and abscessed leg had led to her G.P. diagnosis of advanced frailty. John's mobility was not much better, however, so much of their daily life involved pottering around their small council bungalow. Betty and John embarked on slightly different responses concerning their carer identity, though both showed awareness of it and reluctance to apply it to themselves:

> ***What do you think about the label carer?***
>
> *Betty:* *Uh huh, yeah some people –*
>
> *John:* *Well, yes, there is.*
>
> *Betty:* *- to look after each other, so they are both carers. Yeah. They can work it.*
>
> *John:* *There is a girl up the road, isn't there, Betty?*
>
> *Betty:* *Yeah*
>
> *John:* *[Betty]'s got bad legs and a little girl who lives, that's the advantage of being in this set up, erm, she, her friend drives her now because Betty can't drive, so, you know, she helps that way and you find, I suppose when you live in a town, if, erm, you know, you get to know people, I think that's the main, for us anyway, it's getting to know people – [pause]- and helping one another, you know - if you need it, if you need help but the, erm, and the clubs as well, like the over-60s, but erm, you know, meeting people but while you, while you keep your health, being able to go out and meet people -*
>
> *Betty:* *- and talk to people and yeah. (int 1)*

Fundamental to their discussions of care was the importance of taking personal responsibilities for one's own health and building up social networks to "*work it*" so they could remain independently home with the occasional instrumental support of neighbours. Notably, John conceded that much of the community groups relied on being able to "*go out and meet people*" which neither were able to do currently. Nevertheless, both remained remarkably optimistic, describing how they were attempting to "*make do and mend*" (int 1). This phrasing, redolent of the British war logic, fit into the couple's detailed reflections of having to ration as children during World War II. Their notions of self-sufficiency similarly inflected their understandings of care, with the only task Betty conceded that John helped her with was breakfast:

> ***How did he look after you?***
>
> *Betty: He did the cooking didn't you made lovely scrambled egg better than I could make.*
>
> *John: Well you always burn the saucepan.*
>
> ***Were there any other ways you had to help?***
>
> *John: No. Because you sat in the chair most of for about a year didn't you?*
>
> *Betty: I hobbled about I need I'm not one for sitting for hours in a chair but I like to potter on. (int 3)*

This passage revealed the egalitarian nature of their relationship and their household management. This dynamic was also evident in their reminiscences of their long marriage and life working together running youth hostels. Striving to self-manage their own respective personal cares undoubtedly reflected a desire to take the strain off one another.

John's diagnosis of terminal bowel cancer, with six months to live, between the first and second interview could have been a significant turning point in the couple's carering story. Their narrative remained one of in John's words of "*muddl[ing] through*" (int 2) though John quipped when Betty was out of the room that they were now "*babysitting each other*" (int 2). For the most part, Betty successfully steered the conversation away from John's despondency toward a radically hopeful outcome which meant their identity as a couple remained intact:

> ***And you can like if you shower all by yourself? And stuff in terms of it doesn't…***
>
> *John: They don't let you go from the hospital 'til you've got to show 'em you can work with the bag on. Do that.*
>
> ***Do you find you have to help out?***
>
> *Betty: No I mean he's done it, I mean I would do if I had to but he seems to cope alright don't you?*
>
> *John: Mm. Don't know. Done the first bit couldn't do all of it cos I was too old and too frail.*

Betty: But there's a lady on the television and she had breast cancer and she had radiotherapy. I suppose they try that don't they first if they think they can do it with it

John: Need to just get some more fire radio.

Betty: [pause] just keep going John.. did I tell you I fell out of bed? (int 3)

Betty crafted an account where illness was something to be overcome rather than a formidable obstacle by appealing to cultural imperatives to stay optimistic gleaned from the mainstream media. Ironically, Betty's narrative pivot designed to outline their control over the situation underscored their vulnerability. Betty continued the above passage by explaining she had to wait two hours for the ambulance to arrive at their remote village. When asked, "what did you do when she was on the ground?", John responded:

***John**: I don't know suppose I got down and had my normal cup of tea.*

***Betty**: Did you? Left me. [pause] No but you kept saying "do you want a cup of tea" I said "no thanks" but he just couldn't do anything (int 3).*

That John "*couldn't do anything*" in Betty's time of need showed how the process of carer identification was bound up with the changing abilities of each to care for their own and each other's bodies. Precisely because of these changes, it became even more important for Betty and John to preserve their identity as a self-sufficient couple. For them this necessitated with the disengagement from the carer identity. They preferred radical hope, summarised aptly by Betty's sign-off of their third interview where she turned to John and said: "*we're fine the sun's shining isn't it here? You're alright love"* (int 3).

Discussion

This chapter introduces the term *carering* to demonstrate the way that carer identification is a discursive practice. This addresses an important gap in the carer identity literature by highlighting the multiple external factors motivating carer identification. This chapter also addresses how individuals come to "psychically suture" the identity onto their sense of self (Hall, 2000). I contend that older spouses should not be homogeneously characterised as either using or rejecting the carer identity. In doing so, this chapter adds to the growing calls in the literature to identify alternative strategies to support people involved in caring, given that not every older partner wants to, or will, self-identify as a carer.

What this chapter adds

The first key contribution is to introduce carer identification as a discursive practice I have termed *carering*. Through interacting with carer organisations and health care professionals, participants encountered broader carers' discourses and imperatives to self-identify. However, these discourses were only embodied when participants felt that the qualities assigned to being a carer, such as experiencing social isolation and providing 24/7 care, reflected their own personal experience. To this end, being a spouse need not necessarily conflict with being a carer, as has been previously mooted (Molyneaux, 2011; Turner et al., 2016). Participants embraced a fluid understanding of identity, which transformed over time in relation to their own understanding of their context and material changes to their own and their partner's physical health. Interestingly, Charles presents a case where someone identified as a carer but was attempting to back away from it: challenging the deterministic trajectory offered by Caregiving Identity Theory (Montgomery & Kosloski, 2009).

In line with previous studies, normative expectations around familial care were fundamental in influencing carering. Novelly, I observed that older husbands' fear of compromising their wives' femininity and position in the domestic setting shaped whether and when older men engaged as "carers". This adds to previous findings that older men engage in caring as a way to reciprocate care received by their wife across their life-course (Milne, 2003). I add that older men's minimisation of their caring identity, at least in front of their wife, was part of this reciprocity. I also observed that carering frequently occurred on an unconscious level (as gender and heterosexuality also tend to), with their logic of identification only brought forth and explicitly reflected because they were asked to do so in the research context (Butler, 1995). This is another reason why it is preferable to view "carer" as a discursive practice rather than a quality of a cognisant "knowing subject" as in much of the current literature (Eifert, 2015; Funk, 2019).

The second key contribution is the exploration of older partners who partially or consistently disengaged from carering. This finding fits with recent studies questioning the orthodoxy of carer identification as an inherently emerging identity (Beatie, 2021; Henderson, 2001). Contrary to previous theories (Montgomery & Kosloski, 2009), neither lack of awareness about the carer term nor newness to caregiving could sufficiently account for their lack of use of the identity (O'Connor, 2007). I posit that such disengagement with the carer identity was related to a wider protective strategy of self-and-partner preservation. This process has analogies to the concept of disidentification in queer scholarship (Munoz, 1999). This tactic has been identified as a way family members manage threats to their older care-recipients health (Knowles, 2016). Previous research has found that frail older adults use this strategy to manage the challenges of daily life (Nicholson, 2012; Wiles, Miskelly, et al., 2019) and consultations about advanced care planning with health care professionals (Etkind et al., 2019). By focusing on frail older people providing care, we combine the insights of these studies and contribute much-needed insight into the way carer identity shaped coping strategies (Corden, 2011). By emphasising their marital identity, and by stressing the things they could for themselves, participants fashioned a positive “persistent present” which strove to normalise and downplay changes (Greenwood et al., 2019; Nicholson, 2012). I suggest that such therapeutic plotlines (Frank, 2010; Mattingly, 2014), which reject the carer identity and centre on *biographical continuity,* are particularly important for those experiencing poor health and managing threats to their own independence: in other words, precisely the “vulnerable” oldest-old people whom policy-makers want to reach.

Contribution for practice

Given the range of engagement with carering amongst older partners, I suggest a dual approach is required to optimise their support. For those who identify as carers, health and social care professionals need to ensure that the resourcing and infrastructures are sufficient so that when older partners seek help, they receive it. Evidence presented here indicates that formal care is not currently meeting the preferences of older partners as in the second example above, where the lack of awareness of carers’ entitlements by his G.P. actually deepened his ambivalence around whether he ought to pursue the carer identity. My findings align with the conclusions of a recent scoping review that interest in carer awareness in policy has not necessarily resulted in tangible improvements in support for older carers (Henwood, 2017). A starting point for improving the context of care could usefully centre on questions about what systems are needed to improve older partners’ material needs and physical and emotional competencies, in order to support them in their caring roles? Addressing deep-seated feelings of isolation identified here and in previous research with the oldest-old(Greenwood et al., 2019) also appears urgent. Befriending services for those looking after a partner might be a fruitful first step (Wiles, Morgan, et al., 2019). This is particularly important for people who are unable to get out of their house to attend conventional carer groups.

For those disengaged with carering, we recommend focusing on older couples as the joint unit of care rather than viewing their needs individually. This aligns with the shift to thinking about relationship-based care which is receiving increasing attention in chronic care and palliative care models (Ateş et al., 2018; McCarthy, 2020; Wadham, 2016b). Operationalising the older couple as the unit of care could be achieved by ensuring that every time either partner comes into the system, they are asked about their partner and their own needs (Ewing et al., 2018). Such requirements could be revised at intervals through regularly, proactively offered G.P. or nurse appointments (Ewing et al., 2018). Linking of older couples' health and social care clinical files, with their consent, might also help ensure meeting of the couple's needs irrespective of whether one, both, or neither identify as carers. This would help promote couples' self-preservation strategies whilst ensuring that they do not slip through the cracks.

Conclusion

This chapter introduces the concept carering to reframe carer identification as a discursive practice. It addresses a significant gap in the carer identity literature by highlighting the multiple external factors motivating carer identification. It also considers how people psychically square the carer identity with their sense of self. I contend that older spouses should no longer be homogeneously characterised as either using or rejecting the carer identity. Rather, the degree to which older partners engage with carering is based on their wider interactions with the formal and voluntary sector, whilst simultaneously shaped by the power dynamics in their relationships and the changing circumstances of both members' bodies. This adds to the growing calls in the literature to explore alternative strategies to supporting people involved in caring that do not rely on carer self-identification.

Chapter summary

Chapter 4 contributes important new knowledge about how we conceptualise carer identification as a discursive practice. This chapter also addresses an important gap in the literature identified in Chapter 2 in terms of older partner's understandings and uses of the carer identity. I conclude that while some older partner's do identify as carers, others do not, or only do so in particular circumstances. Consequently, alternative strategies need to be explored to effectively support older partners, something that is elaborated on in Chapter 6. Another important contribution of this chapter is to focus on how older partners identify as carers in relation to formal and voluntary care services. In Chapter 5 I will take this engagement with wider services further by considering how participants attempted to integrate care services for themselves and their partners.

Chapter 5: What role do family caregivers play in integrating care?: A narrative study with older partners providing end-of-life care

Introduction

Integrated care, for all its hype, remains an elusive moveable feast of aims and actors. There is widespread international agreement that the status quo of siloed health and social care services are not adequately catering to the growing numbers of older people and those with long-term conditions living at home and requiring complex and on-going health and social support (Charles, 2020). There is also agreement that the "duplication and discontinuity" produced through fragmented care systems results in poor patient outcomes (Age UK., 2020), dissatisfied health care professionals (Sikka, 2015) and family members (Ateş et al., 2018; Williams et al., 2018) and maxed out health budgets (Evans, 2013). Integration, while the much touted solution to the fragmentation, remains a remarkably elusive concept (World Health Organisation., 2016). In its broadest form, integration is a boundary-making practice determining the inclusion or exclusion from any particular group or activity (Anthias, 2013b; Flubacher, 2016; Masoud, 2019).

In health and social care policy integration tends to be described synonymously with joined-up or coordinated care, and can relate to connections made on a systematic, normative, organisational, administrative and clinical levels (Shaw, 2013). Integrated care typically refers to instances where a range of different services or multiple professionals with different roles within an organisation start working together (Ham & Curry, 2011). Integration can be targeted at improving health outcomes on a population level, although more recent approaches have focused on targeting particularly vulnerable groups (Evans, 2013). At present, however, there is no gold-standard for integrating care (Maruthappu, 2015; Threapleton, 2017). Shaw and colleagues contend that this is due to the complexity of problems integration seeks to solve as well as the range of forms it can take (Shaw, 2013). Such ambiguity may also stem from 'integration' being an inherently flexible "boundary object" designed to enable different groups to work together without consensus rather than an actual concept with a definite meaning (Leigh-Star, 2010).

Integrated Care Systems (ICS) are being rolled out across England in a bid to improve the quality and efficiency of the health care sector by shifting away from the existing legislative focus on competition between services (NHS England., 2019; Timmins, 2019). Commissioners and senior bureaucrats have framed themselves as chiefly responsible for promoting conditions for integrated working through policy and funding mechanisms (Evans, 2013; McDermott et al., 2019). There is growing recognition however that it is not possible to "legislate for collaboration" as the delivery of integrated care "ultimately depends on the skills, behaviour, and engagement of healthcare workers"(Coughlan, 2020; McKenna, 2021)(p. 4). Alternative "bottom-up" solutions targeted at health and social care professionals have also been increasingly promoted including initiatives such as multi-disciplinary learning events and co-location of services (Behrendt, 2020; Coughlan, 2020; Dodd, 2011). Ambiguity prevails around what ICSs will look like in practice and whether integration can be achieved through "coalitions of the willing"(Timmins, 2019).

What role does this leave patient and families to play in the integration of services? The ICS roll-out has been criticised for excluding key partners such as patients and their families in the design phase (Timmins, 2019). What is even more surprising is how little evidence exists regarding the impact of integrated care models on patient experiences more generally (Baxter, 2018). This is despite growing calls in the literature to include patients and their family into planning, conducting, and evaluating integration work (Coughlan, 2020; Leutz, 1999; Wilson, 2016). When patients have been included, their contributions tend to be limited to patient satisfaction scores about pre-exiting interventions (Youssef, 2019). Such research has importantly demonstrated that patient's understandings and experiences of care integration may differ from those of health practitioners and policy-makers (World Health Organisation., 2016; Youssef, 2019), and that leaving out their views and values often results in building inequalities into integrated models (Gillam, 2012; Nadeau, 2017; Wrenn, 2017). While family members feature ambiguously in policy as both co-providers and co-recipients of integrated services(National Voices., 2013) (p.3); (vanderEerden, 2014), little empirical research exists around the role family members play in integrating services for older relatives, though few studies on the topic highlight the important linking role adult-children often perform in navigating care systems (Liu et al., 2017; Williams et al., 2018).

To explore the role family members currently play in integrating care services, this chapter focuses specifically on older partners caring for their partner approaching their end-of-life. This focus is guided by the fact that despite older people comprising the biggest users of health and social care services, particularly at the end-of-life (35, 36), their views and experiences have largely been excluded from research and policy (Threapleton, 2017).

Aim

What roles do older spouses play in integrating formal care in the context caring for their partner who is approaching end-of-life?

Methodology

The methodology for this chapter is presented in Chapter 3. It is also relevant to add that my positionality as a New Zealander was particularly important as participants took careful detail to explain the UK health and care system to me expecting that I was totally unfamiliar with it. This dynamic resulted in rich context about their daily caring practices. Indeed, once I came to analyse the data I identified that interactions with health and social care animated much of the interview talk. Looking closer, these stories focused on the ways participants had attempted to (not always successfully) arrange the best care for their partner in light of their physical, material and social environment. I identified three broader categories that participants used in positioning themselves in these stories: 1) networkers (building up networks of support for their partner and self); 2) home keepers (keeping their partner at home for as long as possible); 3) vigilant visitors (attentively observing the quality of non-home care). In this chapter I present three narrative case studies in order to "discover and make sense of the finer differences between apparently similar cases" (Hennings et al., 2013). These cases were selected as they reflect a spectrum of feelings of integration and receiving formal support.

Results

Donald and Rita: The "lucky" ones

Donald and Rita (White British, aged 75, 73 respectively) relocated in a small, rural village about 20 years ago when the impacts of Rita's Chronic Obstructive Pulmonary Disease (COPD) and spinal degeneration forced her to retire early from teaching. Approaching the end of her slow progressive illness, for which she had been placed on an end-of-life care registry by her General Practitioner (GP) for the last four years, Rita was reliant on her oxygen machine to breathe and her mobility had declined to the point that she was only able to leave their house with great difficulty. She reserved the feat, assisted with a walker, for her weekly morning church group. Donald, on the other hand, thought himself fortunate that his only health issue was type-2 diabetes.

Over the course of Rita's illness both emphasised that they felt incredibly supported by the health system with Donald remarking "*we are lucky did I say before how lucky we are medically?"(*int 2). Such luck was framed in relation to their close relationships with doctors at their local surgery which resulted in first-name basis care:

> ***Do you know your doctor?***
> *Donald: I know [doctor 1]. very well and I know [doctor 2]. and the other lady, [doctor 3]. We know them very well. There are locums, of course. It's excellent. In fact, you can phone sometimes early in the morning and get an appointment the same day if you want.*
> *Rita: Whenever you phone you get a personal feedback, which is good. You're not just a number on a list. (int 1)*

Another feature of their luck was just how immediately accessible their General Practitioner (GP) clinic was both because it was "*down the road around the corner*" but also because it was so responsive, as Donald explains:

> *...if you ring particularly the [local GP surgery] number early in the morning at 8am you might have to try a few times cos there'll be other folk doing the same thing, they will almost certainly get you a doctor out the same day. (int 2)*

The certainty of support offered by their GP surgery meant Donald could confidently operate as a home-keeper discerning when Rita's symptoms warranted professional attention. Combining information gleaned from Rita's past episodes of illness and close monitoring of her current symptoms, Donald talked me through his process of distinguishing what he felt was a "normal" stint of illness from something more serious:

> *If you know she can take medication for, she's got a stomach upset mainly. She says she's feeling a little bit better and she's got a headache. So you take Paracetamol as everybody else does I suppose in one way or another other analgesic similar. And I think I know when to tell her not to take too much but to take enough and she's making strides and I suppose basically after so many years with her I know very well whether she's doing well enough or not doing well enough and if she says "I'm sorry I'm feeling worse and worse", then I'd get straight on to the doctor but I can't think that's going to happen at the minute. (int 2)*

Donald characterises going to the doctor as the last resort informed by their joint preference to manage Rita's care independently at home. When Rita's care required escalation, Donald accompanied her to every GP or hospital appointment, acting as a vigilant visitor, striving to decode and contextualise any medical information and taking the opportunity to clarify his own concerns and responsibilities:

> *Rita: I need Donald to always come to the doctor with me, to listen. There hasn't been an occasion when I have asked him not to come. Because I feel what is about me is important for him to know and he also can listen and help me remember what the doctor has said afterwards. And we can discuss it or otherwise I might be putting it in wrong context.*
> ***I: So you find it useful?***
> *Donald: Yeah. But you don't mind?*
> *Rita: No I always assume. Especially when we see [doctor 1].*
> *Donald: She is a personal friend… but she tends to think you are like a medical student. .. she doesn't keep it to "take this", she is very direct. I wouldn't be a bit surprised if she didn't remember all of it.*
> *Rita: It's more that if I am discussing something that has worried me I find if the doctor is interpreting it as well. I find it important for Donald to help to explain why I have been feeling unwell. He can ask question there from the doctor which makes it clearer for him.*
> ***I: Do you find it helps you to clarify?***
> *Donald: Yes it does make the situation clearer. Fortunately, we are basically looking at the same symptoms. (int 3*)

As they always attended medical appointments together and were known to the surgery as a couple, Donald was proactively offered respite once a year. Neither Donald nor Rita was enthusiastic about this respite service, however, because it separated them. Rita conceded that she would only go again if Donald "*requested it*" (int 1). Rather than formalised support they desired organic socialising through their close church community support, networks they had both cultivated since moving to the village. Donald described this as the key reason he was "*unusual*" in that he experienced no social isolation whilst caring. His networking ensured that people remembered Rita illustrated in his description of her recent birthday:

> *It was like Piccadilly Circus through here. They were overlapping. There were three or four ladies here at a time sometimes and all these cards that she's still got. A lot of people remember because they don't see her out so much. Better make an effort. (int 1)*

By successfully networking with medical professionals and the wider community, with episodic experiences of "vigilant visiting" to keep up with Rita's illness progression, Donald was able to keep care home, leaving them both feeling "lucky".

Evelyn: "I know all the tricks"

Four months into their late-life marriage, 80 year-old Rupert fell down the stairs following a mini-stroke, was taken to hospital and subsequently diagnosed with advanced Vascular Dementia. Evelyn was told he had two months to live. Against the doctor's reluctance, on account of her noticeable frailty which was a residue of her battle with lung cancer, Evelyn "*fought tooth and nail*" to get Rupert home:

> ***And what was the process of getting Rupert home in that case?***
> *The consultant looked me in the eye and, said Mrs [last name]., you cannot take him home there is no way you will cope with him.*
> ***Really?***
> *And I looked back and I said, "with God's help I will".(int 1)*

Evelyn described the work keeping him home as one of assembling puzzle pieces:

> ***Do you have to always organise…?***
> *Every piece of the puzzle is like that. It isn't, it wasn't just day care, it's everything. If you want any information erm that somebody will give you a phone number, then you ring that and they'll say, no, you want this number, then you ring that and they'll ring you back and they don't and you ring again and then they tell you to ring somewhere else. Awful.(int 1)*

The fragmented system prompted Evelyn to develop her own strategies to ensure that Rupert (both white British, now aged 70 and 85 respectively) could stay at home as he explicitly requested. This process included co-ordinating his services as well as cultivating her own support strategies so that she remains physically and psychologically capable of home-keeping. For example, once the day centre stopped taking her husband because his dementia was too advanced, she as a "self-funder" had to "do the ring round and find the prices" for an overnight Health Care Assistant (HCA) so at least she could get some sleep. Ultimately it was her physical inability to lift her husband when he fell, coupled with her experience that you have to wait "hours and hours" for doctors, that she decided to ring the ambulance and have him transferred to hospital during his final illness (int 3)

Evelyn vigilantly visited Rupert every day at the hospital to oversee, and in some instances deliver, his personal care. Reflecting on the quality of her husband's care in hospital at an interview shortly after his death she explained:

> *It was horrible, he was dirty, he was smelly, he hadn't had his hair washed for three weeks, he hadn't been washed properly, he'd got a dirty gown on and he was always a smart man, it was horrible (int 3)*

By demanding he be cleaned and shaved regularly as well as feeding him and brushing his teeth herself and coming each day with a clean pair of pyjamas, Evelyn brought homely care into the hospital. Despite playing such a vital role she felt that she was:

> *...treated as if you're an idiot. I think they think you're the same calibre as the care staff ... I know a lot of doctors have to erm quickly assess what sort of level they speak to you at. (int 2)*

This prompted her to alter the way she spoke to staff in order to successfully network, combining a degree of deference and gratitude, in order to get her way as she explained while sat at the bedside of her husband in hospital: "*I've been in this hospital too many times. I know all the tricks.* [whispering]". She also became good at targeting potentially sympathetic HCAs to help her gain additional knowledge or supplies on the ward as she proudly announced: *"I know where they keep all the extra supplies...That's what they're there for, isn't it*? (int 2)". Where words failed, she used props; in one instance bringing her micro-biology textbook to symbolise that she too had scientific knowledge and that her opinion ought to matter. Her retinue strategy was to cry: in hospitals, in G.P. surgeries, over the phone for ambulances. Lamenting how a G.P. visit ordinarily took three weeks in her urban middle-sized city she explained:

> *No. If you go up to the doctor's surgery, if you cry in the waiting room they'll be... ever so quickly find somebody to see you.*
>
> ***Ah, why do you think that's...?***

> *Well, they don't want you to upset the other patients in the waiting room, do they?*
>
> ***Right. So you don't think it's about you?***
>
> *[Laughter]. Yeah, but you... you have to, when it takes so much effort to get up there and unless it's early morning you can't walk, we've got to arrange transport to get us up there. You can cry quite easily. With frustration as much as anything.(int 2)*

While she acknowledged that these emotional displays were intentional performances, she acknowledged that the emotional and physical toll of arranging rides and co-ordinating their movement between spaces made her expression no less sincere. To improve the situation for others like her, Evelyn took to making "*a list of useful numbers for carers*" which she explained had attracted much interest from a range of the service providers she was involved with:

> *the GP has said she wants a copy and [local hospital] have said they wanted a copy (laughter) His dementia group has wanted a copy… I was telling the paramedics and they said the Ambulance Service would like a copy as well. (int 2)*

By cultivating a number of "tricks", including keeping herself well to ensure care stayed home, adjusting her communication style to ensure she was listened to in particular networks, and vigilantly visiting to protect her husband's dignity in hospital, Evelyn forcibly integrated her husband's care so that she was with him until his end.

Carol: "I have no body"

Carol (white Welsh, 77) felt acutely alone in caring for her husband Charles (Jamaican, 89) since his diagnosis of prostate cancer and Alzheimer's disease, which 10 years on had left him unable to move independently or speak. Charles, had only recently returned back home from a social care funded care-home which Carol had placed him so she could rest her hernia which had painfully compromised her mobility. Nevertheless, because "*he nearly died when he was in care*" she had resolved to keep him home:

> ***So he was at a care home and came back out?***
>
> *Yes, because he was in a nursing home and they did not contact me to tell me, I had not been well myself with my throat so I hadn't, I'd gone in every week, every week I went in, three or four times a week but this one week I didn't go the Monday, I didn't go the*

> *Tuesday, I didn't go the Wednesday, that was all and then I phoned up on the Thursday … and they said that he was short of oxygen and I asked them "should I come in or I will come in" and they said, "No, it's alright, we've notified the doctor, we'll let you know," and I spoke to one of my friends on the phone, she said, "You do what you want to do?" So, I got a minicab, arrived at the hospital, thanks to God, just as the ambulance turned up so they hadn't phoned me (int 1).*

Even her "vigilant visiting" was not enough to protect him as they had not listened to her concern for his breathing problem, which she explained "*even my grandson had noticed*" to underline the inadequacy of care (int 1). Having Charles in a care home for her respite adversely impacted her economically and psychologically:

> *It would have took my pension, nearly all my pension, just to get to see him and then that means I would have no money. If my son wasn't here, how would I have food, how would I pay my electric, my telephone, if I'm paying money to keep going to visit and they used to say, "Oh no, it's a respite, you're supposed to have a rest," but if I'd had a rest he'd have ended up dead. (int 1)*

When Charles returned home he received the upper-limit of care support offered by social services: a HCA three times a day to help him get dressed, showered and toileted. Carol had also begun to receive the weekly carer's allowance. Nevertheless she felt "*deserted as it were, you're abandoned, you feel like you're abandoned anyway"*(int 1). She explained:

> *If they have a family that's looking after them, who's looking after the family? Who's looking after them? No one. They don't seem to care. They don't seem to care about the person who's caring for them. That's what, isn't it, Charles? It seems, as I said before, the care thing, you're penalised. You're trying to be the person that you should be because you love the person and yet you're being penalised for loving the person and you want them home with you. When you're married, the vow was for better, for worse and in sickness and in health (int 1).*

Interestingly Carol identified her lack of support not as an individual but as a systematic problem:

> *No, we do definitely need more care. I think the care systems they reckon it's very good but they're not looking at it from each individual's point of view. You as a wife, why would you*

> *give up the right to live with your husband when they should be giving, providing care in the home? Apparently it's a lot cheaper, the care network said, that you're at home, so why isn't it that you're not using that money, some of that money, to help the person at home? and say well, you're doing a fine job, you're doing something, you're looking after your husband, so that enables a person who has nobody to care for them to be in care? (int 2)*

While she was good at articulating the problem she found it difficult to solve, particularly because she was not sure who best to network with. While she tried to take the issue up with her husband's HCA, this merely reinforced that her husband, not she, was the legitimate recipient of state concern:

> *...It's like the Social Services, I haven't got a social worker, I have no support worker, I've nobody. So last year, the lady now she's finished, she said her duty was to him not to me. (int 1)*

Our final interview was cancelled as Carol and Charles had to move out of their council estate as it was being demolished by developers, in turn razing their chances of Charles dying in the place he called home. Consequently, Carol's home keeping as well as networking and vigilant visiting were all relatively unsuccessful, primarily because formal services did not heed her demands. This left her feeling that she was a "*no body*" (int 2).

Discussion

To my knowledge, this chapter is the first time that family members' views and experiences of integrated care have been investigated in the context of their daily lives. I contend that older partners play a fundamental role in integrating their own and their partner's care. They deployed a range of interconnected strategies to integrate care including: home-keeping, networking and vigilant visiting. I conclude that formal care providers play an important role in mediating the success of their attempts at integration. In addition, I demonstrated how feeling integrated and receiving formal support did not necessarily correlate. Older partners had a different interpretation of integrated care from health care providers and policy makers.

What this chapter adds

First, this chapter clarifies the active role that family members play in integrating their partners' care across multiple care contexts. This finding helps to clarify the hitherto ambiguous role that family members occupy in integrative models and has analogies with previous studies about "bridge" people, typically younger English-speaking family members, who connect and support older migrants for whom language barriers impede access to health and social care services (Godoy, 2019; Liu et al., 2017). I add that older people themselves can act as integrators using a wide range of strategies, albeit not always successfully, to engage with health and social care services. This analysis highlights that older family members are key stakeholders who offer a unique hinging role in deciding whether/ when/ and the degree to which their partner's connect with wider services. For this reason I have stayed with the language of "integrator" rather than the other popular term navigator which frames family members as merely operating within the health or social care (Godoy, 2019; Williams et al., 2018). Rather, this analysis highlights the ways in which caring spouses persistently pieced together alliances and information in order to provide good care. Sometimes this involved rejecting formal support such as available respite options and drawing on other supports such as their church community. Thinking about family members as networkers, vigilant visitors and home keepers provide new lens for policy makers and health and social care professionals to conceptualise the contributions that families make to integrating care.

This analysis has highlighted how older partners also have their own legitimate health and social concerns and needs as well. Consequently, I suggest that new integrative initiatives should consider older couples needs in tandem. This was most strongly illustrated where the declining emotional or physical capacity of the "healthier" spouse was the reason for their spouse's care transitions. This finding supports previous research that conceptualises older caregivers as both co-workers and co-patients (Ateş et al., 2018; Grande & Ewing, 2019). Considering couples' needs together could be operationalised by linking older couples files, with their permission, on NHS databases(Dawda, 2019): this would be greatly enhancing by improved data-sharing across health and social care. GP surgeries could also actively offer double appointments to older couples so that each member has time to address their needs. This is a strategy promoted to support identification and support of younger carers (Cook, 2019) and parents with new-born babies (Gilworth, 2020) and appears equally useful for older people. Usefully, joint appointments would facilitate the co-location of integrators (family member and GP) which is a strategy previously identified for good integrated working (Coughlan, 2020). The promotion of the *Jointly* digital application, designed by carers, could also help here by enabling technologically savvy family members to record both their profiles, medications, calendars and notes and share this with members of their wider care network (Carers UK., 2021). This would help harness participants' desire to be actively involved in arranging care.

Training about the technology and potential the provision of smart phones for this older population would be needed to ensure equal access to ensure inequalities are not built in this initiative (Nadeau, 2017).

This paper also stresses the important role service providers play in shaping the success of older partners caregiving attempts and indeed in motivating them in the first place. Participants networked and vigilantly visited in order to protect their partner's dignity and ensure their safety whilst in non-home spaces. They tried to keep care home because it meant they had greater scope and control to manage care. The extent to which they were successful in these practices hinged on supportive and timely communication between themselves and formal care providers. The need to improve health care professional and family communication is well documented (Lowson et al., 2013; Ventura, 2014). I contend that improved communication and relationships between older patients and carers and health and social care professionals must be at the heart of further integrative initiatives. This analysis attests to the benefits when older couples knew their GP, underscoring personalised consultations which empowered couples to make choices about their care. As outlined in the literature on building professional collaborations, these relationships require time and space to develop and is therefore best achieved through continuity with a single GP (Coughlan, 2020; Leutz, 1999). There is evidence that being able to build-up relationships with patients is also in line with GPs' preferences (Abrams, 2020; Miskelly et al., 2020).

This links with the additional finding that it is not enough just to have services in place, but they must also feel caring and supportive, for example by feeling dignifying and responsive. This finding adds to literature that not only do patients, but family members also, have different understandings of integration than policy-makers and health care professionals (World Health Organisation., 2016; Youssef, 2019). I posit that integration has experiential, practical and affective dimensions, as does its related concept of belongingness (Anthias, 2013b). To capture family members' nuanced views and understandings, they could be included through the conceptualisation, implementation and evaluation stages of any new integrative initiatives. Fortunately the opportunity already presents itself as the formation of Integrated Care Systems have been left up to local areas to design appropriate structures and appoint their members (Charles, 2020). Reflecting the range of integrative work conducted by family members, we urge that family caregivers need to be appointed central roles.

Conclusion

This chapter novelly demonstrated how older partners act as care integrators using a wide range of strategies, albeit not always successfully, to engage with health and social care services. I outline some of their strategies as home-keeping, networking and vigilant visiting. This analysis also suggests that feeling integrated and receiving formal support did not necessarily correlate. Older people often had a different interpretation of integrated care from health and social care providers and policy makers. As key members of integration teams already, we contend that family members views and experiences would prove a valuable resource for policy makers and health and social care professionals seeking to design and implement the new Integrated Care Systems.

Chapter summary

This chapter asserts that family caregivers act as integrators of care through a range of practices such as home-keeping, networking and vigilant visiting. This paper therefore presents a more complex picture of service use than is depicted in the systematic review in Chapter 2. Chapter 6 will focus on the ways in which older partners engage with a particular medical technology, the dosette box, in their practice of home-keeping. Chapter 6 will pick up on ideas explored in Chapters 4-5, around how older partners utilise strategies to engage with health and care professionals and systems on their own terms. This final empirical chapter also seeks to connect the caring experiences discussed in Chapters 2, 4-5 into the wider sociological discussions about how people maintain themselves in circumstances that deplete them.

Chapter 6: The dosette box as a technology of the bearable within older spouses end-of-life caregiving practices

Introduction

Berlant contends that the long process of delegating worse life and earlier death to the poor and hyper-exploited has now become a generalised tendency contributing to the process of “Slow Death” across Euro-American societies (Berlant, 2007b). Berlant explores this phenomena through subtler mechanisms located in “zones of ordinariness” whereby certain populations are excluded from the “comforts and protections even of phantasmatic sovereignty” (Berlant, 2010)(np). She traces the way that promises of a good life such as wealth, health and/or heterosexual nuclear families, frequently result in unsustainable processes that wear aspirants out (Berlant, 2011). Nancy Fraser, like Berlant, inculcates globalizing financialized capitalism, both in terms of the economic conditions and the social mores that service it, as producing the harsh circumstances that make the “good life” akin to a “sacrificial model” (Berlant, 2010; Fraser, 2017). Fraser argues specifically that “financialized capitalism’s rapacious subjugation of reproduction to production” has resulted in the state and corporate disinvestment from social welfare meaning that “families are being required to care for children and elders despite their diminished ability to provide it in light of the mounting emotional and economic costs of living and working” (Fraser, 2016) (p. 117).

These economic shifts have also led to the devaluing of activities and people involved in social reproductive work because it sits outside of profit-orientated productive labour; further entrenching the “crisis of care” across the West (Fraser, 2017; McDowell, 2004). Berlant contends that the values that are instead lauded such as rational self-reliance propagate a heavy “weight of individualism” as individuals become solely responsible for their life choices rather than acknowledging how “organisational/structural and representation/ discursive arenas” dramatically shape the contours of their opportunities (Anthias, 2013a; Berlant, 2011). Consequently, Berlant argues that a central concern for critical theorists must be to understand how can people maintain lives in environments that deplete them?

One decidedly modern response to this question has been technology. Technology for the purposes of this enquiry is defined as “a manner of accomplishing a task especially using technical processes, methods or knowledge”(Merriam-Webster, 2021). Technology has widely been configured as a solution to modern ills ranging from social connection to environmental catastrophe (Biehl and

Moran-Thomas, 2009). Scholars inspired by Science and Technology Studies (Rabinow, 2006; Suchman, 2007; Turkle, 2008) and feminist and queer studies (Attwood, 2017) contend that technology can produce new, potentially more satisfying kinds of intimacies, including those with technologies themselves. Likewise, ethnographic research in the tradition of disability studies has shown how medical technologies can help individuals learn about their bodies and conditions and subsequently form collectives to petition for more legal and political rights (Petryna, 2002; Phillips, 2010).

Other scholars have been sceptical about the new promises of technology positing that it likely reinforces pre-existing power structures that further embed exploitation (Latimer, 2018; Schiller, 2019). For example, feminist scholars Hobart and Kneese (2020) contend that new technologies styled as "self-care" devices such as fit-bits and smart phones enable individuals to "maintain productivity in the face of adversity and exhaustion" (p. 4). Yet in doing so they offer "a fresh iteration of the Weberian Protestant work ethic" rather than something actually nurturing or emancipatory (Hobart, 2020)(p. 4). A similar debate is being had around telecare devices which are particularly important in the COVID-19 context whereby social distancing measures require care be provided from afar via electronic consultations (Monaghesh, 2020). Mort and colleagues (2015) argue that while telecare appears to offer greater control and personalisation of care options, in practice sick people are left to provide more care for themselves despite not necessarily being "equipped, trained or physically able to do so" (p. 447).

This chapter takes up this question of technology's capacity to make life more bearable from the vantage of older partners providing end-of-life care. These actors are of considerable sociological interest, occupying an ambivalent status ripe for sociological enquires into identity and the construction of normativity. As a member of an older married couple, they seemingly exemplify the chief ingredients of a "good life" characterised by securing romantic attachment (Berlant, 2007) yet their older bodies, through their association with ill health and dependency, remain culturally devalued (Higgs & Gilleard, 2015; Jones, 2006). Second, older carers very presence is an unintended outcome of biopolitical regimes being so successful at fostering life through public health campaigns, public sanitation initiatives and developments in medical technology that people are now frequently living to advanced ages with an unprecedented degree of care needs (Buch, 2015a). Social support structures have not been able to keep a pace with this growing need resulting in older people themselves providing care for others who are also very old (Morgan et al., 2020). Given that these people are potentially grappling with the "double jeopardy" of caring whilst managing their own poor health (McGhan et al., 2013), the fragility of their situation presents a very real test case in the limits of navigating a good life in spite of physically and emotionally depleting contexts.

In addition, this chapter aims to contribute to the growing scholarly interest about the way technology mediates older people's daily lives and material and social contexts (Buse & Twigg, 2018; Cleeve, 2020; Latimer, 2018; Yatczak, 2018). Enquires have largely focused on "high-fi" technologies such as computerised monitoring machines and robot companions to explore the ambivalent ways technology can be incorporated into care regimes in contexts where human support is limited (Pols & Moser, 2009). Influenced by material culture studies, more research studies have focused on the ways in which "quiet, routine, almost unnoticed" low-fi technologies such as beds, buttons and doors actively mediate the contexts and relationships through which care is "felt and lived" (Buse & Twigg, 2018; Lopez-Gomez, 2020; Maller, 2015; Pink, 2014). In line with a feminist lineage, these studies have also sought to connect private matters of caring with wider institutional regimes that delimit the conditions in which caring occur. For example, Buch (2015b) explored the way that older Chicagoans used doorways to maintain boundaries of their private residence from the broader community and uncaring bureaucratic regimes which threatened their continued personhood and independence. Araujo and colleagues (2019) demonstrated how a diaper could transform from a mere incontinence product into a weapon for a Brazilian mid-life daughter to wield against her mother with dementia who refused to acknowledge her bladder issues, and the doctor who refused to recognize her resources needs. What remains underexplored, however, is the way that older people themselves engage with technology to care for themselves and others (Cleeve, 2020). Beyond the material implications of care, such low-fi technologies also offer an opportunity to consider post-humanist concerns about the kinds of subjectivities and humans that form through their entanglements with technology (Barad, 2007; Baridotti, 2008; Dilkes-Frayne, 2017).

Theoretical lens

This enquiry is shaped by an Actor Network Theory (ANT), which has as its central ontological claim that "all entities in the world are constituted and reconstituted in shifting and hybrid webs of discursive and material relations" (Blok, 2020)(p. xx). ANT, along with other social practice theories contend that, objects, as well as subjects are capable of shaping the conditions of possibility of everyday life and mediating human action (Law, 2002; Maller, 2015). Shove (2017) explains the common point between ANT and Social Practice Theory is the view that "things which are mobilised in practice are not merely 'used'. Rather, such things are implicated in defining the practice itself" (p. 4). Two prominent critiques of ANT theory are that first, the agency of things has been overstated (Schatzki, 2010) and secondly that ANT theory has become static, removing emphasis from the performance of activity, or doing (Shove et al., 2012). For these reasons scholars, including those interested in everyday health practices (Blue et al., 2014; Maller, 2015), have begun adopting Shove's (2012) Social Practice Theory which centres materials, competences, and meanings.

This chapter keeps ANT as its travelling companion for three main reasons. First, I aim to contribute to the new generation of ANT scholarship that strives for a more complicated picture of agency (both of humans and things) and which has embraced performativity (Blok, 2020). For example, Ossandón, drawing on Callon, contends that ANT scholars are precisely in the business of "teach[ing] readers how to relate with their objectives of study in new ways" (Ossandón, 2020, p. 54). Ossandón (2020) contends that ANT thinkers are well placed to reflect on how in the process of producing knowledge, they distribute kinds of agencies in their accounts:

> "Theories distribute agencies, but not only in the sense that they mobilise scripts prefiguring the actions of those whose actions are explained, but as they prefigure the particular characters that will use them" (p. 47).

This helps to reflect on my starting premise, guided by critical gerontology, that very old people are not passive, frail objects of care but capable of agency, resourcefulness and creativity (Wiles, Miskelly, et al., 2019). With an ANT-focus on objects and networks, I then seek to deepen and problematise the account of agency I have explored in the previous two empirical chapters.

This leads me to the second reason for embracing ANT theory which its "adaptability and sensitivity"(Mol, 2010). Mol (2010) contends that ANT theory "helps to to tell cases, draw contrasts, articulate silent layers, turn questions upside down, focus on the unexpected, add to one's sensitivities, propose new terms, and shift stories from one context to another"(p. 262). This is underpinned by ANT's focus of "following" research participants' interests and interactions in order to comprehend actor-networks (Blok, 2020; Latour, 2005). The open-endedness of the approach both in terms of data collection and analysis is its strength. ANT differs from Social Practice Theory which directs analysts to partition findings into a "materials, competencies, and meanings" framework (Shove, 2012). By contrast, ANT exalts in-depth cases and tease out the complications, contradictions and messiness they contain. This aligns with my narrative methodological approach (Riessman, 2008). A final reason for staying with ANT theory is that it places my work in conversation with seminal scholarship about care practices which similarly draw on and enhance this theoretical practice (Mol et al., 2010; Pols et al., 2009).

Having covered why I selected ANT theory, I now explain how I have used it in this chapter. This paper explores three older women's entanglements with a single medical technology: the dosette box, a brand of pill box for organizing daily medications. During these interviews the researcher was sensitized to the importance the dosette box initially as a silent witness to interview where it sat on surfaces such as the living room or dining room table where interviews typically took place. When participants rattled the box and opened its seals its presence became audible. Participants also frequently directed their talk to describing their use of the box as well as its contents, as a means of making tangible aspects of their caring.

Interestingly, the concept of a box is an important heuristic at the centre of ANT enquires. First, Latour playfully contends that ANT as an analytic strategy offers "Pandora's hope", as it strives to open up understandings of scientific knowledge, like other knowledge practices, as a socially constructed discourse and practice (Latour, 1999). Second, drawing on an engineering studies definition, Callon defines a "black box" as a "way of talking of the simplified points that are linked together in an actor-network: a simplified entity that is nevertheless also a network in its own right" (Callon et al., 1986) (p. xvi).

Callon contends that rather than reducing the complexity of knowledge practices, a black box whose operation has been reduced to a few well-defined parameters gives way to a swarm of new actors and meanings; thus offering a detailed opening onto actor-worlds (Callon, 1986) (p. 29). While scholars have since criticised the "black box" method for promoting a technologically deterministic and static view of actor-network relations (Winner, 1993), a new wave of constructionist case studies have focused intently on the social consequences following the introduction of technologies (Pinch, 2012). More research is needed to explain instances when technologies fail to perform as expected (Pinch, 2012).

Findings are presented below in series of narrative case studies, which been described as a "veritable gold mine" for ANT scholars interested in tracing the subtleties that arise through technologies introduction and incorporation (Pinch, 2012)(p. 366). ANT scholars hold that analysts can never know beforehand what the implications of introducing an actant into a network (Callon, 1984;

Latour, 2014). Therefore only through comparing the different versions given by successive informants of the "same network" will analysts have "enough to evaluate the reality of a claim" (Latour, 2014, p. 118).

Aim

I was therefore brought to ask:

- How does the dosette box mediate older partner's experiences of providing daily care for their partner who is approaching their end-of-life?

What is the dosette box, and why is it a thing?

Pillboxes have existed since Ancient Greece, with their word pill, 'Pharmakon', meaning both remedy and poison (Martin, 2006). This janusian logic is reflected also in the idiom of Pandora's box which while seemingly valuable and alluring, once open results in a curse (Hesiod, 1988). The modern pillbox has been contingent on a number of technological developments including the invention of gelatine pill casings 1830s (Morris, 2019) and the development of synthetic plastics at the turn of the 20th century (Bijker, 2012). The demand for these technologies has also been shaped by the growing normative value placed on health in modern societies as a sign and practice of good citizenry (Foucault, 2008).

The Swedish-manufactured dosette box, which this enquiry focuses on, is the most widely used pillbox in Europe (Dosett, 2015) and is endorsed by the NHS (NHS England., 2020a). The stated purpose of the dosette box is to ensure that people remember to take their medication at the correct time and in the prescribed dosage (Dosett, 2015). It is offered as a "tool" for family members and professional carers supporting older people who require daily medications (Helping Hands., 2020). The widespread need for such technology is supported by a 2014 NHS survey that found that almost half of all UK adults are currently take prescription medication daily, with two million pensioners taking seven different prescription drugs per day (NHS England., 2014a). This is reflective of the high rates of multi-morbidity outlined in Chapter 1.

Aesthetically, the form of the dosette follows its function. It consists of a clear plastic tray that organises medicines into separate compartments for different times of the day for each day of the week. Each box contains a week's worth of medication and has clear labels with times and days (Helping Hands., 2020). Unlike medications, the dosette is not automatically free for everyone over 65 (NHS England., 2020a). There have been recent shifts to making the box more generally available with an NHS website offering free boxes to patients who have over four medications (Simple online pharmacy., 2020).

The NHS endorsement of the dosette box is emblematic of broader shifts occurring across the West in the 20th century, with the primary locus of care moving from formal institutions back to the community: patients and their families are now responsible for many orally administered daily medicines, rather than trained health care professionals (De Nooijer, 2020; Heaton, 1999). Foucauldian scholar Janet Heaton locates such changes with the ongoing dissolution of the medical gaze:

> *By operating through more generalised networks of surveillance, such as the family, rather than more structured hierarchies of observation, such as the state, the vicarious authority of the medical gaze has allowed individuals increasingly to become implicated in the monitoring of their own bodies and … as relays of the medical gaze in overseeing the health of those around them (Heaton, 1999)(p. 771).*

Consequently, research published in clinician-orientated journals have focused on whether families are receiving the appropriate amount of support to administer such medication at home (Kripalani et al., 2007; Kwan, 2013; Thomas, 2018). Evidence confirms that older spouses are less likely to receive support when administering medication, underscoring calls to improve their training and support (Joyce et al., 2014). In these discussions the dosette box features as a device for improving medication adherence, though it’s efficacy is unclear (Gillespie, 2015). Through characterising medication provision as a linear process that one can succeed or fail at, less consideration has been made of the alternative interpretations of this process, including the impact it has on the nature of the relationship of those involved.

Such scholarship thus has much to gain from the sociological and anthropological literatures which have explored how modern conceptualisations of both health and personhood are shaped by regular pharmaceutical practices including what is “acceptable” and what is “pathological” (Bundy, 2017; Martin, 2006; Rose, 2001). This paper explores how three older women were entangled with the dosette box and the implications this had on their attempts to make their lives bearable. Participants, referred to here with researcher-selected pseudonyms, are quoted at length in indented paragraphs with the interviewer’s questions presented in bold.

Results

Radhika : "I have also these problems with me"

Radhika, Indian aged 80, used her dosette box to craft her and her husband Rahul's (Indian, aged 84) daily care rituals around optimising health. As a response to the initial interview question "what's it like to look after your spouse?", she slowly rose from her seat on the couch to retrieve the two dosette boxes which sat one atop another on a white bookshelf in the centre of her small council apartment. Delicately opening one morning tab with her gnarled, arthritic fingers, Radhika meticulously explained the symptoms (like memory) or organ (like kidney) to which each of the eight pills in her husband's dosette box related. She notably lingered on the large oval vitamin D tablet which she had acquired from a health store, and subsequently added to both of their boxes to "improve their mood" (int 1).

Following the lengthy explanation of the contents of her husband's dosette box, I tried, perhaps too quickly, to pivot the conservation back to care. Radhika took this opportunity to describe some of the contents of her own dosette box:

> ***Cause I was wondering what are the other ways you care?***
>
> *[Radhika taps the dosette box with her finger]*
>
> ***… oh yeah I've seen that before. So those are your ones?***
>
> *This is my vitamin D and one medicine every Monday I take for my arthritis. Once a week this is the tablet.*
>
> ***Do you find that your arthritis makes it hard to care for him?***
>
> *That is what I'm saying. Because the doctors say "keep yourself active" and that's all. So nothing. But if I get more pain then I apply [raises gel bottle]. I can't fold my fingers also. It used to be like that. Twice or thrice I had an injection. That's why I am keeping myself active doing exercise if I like it or not. And not only once, I have divided into four times. Immediately before getting up I do some exercises lying down only.*
>
> ***It sounds like you are really taking doctors' orders.***
>
> *Yes I have taken them as part of my life [laughs](int 1)*

With the box in hand, Radhika asserted the importance of her own self-care as fundamental to being able to sustain Rahul’s care. Her dosette box worked as her accomplice allowing her to follow doctor’s orders. She also linked her medical regime to her wider aspirations of keeping active, acknowledging health discourses endorsing the personal responsibility of active ageing (Stenner, 2011). While committed to the principle and its authority, Radhika found it increasingly difficult in practice to remain active due to her arthritis and declining hearing and Rahul's declining memory and worsening asthma meant that they were currently housebound.

Nevertheless the constant demands of caring remained ever-present, coalescing around the dosette box which was the central organiser of their day; highlighting the ways that “technologies help to shape ways of living with disease”(Pols & Moser, 2009, p. 161). She timetabled each activity on a whiteboard she referred to as “his chart” propped up on the dining room table which divided into hour time slots from 5 am-8 pm, with medication time appearing thrice. Such timing was then reflected again on the box itself as it was arranged in a tripartite fashion of morning, lunch and night. The temporality inscribed by the dosette box mediated Radhika’s sense of self most clearly outlined in her response to a question about whether she saw herself as a carer:

> *Definitely mam because I have to start from the going to bed and have to finish. I give him medicine and eye drops and then ask him to do this thing then tell him to go to bed. And in the morning again his medication and all these things. So yes I am his carer, his full day carer. [laughs] (int 1)*

In this way the dosette box as the dispenser of such medication offered a form of what Berlant (2011)has termed “processual absorption and a way of being in the world” (p. 133). Previous anthropological studies have identified ritualised forms of caregiving as key to being able to manage the uncertain demands of caring for bodies with chronic illness (Aulino, 2019, Mattingly, 2014). By contrast, Berlant contends that “habitual modes of being are also techniques of self-annihilation and negation” (Berlant, 2011, p. 113). The later interpretation was particularly applicable for Radhika as she unsuccessfully asserted her own co-patient status with reference to her own dosette box.

Rahul’s cognitive decline made it palpably difficult for him remember anything, including Radhika’s health concerns. Her frustration at her failure boiled over during the second interview where Radhika addressed the following at Rahul who stared at her blanked-eyed without responding:

> ***I was wondering when you said the husband has to look after the wife?***
>
> *I don't, that's what I told him because he always say [mimics husband] "I am old I am sick like that".*
>
> ***What do you say to that?***
>
> *That's what I'm thinking what do you give him in reverse this thing so he should realise I said, "I am also old I have also these things problems with me". (int2)*

This made it increasingly difficult for her to gain her Rahul’s “enrollment” as Michel Callon refers to it, in her interpretation of their dual boxes as mirroring their mutual need (Callon, 1984). The psychological strain of having her traditional ally turn against her forced the realisation that she needed external assistance. She lamented that “in India the ladies don’t take so much of the burden which I have got” because families tend to live intergenerationally. Since her son and daughter-in-law who lived in the same city had busy working lives and chose to live separately, she had to adjust to having a social services funded health care assistant (HCA). The dosette box featured as an actant in this hand-over process, no less because it was an object through which Radhika could clearly teach and judge the quality and timeliness of his care (Andersen, 2019). Rather than having respite, bringing an HCA in resulted in her caring role changing from doing the care to instructing and overseeing it:

> ***He’s good? He’s up to your standard?***
>
> *So now he knows how many tablets have to be given what time … and now he does the bed then making breakfast and then doing the utensils which are tea and breakfast utensils. And so one hour passes like that his medication and…*
>
> ***You do you find that helps you?***
>
> *It helps me. Get in because he does everything what type of things I want I always get at him “this is not the way to do this” so he has become perfect now huh. (int 2)*

The dosette box thus perforated all aspects of caregiving situation, making it bearable whilst also enshrining a level of daily care that in the process was wearing Radhika out.

Helen: "I press the button"

For Helen, white British aged 80, the dosette box gave the semblance of control and empowerment in an otherwise tumultuous caregiving narrative that had spanned over twenty-five years in which crisis had become ordinary (Berlant, 2011). Despite "hav[ing] to be attentive all the time" to her husband Barry's (white British, 84) care needs resulting from his end-stage Vascular Dementia, Chronic Obstructive Pulmonary Disease (COPD) and Heart Failure, Helen found it difficult to talk about the subject. In an interview otherwise full of strained silences which were filled by her mid-life daughter who also participated in the interview, it was the dosette box that finally got Helen talking:

> ***I: Are you in charge of medication?***
>
> *Helen: I do, yes. After he came out of hospital there were heart pills, new ones, and I was going, [argh] I can't cope. There was so many to arrange and I was frightened I wouldn't get the right ones. I just happened to go in the chemist one day and I said "do you ever do things like a dosette box that I can have a monthly box", and they did. It's made a tremendous difference.*
>
> *Daughter: They're amazing.*
>
> *Helen: I put them out for him. I press the button and press the thing out for him, but at least I haven't got to count out 12 or 15 tablets every morning, again at lunchtime and in the evening (int 1).*

By framing herself as the person who had the idea to get one in the first place, as well as being the person who would subsequently "press the button" Helen presented herself as a "knowing subject" enacting her agency in a "transformative and transcendent sense" to improve her situation (Berlant, 2011, p. 136). Berlant contends that people often "misrecognise" the degree of their agency when engaging in strategies, for example sex or compulsive eating, designed to alleviate or at least side-step the pressures of contemporary life (Berlant, 2011, p. 122). ANT thinkers suggest human actors always navigate their agency in relation to technology as well as other non-human actants rather than independently (Law, 2002a). Armed with this insight it is interesting to consider the ways that the dosette box also choose Helen.

The box was required in the first place in resolve the problem of how Helen could continue to manage Barry's complex medical regime despite his unwillingness to adhere to doctor's orders. Helen explained that caring under these circumstances made her feel she could *"run, scream, cry"(*int 1). Above she explains her immediate relief at having brought the box home as it instantly became her ally by containing, locking and hiding medication from Barry's reach and helping to share the load of policing his dangerous attempts at self-care:

> *Helen: Yes, but he did take the wrong ones. That's why I hide them now because he did once take them when I wasn't at home because he wanted to go to bed to get to sleep. He'd obviously got very anxious. Now I hide them. I don't want that to happen. He takes headache pills. I've stopped that now. A day I put out if he wants eight because he was taking the full ten that I would put out because of his headaches. (int 1)*

The materiality affordances of the dosette, including the process of counting, placing, checking, administering, resulted in Helen developing a form of "tactical knowledge" (Pink, 2014) which she used to cultivate her feelings of control. This helps to explain why her attachment to the box, like Radhika, was orientated towards the process engendered by the box rather than the object per se; (Berlant, 2011)(p. 136). While the box contributed to successful medical compliance it did not remove the pre-existing tensions that were arguably more pronounced because of the changing hierarchies within their relationship:

> *Helen: Today he said again "you're taking over my life. I'm able to decide what I want you're trying to rule me". I said "I'm not. I'm trying to prevent you from having pneumonia again. That's why you've got the thickener in your drinks. It's a silent killer they told me, you know so therefore". (int 1)*

She explained that this led to deeply conflicted feelings about her husband whilst shoring up her belief that through her coalition with the dosette box Helen had cultivated an infinal "holding environment" within the home keeping him alive (Berlant, 2011, p. 146):

> *Helen: When I get my bad moments when it is like that I say "don't drink then". I know I shouldn't but every now and again I think if you don't drink you'll get pneumonia. Then he will say "perhaps that will be a good idea then. I don't want to live."*
>
> ***I:How does it make you feel when he talks about death and dying?***
>
> *I just think perhaps that will be the easiest way out. [laughs] I've done my best. It's been ongoing for so long. Alright just please yourself and if that's what happens, that's what happens. It's hard. [sigh] (int 1)*

The authority and knowledge gained through using the dosette box gave Helen the means and courage to monitor her husband's General Practitioner (G.P.). Helen felt they were "at the end of the line" with their current G.P. because he had done little recently to review medications and vary the contents of the dosette box. Helen felt the G.P. was thus not as committed as he ought to be to bettering her husband's health or at least improving his behaviour to make caring for his care less "obviously demanding [laughs]" (int 1). Thus while caring left Helen "shattered", with assistance from the dosette box she was able to fulfil normative expectations to care for her spouse, whilst attaining some sense of control over her constant state of crisis.

Joan: "There's a slip between cup and lip"

Joan (73, white British) referred to herself as a "very can-do woman" caring for her second husband, Richard (79, white British) for the last nine years as he had developed Parkinson's and end-stage Lewy body dementia. Having just returned home from hospital herself after having collapsed due to exhaustion, Joan surprisingly orientated her second interview around a range of issues involving Richard's medication:

> ***I:So it's about the right medication?***
>
> *R:Yep I'm lucky I've got a very good chemist up the road. But there's lots of little what shall I say we've got an old English saying "there's often a slip between cup and lip" which is just an old one. But my G.P. had phoned me and said she needed to have a talk to me and I must have it must have been when the painters were here and I missed the call and they didn't bother to call back. And this time when I went up to get his dosette boxes the chemist said to me "Joan" he said "I'm a little bit worried because they've moved two of the tablets from his*

> *morning one and a night time one" and I said "what are they" and he told me and I said "well I don't understand" and he said "this is the prescription that he was working from and it just said Rivastigmine cancelled". (int 2)*

Here the box was an actant in the care chain connecting herself with the actions and thoughts of her chemist, G.P. and the supplier of Richard's dosette box. As the passage above attests, all actants in the network took up-keep. The dosette box needed checking for errors, the pharmacist requires sweet-talking, Joan and GP had to be readily available at the end of the phone.

Joan emphasises that the reason for these fragile relations were a product of the wider healthcare system which epitomised through the old British idiom "*there's often a slip between cup and lip"*. While the NHS was ostensibly committed to principles of universal healthcare, Joan highlighted that the layers of bureaucracy and lack of integration resulted in poor care in practice. As such the dosette box was a bodyguard against health care professionals potential mishaps:

> *So you can imagine if I hadn't had a… because when you see that like that [shakes dosette box] you know I only count the number I know there's two in there two in there five in there five in there but there must be people who are living on their own.*
>
> ***Yeah who aren't maybe…***
>
> *Who just open it or the carer opens it and just takes the tablets you know, as you say if you're not on the ball really all the time it can be very hit and miss. (int 2)*

The importance of always being "on the ball" attests to the vital stakes involved in acquiring "tactical knowledge". Such knowledge was challenged when her husband's care entered the hospital. Framing herself in the "educated consensus" Joan continued that it was widely known that being in hospital was dangerous for people with Parkinson's, a piece of knowledge shored up by her experiences of hospital doctors throwing away Richard's dosette box upon entering hospital:

> ***Do you find when he is in hospital do you have to give him some of his tablets?***
>
> *They won't let me, they won't even… it's very strange. This is what I get now which saves me hours of time. [Rattles dosette box.] Because he's on as you can see a lot of tablets but when he goes into hospital I take this with me but they won't let him use them because they're not in their sealed packets. (int 2)*

Joan interpreted this as a sign of displacement of her position in the care hierarchy; shifting from "conductor to second fiddle" (Lowson, 2013). She found this particularly affronting because at home the same box signalled her place at the top of the care hierarchy above her HCA who she monitored in a similar way to Radhika, and at least on par with her local pharmacist. This enshrined the importance of keeping care at home which with the support of her dosette box she felt this was something she very much could do.

Discussion

This chapter adds rich empirical evidence to questions raised by critical theorists as to the ways that people maintain lives amidst the environments of late-stage capitalism that deplete them (Berlant, 2011; Fraser, 2016). It makes an important contribution to understanding how people attempt to use low-fit technologies to foster a sense of agency and control amidst their uncertain contexts (Cleeve, 2020; Latimer, 2018; Maller, 2015). First, the dosette box made everyday life bearable by allying with older caregiving spouses in their attempts to independently and creatively incorporate medical compliance as a durable feature of their daily care routines and relationships. Second, the dosette box, as a teacher, fostered a form of "tactical knowledge" (Pink, 2014) as it demanded pressing, placing, counting, and monitoring, which they could then use to cultivate their sense of self-efficacy and expertise for their partner's care. As such the dosette box played a fundamental, agentic role in keeping care home rather than conventional understandings of it as a mere tool (Helping Hands., 2020).

Nevertheless, just as the pillbox from its inception has had an ambivalent status, so too did the dosette box. Whilst improving these womens' handle on their responsibilities and their husbands, the dosette box demanded an even higher level of regular, vital care of them. This finding aligns with an ANT perspective that the while "effective exercise of choice requires the support of science and technology" it often "simultaneously contribute[s] to the creation of constraints on action"(Callon, 1986). I contend that the dosette box shares the ambivalent status of more high-fi technologies such as fit bits and smart phones, which at once promise control over oneself but result in doing more health-orientated work in the service of the wider biopolitical regime (Hobart, 2020). Indeed, the analysis presented here aligns with Maggie Mort and colleagues (2015) observations that the introduction of telecare services in the home indicates that older people are capable of managing themselves and therefore need no additional or proactive formal support; thus entrenching a greater degree of self-care. The dosette box is therefore an artefact of the subtle processes of exclusion operating at the heart of late-capitalism whereby people are displaced from agency over their lives and yet still expected to bear the "weight of responsibility" for all their choices as well as those of close family members (Berlant, 2010)(np).

Hierarchies produced through the introduction of the dosette box similarly trouble the agency afforded by the dosette box. This analysis presents instances where patients tried and failed use the dosette box to assert their own subjectivity, either as a co-patient in the case of Radhika in relation to her husband or as a co-worker in Joan's case qua hospital doctors. My analysis here contributes to calls the ANT scholarship to be more attentive to social consequences of "failures" of "enrolment" and "incorporation"(Pinch, 2012). While the perils have been well-documented when it comes to negotiations between scientists and the people and things they study, we add that enrolment may occur even amongst natural allies such as spouses (Callon, 1984). Such failure may be due to historically imbalanced patriarchal family compositions, observed in the first two examples, but also due to issues of cognitive decline which changes the ways people engage with fellow subjects and objects; a topic ripe for future research (Schillmeier, 2019). The consequence of this was that care-providing partner's bodies were instrumentalised as yet another object mediating care practices, highlighting the deep entanglement of individuals not only with technology, but as technology too (Barad, 2007).

A second way in which the dosette box was used to make circumstances seemingly more bearable was by reversing the "medical gaze" back onto the medical establishment (Biehl & Moran-Thomas, 2009; Heaton, 1999). This presents a useful contribution to sociology of health as it complicates the narrative that the shift of care from institutions to the community across the 20th century has resulted in the devolved medical gaze which has made patient's lives and homes totally visible to the medical profession (Foucault, 2006; Heaton, 1999). I contend that the dosette box, owing to its clear plasticity, made the operations of medical power partially transparent also. The older women in this analysis attempted to "work the system... to their minimum disadvantage" by monitoring the medical management of doctors, health care assistants and pharmacists (Scott, 1985). The dosette box also served as a barometer of medical professionals' commitment to improving these older couples' circumstances, further indicating alternating views on interpretation about their partner's end-of-life status. In this way we argue that the box operated as a "weapon of the weak" which John Scott (1985) has described as "ordinary", "piecemeal" and "low-profile" techniques used by relatively powerless groups" to improve their everyday lot (p. xvi). This insight builds on the body of social theory exploring the ways patients and their relatives have sought to subvert pre-established avenues of power in order to make medical professions see and listen to them so as to improve their situation (Araujo, 2019; Farge & Foucault, 2012; Petryna, 2002). The crux of older women's power was the regime's reliance on their ability and willingness to provide home care so as to keep their husbands out of costly institutional care; one of the key pillars of neo-liberal health care (Fraser, 2017). Officials were therefore inclined to heed some of their requests about increased medical and social support (Farge & Foucault, 2012).

Rather than linking their claims to the collective struggle of say "carer's rights", as has previously been observed amongst disability activists (Phillips, 2010, Petryna, 2002), these older spouses typically used this information to petition for better care for their partner on a personal level. This reflects Scott's assertion belief that most forms of struggle from the subordinate classes "stop well short of collective defiance" given the danger and emotional energy required with large-scale protest movements (Scott, 1985)(p. Xvi). Hobart and Kneese (2020) make this point even more succinctly: "things like chronic illness are incompatible with capitalist productivity and even visible forms of activism: it is difficult to join street protests if you are a caretaker" (p. 4). The dosette box therefore offers older people the ability to maintain their own and partner's lives, nonetheless the material restrictions of caring and the sheer time it takes makes it difficult to collectively challenge the environments that deplete them. Further research is required around what other technologies, such as social media forums, could help foster wider solidarity amongst people involved in caring.

This point links with the wider implications of "technologies of the bearable" in circumstances beyond caring. This concept has analogies with Rosi Baridotti's discussion about "thresholds of sustainability" (p. 211) which occurs at the material and/or discursive limits of life itself and are full of potential for generative change and transformation (Baridotti, 2008). Baridotti contends that pain is often a part of change and transformation and therefore we need to consider ethical sustainability for those on the front lines (Baridotti, 2008). "Technologies of the bearable" can be seen as things and objects that people are entangled with, not necessarily consciously, which help to produce and/or maintain these "thresholds of sustainability". On this view, "technologies of the bearable" promise a material-based analytic approach useful to environmental and anti-racism activism which like care activists, seeks to challenge the wider "sacrificial model" of late-stage capitalism (Berlant, 2010).

Conclusion

This chapter contributes to the growing body of sociological scholarship focusing on the way people utilise technology to make their everyday lives bearable amidst structural changes making the good life – and by association a good death – increasingly unattainable. It demonstrated how the dosette box both helped partners control their situations whilst also resulting in their shouldering of more caring responsibilities. Consequently, while I assert that the dosette box be viewed as a “weapon of the weak”, it is best conceived of as a double-edged sword. I conclude by considering how “technologies of the bearable” may have wider application beyond caring.

Chapter Summary

Chapter 6 homed in on participants’ use of one medical technology, the dosette box, in order to provide theoretical insights into daily end-of-life caring. This chapter therefore offers a useful contribution to a literature in need of sociological and anthropological engagement, as outlined in Chapter 2. Chapter 6 also presents a material-based analysis which adds another dimension to the discursive analysis offered in Chapter 4 around “carering”. In the final chapter I consider what these theoretical insights have for recommendations for policy and practice. I offer Chapter 7 as a way of thinking about how we (policymakers, researchers, practitioners) can advance older partners attempts to make their end-of-life caring not merely bearable but also a situation where they may flourish.

Chapter 7: Conclusions

> *"It is a matter of recognizing that dependency fundamentally defines us: it is something I never quite outgrow, no matter how old and how individuated I may seem. And it isn't that you and I are the same: rather, it is that we invariably lean towards and on each other, and it is impossible to think about either of us without the other." (Butler, 2014)(p. 33)*
>
> *"I don't think anyone understands how little care we really do get." (Mary)*
>
> *"We're fine, the sun's shining isn't it here? You're alright love." (Betty to John)*

Concluding remarks

This thesis set out to explore the experiences of oldest-old partners providing end-of-life care. Research in this area is important and timely because internationally populations are rapidly ageing, and health and social care sectors both in the UK and internationally are not currently set up to respond to the particular needs of this age group (Oliver, 2014; Pollock, 2018). This thesis presents new insights into:

- The state of the field of knowledge about oldest-old family caregiving, including important gaps
- Problematizing older partners' engagement with the carer identity
- Older partners' attempts to integrate their own and their partner's care
- How older partners manage daily medications

In this concluding chapter, I will provide a brief overview of the key contributions made in Chapters 2, 4-6. I will then consider over-lapping insights cutting across chapters. I will then present implication for future policy and practice. Finally, I will discuss the strengthens and limitations of the study and directions for future research. In the epilogue I will return to reflexively considering my place in creating this research.

Key contributions of each chapter

Chapter 2: Systematic review of oldest-old spouses experiences providing end-of-life care

Chapter 2 presents a mixed-method systematic review of the experiences of oldest-old caregivers whose partners are approaching end-of-life. This identified a small, yet medium-quality evidence base comprising 19 studies. The most significant finding of this paper was the upsurge of research in this area, with 10 of the included studies published in recent years. This attests to the growing interest in the academic community of putting oldest-old spousal caregivers on the policy agenda. The first theme identified in review, the embodied impact of care, was perhaps the least surprising given that poor health outcomes amongst carer populations is already well-documented (Braun et al., 2007; Pinquart & Sörensen, 2003). Studies in this review evidenced that oldest-old partners were often already in poor health whilst caring. Three longitudinal, quantitative studies also associated caring with increased frailty both during and post-bereavement (Dassel, 2016; Potier, Degryse, Aubouy, et al., 2018; Potier, Degryse, Bihin, et al., 2018). More research is required to ascertain whether caring increases rates of mortality within this age group given the conflicting findings presented in this review (Dassel, 2017; Sampson et al., 2016). In line with the positive turn in caregiving studies, I contend that further research is required considers how caregiving could be life-sustaining (Roth et al., 2015).

The second theme identified the multiple ways caregiving spouses conceptualised their caring, both in relation to their partner's condition and expectations about gender and place. The review indicates that end-of-life caring is more complex that "something you do" because of being married (Turner et al., 2016). Again specific to this age group the widespread prevalence of dementia caring played an important role in partners taking on new roles such as protector of their spouse's dignity and personhood as well as contributing to feelings of loss associated with declining communication and sexual intimacy. These findings suggest we have far more to learn about how this group's advanced age, gender and other aspects of identity characteristics intersect to shape their caregiving experience. I also identified a need to clarify whether the term "carer" is an appropriate label for this age group as few studies explicitly addressed this.

The third theme, learning to care, involved skills acquisition and developing coping strategies to continue to provide care. This was perhaps the most unexpected finding as it challenges assumptions that family members already know and are able to provide care by virtue of being in a relationship with the person approaching their end-of-life. Studies addressing this theme also highlighted the vast amount of energy and skill end-of-life care involved such as navigating multiple care systems and dealing with a variety of health care professionals inside and outside of the home. Of concern was the finding of included studies that oldest-old spouses provided much of this care with little informal or formal support, an equity issue also raised in UK policy (Dixon et al., 2015). I suggest that more evidence is needed to understand reasons for limited support as well as a deeper understanding of the processes through which older partners learn to care. Ultimately, this systematic review depicted a nascent research field with a range of future lines of enquiry which could benefit from theoretically informed research.

Chapter 4: Problematising carer identification

Chapter 4, the first empirical chapter, explored the way partners actively engaged or disengaged with the carer identity. The first key contribution was to introduce "carering" as a way of conceptualising carer identification as a discursive practice. Through interacting with carer organisations and health and social care care professionals, participants encountered broader carers' discourses and imperatives to self-identify as carers. However, my analysis demonstrated that these discourses were only embodied when participants felt that the qualities assigned to being a carer, such as experiencing social isolation and providing 24/7 care, reflected their own personal experience. By emphasising the external and internal aspects of carer identification, this chapter presents a contribution to theorising carer identification, bringing it more in line with contemporary sociological thinking about identity (Hall, 2000).

A second related contribution is to emphasise the importance of reciprocity and the relationality in the construction of the carer identity: something that continues to be over-looked in carer self-identification approaches focused on the individual (NHS England., 2016b). A novel example provided in this thesis is where older husbands' fears of compromising their wives' femininity and position in the domestic setting shaped whether and when they engaged as carers. This adds to previous findings that older men engage in caring as a way to reciprocate care received by their wife across their life-course (Milne, 2003; Russell, 2001). I add that older mens' minimisation of their caring identity, at least in front of their wife, was part of demonstrating reciprocity.

A third contribution was identifying older partners who partially or consistently disengaged from carering. This aligns with recent studies questioning whether carer self-identification strategies are the best way to identify and support all people in caring roles (Beatie, 2021; Henderson, 2001). I posit that the disengagement with the carer identity observed amongst some of my participants was related to a wider protective strategy of self-and-partner preservation. This supports the need to pursue alternative strategies of identifying and supporting older partners engaged in care, which I explore in the recommendations section below.

Chapter 5: What role do family caregivers play in integrating care?

Chapter 5 explored the way partners play an active role in determining when, and in what capacity, their partner is linked into health and social care services through strategies such as home-keeping, vigilant visiting and networking. Importantly, I highlighted how participants were also potential or current recipients of their own integrative care due to their own health or social issues. This supports previous research that conceptualises older caregivers as both co-workers and co-patients (Ateş et al., 2018; Grande & Ewing, 2019) and suggests that older partners may be both "hidden patients" and also "hidden integrators" (Aoun, 2005; Hoerger & Cullen, 2017). This helps to clarify the hitherto ambiguous role that family members occupy in integrative models (National Voices., 2013; vanderEerden, 2014). This is particularly timely with the emergence of Integrated Care Systems across the UK which are specifically aimed at facilitating integrated care across the health and social sectors (NHS England, 2019).

Second, this chapter offers a useful extension to the burgeoning literature on care navigation by highlighting how older partners engaged in a range of activities prior to admission into formal care settings (Godoy, 2019; Liu et al., 2017). I also add that when their partner was admitted into a hospital or care home, participants appealed to their own strategies rather than passively navigating pre-existing systems or merely learning about official information and processes as the term navigation implies. Evelyn's strategy of crying as a means of attracting health care professionals' attention, demanding immediate care, serves as a poignant example. Consequently, this analysis stays with the term "integrator" as a way of reconceptualising the active and complex roles older people play whilst providing end-of-life care for their partners. This has implications for the status of older partners both in relation to health and social care professionals and in terms of service design which is explored in the recommendations section.

Chapter 6: The dosette box as a technology of the bearable

Chapter 6 focuses on the ways the dosette box made participants' daily caregiving bearable, thus offering an interesting answer to Lauren Berlant's sociological question: how can people maintain lives in environments that deplete them? Older partners treated the dosette box as an ally in their attempts to creatively incorporate medical compliance as a durable feature of their daily care routines and relationships. The dosette box fostered a form of "tactical knowledge" (Pink, 2014) as it demanded pressing, placing, counting, and monitoring. Through this process, participants cultivated their sense of self-efficacy and expertise for their partner's care. This finding adds useful theoretically-informed insight into how family members come to "learn to care" which is currently missing in the extant literature (Morgan et al., 2020).

Second, this chapter contributes to understanding about how people interact with low-fi technologies to foster a sense of agency and control whilst caring for others (Cleeve, 2020; Latimer, 2018; Maller, 2015). Whilst promising a handle on their caring, the dosette box also demanded an even higher level of regular, vital care from older partners which is similar to other health-related technologies such as fit-bits and telecare (Hobart, 2020; Mort, 2015). My unique contribution is to emphasis the relationality of these health-related technologies: not only were they used to by one partner to cultivate their own health so as to keep caring for their partner, they also used these technologies to work on their partner's health. An additional insight here is that under current power structures which require people in the least privileged position to provide social reproductive work to support the wider biological order (Fraser, 2017), technologies of the bearable are likely to always comprise some sense of alleviation and restriction. Social theorists such as Foucault and Baridotti contend that the limits imposed by power structures are not necessarily an anathema to freedom, as limits are always conditions of possibilities (Baridotti, 2008; Simons, 2001). I observed that the balance of power was sometimes weighted too heavily towards caring partners being controlled by the circumstances of caring and the associated technologies, contributing to their physical depletion. Further research should consider how technologies can be used to strike a more bearable caring balance.

Attending to the dosette box clarifies how agency relating to caring is always entangled with other people and technologies. This finding challenges the Descartian notion of rational, individual decision-makers which feminist scholars have long been sceptical (Berlant, 2011; Butler, 2014) yet something that has only recently been deconstructed in the end-of-life care research (Borgstrom & Walter, 2015). This serves as an important reminder that end-of-life care models endorsing personalised care have the potential to place too much weight on individual decision-making at end-of-life (Borgstrom & Walter, 2015).

A third contribution of this chapter is to demonstrate how participants colluded with the dosette box to reverse the "medical gaze" back onto the medical establishment whilst pursing better care for themselves and their partner. Working with the dosette box, participants were able to closely monitor the professionals' actions and intentions, in a reversal of these professionals' focus on patient and family understanding and acceptance of a terminal condition, as expressed in Advanced Care Planning. This has parallels with the practice of "vigilant visiting" introduced in Chapter 4 which was a strategy deployed to watch over the quality of care provided by hospital and care home staff. Through these examples, I contend that the medical gaze affords some power to patients and families too, thus troubling the more standard narrative the devolved medical gaze merely opens up patients' lives and homes to the medical profession (Foucault, 2006; Heaton, 1999). More research about the uses of medical technologies as "weapons of the weak" would be useful to continue the problematising of the circulation of biopower in contemporary society (Scott, 1985). Finally, I assert that "technologies of the bearable" may have wider application beyond caring in old age to more generalised crises of care concerning how we care for others (including those of different ethnicities and abilities) and our environment (Fraser, 2016).

The Fourth Age as "decline, frailty and dependence"?

Taken together this thesis marks a contribution to re-imaging the fourth age, by presenting a far more complex picture of these older couples' daily lives than merely comprising "decline, frailty and dependency" (Gilleard & Higgs, 2010). As the above chapters have documented, older partners were actively engaged with a range of practical and identity-related tasks associated with their partners' care. Frailties and decline were of course present, and the fluctuating capacities of both members of the couple provided the context for caring. Nevertheless, where this analysis departs from Higgs and Gilleard's conceptualization of the fourth age is through asserting that participants managed such frailties and decline resourcefully through seeking help, demanding attention or modifying expectations. I did not meet any couple who were passively waiting out the end-of-life process. This builds on more recent critical gerontological utilizing "resilience" and "capability" frameworks which draws attention to the range of strategies older people use to grapple with physical or cognitive limitations whilst striving for a good life (Lloyd et al., 2016; Nicholson, 2012; Wiles, Miskelly, et al., 2019).

My findings align with Etkind and colleagues' (2019) work with older patients approaching end-of-life which emphasized how they were always striving for an "achievable normal" in relation to their understandings of a “good life” and their available socio-material resources. My participants here were also involved in various process of “normalisation” which Williams (2000) has explains as a form of:

> bracketing off the impact of illness, so that its effects on the person’s self-identity remain relatively slight, or of treating the illness or treatment regimen as ‘normal’ in order to incorporate it more fully into the person’s identity and public self (p. 44).

The clearest example of this is John and Betty’s disengagement from carering but it was also more subtly present in Radhika’s account where she had taken “doctor’s orders” as part of her “life”. That “normal” was particular to each couple explains the diversity captured through this analysis in terms of the range of engagement with the carer identity, the varied extent and nature of integrative work and different uses of the dosette box. As such, this thesis ultimately resists presenting one version of oldest-old caregiving, something that has important implications for policy and practice.

While partners persistently encountered “dependency” it did not take a passive form but one that involved mutual “lean[ing]”, in Butler’s phrase. This attests to Butler’s wider reflection that no one outgrows our fundamental relationality as human beings. My findings support insights from the feminist ethic of care scholarship and specifically with Kittay’s notion of “nested dependencies” (Kittay, 2011; Tronto, 1993). Earlier studies applying the feminist ethic of care largely promote a “healthy” care provider and an unhealthy and disabled dependent, thus sustaining ideas of the mid-life, able-bodied person as the archetypical carer (Chattoo, 2008; Kittay, 2011; Lawton, 2000). My contribution here is to explore cases of mutual vulnerability and co-dependent health concerns. Participants caring was embedded in relation to their wider martial histories and emotional dynamics between partners. Attesting to the reciprocal and relational caring amongst this age group, I observed that sick spouses also contributed to this process either explicitly by stating their preferences as did Rita and Betty. Spouses who were non-verbal, such as Dolores, still played an important role through their physical presence and their partner’s perceptions of their needs and identity. This explains why Charles would not call his “intelligent lady” a caree in her presence. These findings hint at the active roles that cognitively-impaired spouses can play in their own care, which a few studies have also begun to address (Atta-Konadu, 2011; Hellstrom, 2015). The material rather than discursive quality of ANT theory seems particularly useful to capturing non-verbal individual’s contributions to a broad range of human activity, but especially caring. Prominent for this age group was the need to “stay well” to keep caring for their partner. This “will to health” has been acknowledged in previous research around family practices (Fullaghar, 2009), yet it seems even more concrete in the end-of-life context where individuals are dealing with their own health and care issues and needs. For oldest-old couples *health* was neither abstract nor long-term goal, but rather an immediate, functional requirement of keeping care at home.

Recommendations for practice and policy

I began this conclusion with Mary's reflection that she feels that most people are unaware of "how little care we get". Such sentiments were shared by Carol who felt "abandoned" by services who were only interested in her husband rather than her own limited mobility and feelings of isolation. Not everyone of course shared these feelings, with Betty and John emphasizing their self-sufficiency: indeed, Donald felt he was being offered more formal support than he felt he needed. Acknowledging the variety of oldest-old carers then, I conclude with four recommendations for policy and practice which have threaded across the chapters. The governing principle of these recommendations is to support what older partners can do whilst also recognising serious concerns of unmet care and support needs.

Think couple not carer

A strong theme across all chapters is the need, to in the words of Forbat (2009), to "think couple" when designing support strategies for older partners. This is because older partners also have their own legitimate health and social concerns and needs. This point was most strongly illustrated where the declining emotional or physical capacity of the "healthier" spouse was the reason for their partner's care transitions. "Thinking couple" aligns with the shift to thinking about relationship-based care which is receiving increasing attention in chronic care and palliative care models (Ateş et al., 2018; Larkin et al., 2018; McCarthy, 2020; Wadham, 2016b). This approach is theoretically underpinned by Butler's idea that the person indelibly rests on a wider relational context to greater to lesser degrees meaning that no one is truly an individual separate from others. While this approach appears on the surface as a challenge to "personalized care" models by shifting the unit of care from an individual to a couple, on closer inspection it actually closely aligns with existing policy (National Palliative and End of Life Care Partnership., 2015). The "House of Care" model underpinning end-of-life care best-practice places families, health care professionals and patients as interconnected (National Palliative and End of Life Care Partnership., 2015). "Thinking couple" takes seriously this interconnection, emphasizing that the individual views and preferences of very old couples at end-of-life cannot be separated out. Moreover, thinking couple chimes with the commitment to “holistic assessments” and “holistic support”, which already features in palliative care policy. For example, NICE end-of-life care guidance (2017) outlines that:

> *Service providers ensure that systems are in place to offer families and carers of people approaching the end-of-life comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.*

Thinking couple also presents an alternative identification strategy to access people involved in hands-on caring yet disengaged from the carer identity. Keeping with the terminology of couple has the added benefit of being language all participants comfortably use to describe themselves. Therefore introducing it into an academic and policy context therefore conveniently avoids reinscribing an “analyst’s account” of the situation (as discussion in Chapter 2 in relation to the term “carer”) (Adams, 2002). For this reason I myself moved away from using the term “dyad” increasingly used in dementia research(Coeling, 2004; Ryan & McKeown, 2018) between conducting my systematic review and analysing my empirical work. Staying with the couple also usefully bridges concerns between feminist and disability scholars about the hierarchies of power generated through such labelling of carer and cared-for (Rummery, 2012).

Thinking couple practically

Operationalising the older couple as the unit of care could be achieved through a range of strategies. First, health and social care practitioners could usefully ensure that every time either partner comes into their care system, they are asked about their partner and their own needs (Ewing et al., 2018). This could be achieved by combining the Carers Needs Assessment Tool (CSNAT) with the Service Needs Approach for Patients (SNAP), which are validated tools increasingly being used in clinical practice (Ewing et al., 2013; Gardener et al., 2019). Given the fluctuation of needs and capabilities captured in this analysis, these assessments would need to be revised at intervals through regularly, proactively offered G.P. or nurse appointments (Ewing et al., 2018). My recommendation to think couple is complements recent studies by Ewing and Farquhar, originators of the CSNAT and SNAP tools respectively, which emphasis the need to capture more information about relationships in service provider needs assessments (Ewing et al., 2020; Micklewright & Farquhar, 2020).

Second, thinking couple could be actioned through linking of older couple’s health and social care files with their consent (Dawda, 2019). This would help ensure meeting the couple's needs irrespective of whether one, both, or neither identify as carers. This would be greatly enhancing by improved data-sharing across health and social care. Third, GP surgeries could also actively offer double appointments to older couples so that each member has time to address their needs. This is a strategy promoted to support identification and support of younger carers (Cook, 2019) and parents with new-born babies (Gilworth, 2020), and would be equally relevant for older people. Joint appointments would facilitate the co-location and co-ordination of integrators (family member and GP) which is a strategy previously identified for good integrated working (Coughlan, 2020).

Reflecting the relational nature of caring, it is important to design strategies that promote their “thinking couple” too. The promotion of the *Jointly* digital application, designed by carers, could also help here by enabling family members to record both their profiles, medications, calendars and notes and share this with members of their wider care network (Carers UK., 2021). This would help promote partners’ active documentation of all their integrative work. This approach would also offer guidance to health and social care professionals in the case where the caring partner is unavailable (for example due to acute illness) (Nicolini, 2009). Strategies, either on line or paper-based, that document both partner’s conditions and service involvement would also help to legitimise the needs of the care-providing partner, something that this analysis and previous research indicate needs to happen more (Ewing et al., 2013). Getting older people online more broadly may also open up opportunities for social interaction with other people in caring roles, something that has been found to positively foster solidarity in a Swedish study with mid-life carers (Andreasson, 2017). As discussed in Chapter 4, training and access to technology is likely required for an app-based solution to be successful for this age-group. While online technologies are not going to be for everyone in this age group, evidence attests to the rapid increase in the proportion of older UK adults regularly using such technologies (Centre for Ageing Better., 2020). Moreover, with the increase technological fluency of the “boomer” generation, online solutions may be increasingly useful for future cohorts of the oldest-old.

Think couple openly

An important caveat to this solution is acknowledging that the variability of oldest-old couples. Gopinath and colleagues' (2018) recent review of dementia caregiving concluded that that most studies use the term "couple" in an undifferentiated way. This is corroborated by my systematic review which included only a handful of studies that reported participants poor-quality relationships, with such studies concluding unsurprisingly that relationship strain resulted in poor care outcomes for both members involved. By contrast, my empirical findings presented in Chapters 3-5 depicted a range of complex family situations. I witnessed harmonious unions that typified notions of romantic love (I am reminded of Charles' declaration of being carried out of his home only in a double-coffin with his wife). This analysis also captured discontented relationships, thus challenging a particular kind of harmonious "willing and able" family presented in end-of-life care policy. For Helen marital disharmony was present prior to her husband's palliative diagnosis, whereas Radhika concerns stemmed more directly from her husband's forgetfulness relating to his advancing Vascular Dementia.

Clinicians and policy-makers must be aware of aware of historic power imbalances occurring in some couples, whilst acknowledging that amongst the oldest-old, who are meant to typify "traditional gender values", more equality-focused relationships models were also present. Rather than making assumptions about these couples based on their identity-characteristics, formal care providers need to open up conversations about their relationships and caring arrangements, promoting strategies that strengthen the couples' relationship and communication strategies (Riley, 2018). The finding that some partners want to, as Helen put it, "run, cry, scream" challenges assumptions at the heart of health and social policy that all families are willing and able to provide care (Payne, 2010). By re-designing policy and practice with such awareness, appropriate alternatives for care in the home, such as excellent provision in care homes, could be more proactively and non-judgementally planned for and provided.

Improving communication between formal care providers and older couples

The need to improve formal care providers and family communication is well documented but needs restating given the importance it played in participants' daily experiences of care (Lowson et al., 2013; Ventura, 2014). My analysis attests to the benefits of older couples knowing their GP as it underscored personalised consultation, which empowered couples to make choices about their care. Participants' vigilant visiting was particularly pronounced where they experienced poor communication with formal care staff. Improving communication between formal care providers and older couples will requires time and space to develop and is therefore best achieved through continuity with a single GP and familiar care staff (Coughlan, 2020; Leutz, 1999). It is not enough just to have services in place: they must feel supportive, responsive and dignified (World Health Organisation., 2016; Youssef, 2019) This emphasises the importance of listening to and including older partners' views about care.

Treating family members as care experts

Improving communication might be best achieved through re-positioning carers as "experts". While this is already government policy although evidence presented in this thesis suggests that this has not always translated into practice (HM Government., 2014). I suggest that policymakers and health and social care professionals have much to learn from the tactical knowledge that older partners acquire through their daily provision of care. Working with partners, formal care providers could usefully formulate strategies that centre the physical capacity and medication needs of both members of the couple. While older partners were experts in their partners' hands-on care and symptom history, this does not mean that they necessarily knew all the relevant information or people to contact. This distinction was evidenced in the case of Carol who attempted unsuccessfully to integrate care, since she did not know who to address with her concerns. Consequently, formal care providers could usefully do more to share information about available services whilst also listening to what older partners' feelings and preferences about their care. Valuing family members as care experts also involves including them from the conceptualisation, implementation and evaluation stages of new integrative initiatives. Doing so would already be in line with NHS England directives to include lay people into the development of end-of-life care initiatives:

> *Fundamental to any commissioning plan for end of life care is a local strategy, jointly developed with local people and key partners, clearly setting out your vision for end of life care. (NHS England., 2016a, p. 12).*

The roll-out of Integrated Care Systems presents an opportunity to put these commitments into practice by inviting family members into the planning and implementation processes.

Thinking outside the box for support options

This thesis supports growing calls in the literature to think outside the box when it comes to designing appropriate supports for older people (Grande & Ewing, 2019; Pollock, 2018). This thesis documents a frequent disconnect between older couples' needs and available support options. This likely emanates from carer policies revolving around getting carers back into, or enabling them to retain, employment, which is not relevant for most retired carers (Barnes, 2011; Department of Health and Social Care., 2018). Policies also tend to assume an able-bodied carer able to attend support groups, which again is not appropriate for many oldest-old couples (Grande & Ewing, 2019). Policies also draw heavily on the carer terminology which Chapter 3 has emphasised is not appropriate for all older people involved in caring.

Social prescribing presents a potential strategy to facilitate tailored care for older couples. Social prescribing initiatives are being widely developed in primary care (NHS England., 2020b) and involve primary care staff and local agencies referring people to a link worker or care navigators who focuses on practical and emotional support (NHS England., 2020b). A benefit of link workers/ care navigators is their capacity to support other aspects of care such as medication organisation and transportation, which have featured as important in this analysis, yet older partners may not be able to fit into a standard 10-minute GP appointment. Such initiatives would ensure that older couples always have a designated person they can ring with their queries, ensuring that older people do not end up in Carol's predicament feeling like "no one cares". A successful example of this has been Carer's Network social navigator scheme in London which provides couples aged 80 approaching end-of-life with someone they can always contact about health and social concerns as well as issues with housing, security, and pensions (Carers Network., 2021) As many of the link works/ care navigators that social prescribing rely on are from the voluntary sector, policy-makers need to think about increasing funding to such charities (Petrie, 2018).

Strengths, limitations, future research

The key strength of the empirical study is the longitudinal, narrative nature of the study design. Longitudinal interviews allow action and shared understanding to unfold over the course of time and provide additional context to the caregiving situation, strengthening the quality of insight provided (Chase, 2017). If I had not used a longitudinal study design, I may have never known that John was to receive his own terminal diagnosis two weeks after our first interview. I may never have found out that Mary died. The additional strength of the narrative approach lies in enabling oldest-old people to talk back to the policies and theories that impact them: a fundamental ethical goal of this project.

A weakness of a narrative method was that it predominantly relies on discursive evidence. While I was able to include material aspects into my analysis through observations made in field-notes, I realised that more explicit observational or ethnographic methods would be required to deepen an analysis about the embodied aspects of care. I have attempted to tease out some of the inter-subjectivity and materiality of oldest-old care in Appendix 15 which was written as a commissioned book chapter. I hope to continue this train of enquiry in my postdoctoral work.

While a sample size of 19 participants from 17 couples is large as far as qualitative studies go, it remains a small sample in quantitative terms, thus limiting the generalisability of findings. The strength of this dataset is that it captures a range of end-of-life conditions, included gender variation and included participants from a range of socio-economic positions. A limitation of this data was that all participants except one were white. In addition, two partners with dementia were ethnically Indian and another was Jamaican. This may reflect my cultural limitations as I was restricted to conducting interviews in English. Ideally future research would be conducted with a multi-cultural team who can draw on several community connections and conduct interviews in participants preferred language in order to enhance the diversity of participants.

Another limitation that all participants were in heterosexual marriages, although four participants were in their second marriages, which appeared to involve different power dynamic (in terms of their relationship and in terms of involving step-children in care) which would be worth exploring in future research. Future research needs to specifically include the experience of ethnically and sexually diverse partners in caregiving roles. More research could be conducted with the over 85 group as most of my participants were aged around late-70s or early 80s. Limitations surrounding the over-representation of cognitively-impaired partners and women are discussed in Chapter 3.

Other people in caring roles who may not have put themselves forward for the study are likely those with very heavy caring responsibilities. For example, those whose partners were immanently dying or those caring for someone with behavioural issues that makes receiving guests and/or leaving one's home difficult. Two potential participants ultimately chose not to take part for each of these reasons. Alternative approaches to interviews such as email and/ or phone interviews could potentially help to increase participation.

My analysis highlights the benefit of interviewing couples together to capture their dynamic. Most couples chose to be interviewed together. As participants had to be cognitively-intact to participate, only two couples were both formally considered participants. Twelve cognitively-impaired partners were also present during the interviews though they were excluded from becoming participants because of this ethical requirement. This was a limitation of this study as their presence and voices heavily shaped the interview context. People with dementia that I spoke to had interesting observations to make about their care, their partners and their conditions. Future research should build on strategies used in previous research, such as process consent, to include people with some cognitive impairment in a safe and supported fashion (Atta-Konadu, 2011; Bentley, 2021; Boyle, 2013). My systematic review provides glimpses of such caring partners when they were reported as having been excluded from such studies. Using the longitudinal Cambridge City Cohort over 75 database with 174 couples at the baseline survey, I have begun some research in this area. I compared the functional daily activities of living between couples where both were cognitively-impaired, one partner was and where neither were. Unsurprisingly, cognitively-impaired couples fared worse on almost all measures (Appendix 16). Further research with people who are cognitively-impaired and caring is urgently required.

A strength of this study was including oldest-old peoples' own voices, which are often left out of research. A limitation is that much of the findings presented here are based on relayed conversations with health and social care professionals, without explicitly including their views. Triadic approaches used by Sutherland (2016) and Hoare (2017) present fruitful ways of connecting the experiences of dying people, their family and a health care professional to provide a more contextual, multi-vocal account of care. I suggest that Healthcare Assistants could usefully be included in future research as they provide a large proportion of hands-on palliative care in the home, other than partners (Fryer, 2016). Future research could also think about being less "place" focused but more "people" focused as some of the most profound insights of this study were discerned from listening to participants talk about their movements across care settings. This fits with theories of post-place care particularly prominent in critical geography (Ivanova, 2020).

Another fundamental research question which was outside the remit of this study was understanding why these couples were receiving such limited specialist palliative care services despite at least one member of each couple having a formally diagnosed end-of-life condition. Such a question would benefit from more quantitative mapping in the vein of Sampson's retrospective record review

(2016). Insights from this analysis would indicate that there is no simple explanation such as "ageism" (Higgs and Gilleard provide an interesting discussion about this in the COVID-19 context)(Higgs & Gilleard, 2021). Sometimes participants did not recognise their own needs or willfully overlooked them in order to maintain their interpretation of the situation, exhibited by Betty's consoling remarks included at the beginning of this chapter. Further research could also consider the extent to which oldest-old couples received something that their clinicians would have viewed as palliative care but they did not necessarily interpret as such. This question is particularly pertinent in light of the finding in Chapter 4 that families and patients often have disparate understandings of intergrative measures than clinicians or policy-makers. This also likely reflects the fact that the majority of palliative in the home is not provided by specialists, but rather by GPs, Community Nurses and HCAs.

Another important piece of the puzzle deserving further research is instances where the carer dies first. While I know what happened in the following six-months to Paul after Mary's death, it is not my story to tell in the context of this thesis. Given the strong empirical evidence about the physical and cognitive toll end-of-life caregiving places on family members, it is essential that this is further explored so that such eventualities can be planned for on a couple, wider family and structural basis. Future studies addressing this issue could usefully involve record reviews, be prospective, or be secondary analysis of data already collected through some of the longitudinal ageing cohort studies, such as the Cambridge City Cohort over-75 study. Further research is needed to clarify whether end-of-life caring amongst the oldest-old increases mortality. This would be important to inform future changes to health and social care provision, to ensure it is responsive for the needs of the oldest-old without entrenching inequalities for those providing care.

Epilogue: Changing my mind

The process of this thesis has irrevocably changed my understanding of power and my tolerance for complexity. My first degree in history and politics coupled with my wider feminist activism, inculcated in me a strong sense of social justice. My ethical commitment shaped my initial research objective for this doctorate: what can we (the state, researchers, voluntary sector) do for such vulnerable people? Through spending extended time with my participants, I realized quickly that my rendering of my participants as merely vulnerable was problematic. In making such assumptions about their vulnerability I was inherently overlooking the creative contributions my participants were making to their own and their partner's care. This links with Farmer's reflection that the ascription of risk to a particular group is a 'structural violence' because it stigmatises groups of people as inherently, rather than situationally, vulnerable (Farmer, 1999). My initial research question also reinforced traditional renderings of the fourth age as "decline and dependency": something this thesis has subsequently challenged.

My mind was also opened by deep engagement with the works of Foucault and Berlant, who both powerfully contend that power is never a top-down, nor straight-forward process. Rather people are always capable of counter-conducts through strategies to make their lives – if only momentarily and however illusory – more bearable. Such a perspective prompted a shift in my thinking to consider: what are older people, capable of agency, thought, versatility, doing for themselves and their partners whilst navigating the harsh realities of mortality. Based on these findings, what would make a positive difference for their everyday lives?

This research was also undoubtedly shaped by my first-hand experience of oldest-old caring during my final year of my PhD. Upon returning back to New Zealand due to the COVID-19 pandemic my fiancé Nick and I quickly became involved in his 86 year-old grandfather's end-of-life care. Bob managed his dwindling health over a period of a year and half with the support of his 87 year-old wife Betsy and their extended family up until his death in August, 2020. Bob, a Professor of Pediatrics, frequently acknowledged that he was not sure whether it would be his kidney, cancer, or heart failure that would be the end of him.

Much of the writing of this thesis was done interspersed with family visits where Nick and I tried to maximize our time with Bob and Betsy and support other members in the family providing more instrumental care. On one occasion, six of us were sat around the table for dinner discussing the details of Bob's admission to hospital that morning when Betsy, 87, collapsed on the table, wine everywhere. When she came to, her first words were "I'm fine, where's Bob". We had to strongly insist she go to the hospital, where she was diagnosed as having had a mini-stroke and kept in hospital over-night. Betsy's stroke brought home both the toll of providing end-of-care but also the intensity of connectedness between long-term spouses. Betsy wanted to know where Bob was for her own security in her moment of acute vulnerability. Rendered in this way, I was compelled to reflect on my initial implicit viewpoint that older women in caring roles, such as Betsy, were oppressed due to prevailing gender norms that expect women to do the caring.

Choice at end-of-life is inherently relational as I have found out, and someone can continue to care even when it is physically and emotionally straining. In Bob and Betsy's care arrangement they were very much "leaning together", resourcefully drawing on family members both for instrumental and emotional support. Bob used his iPad to read studies about his condition and conferred with Betsy, a former nurse, about the implications for his prognosis. Betsy used her WhatsApp voice note to record up-dates which she sent to the wider family group chat. Following a fall, Bob was admitted to hospital (under COVID-19 restrictions). Through careful negotiations with a range of hospital and hospice staff, he was discharged home where he died the in the early hours of the following morning with Betsy holding his hand.

That it took first-hand experience to reconceptualize my own understandings of the “burden” narrative around end-of-life care, attests to fact there is much more research needed to complicate this cultural script. This thesis is a step in what I see as my life-time’s work of exploring different narratives about how we live and die in advanced old-age.

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Appendices

Study approvals

Appendix 1: NHS Human Ethics Application

NHS
Health Research Authority

FULL/LONG TITLE OF THE STUDY

Older frail spouses’ experiences of providing end of life care: a narrative analysis

SHORT STUDY TITLE / ACRONYM

This study will be referred to publically as the ‘Looking after my spouse’ study or the LAMS study.

PROTOCOL VERSION NUMBER AND DATE

1.0 9.11.18

RESEARCH REFERENCE NUMBERS

IRAS Number:	253939
SPONSORS Number:	University of Cambridge
FUNDERS Number:	Woolf Fisher Trust, New Zealand.

LIST of CONTENTS

KEY STUDY CONTACTS

Chief Investigator	Dr. Stephen Barclay
Study Co-ordinator	Tessa Morgan
Sponsor	University of Cambridge Contact within sponsor institution: Ms Carolyn Read Research Governance Officer Institute of Public Health Forvie Site, Robinson Way Cambridge CB2 0SR cad50@medschl.cam.ac.uk 01223 769291
Joint-sponsor(s)/co-sponsor(s)	NA
Funder(s)	Woolf Fisher Trust PO Box 17084 Greenlane, Auckland New Zealand, 1546. 09 528 2927
Key Protocol Contributors	Dr. Stephen Barclay Tessa Morgan Dr Robbie Duschinsky
Committees	Positive Ageing PPI group Sabina Taylor Senior Administrator st653@medschl.cam.ac.uk Palliative and End of Life group Angela Harper Senior Administrator ah523@medschl.cam.ac.uk

STUDY SUMMARY

It may be useful to include a brief synopsis of the study for quick reference. Complete information and, if required, add additional rows.

Study Title	Older frail spouses' experiences of providing end-of-life care: a narrative analysis
Internal ref. no. (or short title)	Looking after my spouse study
Study Design	Qualitative narrative analysis
Study Participants	Older spouses caring for their spouse/partner approaching their end-of-life
Planned Size of Sample (if applicable)	15 carers and their partners.
Follow up duration (if applicable)	6 months.
Planned Study Period	February 2019-December 2019 (to conduct field work) Final completion September 2021
Research Question/Aim(s)	To explore what it is like to support your spouse who is at end-of-life at home when you yourself are older and frail.

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	FINANCIAL AND NON FINANCIALSUPPORT GIVEN
Woolf Fisher Trust	Living costs and course fees for four years.

PO Box 17084 Greenlane, Auckland New Zealand, 1546.	They also provide yearly check-ins with PhD candidate to ensure her studies are on-track.

ROLE OF STUDY SPONSOR AND FUNDER

The Funder does not have any influence over the design or application of the research project.

The Sponsor is responsible for ensuring the study is conducted ethically, and in a way that does not contravene the requirements and procedures of the University of Cambridge.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

Study Steering Groups

As well as extensive wider stakeholder involvement in the preparation of this application, this study has also been directly guided by two PPI groups at the University of Cambridge's Department of Public Health and Primary care (the overarching body sponsoring this study): 1) the Palliative and End of Life group convened by Dr Stephen Barclay, 2) Positive Ageing PPI group convened by Dr Jane Fleming and Dr Joyce Cocker.

The former gave feedback on the formulation of research questions and choice of research participants (e.g. to interview participants as dyads where possible). This group is convened by the chief investigator of the study. The later have had continuing input in the recruitment and public facing side of the project, including both the design and wording of the recruitment poster. The PhD student is a regular attendee at this meeting but does not have formal connections with this group.

PROTOCOL CONTRIBUTORS

The protocol should:

The funder and sponsor have not had any input in the study design, data analysis and interpretation, manuscript writing, and dissemination of results. The sponsor has helped to ensure the ethical robustness of the study by reviewing the application very closely. Neither the sponsor nor funder has a final decision regarding the findings of the research.

This protocol has been heavily influenced by PPI involvement over the course of an 8-month informal consultation period. For the explicit purposes of PPI Tessa Morgan (TM) has spoken with six current or former carers individually. TM has spoken with two palliative care teams, and two health care professionals on their own and one care home manager to ensure the health and social care relevance of my project. TM has spoken to five academics working in my general area but who are outside of my specific research group to ensure the wider academic interest in my project. TM have also spoken with policy people representing five carer-orientated organisations to ensure the sector relevance of my project. In addition, TM presented on her area of interest to the End of Life Ambitions group (representing all palliative care organisations in the UK) on the 13.3.18 and it was received as timely important research.TM has conducted formal PPI about the specific design of my project at the following established PPI groups:

21.12.2017- Palliative care PPI group arranged by Dr Stephen Barclay. 5 participants in attendance.

16.02.2018 – Frailty community event with the purposes of PPI, arranged by Dr Louise LaFortune. Over 40 people in attendance, TM conducted a focus group with 6 participants.

31.07.2018- PIRAD (now the Positive Ageing PPI group) organised by Jane Fleming with 14 former and current carers in attendance.

KEY WORDS:	Family carers, palliative care, end-of-life care, oldest-old, care in community, primary care

STUDY FLOW CHART

STUDY PROTOCOL

Older frail spouses' experiences of providing end of life care: a narrative analysis

1 BACKGROUND

Drawing on social science theories and methods, this study will look at how both features of individual's identity and their wider context influence how they think about and do/ receive 'care'. This study will involve two interviews over a 2-6 month period of time with approximately 15 couples, where at least one of them is reaching their end of life and the other is frail. Couples will be interviewed separately and together so each can talk about their own experiences and to gain insight to their relationship. Participants will be recruited through palliative care teams, hospice at home, GPs, older people's charitable organisations and a flyer in the community. Enabling couples to talk about their experiences of care over a period of time will contribute to better understanding of what palliative care at home involves and how older couples make sense of it. In exploring this understudied but relevant area for healthcare and clinical work, this study will inform future policy and practice. This study is funded by the Woolf Fisher Trust based in New Zealand.

2 RATIONALE

As populations age rapidly across the world, peoples' need for palliative care services will similarly expand (Etkind et al. 2017). Within the current context of resource-limited health care sectors, many governments are emphasizing the importance of providing palliative care in the community (WHO, 2007). Consequently, family members are increasingly be expected to take on intense and often prolonged end-of-life care duties (Turner et al. 2016; Exley and Allen, 2007). There is a significant evidence base to suggest that providing such care detrimentally impacts both the psychological and physical health of family carers, and there is recent research to suggest that older women supporting their husbands are the most vulnerable to such negative health impacts (Chappell et al., 2015).

Little research to date has considered the impact caregiving for a family member has on people 75 years and older yet there is growing evidence to suggest older people will increasingly be providing this care. In one of the few published examples on 'oldest old' spousal carers, Turner et al. (2016) found that while there was a high level of willingness to provide care by their participants, which was understood as being an expected aspect of being married, they found that physical restrictions – such as frailty - inhibited their ability to provide care. Building on this work I am particularly interested in how physical and mental frailty affect the gendering of power in relation to marital duties and care relations (Grenier, 2006; Arber and Ginn, 1995). This research will thus respond to a corresponding gap in the literature on frailty, which rarely considers how family caregivers are often themselves older and frail.

This study will also help to contribute to the feminist literature on the ethics of care, which at present remains philosophically tied to the lives of reproductive women (Tronto, 1993; Held, 2006); one of the reasons the enthusiasm with which feminists have previously embraced this mode of thinking has waned in recent years. Considerations of death and dying, as much as birth and child-rearing, can help to enrichen our understandings of structural organisations (such as 'the health care system' and 'the community') as well as the cultural value of gendered contributions to society (considering the significance of emotional labour and whether we should or even want to consider care 'work').

This research will ultimately help to bridge a gap in the wider palliative care literature around the tension between the expression of needs and the acceptance of help by closely considering the label of 'carer' itself – a word often acting as a key to services (Grande, 2009). By expanding my study to include people who may be doing care but not identifying as carers (preferring their label 'wife' or 'husband' for example) I hope to locate 'hidden carers' whose voices are currently missing from the evidence base around family caregiving at end of life (Phillip, Gold, et al. 2014).

3 THEORETICAL FRAMEWORK

The human "impulse to narrate" has received renewed interest since the 1980's "narrative turn" in the humanities and social sciences (White, 1980, p. 10; Labov, 1972). More recently health researchers looking to challenge positivist claims to a fixed reality have embraced narrative analysis to understand how patients and their families narratively construct their identities in relation to their health experiences (Earthy & Cronin, 2008; Elliot, 2005; Bingley, 2008). Narratives analysis – as a case-centred approach – has remained a significant tool of intersectional thinkers as it ensures marginalised people get to tell their stories on their own terms and that they are not subsequently 'torn apart in analysis' (Hill-Collins, 2000). Recognising that participants produce narratives that are 'edited views on the world', or 'factions' (Bury, 2001; Sandelowski, 1991) their scientific value is found in the wider interviewing process which is a site of social negotiation (Mishler, 1984) that explores "the contradictions of social interaction and self-presentation" (Bury, 1999, p. 278) and consequently helps to illuminate how participants "experience their worlds" (DeVault, 2002, p. 76). To aid analysis I will situate participants' narratives within a rich, thick description of the context drawing on sociological, historical and anthropological writings about the United Kingdom and the Global North from the 20th and 21st century onwards (for example MacFarlane, 1978).

A narrative analysis views all parties in the interview as "necessarily and ineluctably active" in the production of meaning which "is actively and communicatively assembled in the interview encounter" rather than transferred from interviewee to interviewer (Holstein and Gubrium, 2002, p. 114). Thus the social location of all discussants is especially important when analysing such narratives: I am particularly interested in how my younger age, female gender and migrant status will influence the talk (Hollway and Jefferson, 2013). This also means that participants ought to be included in the analysis as well as the collection process. As part of this member-checking process participants will have the opportunity to respond to my interpretations of their key narratives which will form the basis of the subsequent conversation (Charmaz, 2006; Lincoln & Guba, 1985).

4 RESEARCH QUESTION/AIM(S)

RQ1: What is it like to care for one's spouse at end-of-life for someone who is themselves older and with health issues?

RQ2: What is the nature of the care provided?

RQ3: How do older spouses navigate their caring activities in the context of their other identities?

RQ4: What kinds of support do oldest-old carers have and what do they need?

RQ5: How is their caregiving influenced by wider health and social contexts?

4.1 Objectives

The fundamental aim of this PhD is to understand and make visible the experiences of oldest-old spouses/partners who are providing end-of-life care at home for their spouse/partner.

4.2 Outcome

In addition, I will try to understand how best health and social care systems can support these carers. I will also consider what these carers can teach us about the meaning of care and the construction of older identities in late modernity.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

Participants

People over 75 who are providing care for a spouse with a life-limiting illness. The person who is providing care is 'frail'. I will also hope to interview their spouse with the life-limiting illness provided they can give informed consent (e.g. that they are not cognitively impaired).

Data collection

Using detailed narrative methods (Reissman, 2008) this study will involve two or three interviews over a 2-6 month period of time with approximately 15 dyads, where at least one of whom is reaching their end of life and the other is frail. Tessa Morgan (TM) will conduct and analysis all interviews. All interviews will be audio-recorded and TM will record field notes after each interview in my diary.

Spouses will be interviewed both separately and together, a strategy that has been employed successfully in previous studies (Rose and Bruce, 1995; Thomas et al. 2009) to both enable participants to freely discuss their views as well as offering interesting insight into what different members of a dyad view their contributions as being. If they only wish to be interviewed together TM will respect my participants' wishes and only conduct dyadic interviews.

TM will also ring participants at the mid-way point (approximately a month into the study). This phone call will not be recorded, although – with participant agreement - field notes will be recorded in relation to what is discussed. The point of this phone call will be to check-in that the participants are still interested in being part of the study, and to ascertain whether there has been any change in the caring relation. If there is rapid decline or if the patient has been moved to a care home there may be an impetus to conduct interviews earlier than expected. Given the nature of the situation, these phone calls will also be used to check that the 'patient' is still alive. TM will not interview carer/patient if one of them dies within my interview period unless the participant explicitly asks for this.

Data analysis

TM will conduct a case-based and thematic analysis of the data to form an in-depth understanding of how each individual narrative evolves and how it fits with narratives from other participants (Maxwell and Chimel, 2009). TM will conduct analysis concurrently and will ask participants in the second interview if her interpretation of their account offered in their first interview fits with theirs. All data will be de-identified and participants through the analysis process will be referred to by their unique coded (for example Participant 1). In publications, references to places or personal details that might reveal the identity of the participant will be changed to protect their identity. Coding of transcripts will be support through the data management tool NViVO and this will take place once all the data has been collected and all the transcripts transcribed. A university-certified transcriptionist will transcribe all transcripts. Storage of manual files, including notes and consent forms, will be kept in a locked cabinet. Contact details will be destroyed after the study has finished. An electronic copy of personal contact details will be kept on a secure university computer. Any identifying information will be destroyed once the study is complete and all corrections to any journal publications completed. All de-identified data will be destroyed after 5 years in line with the University of Cambridge's data protection policy.

6 STUDY SETTING

Interviews will be conducted at the place of the participant's choosing. We are expecting that this will likely be their home. Meeting participants in their homes be help to give context to their descriptions of providing care at home. However, if participants prefer to meet somewhere else, for example at a café so that they have space to talk freely about their situation without their partner or other member of the family hearing, that is where the researcher will meet them. Indeed, this decision is likely to add detail to the context of their caring relationship – which will thus add to the study's focus on understanding carers' predicaments. Participants will either be approached by a member of a GP surgery or palliative care team and asked if they would be interested in potentially participating in the 'Looking after my spouse' study. If they are happy to learn more about the study and have their details passed on by the recruiter then the researcher will promptly be in touch with a letter inviting them to the study and a one-page information sheet about the researcher and the research. This is a multi-centre research project and the only variance between sites is that recruitment flyers will also appear in GP surgeries, which will give participants the opportunity to self-select into the study by directly contacting the researcher.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

7.1.1 Inclusion criteria

'Carer' must be aged 75 and over and looking after their spouse/partner who has a life-limiting condition (e.g. dementia, non-curable cancer, Parkinson's chronic heart failure, COPD). In exceptional cases a carer under 75 (but no younger than 70) may be allowed to participate where carer has contacted researcher to take part (e.g. by responding to poster) and meets the other criteria exactly.

Able to provide informed consent. Written and verbal consent will be gained at the beginning of each interview. If the carer but not the cared for can provide such consent (e.g. in the instance where the cared for has advanced dementia) only the carer will be interviewed.

Participants must speak and understand English enough to provide informed consent and participate in interviews.

'Carer' will be frail as determined holistically and guided by the clinical frailty index.

Living at home with spouse at least at the beginning of the interview.

7.1.2 Exclusion criteria

Carer aged under 75 (other than exceptional cases where carer has contacted researcher to take part, is over 70 and meets the other criteria exactly).

Person receiving support does not have a life-limiting condition, for example, diabetes or serious mental health issues.

Carer cannot provide informed consent.

Participants do not speak English.

At the beginning of the study, the couple or one member of the couple live somewhere other than home, for example, where the cared-for is living in a care home.

7.2 Sampling

Narrative studies tend to have a small number of participants given that this methodology relies on in-depth case-based analysis. The longitudinal nature of this research design places additional need to keep numbers small into to ensure the analysis of data is manageable.

7.2.1 Size of sample

Fifteen dyads have been selected as a good medium to balance the need for a range of caregiving experiences across different palliative conditions while also being able to perform in-depth analysis of each case. Given the nature of the topic, 15 has also been selected with the expectation that some participants will not take part in both interviews.

7.2.2 Sampling technique

A purposive sampling strategy has been used to ensure the richness of the caregiving narratives and is in line with this studies desire to understand how age impacts caregiving experience. The recruitment strategy via GPs and palliative care teams has been designed to reflect this desire for rich data-cases as these professionals will have access to these carers who would otherwise be hard to reach. They will also be able to exercise their professional judgement about the health status of the person being cared for and the carer to further ensure their fit with the project.

In addition, participants will have the ability to self-select in which will comprise a form of convenience sampling.

7.3 Recruitment

Health care professionals will identify participants who meet the criteria. Recruiters will be specifically asked by the researcher to identify people:

a) Aged 75 or older;
b) Looking after their at spouse who is nearing end-of-life;
c) Living at home with their spouse;
d) Deemed frail in the professional judgement of the health care professional.

7.3.1 Sample identification

Recruitment

The participants will be recruited through health care professionals (GPs and palliative care teams) who will ask them if they would like to participate in a study about looking after a spouse with a serious condition. If they agree, the health care professional will pass on their contact details to the research who will promptly be in touch with a letter inviting them to the study and a one-page information sheet about the research as well as a phone-call.

No confidential information will be passed between recruiters and researcher without the informed consent of the participant. There will be no payment transfers for this study.

Where participants have opted in by responding to the flyer in the GP surgery or other community space, TM will screen them over the phone for their eligibility and then arrange a time and place to meet that suits the participant/s. TM will make the determination of the ‘frailty’ of the carer using the clinical frailty index when she meets participants, thinking holistically about their emotional and physical health.

7.3.2 Consent

All participants will be given at least 24 hours to consider their involvement in the study. They will have the opportunity to ask questions about the research to the person recruiting them as well as to the researcher both over the phone and in person. During the consent process at the beginning of each interview participants will be given time to read over the participant information sheet and have the opportunity to ask questions. The participant interview sheet, which they will be talked through outlines the purpose of the research, the benefit and burdens of participating in the research as well as their ability to stop the interview at any point or decide not to answer any questions they do not want to.

Dyadic consent

A key ethical issue will arise when one spouse consents to be part of the study while the other does not. As this is a study primarily about carers, I will interview the person caring even if the patient in the dyad would not like to participate or lacks capacity to participate in an interview themselves (due to poor health, dementia etc.). This is based on the understanding that carers' ability to know what is best for themselves in relation to their circumstances. However, I will not pursue an interview with one partner if the other does not wish for either to be interviewed, to avoid the potential for harm to participants through contributing to conflict in the relationship. Likewise, if one member of a dyad wishes the data of both members withdrawn from the study, this will be done for the same reason.

In the case where the 'cared for' dies between the first and second interview, I will be guided by the carer in terms of their future involvement in the study. There will be no pressure to continue on this the study. If the 'cared for' dies before the first interview has taken place, the bereaved carer will not be asked to participate in the research.

Cognitive impairment

I will only interview participants who are cognitively able to give written informed consent to participate in two one-hour interviews. I have engaged in research with older people for the last two years and have experience of using my judgement to determine capacity to consent (veering always on side of caution). If it becomes apparent when I have arrived at the interview or during the interview, that the participant is cognitively impaired I will complete a truncated version of the interview but will not include this data within my analyses. If capacity to consent appears to fluctuate during the interview, I will utilise approaches of 'ongoing consent' (Renold et al, 2008) to touch base with participants about their desire to continue, and whether a break might be helpful.

8 ETHICAL AND REGULATORY CONSIDERATIONS

This research at all times will aim to uphold the dignity of participants by conducting ethically robust research. Past research has shown that participants with serious conditions in a caring role or those approaching end of life frequently benefit from talking about their experiences and welcome the opportunity to contribute to future service improvements (Murray, 2009). The Palliative care user group consulted for this project said that this was true of their experience.

No physical risks to participants are anticipated; however, some may find talking about illness and care distressing. If this happens, the researcher will assess the situation and if considered necessary, advise contacting either contacting their GP or another member of their primary or secondary healthcare team, or ask permission to do so on the participant's behalf. The researcher will also have contact details for relevant support lines and services if needed, such as the Carer's trust and MacMillian. At no point will the terms "palliative", "terminal", "end of life" or "dying" be used by the researcher unless used by the participant first.

The protocol has been reviewed and approved by the Carolyn Read to ensure it meets all the standards of the University of Cambridge. All research will be conducted in line with site-specific approvals.

8.1 Assessment and management of risk

Some may find talking about illness and care distressing: if this happens, the researcher – experienced with conducting qualitative research with this population - will assess the situation and if considered necessary, will encourage participants to contact either their GP or another member of their primary or secondary healthcare team, or ask permission to do so on the participant's behalf. The researcher will also have contact details for relevant support lines and services if needed, such as the Carer's Trust and MacMillan Cancer Support. At no point will the terms "palliative", "terminal", "end of life" or "dying" be used by the researcher unless used by the participant first. Participants' information will be treated confidentially, with all participants being given an ID number and a pseudonym, which will appear in any reported findings. Confidentiality will be respected at all times unless consent has been given to disclose the information to specified persons or where the research team agrees that there is potential serious harm and relevant health care providers or authorities need to be informed (for example in the case of domestic abuse).

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

Before the start of the study, a favourable opinion will be sought from a REC (researchers should check if they are required to gain a favourable opinion from the UK Health Departments Research Ethics Service NHS REC) or other REC approval) for the study protocol, informed consent forms and other relevant documents e.g. advertisements.

Substantial amendments that require review by NHS REC will not be implemented until that review is in place and other mechanisms are in place to implement at site.

All correspondence with the REC will be retained.

It is the Chief Investigator's responsibility to produce the annual reports as required.

The Chief Investigator will notify the REC of the end of the study.

An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.

If the study is ended prematurely, the Chief Investigator will notify the REC, including the reasons for the premature termination.

Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

Regulatory Review & Compliance

Before any site can enrol patients into the study, the Chief Investigator/Principal Investigator or designee will ensure that appropriate approvals from participating organisations are in place. Specific arrangements on how to gain approval from participating organisations are in place and comply with the relevant guidance. Different arrangements for NHS and non NHS sites are described as relevant.

For any amendment to the study, the Chief Investigator or designee, in agreement with the sponsor will submit information to the appropriate body in order for them to issue approval for the amendment. The Chief Investigator or designee will work with sites (R&D departments at NHS sites as well as the study delivery team) so they can put the necessary arrangements in place to implement the amendment to confirm their support for the study as amended.

Amendments

Any amendments will be submitted to the REC committee if all three researchers involved with this project Dr. Stephen Barclay (Chief Investigator), Tessa Morgan (PhD student conducting research), Dr Robbie Duschinsky (Academic supervisor) agree it is necessary. Depending on the type of amendment, TM may consult with the Healthy Ageing and/or Palliative Care group PPI groups for their input. The protocol will record any amendments by stating the current version of the protocol (e.g. version 1 or 2). In the case of any amendments, all recruiters involved in the study will be sent the new protocol.

8.3 Peer review

Independent external review – this project has received ethics approval from University of Cambridge Psychology

ethics board on the 19th of June 2018.

This project has been independently reviewed by two examiners Professor Mike Kelly and Dr Jenni Burt as part of Tessa Morgan's first year viva review process. The project attained approval and she has been registered formally as a PHD student to conduct this

research.

Review within research team – This research has been presented to the Primary Care Unit for the first year PhD

student presentation and received positive feedback.

Review within educational supervisor – Academic supervisors have been involved in discussions about research

design and monitor the quality of the research.

Review within a multi-centred research group - This research is also being overseen by Professor Merryn Gott at the University of Auckland who has similarly endorsed the research proposal.

Other – This project has been presented to the secretary of the Woolf Fisher Trust who is the representative of the funding body supporting this research.

Peer-review at the 'Witnessing End of Life' post-graduate workshop hosted by the University of Glasgow where TM had the opportunity to speak for half and hour on the design of my project and get feedback from a group of 16 PhD and post-doctoral researchers. The design may be slightly modified as a result of such discussions.

8.4 Patient & Public Involvement

Design of research

The research design, particularly the recruitment strategy and phrasing of documents, has been discussed with several carers and health care professionals over the course of an 8-month informal consultation period. For the explicit purposes of PPI TM has spoken with six current or former carers individually. TM has spoken with two palliative care teams, and two health care professionals on their own and one care home manager to ensure the health and social care relevance of my project. TM has also spoken with policy people representing five carer-orientated organisations to ensure the sector relevance of my project. In addition, TM presented the topic to the End of Life Ambitions group (representing all palliative care organisations in the UK) on the 13.3.18 and it was received as timely important research.TM has conducted formal PPI about the specific design of my project at the following established PPI groups:

21.12.2017- Palliative care PPI group arranged by Dr Stephen Barclay. 5 participants in attendance.
16.02.2018 – Frailty community event with the purposes of PPI, arranged by Dr Louise LaFortune. Over 40 people in attendance, I conducted a focus group with 6 participants.

31.07.2018- PIRAD (now the Positive Ageing PPI group) organised by Dr Jane Fleming with14 former and current carers in attendance.

Recruitment

Carers (former and current) have been consulted through the PPI process and have indicated GP clinics would be useful places to recruit through. Through this process I have also met health care professionals, for example Dr Sally Carding, who has now come on board to help recruit for this study.

Analysis of results

I will report my interpretations back to participants when I return for the second interview. Bearing in mind that anything said privately by one partner of the dyad will not be reported back to the other member. In the case the first interview was separate and the second was dyadic I will only share the broad reflections back to the couple to ensure confidentiality and participants' wellbeing. If the carer agrees at the mid-point phone call that the second interview will be dyadic where the first one was individual, I will assure the carer that anything shared at the first interview will remain confidential.

Dissemination of findings

All participants and PPI members will receive a summary of the findings before the final PhD is submitted. I will collaborate with a graphic designer to produce creative ways of visually communicating the findings of this data. I will then work with the advisor-carers of the project to feedback this information to the community and policy-makers.

8.5 Protocol compliance

Accidental protocol deviations can happen at any time. They must be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

Deviations from the protocol which are found to frequently recur are not acceptable, will require immediate action and could potentially be classified as a serious breach.

8.6 Data protection and patient confidentiality

We will follow the Data Protection Act 2017 in the way we handle, store and eventually destroy the research data. Priority will be to participant's confidentiality. Any information shared by a participant will not be shared to other family members unless explicitly instructed by them to do so. No information will be shared with health care providers other than in the case of potential serious harm. Audio recordings of interviews and typed-up copies of these recordings will be stored in a secure password-protected file on the researcher's computer. In any written reports, people's names and place names will be changed in order that everything is anonymous. Only Tessa Morgan, the researcher collecting the data will see matched information and the participants will be referred to a pseudonym and ID number in any discussions with supervisors, sponsors, funders and in any publications or presentations coming from this data. Storage of manual files, including notes and consent forms, will be kept in a locked cabinet. Contact details will be destroyed after the study has finished. An electronic copy of personal contact details will be kept on a secure university computer. Any identifying information will be destroyed once the study is complete and all corrections to any journal publications completed. All de-identified data will be destroyed after 5 years in line with the University of Cambridge's data protection policy. The data custodian will be Tessa Morgan. If Tessa Morgan departs the United Kingdom before the 5 year period James Brimicombe, the data manager for the Department of Public Health has agreed that he will become the data custodian. The policy of the Primary Care Unit which is in line with the Data Protection Act 2017 is supplied here: https://www.medschl.cam.ac.uk/research/privacy-notice-how-we-use-your-research-data/

8.7 Indemnity

This project has received indemnity from the University of Cambridge: HVS/2018/2513

Which covers the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research, the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research and potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research.

8.8 Access to the final study dataset

Only the three researchers involved in this project will have access to the full dataset. There is no intention for this dataset to be available for secondary analysis. The dataset will be destroyed five years after the completion of the study.

9 DISSEMINIATION POLICY

9.1 Dissemination policy

The University of Cambridge as the sponsor of the research owns the data arising from the study. Tessa Morgan's doctoral thesis will outline the study findings. In addition, final study report will be produced within a year of finishing the study. A summary of the findings will be sent to all people involved in the recruitment of participants as well as being disseminated to policy-makers and relevant carers' organizations. A summary of the findings will be sent to the sponsor and the funders. The researchers also aim to write journal publications from the data.

For participants wishing to receive findings who were recruited via their GP or other health care professionals, they will receive a copy of the findings from the person who recruited them (who will be aware of any changes in the family circumstances). For participants who were recruited through other channels, including those who opt in themselves, they will be asked at our last meeting if I could ring them to confirm that they would like me to send findings out once the findings are available. They will have the option to provide me with an alternative contact for example a son or daughter if they do not want me to ring in a year but would still like to receive the results.

The dataset itself will not be made publically available to ensure participants' confidentiality. In line with data protection agreement the data will be destroyed after 5 years.

9.2 Authorship eligibility guidelines and any intended use of professional writers

Tessa Morgan will retain first authorship on all publications and Dr Robbie Duschinsky and Dr Stephen Barclay will also be listed as authors on the core papers from this dataset. No professional writers will be used.

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Sandelowski, M. (1991). Telling Stories: Narrative Approaches in Qualitative Research. Journal of Nursing Scholarship, 23(3), 161-166.

Thomas, C., Reeve, J., Bingley, A., Brown, J., Payne., & Lynch, T. (2009). Narrative Research Methods in Palliative Care Contexts: Two Case Studies. Journal of Pain and Symptom Management, 37(5) 788-796.

Turner,M., King, C., Milligan, C. Thomas, C. et al. (2016). Caring for a dying spouse at the end of life: 'It's one of the things you volunteer for when you get married': a qualitative study of the oldest carers' experiences, Age and Ageing, 45(3): 421–426.

Ventura, A., Burney, S. Brooker, J, et al. (2004). Home-based palliative care: a systematic literature review of the self-reported unmet needs of patients and carers. Palliat Med 28:391-402.

White, H. (1980). The Value of Narrativity in the Representation of Reality. Critical Inquiry, 7(1), 5-27.

Wiles, J. L., Rosenberg, M.W., & Kearns, R.A. (2005). Narrative analysis as a strategy for understanding interview talk in geographic research. Area, 37(1), 89-99.

11. APPENDICIES

11.1 Appendix 1- Required documentation

List here all the local documentation you require prior to initiating a participating site (e.g. CVs of the research team, Patient Information Sheet (PIS) on headed paper etc.).

11.2 Appendix 2 – Schedule of Procedures (Example)

Procedures	Visits (insert visit numbers as appropriate)			
	Screening (over phone)	Baseline	Month 2	Month 3 (if necessary)
Informed consent	x			

Interview		x	x	x

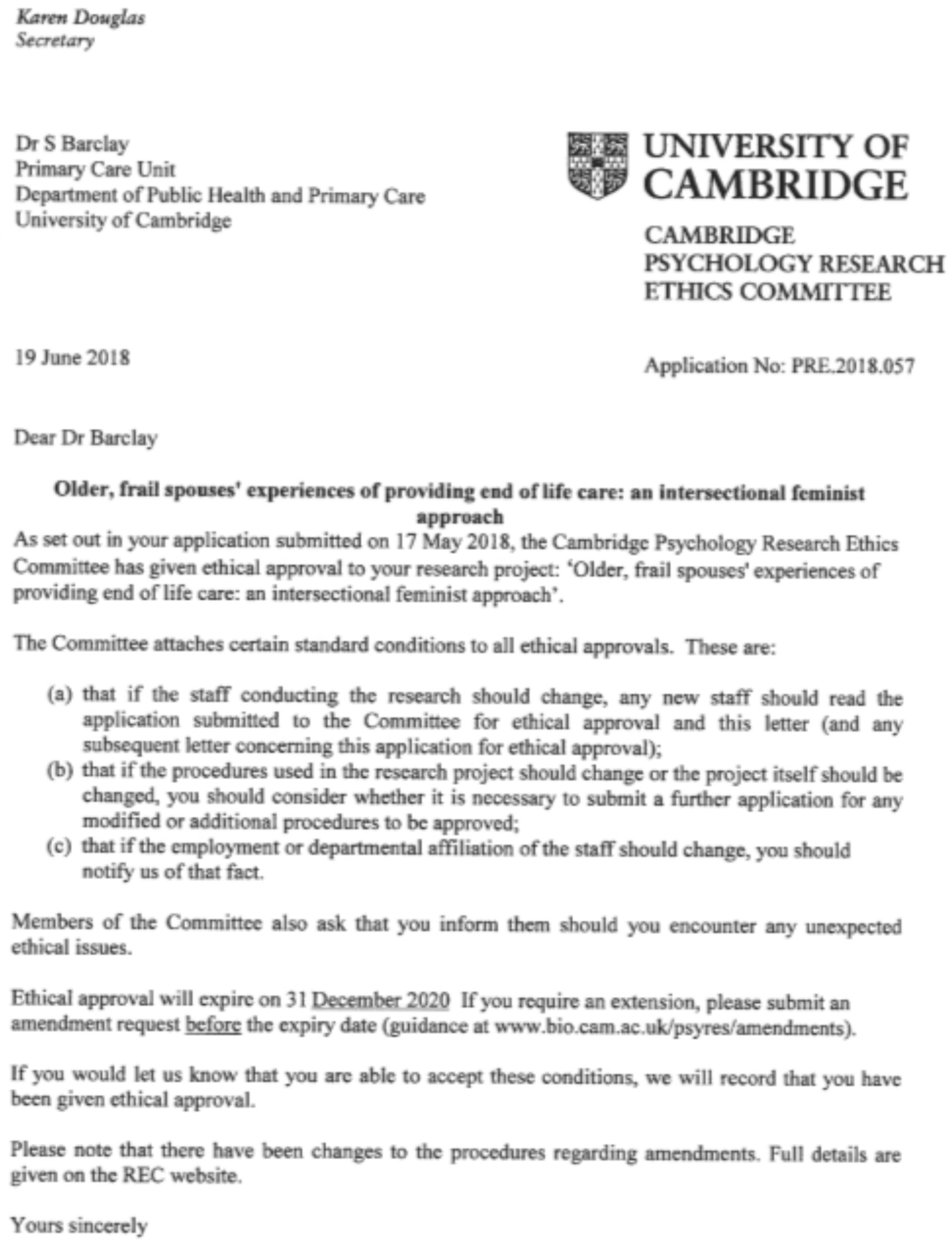
13.3 Appendix 3 – Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made

List details of all protocol amendments here whenever a new version of the protocol is produced.

Protocol amendments must be submitted to the Sponsor for approval prior to submission to the REC.

Appendix 2: University of Cambridge Psychology Research Ethics Committee Approval



Karen Douglas
Secretary

Dr S Barclay
Primary Care Unit
Department of Public Health and Primary Care
University of Cambridge

UNIVERSITY OF
CAMBRIDGE

CAMBRIDGE
PSYCHOLOGY RESEARCH
ETHICS COMMITTEE

19 June 2018

Application No: PRE.2018.057

Dear Dr Barclay

Older, frail spouses' experiences of providing end of life care: an intersectional feminist approach

As set out in your application submitted on 17 May 2018, the Cambridge Psychology Research Ethics Committee has given ethical approval to your research project: 'Older, frail spouses' experiences of providing end of life care: an intersectional feminist approach'.

The Committee attaches certain standard conditions to all ethical approvals. These are:

(a) that if the staff conducting the research should change, any new staff should read the application submitted to the Committee for ethical approval and this letter (and any subsequent letter concerning this application for ethical approval);
(b) that if the procedures used in the research project should change or the project itself should be changed, you should consider whether it is necessary to submit a further application for any modified or additional procedures to be approved;
(c) that if the employment or departmental affiliation of the staff should change, you should notify us of that fact.

Members of the Committee also ask that you inform them should you encounter any unexpected ethical issues.

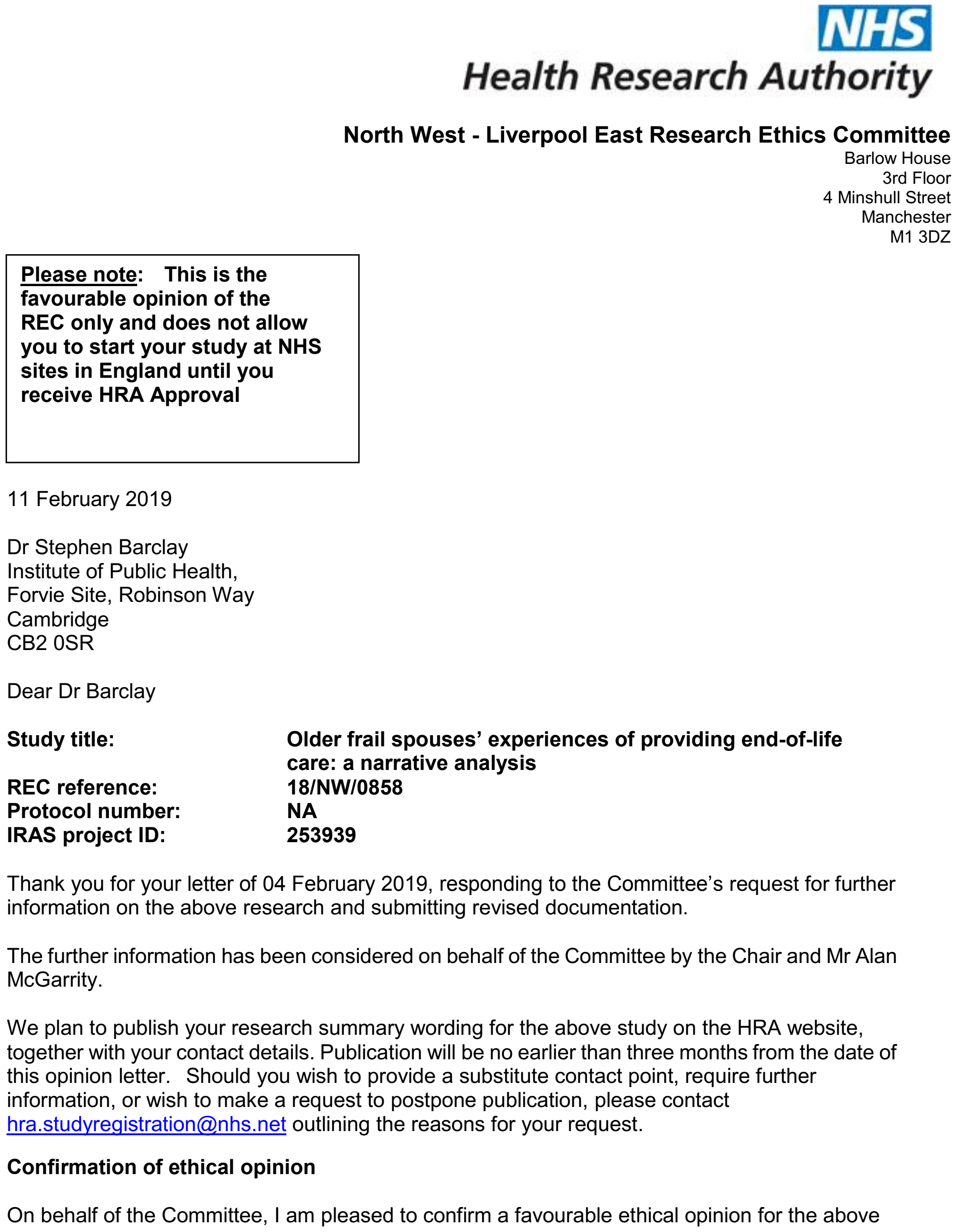
Ethical approval will expire on 31 December 2020 If you require an extension, please submit an amendment request before the expiry date (guidance at www.bio.cam.ac.uk/psyres/amendments).

If you would let us know that you are able to accept these conditions, we will record that you have been given ethical approval.

Please note that there have been changes to the procedures regarding amendments. Full details are given on the REC website.

Yours sincerely

Appendix 3: NHS Health Research Authority Approval



NHS
Health Research Authority

North West - Liverpool East Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

11 February 2019

Dr Stephen Barclay
Institute of Public Health,
Forvie Site, Robinson Way
Cambridge
CB2 0SR

Dear Dr Barclay

Study title:	**Older frail spouses' experiences of providing end-of-life care: a narrative analysis**
REC reference:	**18/NW/0858**
Protocol number:	**NA**
IRAS project ID:	**253939**

Thank you for your letter of 04 February 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Mr Alan McGarrity.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above

Systematic review documents

Appendix 4 Checklist: PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3-4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	N/a- stated p.6
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4-5

Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	21
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6, 21 (Table 1)
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6-7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	6, 21 (Table 1)
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6-7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	7
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	6-7

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	6-7
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	7
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	22
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 3 (Supplementary

			material)
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Table 3 (Supplementary material) Page 8 – who is included in studies. Page 9 – difference of mortality findings.
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Table 3 (Supplementary material)
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	7-11
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Page 8 Page 13 see discussion of exclusion of carers with most severe health. Page 14 reflection on the homogeneity of the studies.

Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Table 3 (Supplementary material)
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	11-14
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	14
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	15
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	15

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

Appendix 5: Search terms used in Medline

1) Carer* or caregiver* OR care giver* OR care-giver* OR help* OR support* OR "home nursing" OR advocate* AND
2) Spous* OR wife* OR wives OR husband* OR partner* or "life partner" OR famil* OR lay OR informal* or "significant other" OR non-professional OR nonprofessional AND
3) "Oldest old" OR (aged adj2 ("75" or "seventy five" or seventyfive)) OR "middle old" OR elder* OR senior* OR pension* OR "deep old age" or geriatric* OR late life OR older adult OR very old OR "older person" OR "older people" AND
4) Palliati* OR end of life OF end-of-life OR terminal* ill*OR 'last year of life' OR frail* OR degenerative OR progressive* OR advanced chronic illness OR terminal care

Limiting requirements:

1) 1985-current
2) English-only

Appendix 6: Adapted version of Popay and colleagues narrative synthesis

Analysis	**Description of how it was followed**
Textual descriptions of studies	Annotated bibliography of all included studies created which included main findings and an initial reflection from lead analyst about content and quality of each study.
Tabulation as means of transforming data into common rubric	Table created to display characteristics of quantitative and qualitative studies, which enabled initial mapping of the characteristics of studies. This helped to identify the relative homogeneity of research participants, which is relevant to later stages of analysis.
Assessing robustness of studies using two quality appraisal tools.	Decision made to assess the quality of studies before the synthesis was conducted to ensure that the evidence underpinning the synthesis was not biased on low quality studies. Using Gough's weight of evidence enable us to determine the general quality the studies methodologies as well as the extent to which they contributed to answering the aim of the review. The Feminist quality appraisal tool enabled a consideration of how power, inequity and gender were considered at each stage of the process (for example, who is included in each study, what theoretical framework are utilised within studies). This approached was used as it reflected our hypothesis of the 'theory of change' insofar as we expected that gender would shape the experience of caregiving.
Groupings and clusterings	Three distinct types of studies were identified: 1) Caring retrospective vs. prospective 2) Main focus was physical/psychological impact vs. everyday practice of caregiving 3) Dementia vs. non-dementia studies.
Translating data: content analysis	Summary descriptions of qualitative and quantitative studies were produced. These were further refined and combine to characteristics of study methodologies and qualities of the carers and care recipients included in studies.
Translating data: thematic analysis	A thematic analysis was conducted with above groupings in mind, to consider the "main, recurrent and/or most important (based on the review question) themes and/or concepts across multiple studies"(Popay et al. 2006, p. 18). For example, themes included: 1) Physical impact of caregiving 2) Maintaining normality 3) Findings way to cope Overarching latent themes were then identified by considering the underlying concepts connecting themes. These included:

	1)Embodying care 2) Conceptualising care 3)Learning to care
Vote-counting (with textual data)	This approach was adjusted so it could be applied to textual as opposed to statistical data. Where statements were made about the nature of caregiving (for example, that it increases one's risk of mortality or that it was informed by a desire to maintain normality) each study relevant to the statement was inspected to see if it affirmed or contravened the statement. Studies supporting the claim were inserted as references in-text. Where statements were in dispute this was made explicit. This approach safe-guarded against focusing too much on one or two studies.
Sub-group analysis	Gendered sub-group analysis was undertaken – aided by the feminist appraisal tool which sensitised us initially to any gendered discrepancies reported in each study. In addition, each theme was considered in relation to the three groups identified at the 'grouping and clustering' stage.
External validation	A version of this manuscript was delivered at two conferences with practitioners to determine whether the key narratives presented were credible and recognisable from the perspective of health care professionals and other academics with an interest in this population group. This helped to solidify that what is presented in this publication is not only a "trustworthy" but also a relevant story. The wider conceptualisation of this research project and its research questions have also been shaped by two formal Patient and Public Involvement (PPI) groups which are focused around experiences of palliative care and older people's health respectively.

Appendix 7: Characteristics of included studies

Study details	Aims and objectives	Study design	Caregiving spouses' characteristics	Care-receiving spouses characteristics	Context of care	Key findings	Quality
Orit Shavit, Aaron Ben-Ze'ev, Israel Doron (2019) Love between couples living with Alzheimer's disease: narratives of spouse care-givers *Ageing & Society* 39: 488-517.	To describe and analyse the meaning of love in relationships between couples living with Alzheimer's disease (AD).	Qualitative narrative approach. Semi-guided interviews. Thematic analysis (focused on case-based analysis).	16 spousal carers. Mean age carer= 75.25. Gender = 8 women, 8 men. Ethnicity= A range of origins listed including 5 Israeli, 1 Syrian, 1 Moroccan, 1 Yemeni. Note that	All had moderate to severe AD. Mean age = 77.8. Mean Duration of caregiving = 4.9 years. Mean length of marriage 51.81 years.	Israel. Home-based care.	Love takes on many forms in face of AD (can enhance, can diminish, may not have been there at all). Intimacy gained different meaning as a result of disease. Not being able to communicate resulted in a continuum of 'we' and 'I' narratives from carers about their relationship.	A= Medium B= High C= High D= High Feminist appraisal = Medium. Main author reflexively discusses her positionality. The social construction of love and being a good wife explored. Potential ways of alleviating issues

			Arabs were excluded.				with intimacy suggested.
Florence Potier, Jean-Marie Degryse, Benoit Bihin, Florence Debacq-Chainiaux, Chantal Charlet-Renard, Henri Martens, Marie de Saint-Hubert (2018) Health and frailty among older spousal caregivers: an observational cohort study in Belgium *BMC Geriatrics*, 18: 291-300.	Longitudinally assess the health of older spousal caregivers considering frailty, nutrition, cognition, physical performance and mood disorders.	Longitudinal, observational cohort study. Range of clinical instruments such as Frailty Phenotype and Mini Nutritional Assessment and Zarit Burden Index. Confidence intervals between baseline and second survey used to analyse change over time.	82 community-dwelling spouses. Mean age at baseline = 80 (range = 77-85). Gender = 54% women, 46% men. Ethnicity not reported.	83% of care recipients had cognitive impairment, 68% with behavioural disorders and most with moderate frailty on Katz index. 27/78 dead at 16 month follow-up stage. Mean age = 81 years.	Wallonia, Belgium. Home-care at baseline. Only 51/78 at home at 16 month follow-up. Duration of caregiving not reported.	1/3 caregivers frailty status worsened. Of particular concern was unexpected weight-loss and lower activity. Nutrition, cognitive status, reported level of burden and mood assessments all stayed stable.	A= Low B= Medium C= Medium D= Medium Feminist appraisal: Low. Indicates no differences between genders in terms of nutrition and notes of caregivers no longer giving home care 21/27 female. No gendered analyses provided.
F Potier, J-M Degryse, G.	Explore if older spousal	Cross-sectional analysis of	79 older spousal carers compared	82% had cognitive	Wallonia, Belgium.	Controlling for age, gender and	A= Medium

Aubouy, S Henrard, B Bihin, F. Debacq-Chainiaux, H. Martens, M. de Saint-Hubert (2018) Spousal caregiving is associated with an increased risk of frailty: a case-control study *The Journal of Frailty & Aging* 7(3): 170-175.	caregivers are at greater risk for frailty compared to older people without a load of care.	baseline data from cohort study. Multivariate logistic regression analysis. Variables compared between caregivers and controls using Mac Nemar test for categorical variables and Wicoxon signed rank test for continuous measures.	to control group of non-carers. Mean age carers 79 (range 76-84) Mean age control group 78 (75-82). Gender = 53.2% women for both carers and control group. Ethnicity not reported.	impairment, 68% with behavioural disorders. 27/78 dead at 16 month follow-up stage (insight drawn from companion study). Care-receivers age (M= 81.4 SD 5.2).	Home-based care. Duration of caregiving not reported.	comorbidities, caregiving is associated with a risk of frailty (6x that of non-carers), the consumption of antidepressants, shorter nights sleep and more difficulties maintaining social network. Caregivers' frailty not associated with cognitive or functional status of care-receiver, although it was associated with nurse at home.	B= Medium C= High D= Medium Feminist appraisal = Relatively equal proportion female and male. Nutrition not found to vary despite expectation. No gendered analyses provided.
Florence Potier, Jean-Marie Degryse, Severine Henrard, Genevieve	Study the links between sense of coherence (SOC), burden,	Cross-sectional analysis of baseline data from cohort study.	79 older spousal carers.	82% had cognitive impairment, 68% with behavioural	Wallonia, Belgium.	Older caregiver age and high SOC associated with lower caregiver burden.	A= Medium B= Medium C= High

Aubouy, Marie de Saint-Hubert (2018) A high sense of coherence protects from the burden of caregiving in older spousal caregivers *Archives in Gertontology and Geriatrics* 75: 76-82.	depression and positive affects among caregivers of frail older patients.	Multivariate logistic regression analysis. Caregiver's characteristics were analyzed by burden severity and SOC level.	Mean age = 79.4 (SD 5.3) Gender = 53.2% women, 46.8% men. Ethnicity not reported.	disorders, and moderate frailty. 27/78 dead at 16 month follow-up stage (insight drawn from companion study). Mean age = 81.6 (SD 5.3).	Home-based care. Median duration of caregiving = 3 years.	Higher burden among carers of care recipients who had more ADL dependence. No difference socio-economic status, gender and clinical measures, such as the comorbidities, cognition, physical performance, frailty and malnutrition.	D= Medium Feminist appraisal = Low. Mention that gender not found as difference. No deeper explanation provided.
Carol Thomas, Mary Turner, Sheila Payne, Christine Milligan, Sarah Brearsley, David Seamark, Xu Wang, Susan Blake (2018)	To illustrate the relevance of 'relevant background worries' in family carers' accounts of caring at home	Qualitative cross-sectional observational study. In-depth, semi-structured interviews. Narrative analysis of a subset of	30 family carers. Median age: 70-79	Older dying adult with malignant and/or non-malignant condition.	England, United Kingdom. Home-based care.	The importance of discussing 'relevant background' worries such as discussing death, losing friends during and after caring and fears associated with	A= High B= High C= High D= High

Family carers' experiences of coping with the deaths of adults in home settings: A narrative analysis of carers' relevant background worries *Palliative Medicine* 32(5): 950-959.	for a dying adult.	transcripts from wider study (N=59).	Gender= 23 women, 7 men. Ethnicity = 28 White-British, 1 White-European, 1 White-North American.	Median age = 80-89. Gender = 21 Males, 9 Females.	Median duration of caregiving = 11 months. Range 2 weeks to 11 years.	partner forgetting who you are.	Feminist= Low. No specific gendered analysis offered.
Kara B. Dassel, Dawn C. Carr, and Peter Vitaliano (2017) Does Caring for a Spouse With Dementia Accelerate Cognitive Decline? Findings From the Health and Retirement Study, *The Gerontologist*, 57 (2), 319-328.	Examine whether dementia compared to non-dementia spousal caregiving is related to cognitive health.	Quantitative longitudinal data from 8 biannual waves of the telephone Health and Retirement Survey (1996-2010). Bivariate analyses, ordinary least square regression	Total sample 1255 surviving spouses, 192 cared for spouse with dementia. Mean age of dementia carers = 76.417 (SD 8.9). Mean age of non-dementia carers 72.38 (SD 9.67).	All had died within the period of the study. With dementia = 192. Without dementia = 1063. Age not reported.	United States. Home and rest home based. Duration of caregiving not reported.	Controlling for baseline health and contextual factors (e.g., frailty status, age, education), dementia caregivers had significantly greater cognitive decline ($p < .01$) compared to non-dementia caregivers. Dementia caregivers cognition continued to decline after caregiving tasks has ceased. Dementia	A=High B=Med C=High D=High Feminist analysis – Low, no discussion of gender.

		applied to 2 waves before and 2 waves after death of care recipient.	Gender = 74% women, 26% men. Ethnicity = 80% non-hispanic white.			caregiving may trigger an underlying neuro- pathological disease process.	
Lisa Ann Williams, Lynne S Giddings, Gary Bellamy and Merryn Gott (2016) ‘Because it’s the wife who has to look after the man’: A descriptive qualitative study of older women and the intersection of gender and the	To explore how gender norms constructed older women’s views about the appropriate roles of women and men in providing palliative and end-of-life	Qualitative focus groups using vignettes around advance care planning. Thematic analysis.	39 older adults. Age range 50-99. Median between 70-79. Gender = 36 women, 3 men. Ethnicity of participants: NZ European/ Māori	Not specific about those who participants had cared-for other than stating that they were end-of-life. Age not reported.	Auckland, New Zealand. Range of care locations. Duration of caregiving not reported.	Caregiving was heavily tied to normative ideas about gender. It was taken for granted by female participants that women should provide end-of-life care.	A=High B=High C=Medium D= High Feminist analysis- High, considering societal constructions of femininity and masculinity and how this plays out

provision of family caregiving at the end of life, *Palliative Medicine*, 31(3), 221-230.	care for family members.		= 1; Niuean = 1; Irish = 1; Australian = 1; NZ European = 31.			Women were viewed as naturally adept to care whereas men were not. Recognition that in their own lives, adhering to norms doesn't equate to being happy with them.	in everyday life, for example, through the use of humour.
Kara B. Dassel and Dawn C. Carr, (2016) Does Dementia Caregiving Accelerate Frailty? Findings From the Health and Retirement Study, *The Gerontologist*, 56 (3), 444-450.	To examine the relationship between care-recipient and whether, compared with the wave prior to death of the care-recipient, spousal caregivers were frailer: 1)	Quantitative longitudinal data from 7 biannual waves of the telephone Health and Retirement Survey (1998-2010).	1246 surviving spouses. Mean age of dementia carers = 75.97 (SD 9.152). Mean age of non-dementia carers = 71.87 (SD 9.863).	All had died within the period of the study. With dementia = 187. Without dementia = 1059.	United States. Home-based and rest-home care.	Dementia caregivers had 40.5% higher odds of experiencing increased frailty by the time the death was reported and 90% higher odds in the following wave compared with non-dementia caregivers. Negative health	A=High B=High C=Medium D= High Feminist appraisal = low, no discussion of gender.

	in the wave the death was reported and 2) 2 years after the death was reported.	Bivariate analyses and logistic regression models applied to 1 wave before and 2 waves after death of care recipient.	Gender = 73% women, 27% men. Ethnicity = 78% Non-hispanic White, 12% non-hispanic black, 7.5% Hispanic, 1.5% other.	Age not reported.	Duration of caregiving not reported.	consequences of caring for a spouse with dementia persist following the cessation of caregiving duties.	
Elizabeth L. Sampson, Rebecca Lodwick, Greta Rait et al. (2016) Living With an Older Person Dying From Cancer, Lung Disease, or Dementia: Health Outcomes From a General Practice Cohort Study, *Journal of Pain and Symptom*	Undertake a retrospective national cohort study to describe the demographic characteristics, health outcomes, and primary care service use of cohabitees of people dying with cancer (lung or coloretical),	Retrospective quantitative study using UK primary care database. Analysis using Poisson regression for morbidities. Mulitvariate Cox proportional hazards ratios for mortality.	13,693 co-habitees of people identified at end-of-life. Total mean age of carers = 78. Mean age of carers of someone with: dementia = 82; cancer = 75; COPD = 77.	All had died of dementia, cancer or COPD. Age not reported.	United Kingdom. Home-based care. Duration of caregiving not reported.	No significant variation in health outcomes between carers of people with cancer, COPD and dementia. All experienced significant increase in GP visits and the prescription of anti-depressants. No mortality differences between	A=High B=High C=High D= High Feminist analysis= low, overwhelmingly female sample, no consideration of gender theory.

Management, 51(5), 839-848.	dementia, or COPD during the year before and after bereavement.		Gender= two-thirds women. Ethnicity not reported.			the three groups. Carers significantly under-identified in primary care records.	
Mary Turner, Claire King, Christine Milligan et al. (2016), Caring for a dying spouse at the end of life: 'It's one of the things you volunteer for when you get married': a qualitative study of the oldest carers' experiences, *Age and Ageing*, 45 (3), 421–426.	To explore the experiences of the 'oldest carers' in caring for a dying spouse at home.	Cross-sectional qualitative design from a larger qualitative study. Framework and thematic analysis.	17 spouses who cared for their dying spouse at home. Age range 80-90. Gender = 9 women, 8 men. Ethnicity = White British = 15, White European = 1, White American = 1.	Range of end-of-life conditions: Cancer = 9; dementia = 3; Parkinson's = 2; Old age = 2; Heart failure = 1; Renal failure = 1. Mean age = 85.6.	United Kingdom. Home-based care. Duration of caregiving: mean = 29 months, median = 11 months.	While spouses wanted to care out of a sense of duty they often were inhibited by their own physical health to do so. Many still providing 24/7 care. Most viewed their role positively.	A= High B= High C= Medium D= High Feminist analysis= low, no gender analysis.

Gwen McGhan, Susan J. Leob, Brenda Baney et al. (2013). End-of-Life Caregiving: Challenges Faced by Older Adult Women. *Journal of Gerontological Nursing*, 39(6), 45-54.	To explore the challenges faced by older adult spousal caregiving providing end-of-life across different life-limiting illness trajectories in distinctive care delivery models.	Qualitative ethnography, instrumental case study. Categorical aggregation analysis.	3 women caring for a spouse. Mean age = 77. Ethnicity not reported.	Partners had ALS, heart failure, lung cancer respectively. Age not reported.	United States. Home-based care. Duration of caregiving not reported. Mean length of marriage 37 years.	Older adult caregivers had their own age-related health issues that increased the difficulty of providing care. increased the demands of caregiving role and in turn impacted their ability to provide care. The type of care delivery model can improve carer burden. Need to recognise carers as co-recipients of care.	A=High B= Medium C=Medium D= Medium Feminist analysis= low, explicit focus on women but no focus on gender.
Minna Maria Poysti, Marja-Liisa Laakkonen, Timo Strandberg et al. (2012) Gender Differences in Dementia Spousal Caregiving *International*	Comparison of the characteristics and burden of male and female spousal caregiving of patients with dementia.	Baseline combined data from two intervention trails (around care coordination and exercise respectively). Quantitative	335 dyads of wife-husband married couples. Mean age of carers =78. Mean	Medium- severe dementia. Age not reported.	Finland. Home-based care.	Male carers have higher rates of comorbidities and cared for partners with more severe dementia than female carers.	A=Low B= Low C=Medium D= Low

Journal of Alzheimer's Disease: 1-5.		Zarit burden scale used for burden and geriatric depression scale used for depression. Logistic regression analysis used.	age of male carers = 77 (SD= 6.2). Mean age of female carers = 78.5 (SD=5.6). Gender of carers = 128 men, 207 women. Ethnicity not reported.	Gender = 128 women, 207 men.	Duration of caregiving not reported.	Male carers experienced less burden including depressive symptoms than women carers. Authors suggest men's higher sense of personal coherence and lower education levels help explain findings.	Feminist appraisal= moderate Considers the gendered context of care (albeit without appeal to gender theory). However, assumptions that women are naturally more included to care are reified.
Sara Sanders and James Power (2009) Roles, responsibilities, and relationships among older husbands caring for wives with progressive dementia and	What are the changes in the roles, responsibilities, and relationships that husbands experience as they provide care for their	Serial, in-depth qualitative interviews. Phenomenological inductive analysis.	17 husbands of Mean age = 77 (SD= 9.5). Ethnicity = all white.	Wives with moderate to severe dementia and chronic health conditions. Age not reported.	United States. Home and rest-home based care.	Older husbands are intimately involved in the care of their wives, providing personal care and emotional support. They actively try to maintain normalcy within their married lives. The health of	A=High B=High C= Medium D= High Feminist appraisal

other chronic conditions *Health & Social Work*, 34, 1: 41-51.	chronically ill wives?				Duration of caregiving not reported. Mean length of marriage = 47 years.	their wife heavily impacts nature of caregiving. Husbands grieved for the impending loss of their partner.	= moderate Engages with stereotypes of male carers in order to nuance them. Little engagement with gender theory.
Helen K. Black, Abby J. Schwartz, Christa J. Caruso et al. (2008), How Personal Control Mediates Suffering: Elderly Husbands' Narratives of Caregiving, *The Journal of Men's Studies*, 16(2), 177-192.	To explore oldest-old men's experiences of suffering in late life.	Qualitative ethnography involving 3 interviews. General qualitative analysis to identify themes.	4 men caregiving for their Mean age 84.5. Ethnicity: African-American = 1; Euro-American = 3.	Wives with moderate to severe dementia. Age not reported.	United States. Home-based care. Mean duration of caregiving = 6 years.	Husbands found ways to cope, with varying degrees of success with caring for their wives. They tried to maintain their self and marriage identities. They strove to find or remind themselves of	A=High B=Low C=Medium D= Medium Feminist analysis= Medium – fit within normative ideas of masculinity e.g. approaching caring like a

						the purpose in their caring.	labor-intensive task and seeking out male carers in their wider sample to explore their particular experience.
JoAnn Perry (2002) Wives Giving Care to Husbands with Alzheimer's Disease: A Process of Interpretive Caring. *Research in Nursing and Health*, 25: 307-316.	To examine the process of becoming and of being a caregiver from the perspective of wives who care for husbands with dementia.	Grounded theory based on symbolic interactionism and using in-depth interviews. Strauss and Corbin's interpretative analysis employed.	20 wives. Mean age = 76.3 (SD 5.61). Ethnicity of carers: African-American = 3; Euro-American = 17.	Husbands with middle and advanced stage dementia. Mean age =78 (SD 6.34).	Washington, United States and British Columbia, Canada. Home-based care. Duration of caregiving not reported. Mean length of marriage = 45 years.	'Interpretative caring' theory emphasising the process of wives' recognition of husband's illness. Wives discussed how they devised strategies to mitigate changes to their daily routine as a result of their husbands' illness. Emphasised importance of maintaining partners dignity.	A=High B=Medium C=High D= High Feminist analysis= low, despite talking about wives no mention of the significance of their gender.

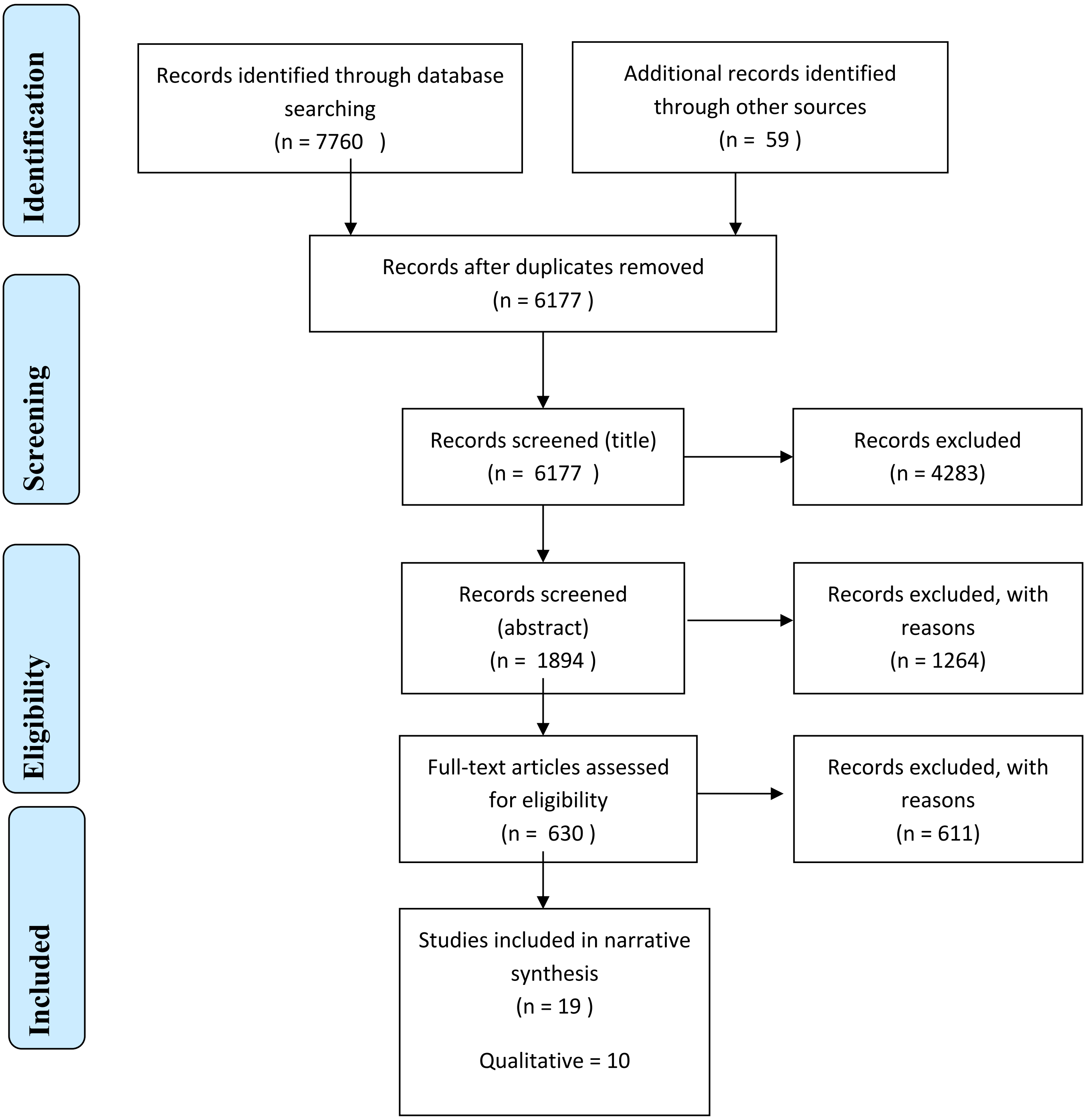
Richard Russell (2001) In sickness and in health: A qualitative study of elderly men who are for wives with dementia *Journal of Aging Studies* 15: 351-367.	To explore the richness and diversity of experiences encountered by elderly men caregivers, as well as the variety of subjective meanings ascribed to their caregiving experiences.	Qualitative research, inductive analysis.	14 husbands. Age range = 68-90 years. Ethnicity: African-American = 1; Eastern-European = 2; Euro-American = 11.	Wives with dementia (but also inclusive of stroke or brain injury). Age not reported.	New York, USA. Home-based care. Duration of caregiving not reported.	Men are capable, nurturing and innovative carers. They struggled with aspects of feeling aspects of their care were invisible. They drew on formal supports when they needed help.	A= Medium B= Medium C= High D= Medium Feminist analysis – High. Situates caregiving within changing place of gender studies, deconstructs gender and sex, considers the role of the male interviewer when speaking with men, seeks nuances in men's answers.
George Siriopoulos, Yvonne Brown,	To look into the experiences	Qualitative phenomenological study.	8 husbands caring for their	Wives with moderate to severe	Alberta, Canada.	The commitment and love men felt to their	A=High B= Low

Karen Wright (1999) Caregivers of wives diagnosed with Alzheimer's disease: Husband's perspectives. *American Journal of Alzheimer's Disease* 14(2): 79-87.	and needs of husbands caring for wives with Alzheimer's disease.	Giorgi's analysis.	Age range of carers = 64-92. Ethnicity = All white.	Alzheimer's disease. Age range = 68-90.	Home and rest-home based care. Duration of caregiving range from 1-10 years.	wives underpinned their caregiving. Caregiving was experienced as a series of losses, some of which were Alzheimer's specific.	C=High D= Medium Feminist analysis – medium, engages with social reproductive theory and Tronto's idea that care roles are not naturally engrained but doesn't push analysis further.
Helen Edwards & Patricia Noller (1998) Factors Influencing Caregiver- Care Receiver Communication and Its Impact on the Well-Being Older Care	To examine communication between frail older people and their caregiving spouses, and its relation to well-being in	Quantitative structured survey administered in person and video-taped observation of communication. urvey method with self-	53 spousal dyads. 27 caring wives, 26 caring husbands.	Cared-for a range of frailty including cancer, respiratory disease and arthritis. Dementia excluded.	Australia. Home-based care, involved with community	Caregiving wives used more overprotective communication than caregiving husbands. Carers with low life satisfaction more likely to use	A=High B= Medium C=Medium D= Medium Feminist analysis= Low,

Receivers, *Health Communication* 10,4: 317-341.	older care receivers.	reported health and communication tone ratings observations. Bartlett's test of sphericity, Kaiser-Meger-Olkin and multiple linear regressions. No ethics recorded.	Mean age = 74.5 (SD 7.14). Ethnicity = Majority born in Australia, with a few from United Kingdom and Europe.	Mean age = 78 (SD 7.35).	care agencies. Duration of caregiving = 9 years (SD 2.68)	patronising communication.	despite flagging discrepancies in expected gendered norms in relation to how women communicated (using language to take control).
Sharon L. Tennstedt, Sybil Crawford, and John B. McKinlay (1993) Determining the Pattern of Community Care: Is Coresidence More Important Than Caregiver Relationship? *Journal of Gerontology*,	To determine whether co-residence is more important than caregiver relationship when explaining amount of care received by frail elderly.	Quantitative, longitudinal telephone survey, with first follow-up (4 yrs after baseline). Multiple logistic regressions and stepwise modelling	445 frail elders and their primary carers. Mean age of carers = 79. Ethnicity no reported.	55.4% of people living with carer and 34.5% living without had severe frailty. Median age range of care recipients = 80-84.	Massachusetts, USA. Home-based care. Duration of caregiving not reported.	Receipt of informal care is more likely for elders co-residing with a caregiver, regardless of who that person is. Co-resident caregivers used formal services significantly less.	A= High B= High C= Medium D= High Feminist analysis- Despite highlighting a number of gendered disparities

48(2): 574-583.		procedures. No ethics recorded.	Gender of spouses living with partner = 60% women, 40% men.				reported across caregivers and receivers no further theorisation. Makes an argument for equity of services so has broad social justice commitment.

Appendix 8: PRISMA 2009 Flow Diagram



Narrative Study documents

Appendix 9: Flyer

Are you over 75 and looking after your spouse or partner with cancer, chronic chest disease, heart disease, dementia or a similar condition?

Tessa is a researcher who would like to learn from your experiences to help others.
Please get in touch with her to learn more.

Phone or txt: 07428 150189
Email: tlm32@medschl.cam.ac.uk
Mail: Cambridge Institute of Public Health,
Forvie Site, Robinson Way, Cambridge, CB2 0SR

UNIVERSITY OF CAMBRIDGE

IRAS Project no: 253939 Version: 1.2 Date: 4.2.2019

Appendix 10: Consent Form

UNIVERSITY OF
CAMBRIDGE

Looking after my spouse study
Participant Consent Form

I confirm that (please tick box as appropriate):

1.	I have read and understood the information about the project, as provided in the Information Sheet	☐
2.	I have been given the opportunity to ask questions about the project and my taking part.	☐
3.	I voluntarily agree to take part in the project.	☐
4.	I understand I can withdraw at any time without giving reasons and that I will not be asked why I have withdrawn.	☐
5.	The ways in which the research will be kept confidential has been clearly explained to me (e.g. not using people's real names, making the information anonymous, etc.).	☐
6.	I consent to the interview being audio-recorded.	☐
7.	The use of the data in research, publications, sharing and archiving has been explained to me.	☐
8.	I understand that the information I provide will be confidentially maintained in line with the information sheet.	☐
9.	I agree for the information I provide to be made anonymous, stored securely, and held for future research undertaken by the researcher.	☐
10.	I am happy to be re-contacted to contribute to later stages of the research.	☐
11.	I, along with the researcher, agree to sign and date this informed consent form.	☐

Participant:

Name of Participant Signature Date

Researcher:

Name of Researcher Signature Date

IRAS Project no: 253939 Version: 1.2 Date: 04.02.2019

Appendix 11: Participant Information Sheet

UNIVERSITY OF
CAMBRIDGE

Looking after my spouse study

Participant Information Sheet for interview

You are being invited to take part in a research study. Please read through the following information, and feel free to ask any questions if you would like more information. You are free to decide whether or not you would like to take part.

Who is the researcher?

Tessa Morgan is a PhD student in Primary Care at the University of Cambridge. This research is being done as part of her studies.

Nature and aims of research:

This research aims to explore experiences of care amongst older couples.

Do I have to take part?

Taking part in this research is entirely voluntary. You also have the right to withdraw any audio recordings/transcripts for up to one month post-interview.

What does taking part involve?

You will be contacted by Tessa, the researcher, to arrange an interview lasting around one hour, in a place and at a time of your choosing. You also have the option of getting in touch with Tessa directly, either via phone, email or in writing to indicate your interest in this study. Tessa will telephone you about one month later to ask how things are going and arrange a second interview about one to two months later. She will make field notes of this phone call. She may also arrange a third interview with you one or two months after second interview. The interview will be very informal; Tessa will lead a discussion about what looking after your spouse, or receiving care from you spouse, involves for you,. She is also interested in learning about your experiences with health services and your support needs. You may choose to be interviewed with your partner and/or separately.

The recording will be typed up (in some instances by an external transcriptionist who has signed a confidentiality agreement), and made anonymous: some quotations will be used in the research analysis and in reports and publications that come from this research or future research. These quotations will all be anonymous: it will not be possible to identify you or anyone else from them.

Risks / disadvantages of taking part.

We do not expect that there will be any risks in taking part. If at any time you feel you do not want to talk about some things, or do not want to continue taking part, you are free to withdraw at any time.

There is a possibility that during the interview some things may come up that you may find distressing. You can discuss with the researcher whether you want to continue taking part in the discussion or not. Tessa, the researcher, can also help you to find further support if you would like that.

Benefits of taking part.

While there are no immediate benefits from taking part in this research, we hope that most people will find it helpful to talk about their experiences of looking after someone or being looked after by a partner. We are aiming to use the findings of this research to help make changes to the way people are helped and supported when looking after others or being cared for.

What will happen to the results of the research?

The results of the research will be presented at conferences and published in scientific journals. It is hoped that the results will be used to develop guidance for best practice for how services support older couples where one or both need care and support.. A summary of the results will be available to people taking part if they would like that. Tessa will ring you after the study has been completed to ask if you would like the findings to be sent to you.

What if there is a problem?

If you have a concern with any aspect of this research, you can speak to Tessa, the researcher, who will do her best to answer your questions. Her contact number and email address are provided at the top of this information sheet.

If you remain unhappy and wish to complain formally, you can contact Tessa's research supervisor Dr Stephen Barclay on sigb2@medschl.cam.ac.uk or through the post: Cambridge Institute of Public Health, Forvie Site, Robinson Way, Cambridge, CB2 0SR.

Privacy and confidentiality

Priority will be to participant's confidentiality. Any information shared by a participant will not be shared to other family members unless explicitly instructed by them to do so. No information will be shared with health care providers other than in the case of potential serious harm.

Audio recordings of interviews and typed-up copies of these recordings will be stored in a secure password-protected file on the researcher's computer. In any written reports, people's names and place names will be changed in order that everything is anonymous. We will follow the Data Protection Act 2018 in the way we handle, store and eventually destroy the research data.

The University of Cambridge is the sponsor for this study based in the United Kingdom. We will be using information about you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Cambridge will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information https://www.medschl.cam.ac.uk/research/privacy-notice-how-we-use-your-research-data/

Transparency

A member of your NHS team will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. The NHS site will pass these details to Tessa Morgan, a researcher at the University of Cambridge. The only people in the University of Cambridge who will have access to information that identifies you will be the researcher who will conduct the interview or else someone who will audit the data collection process. Individuals from University of Cambridge and regulatory organisations may look at your medical and research records to check the accuracy of the research study. As a safety precaution for the researcher, your address will be passed onto her supervisor Dr Barclay so that he knows where she is in case of an emergency. The people who analyse the information – other than the researcher who conducted the interview – will not be able to identify you and will not be able to find out your name or contact details.

Funding

This research is funded by the Woolf Fisher Trust in New Zealand.

***Ethical* review of the study**

The project has received ethical approval from the NHS Research Ethics Service and Research Ethics Committee.

Contact for further information

Tessa Morgan
Cambridge Institute of Public Health

Forvie Site
Robinson Way
Cambridge
CB2 0SR
Email: tlm32@medschl.cam.ac.uk
Phone number: 07428150189

IRAS Project no: 253939 Version: 1.2 Date: 04.02.2019

Couple ID	Pseudonym	Partner providing care	Age	Ethnicity	Care-receiving partner	Age	Ethnicity	Care recipient diagnosis	Number of interviews	Type of carering
1	Margaret	Wife	78	Scottish	Husband	78	Scottish	Alzheimer’s	3	Ambivalent
2	Mary	Wife	74	White British	Husband	74	White British	Alzheimer’s	1 (Caregiver died)	Engaged
3	John and Betty	Husband	84	White British	Wife *	78	White British	Advanced Frailty	3	Disengaged (both)
4	Evelyn	Wife	70	White British	Husband	85	White British	Vascular Dementia (deceased)	3	Engaged
5	Kathleen	Wife	73	White British	Husband	85	White British	Front temporal Dementia	3	Engaged
6	Carol	Wife	77	Welsh	Husband	89	Jamaican	Cancer and Alzheimer’s	2 (Couple evicted)	Ambivalent
7	Donna	Wife	80	White British	Husband	84	Irish	Cancer, Vascular Dementia, Stroke	3	Engaged
8	Donald and Rita	Husband	75	White British	Wife *	73	White British	COPD	3	Ambivalent (both)
9	Helen	Wife	78	White British	Husband	82	White British	Vascular Dementia, COPD	1	Engaged

10	Elizabeth	Wife	71	White British	Husband	72	White British	Alzheimer’s and Vascular Dementia	3	Ambivalent
11	Patricia	Wife	73	White British	Husband	72	White British	Parkinson’s	3	Ambivalent
12	William	Husband	85	White British	Wife	85	White British	Alzhiemers	2	Disengaged
13	Joan	Wife	73	White British	Husband	79	White British	Parkinson’s/Lewy Bodies Dementia	2	Ambivalent
14	Radhika	Wife	80	Indian	Husband	84	Indian	Alzheimer’s	2	Engaged
15	Barbara	Wife	77	White British	Husband	82	White British	Vascular Dementia	3	Engaged
16	Guilia	Wife	89	Italian	Husband	89	Indian	Lewy Bodies Dementia	2	Disengaged
17	Charles	Husband	80	White British	Wife	87	White British	Stroke	1	Ambivalent
			M=77.5		*=care recipient also participated	M= 81.05			41	Engaged= 7 Ambivalent = 8 Disengaged = 4 = 19 (excluding

										mid-life daughter)

*Note Helen was interviewed along with her daughter who also consented to take part in the study as a support person. Given the focus of the study I have not included her details here.

Appendix 12: Characteristics of Participants

Appendix 13: Partners involvement in interviews

Pseudonym	Number of interviews	Number of interviews both partners involved	Couples where both were involved
Margaret	3	2	Yes
Mary	1 (Carer died)	1	Yes
Betty and John	3	3 (Both participants)	Yes
Evelyn	3	2	Yes
Kathleen	3	3	Yes
Carol	2 (Couple evicted)	2	Yes
Donna	3	2	Yes
Donald Rita	3	3 (Both participants)	Yes
Helen	1	1	Yes
Elizabeth	3	2	Yes
Patricia	3	0	No
William	3	2	Yes
Joan	2	0	No
Radhika	2	2	Yes
Barbara	3	2	Yes
Guilia	2	0	No
Charles	1	1	Yes
	41	27	14/17 both involved

Appendix 14: Interview schedule for one-on-one or couple interviews

Could you tell me a bit about what its like to look after your spouse?

- Has this changed since the diagnosis (if applicable)?
- What kind of tasks does you ‘looking after involve?’

Does anybody help you with things on a day-to-day basis (prompts: personal care, shopping, cleaning)?

Do you see yourself as a carer?

Do you receive any formal health or social care services? If so, what sorts of services are they?

- Do any of them involve you identifying as a carer? Is that a label that fits you?
- Is there a label you’d prefer?

Thinking about the future, what sorts of services do you think you’ll need or want?

Appendix 15: Maintenance Art: Paul Stenner’s liminality and the case of older caregiving spouses

Tessa Morgan, Robbie Duschinsky, Stephen Barclay

A. The Death Instinct and the Life Instinct:

> The Death Instinct: separation; individuality; Avant-Garde par excellence; to follow one’s own path to death – do your own thing; dynamic change
>
> The Life Instinct: unification; the eternal return; the perpetuation and MAINTENANCE of the species; survival systems and operations; equilibrium. (Mierle Laderman Ulkeles, Manifesto for Maintenance Art, 1969! *Proposal for an Exhibition "CARE"*)

Born out of frustration of performing the seemingly-incompatible identities of new mother and artist, Mierle Laderman Ulkeles begins her *Manifesto for Maintenance Art* outlining the two properties she views as underpinning the patriarchal capitalist system.[1] She dedicates the remainder of her manifesto proposing how *Care* – the intended name of her new exhibition – provides an animating force that blurs the boundaries between motherhood and art as modes of existence. She writes that she aims to make visible all of the “washing, cleaning, cooking, renewing, supporting, preserving etc.” involved in everyday life by putting her life on show by living in an art gallery for a month. In this “world between a world” offered by the public gallery space, Ulkeles contemplates the sometimes dirty, always constant processes of the everyday social reproduction of the self-as-artist and self-in-society. Through her work, Ulkeles presents an open question: how women’s lives can be remade into something more manageable and just?

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[1] Mierle Laderman Ulkeles (1971) Manifesto for Maintenance Art, 1969! *Proposal for an Exhibition "CARE"* in Jack Burnham. "Problems of Criticism." *Artforum*: 41.

Ulkeles' focus on maintenance as a creative strategy is offered as a deliberate counterweight to the rapid developments of the 1960s. This "decade caught between one America and another" was both one which saw the rise of the women's, civil rights and gay liberation movements and a conservative Richard Nixon presidency amidst the deepening of the imperialist Vietnam war.[2] Interestingly, it is within the period of cultural flux that the concept of liminality is introduced into the English-speaking academy by Victor Turner's advocacy of Arnold van Gennep's 1909 ideas.[3] In attending to questions of what happens when individuals find themselves "betwixt and between" recognisable social states, we can see Turner and Ulkeles as analogous projects of trying to take stock of the liminality of their collective Western milieu.[4]

Scholars have argued that we are now in a persistently liminal period replete with economic and social instability following the 2008 global financial crisis along with slower-burning crises including ecological disaster due to man-made climate change and biological changes meaning we are living for far longer but with an increasing number of chronic life-limiting conditions.[5] Paul Stenner's new theory of liminality has thus arrived at just the right time to be exceedingly useful for fellow critical theorists seeking to make sense of our dizzying historic moment.[6] The particular utility of his theory lies both with the conceptual tools he offers us to 1) precisely diagnosis liminal moments and 2) understand how people can agentically and creatively navigate a range of liminal zones.

Taking up Stenner's call to apply his concept of liminality to empirical research, this chapter draws on three specific cases studies drawn from a year of longitudinal narrative interviews and observations

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[2] Michael J. Heale (2001) The sixties in America : history, politics and protest Keele University Press: Newcastle.

[3] Van Gennep, A. (1960) The Rites of Passage. 2nd edition. Routledge: London; Turner, V. (1967) Betwixt and Between: The Liminal Period in Rites de Passage, in The Forest Symbols: Aspects of Ndembu Ritual. Cornell University Press: Ithaca. pp. 93-112.

[4] Turner, p. 97; see also Mary Douglas (1966) Purity and Danger: An analysis of the concepts of pollution and taboo. Routledge and Kegan Paul: London.

[5] Thomas Piketty (2014) Capital in the Twenty-First Century Harvard University Press: Cambridge, MA; Szakolczai, A. (2014) Living permanent liminality: the recent transition experience in Ireland *Irish Journal of Sociology* 22(1): 28-50.; Lisa Baraitster (2017) Enduring Time Bloomsbury: London; Naomi Klein (2019) On Fire: The Burning Case for a Green New Deal. Allen Lane: London; World Health Organisation (2017) World Population Ageing 2017 Highlights. World Health Organisation: New York.

[6] Paul Stenner (2017) Liminality and Experience: A Transdisciplinary Approach to the Psychosocial. Palgrave Macmillan: London.

Szakolczai, A. (2009) Liminality and Experience: Structuring transitory situations and transformative events *International Political Anthropology* 2(1) 11-38. Wendy Brown (2005) Edgework. Princeton University Press: Princeton.

with 17 older couples all aged over 70,living in the East of England, and where at least one member was diagnosed with a palliative, life-limiting condition and the other was their primary caregiver. Taking seriously the somatic as well as symbolic bridge between life and death offered byUlkeles, the first section of this chapter will consider the ways "uh oh" moments can be triggered by seemingly mundane moments of care that catalyse older spouses' reinterpretation of their situation and self. We will argue that such moments of disappointed expectations are inseparable from the wider "uh oh" moment of biomedicine itself. The second section will then compare and contrast the ways older caregiving spouses make use of what Stenner terms "affective liminal technologies" to pursue – albeit not always successfully – "ah ha" moments that complete liminal passages. We will draw on intersectional theory to further illuminate how people's specific social location can explain why some older caregiving spouses remain stuck in the liminal contrary to their wishes. Ultimately by following Ulkeles rallying call to "zero in on pure maintenance" we can see how the act of older spouses' care work becomes an art *and* sometimes art itself as they navigate the very real circumstances of life and immanent death.[7]

Stenner on liminality

Stenner argues that liminal experiences occur when someone or something is confronted with "this is not" experience, which he defines as "disturbing events" that trigger an "emotional flash of consciousness" as a result of a "disappointment of expectations".[8] He argues that this passage is negotiated via a deep empiricism, which includes the sense data of presentational immediacy (what is currently observed) and causal efficacy (the events immediately preceding the 'event').[9] It is the mismatch between these two senses that prompts an "uh oh" moment. He distinguished further between "devised" "uh oh" moments like marriage or coming of age ceremonies which are expected versus unexpected, "spontaneous" "uh oh" moments like the loss of a spouse from terminal illness or the breakout of war.[10] He argues that in both cases people may draw on "affective liminal technologies" to navigate the discombobulating nature of liminal passages.[11] These technologies are often utilised to bring about an "ah ha" moment defined as "a new insight or intuition permitting the drawing of a new boundary" ultimately ending the liminal experience.[12] He argues that devised "uh oh" moments lend

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[7] Mierle Laderman Ulkeles, Manifesto for Maintenance Art, 1969!, p. 2.
[8] Stenner, pp. 80, 81
[9] Stenner, p. 98.
[10] Stenner, p. 16.
[11] Stenner, p. 25.
[12] Stenner, p. 83.

themselves better to more formalised liminal affective technologies such as ritual, plays, songs, and other culturally enshrined art objects. In fact in some instances they are used to precipitate liminality as attested by Van Gennep's original focus on how rituals often work as rites of passage.[13] Whereas spontaneous "uh oh" moments – precisely because of their unexpectedness – tend to use more discrete and/or makeshift and impromptu symbols.

Stenner's account of liminality provides two important contributions to the existing field of liminality. First, he usefully decouples the concept from the rites of passage, which have until now provided its main explanatory thrust. By doing so Stenner brings back in the ambivalence at the heart of the liminal experience whilst also capturing experiences not necessarily rendered visible by this traditional schema. For example, while the dying phase might make the cut of a liminal state, caring for someone dying is less identifiable as a necessary rite of passage. A second and related point is that he places the onus on the analyst to explain exactly what makes something or someone liminal as oppose to defaulting to pre-existing 'experiences' commonly regarded as liminal. This makes clear the important contributions empirical social scientists can make to the development of the concept through close observation and discussions with their participants.

Third, and perhaps most innovatively, Stenner argues that we must be attentive to the new forms of subjectivity produced within – not only after – the liminal passage. Stenner tells us that the 'uh oh' occurs when someone is faced with a sense of crushing conformity or exhilarating freedom that goes beyond certain expectations that they have had for their life (this is not *my* experience). Liminal periods are thus ripe for the production of new forms of self. What is more, Stenner's focus on processual thought also challenges us to think about *how* these new subjectivities are constructed. While they may form along the lines of the death instinct through dynamic change and deepening individualism they are equally likely to form via life-instinct processes of attempted unification and maintenance (or indeed any combination of the two).

End-of-Life Care and Liminality

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[13] Stenner, p. 14.

Liminality has been widely used in end-of-life studies because death has been associated with a definitive rite of passage.[14] Julia Lawton has argued, however, that in modern times the diminished religiosity of the West has meant the dying period itself rather than the afterlife has become the key liminal passage (note in Van Gennep his discussion of the liminal only begins once the person is dead).[15] It is in this context that those providing end-of-life care are now commonly described as liminal too because of their proximity to death and the expected dramatic changes to self in the post-bereavement period.[16] Nevertheless, by viewing liminality as a description of a state rather than a process associated with material lived specifics of caregiving, end-of-life care studies has done precisely what Stenner warns against: dulling the concept of liminality into an "observable 'it'".[17] The taken-for-grantedness of end-of-life caregiving as liminal is deficient on a number of levels but most notably because the diagnosis assumed to trigger the liminal period is far from clear-cut in the cases of long-term yet life-limiting chronic conditions such as Dementia and Advanced Frailty which disproportionately impact older populations. [18] Moreover, given the cultural expectations to care for one's spouse in sickness and in health, the revelation that one's partner requires care due to illness is associated with a shoring up of one's social status rather than a shattering of expectations.[19] This is particularly prominent for women who are disproportionately expected to care for children, grandchildren, parents across their life course.[20] To understand precisely how end-of-life care is experienced as liminal as well as to make sense of the subjectivities that are produced betwixt social states we therefore need to look to the specific disturbing events that make older spouses go "uh oh".

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[14] Little, M., Jordens, C. F. C., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness. *Social Science & Medicine*,

47, 1485–1494; Navon, L., & Morag, A. (2004). Liminality as biographical disruption:

Unclassifiability following hormonal therapy for advanced prostate cancer. *Social Science & Medicine*, *58*,

2337–2347; Nicholson, C., Meyer, J., Flatley, M., Holman, C., & Lowton,K. (2012). Living on the margin: Understanding the experience of living and dying with frailty in old age. *Social*

Science & Medicine, *75*, 1426–1432.

[15] Julia Lawton (2009) The Dying Process: Patients' Experiences of Palliative Care Routledge: London; Van Gennep devotes a whole section on 'Funerals' in his original work; Szakolczai, A. (2009) Liminality and Experience: Structuring transitory situations and transformative events *International Political Anthropology* 2(1) 11-38.

[16] Jordan, J., Price, J., Prior, L. (2015) Disorder and disconnection: parent experiences of liminality when caring for their dying child *Sociology of Health and Illness* 37(6): 839-855; Caroline Pearce (2019) The Public and Private management of Grief: Palgrave MacMillian: London.

[17] MacArtney, J.I., Broom, A., Kirby, E., Good, P., Wootton, J. (2015) The Liminal and the Parallax: Living and Dying at the End of Life *Qualitative Health Research* 27(5): 623-633; Stenner, p. 178.

[18] Gardiner, C., Ingleton, C., Gott, M., & Ryan, T. (2011). Exploring the transition from curative care to palliative care: A systematic review of the literature. *BMJ Supportive & Palliative Care*, *1*, 56–63; Larkin, PJ., Dierckx de Casterie, B., Schotsmans, P. (2007) Towards a conceptual evaluation of transience in relation to palliative care *J Adv Nurs* 59(1): 86-96.

[19] Howarth, G. (1998) 'Just live for today': Living, caring, ageing and dying *Ageing and Society* 18: 673-689.

[20] Kittay. E. (1999) Love's Labor: Essays on Women, Equality and Dependency (Thinking Gender). Routledge: London.

The ‘Uh oh’

Donna

Donna, as with all the women you will meet in this chapter, is married to a very ill man.[21] At age 80 she is the primary caregiver for her 84 year-old husband Mikey who is six years on from a diagnosis of Vascular Dementia and in remission from Penile Cancer. Most recently he has developed mini-strokes meaning, as Donna puts it, he could drop “like a sack of potatoes” at any moment. His diagnosis and even his castration as part the treatment for his cancer received very little attention in her narrative however. She seemingly incorporates such dramatic occurrences fundamentally back into her understanding that getting older is necessarily involved with developing disease and as his wife she was always going to be the one caring for him. What occupies Donna’s narrative attention and what we argue has triggered her “uh oh” “this is not” experience moment comes about over a seemingly more quotidian matter of tea-making.

The story below features in some variation in each of the three audio-recorded interviews:

> ***R****: …But I have to hide the kettle now and all tablets are out of sight because we’ve had a couple of times where he’s taken my tablets so I’ve had to put them all away hide them and the kettle because good job I was here he decided he would make a cup of tea and I thought I’ll let him just keep an eye on him. So he filled the bowl the washing up bowl full of water put the kettle into it and then filled the kettle up*
>
> ***I: Oh***
>
> *R: and then he was picking it up all dripping to put on the electric [pause]*
>
> ***I: Oh, that would have been dangerous***
>
> *R: and well he would have electrocuted himself I think so that is [pause] a bit of a worry so what I’ve got to do is just take out of sight anything that with the gas, he hasn’t got a clue how to cos you have to press it down hold it and then turn it well he wouldn’t think of that he wouldn’t be able to turn it. And think that oh you know so that is one good thing so really it’s the kettle so as long as everything is out of reach of him doing any damage to himself, and I’m only gone sort of half an hour but in the mornings, I always walk the dog early mornings so I just leave him in bed until the lady comes to sort him out.*
>
> *[Interview 2]*

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[21] Note that all names have been changed to ensure the anonymity of participants.

In this moment the presentational immediacy of Mickey's incapacity to boil the kettle combines with the casual efficacy that had he been left to his own devises he would have severely injured or killed himself. As such it is a moment of recognition that his actions, not simply his body, have become a liability to himself. Deeper still, however, when he is unable to conduct this ritual fundamental to British culture – making of tea both for oneself and others – his autonomy and indeed his adulthood is called into question. Haim Hazan has argued that tea making is a "time-reckoning device" because it is so "deeply entrenched in the daily life" of English adults.[22] For Donna, Mickey's inability to make tea sticks out to her as a point at which she recognised her self and them as a couple *in* time making her home space feel extraordinary.[23] Laura Berlant has described this sense of feeling historical as a process of when "amidst the usual activity of life … norms and intuitions suddenly feel off".[24]

Locating Donna's "uh oh" moment in the mundane seemingly contravenes Stenner's contention that given liminal moments require a "suspension or interruption of recurrent events" they do not occur in mundane settings or "business as usual" routines.[25] Nevertheless, we would argue that taking ordinary insights seriously helps to further contextualise Stenner's theory. In a time of increasing chronic illness amongst other forms of "slow death" as Berlant terms it, "zones of ordinariness" are often acutely difficult to diagnoses as they comprise at once places of "life building and the attrition of human life".[26] Thus it is incredibly difficult from outset to predict what will be experienced as mundane or exceptional. Moreover, because many of our participants could not easily leave their homes (due to caregiving constraints and/or physical limitations), we argue that something altering in their everyday is liable to produce more severe existential whiplash than if it were to happen elsewhere. Indeed, utilising Stenner's conceptual tools to "autopsy" the everyday highlights that the location of the biggest change may be felt on the level of one's subjectivity.[27]

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[22] Haim Hazan (1987) "Holding time still with cups of tea" in Mary Douglas ed. Constructive Drinking: Perspectives on Drink from Anthropology. Cambridge University Press: Cambridge, p. 206.

[23] Stanley Cavell (2018) In quest of the ordinary: lines of scepticism University of Chicago Press: Chicago, p. 20.

[24] Berlant, L. (2008) Thinking about feeling historical *Emotion, Space and Society,* 1*:* 5

[25] Stenner, p. 82.

[26] Berlant, L. (2007) Slow Death (Sovereignty, Obesity, Lateral Agency) *Critical Inquiry*, 33, 4: 754-780..

[27] Cavell, p. 20.

Upon recognising that her husband is no longer able to participate in adult practices, Donna reconsiders her husband's personhood and in turn her own. Like many participants caring for someone with dementia, Donna refers to her husband at different points as 'baby-' or 'child-' like.[28] This 'uh oh' moment therefore attests to a changing level of dependency in their relationship. Donna now must be attentive of her husband 24/7 in order to keep him safe. In this moment she also recognises that she can no longer be reliant on her husband for certain aspects of their joint lives, such as intimacy identifiably exchanged through the making and receiving of a hot drink by someone dear. Thus the moment at which she recognises she must become her husband's ever present minder, as a mother would her child, is also the moment at which the depth of their pre-existing "nested dependencies" as Eva Kittay terms it, reveal themselves.[29]

Through this two-folded process of ontological coalescence Donna senses that she and Mickey have subjectively transitioned from being two individuals to being a dyad. The formation of a dyadic unit between care provider and care receiver has been similarly observed in ethnographies examining health care assistants caring for older adults and familial care provided to dying kin.[30] This scholarship has focused on the dyad emerging from habituated process of intimate, intensive body work through which care providers come to see their care recipient's body as an as an extension of their own.[31] As is made visible through the Donna's "uh oh" moment, their dyadic connection precedes intensive body-work and is rather located in the changing logic of their long-term romantic relationship.

In this distinct context Donna and Mickey's account also indicates ways that the dyad can take a more mutual rather than hierarchical form. This is evidenced in Donna's subtle deployment of the term 'like' following any instance she uses infantilising language. We understand this semantic choice as an act of maintenance, both of his dignity but also of the legitimacy of their kinship connection.[32] It provides a

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[28] A tendency arguably further entrenched by scholarship itself: see discussion in Kontos, P. (2005) Embodied selfhood in Alzheimer's disease: Rethinking person-centred care *Dementia* 4(4): 553-570.

[29] Kittay.

[30] Buch, E. (2013) Senses of care: Embodying inequality and sustaining personhood in the home care of older adults in Chicago *American Ethnologist* 40(4): 637-650;

Mazus, Keren. (2013) The Familial Dyad between Aged Patients and Filipina Caregivers in Israel: Eldercare and Bodily-based Practices in the Jewish Home *Anthropology and Aging* 34(3): 126-134;

[31] Lawton, p. 107.

[32] Boreman, John (2001) Caring and Being Cared For: Displacing Marriage, Kinship, Gender, and Sexuality in James D. Faubion ed. The Ethics of Kinship: Ethnographic Inquiries Rowman & Littlefield Publishers: Maryland.

defence from her becoming her husband's mother, which is taken as the paradigm of one person (the mother) being instrumentalised into the other (baby).[33] Their mutually contingent lives are further attested to by the spontaneous decline of Donna's health amidst Mickey's increasingly rapid decline of cognition and motor function. Between the first and second interview, Donna collapsed at the bedside of her husband who had recently been discharged to a care home from hospital following another mini-stroke. She is subsequently admitted as a patient in a nearby hospital. Rather than her self and body simply being an extension of his then, we argue that they are mutually constitutive of each other. Just as she performs a role of keeping him safe and alive, he also offers her the will and reason to continue to live. In this context it is perhaps unsurprising that it is when he is taken out of her care that her body reveals the full extent of its decline. It is only through her repetition of the tea story against the changing realities of their health and their mutually increasing inability to psychically care for each other that Donna and Mickey's inter-subjective and inter-corporeal connection is made tangible; both to us as analysts but also on some level to Donna herself. In this process it becomes clear that this 'uh oh' moment was never just about when it went wrong for Mickey but rather for them both.

Donna and Mickey's situation thus offer an interesting insight Stenner's contention that there always remains an unbridgeable gap between the psycho and the social (noting that the psychosocial is his broader theoretical framework for liminality). Stenner argues that one must always make an "imaginative leap" if we are ever to feel the pain of another.[34] Nevertheless, we argue that to take seriously the ambiguity and uncertainty at the heart of the liminal is to leave open the possibility for new subjective entities to form within it. We contend that in acute moments prompted by the ontologically challenging and physically draining nature of end-of-life, care may really get under one's skin and form previously unimaginable subjectivities including the dyad.

Bio-medicine's 'uh oh' moment

Donna and Mickey's story can be regarded as a microcosm of a wider "uh oh" moment within the contemporary biopolitical enterprise. Michel Foucault argues that the current modern form of power

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[33] Sara Ruddick (1989) Maternal Thinking: Toward a Politics of Peace Beacon Press: Boston.

See also Nancy Chodorow (1978) *The Reproduction of Mothering.* Berkeley: University of California Press; Lisa Baraitser (2009) Maternal Encounters: The Ethics of Interruption Routledge: London.

[34] Stenner, p. 15.

structures are arranged around the "power to foster life or disallow it to the point of death" in order to ensure healthy, productive populations.[35] The widespread emergence of non-curable, life-limiting conditions such as dementia in late modern society pose a significant challenge to the biopolitical order to continue to "foster life".[36] Ironically this situation can be understood as an unintended outcome of the success of public health campaigns, public sanitation initiatives and developments in medical technology, which mean people are living into such advanced age and are thus increasingly susceptible to developing palliative conditions that allude any biomedical cure. The ensuing rapidly globally ageing populations without the necessarily social support structures (at the level of society and family) to provide such care have subsequently caught international and national organisations "off guard".[37] It is also illustrative of the much deeper crisis of care at the heart of financialised capitalism whereby profit and growth are privileged over the maintenance processes and people involved in the social reproduction of society.[38]

In this context the second half of the definition of biopower "… disallow [life] to the point of death" has become increasingly relevant.[39] In the *Birth of Biopolitics* Foucault prophetically argues that older people occupy a "liminal" status and thus can always be brought back into recirculation from retirement in the event of potentially destabilising crises.[40] A dramatic contemporary example of this has been the recruitment of retired doctors and nurses to fight the COVID-19 pandemic. In the slower burning crisis of the ageing population, we contend that older spouses have been implicitly recruited qua heteronormative social mores and explicitly by the lack of external support to be personally responsible for keeping their partner "in sickness and health", in other words alive. By supporting for their partners to live into their very old age, older spouses help to ensure longevity rates high and the semblance of thriving productive economies that foster life intact. This is despite the individual impact incurred by those providing care.[41] To publicise the extent of the care provided by older spouses (especially without any additional formal support) and the impact it has on their health, however, would undermine the

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[35] Foucault, History of Sexuality. p. 138.

[36] Foucault, History of Sexuality, p. 138.

[37] Elana D. Buch (2015) Anthropology of Aging and Care *Annu. Rev. Anthropology* 44: 277-93.

[38] Nancy Fraser (2017) Crisis of Care? On the Social-Reproductive Contradictions of Contemporary Capitalism in Tithi Bhattacharya (ed.) *Social Reproduction Theory*. Pluto Press: London.

[39] Giorgio Agamben (1998) Homo Sacer: Sovereign Power and Bare Life Stanford University Press: Stanford; Joao Biehl (2005) Vita: Life in a Zone of Social Abandonment. University of California Press: California.

[40] Michel Foucault (2008) The Birth of Biopolitics: Lectures at the College De France 1978-79. Pallgrave: Basingstoke.

[41] Foucault, History of Sexuality, p. 138; Dassel K, Carr D. Does Dementia Caregiving Accelerate Frailty? Findings From the Health and Retirement Study. The Gerontologist. 2016;56(3):444-50; Potier F, Degryse JM, Aubouy G, Henrard S, Bihin B, Debacq-Chainiaux F, et al. Spousal Caregiving Is Associated with an Increased Risk of Frailty: A Case-Control Study. The Journal of frailty & aging. 2018;7(3):170-5.

notion of the universal health care system being responsive to people's needs equally.[42] It would also show up the deeper crises of care which is predicated on some people, typically women, sacrificing their lives in order for other people and cultural norms to prevail.[43] As such older caregiving spouses necessarily occupy a chthonic position in late modernity by being indispensable and yet necessarily invisible. Stenner's conceptual arsenal enables us to articulate seemingly mundane instances of spouse care as structural "uh oh" moments in which the dyad maybe one of many patches deployed by prevailing power structures trying to navigate out of the liminal towards an "ah ha" moment.[44]

The 'Ah ha'

The other innovation of Stenner's concept of liminality is his attention he pays to the resources – which he terms liminal affective technologies – used to navigate through the liminal passage and achieve a denouement – an "ah ha". While rituals have typically been considered a "kind of technology for producing moving experiences that are conducive of psychosocial transformation"[45], Stenner argues that these only apply to devised liminal moments. Spontaneous liminal moments on the other hand both cry out for symbolic expression yet require new forms of symbolic representation because their unexpectedness locates them at the "very edge of semantic availability".[46] By animating the liminal passage as a place people can exercise their agency via different cultural resources, Stenner also raises the possibility that people may fail to reach this "ah ha" moment. While both van Gennep and Turner recognise this outcome they pay remarkably little attention to it. In fact, Turner's observation of young Ndemku initiates leads him to see liminal passages (by which he is referring to the devised kind) as equalising periods where previous signifiers of status are suspended, thus raising the question of how anyone can fail amongst such homogeneity.[47]

To take seriously the fact some people get stuck in the passage shifts the attention to why? One potential response is that people want to remain stuck. Scholars conducting research with community-dwelling

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[42] Dixon J, King, D., Matosevic, T.,, Clark M, Knapp, M. Equity in the Provision of Palliative Care in the UK: Review of Evidence. London London Social of Economics and Political Studies; 2015; See also Elizabeth Ann Davis (2012) Bad Souls: Madness and Responsibility in Modern Greece Duke University Press: Durham.

[43] Sutherland, N., Ward-Griffin, C., McWilliam, C., Stajduhar, K. (2018) Discourses Reproducing Gender Inequities in Hospice Palliative and Home Care *Canadian Journal of Nursing Research* 50(4), 189-201

[44] Stenner, p. 83.

[45] Stenner, p. 25.

[46] Stenner, p. 25.

[47] Turner, p. 99.

older frail adults have found that their participants actively strove to postpone the passage as it was preferable to any ‘end’ that would be associated with institutionalisation[48] or death.[49] Stenner offers a more generally applicable, albeit ambiguous, answer that it has to do with the “capacity of the subject to, as it were, bear the event, and be transformed by it.”[50] Gleaned from the importance Stenner places on subjectivity in shaping experiences of ageing in his previous work, we feel on safe ground to assume he does not view liminality, like Turner, as a period of total subjective erasure.[51]

To better understand what shapes an individuals’ capacity to both utilize liminal affective technologies and access “ah ha” moments we draw on intersectional theory. Avtar Brah and Ann Phoenix (2004) have defined intersectionality as an approach signifying the:

> “complex, irreducible, varied, and variable effects which ensue when multiple axis of differentiation – economic, political, cultural, psychic, subjective and experiential – intersect in historically specific contexts”.[52]

Intersectional thinkers understand identity as always “fluid and changing, always in the process of creating and being created by dynamics of power” and help to show how macro-level processes can influence micro-level experiences including the processes through which people come to comprehend their lives.[53] This dovetails with our discussion above that it is precisely on the basis of some aspects of identity and features of one’s life history that people make casual inferences that trigger “this is not” my experience moments.

To help understand the variance in which some people are able to achieve their ‘ah ha’ moment and others fail the last section of this chapter will compare the cases of Carol and Helen who make dramatically different use of affective liminal technologies despite sharing some key similarities of

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[48] Elana Buch (2015) Postponing passage: Doorways, distinctions, and the thresholds of personhood among older Chicagoans *Ethos* 43(1): 40-53;

[49] Nicholson, C., Meyer, J., Flatley, M., Holman, C., Lowton, K. (2012) Living on the margin: Understanding the experience of living and dying with frailty in old age. *Social Science and Medicine* 75: 1426-1432.

[50] Stenner, p. 83.

[51]; Stenner, P., McFarquhar, T., & Bowling, A. (2011). Older people and ‘active ageing’: Subjective aspects of ageing actively. Journal of health psychology, 16(3), 467-477; Stenner, p. 184.

[52] Brah, A., & Phoenix, A. 2004. ‘Ain’t I A Woman? Revisiting Intersectionality,’ Journal of International Women's Studies, 5(3), p. 76.

[53] Cho, S., Williams Crenshaw, K., McCall, L., 2013, Toward a Field of Intersectionality Studies: Theory, Applications, and Praxis, Signs, 38,(4):785.

them both being in their late seventies (77 and 79 respectively), with slightly older husbands (89 and 82 respectively) who have multiple palliative conditions (Cancer and Alzheimer's vs. Vascular Dementia and Chronic Obstructive Pulmonary Disease (COPD)). In both cases their husbands have only just returned home from relatively long-term stays in hospital and care homes meaning they were both in a position of reconsidering their relationship and bodies in their home space.

Carol

Amidst the intensity of her husband's return home from hospital no longer walking paralleled with the increasingly searing pain of her hernia in her left leg Carol turns to song. Intermittently breaking into song including Nat King Cole's *Unforgettable* across two lengthy interviews, Carol was perhaps an exception in her absolute enthusiasm for creative expression. Evidently thriving under the limelight of the devised experience of the interview, Carol showcased how the art to her caregiving involved the skill of reinterpreting her situation. Carol poignantly exhibited this through her rendition of *Jolene* directed at her husband who had sat deathly still and silent in his adjacent arm chair for over an hour, with only the soft movement of his chest indicating life. However, when she began to sing to the interviewers complete surprize his eyes opened and he even tried to sing too:

> *Carol:… (Singing) Jolene, Jolene, Jolene, Jolene, -*
>
> *Charles: Whoa.*
>
> *Carol:- I'm beggin' of you please, don't take my man. Jolene, Jolene, Jolene, Jolene, please don't take him just because you can.*
>
> *Charles: Oh yeah. (Laughter). [Interview 1]*

It is through her use of affective liminal technologies then that Carol forges her connection with her husband, simulating his personhood by offering him a tune. In sharing this moment she reaffirms his 'dignity' – something she was very concerned with – as a music maker in his own right. Moreover, by reimagining Joelene from man-stealer to undertaker Carol wards off death and in the process undergoes the psychosocial transformation of her becoming his caring defender.

This reinterpretation is extended to her home setting, particularly the living room, which she positively resignifies as a stage for her creative pursuits. This is contrasted to her wider feeling of her home as a ‘prison’ that her and her husband are trapped within because of the couple’s limited mobility and lack of formal and informal support that it would necessitate to get out of the house. In a further act of artistic creation Carol sings for Charlie and me the song she wrote and recorded for their 41st wedding anniversary. In the tune of I’ll Take You Home Again, Kathleen by Bing Crosby she sings:

> *“…I’ll take you home again Charlie, across the oceans far and wide, but remember come back to England to me…” [Interview 1]*

The song achieves two things: symbolically transporting Charlie back to his original home in Jamaica and reassuring him that he will always have a home in her. It is in this way she is able to achieve her ‘ah ha’ moment that symbolically enables him to be cared for and die at ‘home’ whilst assuring them both they will never be truly apart. Ultimately, Carol’s ability to make art of the otherwise despondent situation resulting from the particular biopolitical circumstances attests to the ways that some older caregiving spouses are able to use their “bodies and pleasures” to make a life more liveable in their zones of abandonment.[54]

We emphasise *some*, however, as Carol’s capacity for creative expression is a result of mutually constitutive aspects of her subjectivity that is both produced and made salient through her achieving her “ah ha” moment. Her use of affective liminal technologies is influenced clearly by her working class identity, which as sociologist Lisa McKenzie has noted, is steeped in story telling as a way of making bearable the daily symbolic violence and economic hardship.[55] For example, Carol told stories and sung as a way to ensure her husband knew he would be cared for in a homely way despite the option for him to die at home having been taken away by a private developer who having recently brought up their whole council estate they had lived in for twenty years in order to raze it so as to maximise commercial profit. Her motivation for conjuring a sense of home through symbols and song was also pressing because both of them were migrants to England and thus living away from their homelands. Finally her ability to usher cultural symbols is heavily indebted to her being a Jehovah Witness which is steeped in imagery language and use of song. Aligning with her belief system she also decides not to seek medical

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[54] Michel Foucault (1976) The Will to Knowledge: The history of sexuality V1. Penguin books: London; Judith Butler (2004) Undoing Gender. Routledge: New York.

[55] Lisa McKenzie (2015) Getting By: Estates, Class and Culture in Austerity Britain. Policy Press: Bristol.

attention for her leg thus contributing to her pained mobility and thus materially impacting her narrative situation. For all these intersecting reasons, Carol had an exceptional grasp of tools to narrate and a particular context conducive to narration which underpinned her deft use of affective liminal technologies.

Helen

Unlike Carol, Helen only used words and symbols leanly to articulate her situation which she felt ambivalent towards. The most symbolic she got was when she described how she felt "absolutely shattered". Her incapacity to reflect on herself is consistent with evidence highlighting how little time caregivers get to reflect on themselves.[56] Helen herself reflects that she feels like a "cat chasing its tail". This fits with Ukeles's insight in an interview about her art that: "[c]apitalism is like that. The people who were taking care and keeping the wheels of society turning were mute…".[57] Reflecting this difficulty she had with articulating her situation, at one point in the interview she said:

> *"I could, I could, scream and cry, run [squeak sigh]" [Interview 1].*

Sara Ahmed aptly acknowledges that women who fall outside of traditional feminine stereotypes of being a 'good' caring heterosexual mothers or wives often lack the language to parse their feelings despite having logic in their "gut" that something is not right.[58] Michel-Rolph Trouillot's history of the Haitian revolution similarly suggests that mutiny against the governing elite is seldom thinkable let alone sayable before the event itself. Helen's privileging of affect – her sighing and squeaking – to communicate such a depth of her longing for a way out quietly illustrates this.[59]

When trying to grapple with instances of the inarticulatable, Stenner usefully contributes that "consciousness is the crown of experience" rather than it's content.[60] This is a decidedly different from the conception laid out in the illness literature that "turning somatic into words makes it an experience".[61] With reference to deep empiricism Stenner contends that an experience comprises the sense data of presentational immediacy (what is currently observed) and causal efficacy (the events

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[56] Rebecca E. Olson, 2015. Towards a Sociology of Cancer Caregiving: Time to Feel, Ashgate: Surrey.

[57] Bartholomew Ryan (2009) Manifesto for Maintenance: A Conversation with Mierle Laderman Ukeles. *Art in America* last edited, March 18, 2009, accessed December 9, 2019:

[58] Sara Ahmed (2012) Living a Feminist Life. Duke University Press: Durham.

[59] Michel-Rolph Trouillot as quoted in Kathleen Canning, 'The Body as Method? Reflections of the Place of the Body in Gender History', *Gender and History*, 11, 1999, pp. 499- 513.

[60] Stenner, p. 94.

[61] Frank, A. (1995) The Wounded Storyteller: Body, Illness and Ethics: University of Chicago Press: Chicago

,p. xix.

immediately preceding the 'event'[62]. Importantly, the "data" of experience can be what has been said but also physically or emotionally felt. It need not be externally communicable, nor fully comprehendible, to still comprise an experience.

Honing in on Helen's expressions of affect such as sounds of relief reveals a new Helen creeping in at the edges:

> *Oh its just "ahhh" [sound of relief] you know. I play Mahjong on a Tuesday and it's just a social ... "ahh" I'm away. I sit down and think, wow, this is amazing. He's not there and he can't call me and my time is my own. It does make such a difference. Absolutely makes a difference. I have a friend who is so good who will always ring me and say "what can we do this weekend", or whatever. Most weekends I find I can do something. [Interview 1]*

While this alternative rendering of self brings an 'ah ha' in a sense of making conscious what is on the other side of his death, the transformative power is only partial. She is quickly brought back to the practicalities of the situation by the thought of her domineering husband's claims on her time, speech and thought. This shows that his particular performance of masculinity further entrenches their dyadic subjectivity and in her case mitigates against her ability to achieve an "ah ha" denouement.

Thus Helen example shows how the gendered dynamics play an important role in shaping one's capacity to utilise affective liminal technology, however, when contrasted with loquacious Carol we can clearly see that it is insufficient on its own to explain the disparity. In Helen's case she belongs to the white upper-middle class where the expectation was that she was an acquiescent housewife of a nuclear family. Whereas Carol as a Welsh working class woman has always had to work to economically support her family of nine. Work thus provided her with an avenue to develop her own identity and capacity to assert it as already alluded to above. Ethnicity also undoubtedly shaped aspects of the husband's respective gender performance for whereas Helen's husband occupies a privileged status as a white business-owning male – thus occupying a position of hegemonic masculinity in modern-day Britain, Charles is a Afro-Caribbean working class migrant male occupying a subaltern masculinity with less power relative to other men and arguably his white wife.[63] Consequently, by taking an intersectional approach we can better understand the way structural factors can impact

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[62] Stenner, p. 98.

[63] R.W. Connell (2005) Masculinities Polity Press: Cambridge.

people's capacity to utilise affective liminal technologies and thus further understand reason for the disparities found around people achieving or not achieving "ah ha" moments.

Conclusion: Ta-da?

Paul Stenner's reinvigorated concept of liminality provides applied social scientists with novel conceptual tools to understand urgent questions of subjectivity, experience and inequality engendered by late modern capitalism and rapidly ageing populations. By directing us towards the specific events in which people's expectations for their lives are disturbed – either expectedly or randomly – Stenner provides an entry point into how subjects and their conditions of care are produced, sustained and reworked. Offering us the "uh oh" moment to think with revives the uncertainty inherent in liminal passages, which has been lacking both specifically in end-of-life care research and elsewhere. Similarly, Stenner's innovative discussion of affective liminal technologies restores the creative agency of people inside liminal moments to attempt to navigate toward "ah ha" moments. Moreover, his interest in the mutual connection between self and society embedded in his psychosocial paradigm enables us to reflect more generally on the concept of power and particularly how health and economic contexts prime liminal moments

Drawing attention to the ways that some people fail to achieve "ah ha" moments begins an overdue discussion about the differential circumstances in which people arrive at these transformative life moments. Privileging affective and somatic cues as much as discursive signs makes Stenner's work particularly insightful here as it makes visible those occupying subaltern social locations who are both the most likely to find their experiences as jarring with wider cultural expectations (thus encountering with greater frequency "this is not" experiences) at the same time they are the least equipped with specific cultural scripts to verbalise their oppression.

While this chapter has explored the decisive utility of Stenner's new concept, we suggest three avenues for taking his concept further. First, we argue that Stenner's concept ought to be applied to mundane settings and activities as zones of ordinariness are no less important realms of meaning-making, particularly for those who are physically constrained to home by illness and/or caregiving activities. In this context we can see how people having liminal moments can draw on a range of processes Ulkeles attributes to the death instinct such as development and change and/or life instincts such as maintenance to "bare" liminal passages. Second, we argue that Stenner's concept can be applied to instances of the dyad, which we understand as exceeding the bodily division outlined by his definition of the psychosocial. As we argue above, sometimes care really does get on and under people's skin resulting in a collapsing of subjective and corporeal boundaries. Third, we suggest that an intersectional perspective offers additional grunt to Stenner's attempt to make sense of how and why some people do not transition through liminal moments and/or make use of affective liminal technologies. Given Stenner's admirable interest in bodies and liminal ambiguity we think that all three of these insights can be accommodated within his wider theoretical lens, which thrillingly calls out for application and extension. Thinking liminally about increasingly ordinary instances of end-of-life care we argue that Stenner offers us a better vantage to see and access our historical moment so as to begin to provide nuanced answers to questions such as the one posed by Ulkeles' arguably even more pressing in light of our new biological order:

> B. Two basic systems: Development and Maintenance. The sourball of every revolution: after the revolution, who's going to pick up the garbage on Monday morning?

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Appendix 16:Cognitively-impaired couples: are their daily care needs greater than their peers?

Tessa Morgan, Jane Fleming, Efthalia Massou, Robbie Duschinsky, Stephen Barclay

* Accepted for a Poster Presentation at the European Association of Palliative Care conference. I was not able to attend due to COVID-19.

Background

Responding to the ageing population, palliative care is increasingly focusing on dementia care. Concurrently, dementia research is highlighting the ability of people with mild/moderate dementia to participate in research about their daily care. At present we know very little about older couples where both members have cognitive-impairment and are living in the community. This paper asks: do cognitively-impaired couples, when compared to peers, have greater daily care needs and receive more daily support?

Aim/Methods

Comparing matched older couples from the baseline survey of the Cambridge City Cohort Over-75 Study. Cognitive-impairment was taken as scoring 25 or less on a Mini-Mental State Examination. Care need and receipt of care was determined via Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADL). Analysis methods include chi-squares and linear regressions.

Sample / Results

Total of 174 couples with complete cases were included (M=79.9 years, SD=3.78) of which 12.07% of couples both had cognitive-impairment (N=21), 56.32% were both cognitively-intact (N= 98), 31.6% comprised one cognitive-impaired spouse and one cognitively-intact spouse (N=55). There were significant associations between the three couple-profiles and the needs for help with meal preparation (P=0.018), housework (P=0.021), help with taking medication (P <0.001), bathing (P=0.036) and having issues with walking (P=0.023) and using the telephone (P <0.001); as well as with receiving help with medication (P <0.001) and toileting (P=0.003). In all cases, cognitively-impaired couples reported elevated scores compared with the other two groups.

Conclusion

Cognitively-impaired older couples are in a particularly precarious situation with higher dependency in their ADL and IADLs without receiving higher levels of help than their peers. When discharging home older patients with dementia, professionals need to ensure that the cognitive capacity of their partner has been determined and appropriate support and long-term monitoring for the dyad put in place.

Appendix 17: Palliative care is a feminist issue

By Tessa Morgan

*Blog presenting a synthesised version of my key note for International Women's Day event at King's College London

https://tearairesearchgroup.org/2020/03/06/palliative-care-is-a-feminist-issue/

To mark international women's day we need to discuss gender inequality at the heart of palliative care. This results from the fact that day-to-day care for someone with a terminal condition is provided overwhelmingly by mothers, daughters and wives.

I think this conversation couldn't be more timely with the release last week of the second Marmot Report which found that life expectancy in the United Kingdom has actually fallen for the first time ever. The report found that women from deprived areas have been the most effected. The authors strikingly attribute these women's foreshortened lives to the austerity cuts across the British health and social care sector.

This report adds to the growing weight of evidence that women are facing a range of inequalities both at their end-of-life and when caring for dying relatives. Evidence suggests women are less likely to receive formal palliative care services and are less likely to die in their place of choosing than men.

This is starkly contrasted with the fact women are far more likely to be providing end-of-life care and spend more time doing so than men. Evidence strongly indicates that women's mental health is more adversely effected when compared with men caregivers and non-caregivers and a few studies have also indicated that women's physical health is also detrimentally impacted.

Why then is gender not currently reflected in key documents about inequality at end-of-life? A prime example is the Care Quality Commission 2016 report which catalogues a range of factors leading to disparities in receipt of formal palliative care services such as old age, non-cancer condition, living alone, and sexuality. Despite an admirable attempt to begin the discussion on inequality, the fact gender is not the list indicates a glaring omission.

Merryn's plenary at last years European Association of Palliative Care conference firmly placed gender on the agenda by drawing on the available evidence to show just how. Judging from the lively discussion at the "Caring is a Feminist Issue" event organized by Emel Yorganci as part of the Athena Swan Initiative at King's College London there is clearly a growing research interest in considering gender amongst other inequalities have on people's end-of-life outcomes. To contribute to this growing field of research I offered some of the following suggestions that I raised during my talk at that event:

1) Clarify terms. Sex is a 'biological component, defined via the genetic complement of chromosomes' and should be talked about using labels 'male' and 'female'. Gender refers to those roles and behaviours in society, which are socially prescribed within a particular historical and cultural context and described using the terms 'man' and 'woman'. Even the most mundane aspects of everyday life – how we dress, talk, and socialise and die – are implicated in "doing gender". Thus our analyses need to be attuned to people's everyday experiences.
2) Think intersectionally. We need to consider how gender interacts with other kinds of social divisions including ethnicity, class, disability age because as in the words of Audre Lorde "*there is no thing as a single-issue struggle because we do not live single-issue lives".* This will help us as health researchers identify those most vulnerable to adverse health outcomes.
3) Contextualise care. Rather than thinking that initiatives such as 'care in the community' will solve the problem of deficiencies in care provision, such policy drivers often obscure the amount of daily tending, organising, washing, monitoring provided by specific woman relatives. We should instead advocate for the re-funding

of formal support services (both social and health services) to provide pre-emptive and on-going support for family caregivers and dying individuals in their homes. In this equation we also need to highlight and value the amount of unrecognised palliative care that is provided by health care assistants often working in incredibly precarious situations.

4) Work collaboratively. There is a lot of work to do to identify, analyse and theorise the extent to which gender inequality operates within palliative care. We should draw together our different methodological strengths, access to different sources of data and disciplinary and professional expertise to ensure we produce a robust picture of disparity. Through this mission of putting gender on the agenda we can continue to carefully cultivate and nourish our feminist movement in palliative care.
5) Communicate creatively. Audre Lorde argues that you cannot "deconstruct the master's house with the master's tools". If we want our research to precipitate real societal change (not just an improved 'impact factor') we have to express our findings in a range of mediums not just in academic journal, which are the bread and butter of a university systems dominated by men. Merryn and Lisa Williams graphic novel produced in collaboration with Dr Victoria Egli and Tatiana Tavares, shows how we can creatively communicate gender inequality in a tangible, easily digestible and aesthetically pleasing way. Further research like this – particularly with digital methods – is the way we ensure that our research gets to the health care professionals, families and politicians who need to hear our messages most.

I want to finish by re-stating that advocating for a feminist research approach to palliative care is not just an academic thing but has dire consequences for the multitude of people for whom caring for someone dying is their everyday experience. We have a responsibility as researchers to get with the memo and challenge the current circumstances in which women are dying prematurely without equal access to resources that provide the possibility of a good death.

Appendix 18: Narrative extraction template

Participant number:

Number of interviews:

Length of interviews:

Specific conditions of both:

Nature of partners' involvement:

Key take home of story

Are they a carer?

What does care mean?

How is care talked about?

How is death and dying talked about?

What kinds of support do they have?

Service best practice

What changes occur across interviews if relevant?

Do they tell a coherent/ successful story?

Examples of:

Vital care

Social isolation

Dual Dyad

Ageing/ Health

Gender

Other intersectional factors

Time / Liminality

Space (including care transitions)

HCA

Family

Any additional points?

What other participants are they most like?

Appendix 19: Summary descriptions of participants and their storylines

In this section, I present summary descriptions of each of the participants' contexts of care. I detail their physical health, their referral to the study and the nature of their participation. I highlight changes and/or continuities across interviews regarding the content of narratives and the broader physical/ material context. Recognising that this is a publicly available document, I have omitted any particularly identifying or sensitive material (mainly related to legal disputes or fraught family situations). Each couple presented here has been given a researcher-assigned pseudonym. I have placed a (P) following each participant's name.

Couple 1: Margaret (P) and Andrew

Margaret, aged 77 white Scottish, and her husband Andrew, aged 78 white Scottish, both with heavy Scottish ascents, have been married over 55 years. Margaret received the flyer from a PPI event and self-selected herself into the study. Her reason for participating was both the greater good of the 'cause' (referring to Dementia research specifically) and out of interest for the new company.

This couple reflects the exception in the study as Andrew's palliative condition was officially undiagnosed. This fact emerged through the first interview. Margaret explained that from her experience caring for her mother, she was familiar with Dementia. Her husband refused to go to the G.P. I decided to keep her in the sample because she conceptualised her situation as one of "living grief" because she viewed her husband as approaching his end-of-life (int 1). Moreover through our interviews, Margaret felt that his condition was declining, exhibited through his giving up driving and reluctance to attend any social events despite being incredibly extroverted, preferring to spend his time in his home office.

Andrew was also present for discussions at interviews one and two, although Margaret notably changed the interview direction when he was present to focus on more macro concerns such as funding issues and the NHS. Margaret opted to have our last interview in a café where she was remarkably plain speaking. She stated: "It sounds awful Tessa, but I'd rather see him die early than watch him deteriorate. That sounds awful [tearing up]" (int 3).

Margaret had mobility issues, and prior to the interview had come out of the hospital with stomach bleeding. Between the first and second interviews, Margaret underwent surgery for her knee, which left her incapacitated for two weeks. A female friend who was 70 came and stayed to support them by cooking and assisting her to get to the bathroom. Margaret had help from a cleaner once a week to maintain her house, of which she was very proud.

Central to Margaret's sense of self was that she was a carer for her 16-year-old grandson, who had autism, cystic fibrosis and kidney failure. Her grandson was given an end-of-life prognosis during the first and second interview. When she was physically able to, she had her grandson stay as much as possible. She also explained how she was providing vital emotional support for her daughter and granddaughter. She had another daughter who lived in another city.

Her first key storyline she focused on the emotional terms of losing her partner, explaining "this heart of yours dictates how you will deal"(int 1). Given that the second interview focused primarily on Margaret coping with recovering from surgery, Margaret talked a lot about attending to "the condition of the moment"(int 2), e.g. her limited mobility. By the third interview, which was the most emotionally charged, she exclaimed: "I'm in overload" relating both to her husband's behavioural changes and her grandson's failing health.

Couple 2: Mary(P) and Paul

Mary, aged 74, white British, reflected that her husband Paul's diagnosis of early-onset Alzheimer's disease at 64 had left her "in bed crying, crying, crying"(int 1). After the initial shock, she thought: "This isn't doing me any good, I've got to keep well, and I wanted to keep him going. So I toughened up (laughter)"(int 1). Mary's "toughening up" process involved seeking out her local dementia carers support group, which she and Paul, now aged 74, had remained members of for the past eight years.

Mary was recruited into the study following a presentation I gave at a dementia carers group. She approached me after the meeting to show her interest, explaining that she'd just been diagnosed with diabetes which her nurse had said was associated with the "stress of caring," so she might as well talk about it. Otherwise, she was fit and healthy, she explained, still playing tennis with friends.

The interview took place around her kitchen table in her sizeable two-storied house, which had just seen the kitchen refurbished. Mary introduced me to Paul at the end of the interview. He had been sitting in the living room sitting upright in his chair. He was unable to engage in conversation (something Mary had warned me before we moved to the longe) but nodded his head in recognition of my presence.

Their son and daughter lived in different cities though they offered emotional support by phone. Mary was clear on not wanting to be a burden to her children, so she did not share all the struggles of her experience. Instead, Mary drew much support from the dementia carers group and the singing group they both attended. She also tried to keep in touch with friends and coordinate social events, which Paul was physically able to attend though despite his inability to converse. The interview timing was at a distinct turning point where Mary was considering whether to pay for formal care to come in. She admitted that she was lucky to afford care and that “if you can go private, it’s important to free up space for others” (int 1).

The key storyline of the first interview was “it’s just you and the world and this poor person who we love”(int 1). Mary shared the isolation she felt caring for her husband, who would say nothing unless prompted. Mary took part in just one interview, with the reason explained in Chapter 3.

Couple 3: John (P) and Betty (P)

At their first interview John, white British 85, was caring for his wife Betty, 79, whose limited mobility and abscessed leg had led to her G.P. diagnosis of advanced frailty. John’s mobility was not much better; however. Consequently, much of their daily life involved pottering around their small council bungalow located in a small, rural community. The previous week Betty had fallen over on the pavement in the nearby town, which meant she was staying put at home for the moment.

John and Betty were referred to the study by a retired G.P. who attended the PPI meeting conducted through the University. As a result, they both became participants in the study.

They interviewed together at their request; they were both cognitive-intact (as determined by the referrer and exhibited through our interactions).

The interview began with Betty describing disliking having the district nurse visit her every day to change her leg dressing; she would prefer less frequency. Her greatest concern was that she had to wait around for the nurse as they gave four-hour windows of availability. Betty felt disrespected by this because they were "very busy people" (int 1). This juxtaposition of her framing of herself as busy compared to her present physical limitations underpinned her desire to be viewed as self-sufficient as well as underpinning a general reluctance to be reliant on others. Betty and John also did not want to bother their two daughters, who lived nearby. By the end of the interviews, one daughter visited to deliver groceries and check in on both parents. Previous to this a neighbour had brought them groceries, and another neighbour had become their informal befriender.

The dominant storyline of the first interview was resoundingly "make do and mend" (int 1). Both Betty and John emphasised how they made the most of the current situation. They explained the kinds of resources they could draw on to their community, such as the local transport system and activities for older people that went on, such as a meet up at a local pub every month.

This narrative of making do continued despite John being diagnosed with bowel cancer and only 6 months to live between the first and second interviews. Betty implored John to remain optimistic with the key storyline of the second interview focused on what they've done together throughout their lives typified by Betty's reminder to John: "think of the adventures we've had, though" (int 2).

The third interview foused on their declining physical health. John was clearly physically slowing down and discussed the details of his radiotherapy and how he was adjusting to a catheter. Betty trying to do more, for example by reinstating her cooking responsibilities, though she also discussed a recent fall (see Chapter 4). Despite such obstacles, the main storyline remained "we're fine the sun's shining isn't it here. You're alright love" (int 3).

Couple 4: Evelyn (P) and Rupert

Evelyn, 70 white British and Rupert, 84 white British, were each other's second marriages. They married at the ages of 66 and 80, respectively and had been friends for a long time beforehand. Unfortunately, Rupert had a stroke four months into their marriage. At the hospital, he was diagnosed with end-stage Vascular Dementia, and the doctor informed Evelyn that he had two months to live. Against the doctor's reluctance, because of her apparent frailty, which was a residue of her battle with lung cancer, Evelyn "*fought tooth and nail*" to get Rupert home. For the most part, that is where he had stayed for the last four years.

Evelyn chose to participate after I presented the study at a dementia group. Rupert was present at the first interview, where we shared a cake for his birthday. Evelyn was a very active participant and requested each of her transcripts for review. Through this process, she did not suggest any changes but wanted them to document her experience.

She was very proactive in seeking out all formal care options, and she recognised that it was often difficult to identify what help was available. This aspect is elaborated further in Chapter 5. Evelyn and Rupert were active in their local dementia care group and Rupert attended day centre twice a week. Rupert had had his last day at the day centre the week of our first interview. Evelyn explained that the managers said they could no longer manage him due to his incontinence and mental incapacity. As a couple they also received a lot of support from the Church congregation, with members picking her and Rupert up for medical appointments and driving them to the carer's groups. She tried not to burden her two children or Rupert's as they were busy with their own lives. At the first interview she was trialling a privately-funded health care assistant to come and stay four nights a week so that she could get some sleep.

The key storyline of Evelyn's first interview centred on how she had "gone off the radar" (int 1) through the process of caring. Further illustrating this was her response to my question "how is your health", she explained "I would have absolutely no clue" (int 1). The second interview took place at the Rupert's bedside in a dementia ward in the local hospital a few days shy of Christmas. Rupert had been admitted into the hospital a week prior due to a fall and apparent decline. The central storyline of this interview was that she was "losing him in pieces" (int 2). Indeed, I observed that he was no longer able to speak or chew and was hooked up to oxygen.

The third interview was arranged two weeks after Rupert's death. While I explained that I could come over much later, she insisted I come over the following day. She wanted the company and appreciated the reflection process that interviewing opened-up. She informed me that Rupert had died in the local hospice after an eight-day stay. She had thoroughly appreciated the experience of being in the hospice where "they even wash your underwear if they let you [laugh]" (int 3). The key storyline of her interview came through "because you never get to the end of things, do you?" (int 3). This referred to her process of having to sort out their affairs following his death, such as their finances and all the equipment in their house. It also referred to her enduring commitment to him chiming with her spiritual worldview that it would not be too long until she would be with him again.

Couple 5: Kathleen (P) and Jerry

Kathleen, white British 73, had been married to Jerry, white British, 85, for 54 years. Jerry had been diagnosed as having Pick's disease since 2001. Just before the interview Kathleen had been diagnosed with depression by her G.P. She was now taking medication for this "but only a half" pill (int 1).

They had two children with whom they were emotionally close to though they lived in different countries with their young families. They used WhatsApp to stay in regular contact. Kathleen and Jerry were involved in various groups, such as a dementia group and signing for dementia group. They went to church a lot and held a mid-week bible group. Jerry had had a befriender but had started hiding from her when she arrived, so they cancelled this. Kathleen had just got a befriender herself, which despite being early days, she was enjoying.

Kathleen chose to participate after I presented the study at a dementia group. Kathleen and Jerry were interviewed together for all three interviews. The second interview took place after a home visit from a Psycho-geriatrician who conducted subsequent Mini-Mental State Examinations to both partners. From this, it was determined that Jerry's Front Temporal Dementia (which is subsequently how his condition was referred to) had significantly worsened. However, Kathleen was in good cognitive health but was confused about why her doctor wanted her to take a cognitive test. At the third interview, she was baffled about the whole episode, and she asked, “can you diagnose me” (int 2) at which point, I had to reiterate that it was not my place to do so.

While Kathleen was very candid from the beginning of the interviews, it took until the third interview to be open about her frustrations around Jerry’s catheter. Kathleen said that the positive side was that she could now sleep through the night because Jerry no longer had to get up so frequently – one of the reasons they had agreed to it. However, during the day, there were frequent issues with spillages that Jerry would not tell her about, leading to tension and embarrassment. The catheter, therefore, required intensive monitoring and became a preoccupation of her caring for him.

Another consistent theme across interviews was Kathleen and Jerry’s interdependency. While the first interview began with extended detail about how they had met and their early married life, by interview three, Kathleen explained that they had “never been independent” (int 3) as they had both moved from the family home to live with each other. This is why she found it so challenging that Jerry was increasingly emotionally closed-off, resulting from the nature of his cognitive decline. At the end of the third interview Kathleen described how they had just visited a friend whose husband had died. Kathleen ended our last interview explaining how she “can’t imagine losing a husband” (int 3).

Couple 6: Carol (P) and Charles

Carol, Welsh, 77, had been caring for her husband Charles, 89, Jamaican in their London council house since his Ischemic stroke in 1997. His care needs had increased considerably with his diagnosis of prostate cancer in 2007 and Alzheimer’s disease the following year. Ten years on, he was unable to move independently and was reliant on others for all of his instrumental and personal care needs

Carol rang me two months after seeing the study recruitment flyer at a London-based carers’ event. The first interview occurred in the intensity of Charles’ return home from a socially-funded care home. While Carol had initially placed him in the care home because of her hernia, which meant she walked with pain and was struggling with providing care at home. Nevertheless, because “he nearly died when he was in care” (int 1) she had resolved to keep him home.

Returning home, Charles was provided with a health care assistant three times a day to help toilet and bathe him. Carol insisted of remaining in charge of feeding him. They also had a nurse in frequently to help with his prostrate injections and were also connected with a social worker. Despite this high level of formal care Carol felt that she had "no one" that cared for her as all the services were directed to her husband. During the second interview, she lamented, "you're the only one coming and asking me anything and you're not even from this country" (int 2). This dynamic of not feeling integrated with services, despite her best efforts, is explored further in Chapter 5.

Carol and Charles were very connected with their church, although only Carol could now attend. Between her and her husband, they had nine children though Carol conceded she received "very little support" from them. It emerged through the interviews, however, that Carol and Charles were living with her son, without whom Carol reflected, "how would I pay my electric, my telephone?" (int 1). They were also receiving some support a from grandchild and his partner who would get additional supplies (such as Charles new wheelchair) they needed. Carol had a close relationship with one neighbour who arrived at the house during the interview, seemingly strategically checking on Carol. Carol explained that she had been closer with other neighbours, but people had incrementally had to leave due to the council estate being sold.

Carol's first interview focused on how she as a carer and carers in general, were not receiving the respect that they deserved, which she encapsulated in her rhetorical question: "who's looking after the family?". Our second interview took place in her lounge, which this time was piled high with boxes in preparation for their eviction from their council estate. The interview took on a far more sober term as Carol explained, "you're doomed as it were"(int 2) in terms of their current predicament of her husband being forcibly moved potentially weeks before he was about to die. Due to the move, Carol felt she was not up for a third interview though she reported that they did make it to the new place in one piece.

Couple 7: Donna (P) and Mickey

Donna, 80 white British, was caring for Mikey 84 white British, who had been diagnosed six years ago with Vascular Dementia. He was also in remission from Penile Cancer. Most recently, he has developed mini-strokes meaning, as Donna put it, he could drop “like a sack of potatoes”(int 1) at any moment. They had been married 32 years, as they were each other's second marriage. Between them they had five children and four grandchildren. Donna was the first person recruited into the study via her G.P. Donna and Mickey were both present at the first interview, but only Donna was present at the subsequent two due to the significant fluctuations in both members health across interviews.

At the first interview, Donna was caring for Mickey on her own. She described this as a 24/7 job as he had to be watched at all times. When he fell asleep, she would rush out to do the supermarket shopping or pick up any other supplies. Because of this situation, which she described as “bearing the brunt of it” (int 1). Donna was in discussions with their G.P. about what options she could put in place to leave the house and see friends – something she was missing terribly. Another major struggle was that her husband “kept on with the same thing” (int 1) constantly. This continued as Donna’s main caring concern across the interviews, which by the third, she was still lamenting how he “he goes on and on and on” (int 3).

Between the first and second interviews, Mickey had another TIA stroke and was admitted to hospital where Donna continued to visit him every day despite being a 20km drive each way. A week after, he was sent to a local care home. On one such visit, Donna collapsed next to Mickey’s bed, and so she became a patient in the same hospital Mickey had just been discharged from.

Donna returned home a few days later, unsure of the reason for her collapse, though she said the doctors thought it might be a “heart thing”(int 2). At the discharge proceedings, she was asked if she “had a husband at home, I answered yes, but he has dementia” (int 2). Following Donna’s collapse, both their families, including Mickey’s ex-wife, rallied around Donna in hospital, offering lots of plans and promises of more support going forward. However, by the third interview, Donna scoffed when I asked if such care plans had come to fruition.

The second interview took place a day before Mickey was due to return home from the care home. Donna was ambivalent about his return as she’d got used to being home by herself and also did not want health care assistants coming into the house. Mickey was back at home by the third interview, albeit at the daycare when the actual interview took place. Donna spent her last interview describing the new dynamic in the household with health care assistants coming in twice a day. One of the latest significant issues was that her husband continuously mixed her up with the health care assistants. As she recalled that a few days ago, he had asked her “have you got any other patients today?”(int 3). She despondently concluded that “caring for my father wore my mother out" (int 3). She felt history was repeating itself.

Couple 8: Donald (P) and Rita (P)

Donald, 75 white British and Rita, 73 white British, had relocated in a small, rural village about 20 years ago when the impacts of Rita’s COPD and spinal degeneration forced her to retire early from teaching. Approaching the end of her slow progressive illness, for which she had been on an end-of-life care registry for the last four years, Rita was reliant on her oxygen machine to breathe. And her mobility had declined to the point that Rita could only leave their house with incredible difficulty. So she reserved the feat, assisted with a walker for her weekly morning church group. Donald, on the other hand, thought himself fortunate that his only health issue was type-2 diabetes.

Their local G.P. had referred through them, and both agreed to participate in the interview. Rita nor Donald had any cognitive impairment. For the second interview, Rita was sick and had been in bed for many days, so only Donald took participated. Donald suspected it was just a passing cold but was being mindful of her situation. They were interviewed together at the third interview as Rita was feeling much better.

In terms of their social situation, they had no children but a little jack Russell. They were close with Rita’s sister, who lived in another town. They tried to visit her once a year but spoke on the phone regularly. They were closely connect with their church community. Donald was still active in the community and adamant that he could support Rita largely without external support, as he explained:

> I’m not pressing to find out whether I could squeeze the government for any more than I have got. I have to stand back and think, yes, I am Rita’s carer. If she’s okay, I carry on. I’ve got a lot of other labels that I could pursue. (int 1)

Rita in fact defined her caring as not placing any restrictions on Donald as :

> *Not stopping him from doing anything that he wants to do. Not making myself an excuse for not letting him do something. I want him to feel as free as he can. (int 1)*

Other than Rita's bout of illness during interview 2, their circumstances remained stable as did their narrative about their caring. During the first interview, Donald focused on how despite the world becoming smaller because of wife's illness, they were striving for "small pleasures" such as getting coffee together and attending church. During the second interview, Donald discussed how he hoped he would be perceived as being very caring for Rita, explaining that even if she passed, people would say "well, at least he cared"(int 2). Finally, the third interview again circled back to what the day to day of caring looked like, with Donald exclaiming, "you just need to find ways and means"(int 3).

Couple 9: Helen (P) and Barry

Helen, 80 white British, had been caring for Barry 82 for twenty-five years due to his alcoholism. In total, they had been married 60 years. Although more recently, her caring responsibilities had increased due to Barry's end-stage Vascular Dementia, COPD, Heart failure. Barry had recently returned home from a care home, which before that he had been in hospital for four months. Despite doing so much care, Helen found it difficult to talk about it.

Helen had self-selected into the study after seeing the study flyer at a Dementia group event. Over the phone, we arranged a time for the interview to align with her mid-life daughter's visit. Her daughter also signed a consent form and was very happy to take part. In some ways, this interview bordered on a family intervention as her daughter probed ways to make her mother's life easier. At the beginning of the interview, there was a complex negotiation to get Barry to leave the room. Helen very bravely explained that this interview "is for me"(int 1). Barry returned two hours later to ask if it was his turn yet.

Helen participated in one extended interview. Helen described caring for her husband as feeling like a "cat chasing its tail"(int 1). She provided and supervised all of his personal and instrumental care tasks and rarely had a minute for herself. The emotional strain and manoeuvring Helen engaged in to continue caring are explored in Chapter 6 and Appendix 15.

While Helen received a lot of emotional support from her daughter and grandchild, she would have liked to have had more support in the day-to-day provision of care. Nonetheless, Barry both refused to move into a care home or have health care assistants. Fortunately, Helen explained that she was still able to leave him for stints on his own when he was napping. Describing the reprieve of seeing her friends, she explained:

> "Oh its just "ahhh" [sound of relief] you know. I play Mahjong on a Tuesday and it's just a social … "ahh" I'm away. I sit down and think, wow, this is amazing. He's not there and he can't call me and my time is my own. It does make such a difference. Absolutely makes a difference"(int 1)

Helen opted not to have a second interview after a phone conversation following the interview as she felt she had covered what she wanted to share. Following the interview, her daughter texted me to say that her mother had really appreciated the opportunity to talk and reflect.

Couple 10: Elizabeth (P) and Harold

Harold, 72, white British, had been officially diagnosed with mixed Dementia, both Alzheimer's and Vascular in 2002, around the same time he retired from the public service. He was no longer able to speak coherently due to his cognitive impairment but looked physically well otherwise. Elizabeth, 71 white British, despite not being 75, as it said on the flyer, was enthusiastic about taking part in all three interviews. She had self-selected into the study after seeing the study recruitment flyer at a Dementia group. Elizabeth opted to participate independently in each discussion without her husband, although she introduced him before each interview began.

Elizabeth was very emotionally close with her three children and had regular phone conversations with them. She said she would hate to think that she was ever a burden on her children as she had "made the choice to have them so they didn't have any duty to her" (int 1). Therefore while she had one child living close, she tried not to ask for too much. Two years prior, her family had had an intervention as they observed that Elizabeth was at her emotional brink. As such, she had become very involved in a carer group where she had forged "friends out of necessity"(int 1). She felt relieved that she could now share the problematic aspects of her daily care, such as incontinence, reflecting that she "couldn't believe that these would be things she'd have to discuss" (int 2).

Across the interviews, nothing changed in terms of their physical or material circumstances, but the quality of Elizabeth's interview talk undoubtedly deepened. The first interview focused predominantly on Harold's diagnosis story and what it took to manage the "elephant in the room" (int 1). During interview two, Elizabeth discussed her attempts to empathise with his situation, describing how "it's just a different currency" (int 2). By interview three, she spoke more specifically about how the root of the issue was Harold's behavioural issues and reluctance to acknowledge that he needed help at all. Elizabeth explained how:

> *… So he says I don't need anyone to look after me I'm perfectly able to look after myself I say "that's alright then". (int 3)*

She also opened up about her marriage which she dates in two parts – before and after his dementia diagnosis. She explained that we were married 41 years before his diagnosis and it is this time that she circles back to in order to keep "chugging along" in the present (int 3).

Couple 11: Patricia (P) and Henry

Patricia, 73, white British, had been caring for her husband Henry, 72 white British, for the last 16 years since his Parkinson's diagnosis. They had been married for 40 years and had no children. Henry was in a wheelchair though he could independently move around the house, although sometimes he got stuck and momentarily lost function. Patricia explained that "it varies from hour to hour, so he may be able to turn around sometimes and not others" (int 1). Patricia therefore had to be available to attend to Henry's personal bathing and toileting. Patricia assisted him with dressing and did all of the household management. However, this was becoming increasingly difficult because of arthritis in her hands.

Patricia's recruitment to the study was through her friend, who was involved in the study through the PPI process. She wanted to be interviewed on her own so that she could speak freely. We, therefore, took each of our interviews in a different part of the house from Henry. I informally talked to Henry at each interview and he was welcoming of my presence. Patricia and I discussed meeting in a public place at the end of the first interview. However, following Henry's fall and subsequent hospital admission between the first and second interviews, she was no longer comfortable leaving him alone for too long.

In terms of support, Henry had an O.T. coming in for rehabilitation and was involved with a local dance group that he attended independently. Patricia attended an informally organised social group with three other carers. She was ambivalent about getting more care coming into the house as she explained she was “very supportive of people getting publicly funded services, I wouldn’t really choose to access them myself (int 1).” This fitted with both her husband and her desire not to burden other people or formal services. She was looking for a befriender for her husband, but she hoped she’d be able to meet someone organically rather than going through a formal service.

Patricia’s first interview was slow-going as she reflected that while she is quite an “analytic person” ordinarily, she wasn’t able to access her own situation. She then said that maybe if “[you] asked the right questions, she would be able to” (int 1). With some prompting then, Patricia came to describe her daily caring as a situation where you could just “fizz over, just almost without warning, argh!”(int 1). She explained how being a carer made her feel inadequate as a woman because it made her feel “bossy” rather than “nice”:

> … ***anything else you thought to say or interesting to note?***
>
> *R: I suppose the only other thing is that being a carer …makes you realise you’re not as nice as you thought you were.*
>
> ***I: Oh really interesting. In what way?***
>
> *R: Because of getting so irritated irritable angry. Saying things you wish you hadn’t. Afterwards.*
>
> ***I: I guess it’s fair that there’s high emotion.***
>
> *R: Yeah I guess. You just get to the end of your tether. (int 1).*

The storyline of her second interview focused on her feeling that she must “reign oneself back”(int 2) and think of strategies to make it better. In particular, she discussed needing to improve her sleep so she could manage her moods. The third interview, perhaps the most remarkable of the entire study, focused on the three kinds of loneliness she experienced, paraphrased here as:

1) Lonely in her relationship – they can no longer communicate because she’s deaf and he’s soft of speaking.

2) Loneliness in a group – she feels people with ‘carefree’ lives can’t really understand her experience.
3) Social isolation from her friends – its difficult to give any time to them because of the psychological drain of caring (int 3).

Couple 12: William (P) and Doris

William, 85, white British, had COPD, which “compared with say a year, two years ago then it’s definitely worse” (int 1). He said that it left him “breathless even doing my morning ablutions” and was why he had to use a scooter to travel beyond his room in the independent living facility. William explained that “top of all that lot, I’ve got a problem with a valve in the heart” (int 1) which meant he had to be “careful what I do”. All the while, he was caring for Doris, 85, white British with last-stage Alzheimer’s.

William was recruited to the study by his G.P. and took part in all three interviews. Doris was present for the final two once she had returned home from the hospital. In the last three years, William and Doris had moved to a council-funded independent living facility that had access to 24/7 health care assistants. William and Doris were also supported hugely by their mid-life daughter, herself juggling her full-time job and recovering from cancer. William explained that his daughter frequently rang to check “what are you doing, how are you doing it, no you can’t do that. I’ll get somebody to do that” (int 1). He describes how “without her I don’t know where we’d be” (int 1).

At the first interview, Doris had been hospitalised for ten weeks due to a ruptured bowel following a fall. The first interview centred on how William was continuing to care for Doris whilst in hospital. William visited Doris in the hospital every day with the assistance of their daughter. His visits were as much for him as for her. He explained that he was bored without her being and home, though he “surfed the net” to fill his time (int 1). This feeds into the key storyline of his first interview, which was that “we’ve had a very good community life” (int 1) and now they were receiving care from the wide network in their time of need.

Doris returned home from the hospital between the first and second interviews, instigating a new “the learning curve” (int 2). William enthusiastically explained the ways he was experimenting with foods that his wife can eat with her Stoma bag to ensure her diet “doesn’t get boring”(int 2). William was also “installing all the gadgets”(int 2) to keep her safe in their small apartment in their independent living facility. He frequently describes his care as a team approach to aiding his Doris’s recovery:

> *R: What we’re aiming to do of course is to get her so that she can stand and get her into the wheelchair then we can take the wheelchair down for lunch instead of having the lunch here and we’re working in stages and we’re working towards dealing with that and the carers help and we’ve got to do our bit to try and match the ideals and wants really so… (int 2)*

While the first central storyline of his first interview was about outlining how they have always been “community people”, by the last interview, he focuses on his “new life” of caring:

> *I’ve always been involved in the community quite happy to do that it gives you an outlet rather than just sitting there watching the tv it gets a bit boring again I’ve enjoyed doing that but that’s a section of my life that’s gone now my new life is totally different caring for Doris. getting her to walk making certain she has her medication on time so it’s a different scenario when we retired what I was envisaging was we would go on cruises (int3).*

Nevertheless, he ended his last interview with optimism that they will both make it to their 60th wedding anniversary:

> ***I: Yeah oh wow so you had your fifty ninth anniversary in the hospital.***
>
> *R: [laughs] Yeah so this year of course we’ve had it with just her in. So we’re hoping next year the sixtieth we can actually do it here with neither being in hospital but we’ve got all the gadgets we can think of to make her life a bit easier. (int 3)*

Couple 13: Joan (P) and Richard

Joan 73, white British, referred to herself as a "very can-do woman"(int 1) caring for her second husband, Richard 79, white British for the last nine years his Parkinson's developed into end-stage Lewy body dementia. They had been married for the previous 20 years, and he was her second marriage. She was recruited through snowballing from a friend who had heard about the study from her friend involved in the PPI process. Joan choose to be interviewed by herself. Her husband was in his room upstairs for both interviews, and I met him at the end of the second.

Joan had enlisted a private carer to come twice every day to assist Richard's toileting and bathing since Richard had returned home from the hospital two months ago, newly bed-bound. They could only just afford this with their teacher pensions, but she explained she needed help because she had already strained her back from lifting him. She was now doing physio to recover. Joan attended an informally organised social group with three other carers and was also involved with the local neurological charity that supported both patients and carers. She was also a very active grandparent seeing them once a week. She explained she loved to see her grandchildren's "development" compared to Richard's decline (int 1).

During her first interview, she summarised her experience of caring as one of "living bereavement"(int 1). She outlined the social and emotional difficulties of caring for someone where:

"it's very one way traffic or it is with my husband I don't think he has a clue how hard it is emotionally or physically and as I say there isn't that feedback that you normally get in a relationship which makes it worthwhile. And that for me is the hardest thing but it's just a different sort of relationship. (interview 1).

Between the first and second interviews Joan collapsed and was admitted to the hospital for exhaustion. I spoke to her the day after returning home from the hospital over the phone and visited with her two weeks later, where her interview centred on the physical impacts of caring. She described herself as "running a car on an empty petrol engine" (int 2).

Actively trying to steer the conversation away from what was wrong, Joan also continued to explain want she was doing to make caring more bearable: some of her innovative coping strategies are captured in the Chapter 6. Finally, we decided that two interviews would be enough as she had a lot on her plate and was facing the tricky decision to move Richard into a care home.

Couple 14: Radhika (P) and Rahul

Radhika, 80 Indian, explained that she had been caring for her husband Rahul, 84, Indian, for the entirety of their 60 year-long marriage. Nonetheless, since emigrating from India to England seven years ago and Rahul quickly being diagnosed formally with Vascular Dementia and renal failure, Radhika had taken on more specific caring responsibilities. She lamented that "in India the ladies don't take so much of the burden which I have got"(int 1).

Radhika was recruited to the study by a carer's organisation in London. The recruiter discussed the study with her and then arranged a visit. Radhika explicitly stated she wanted him present for security reasons as she had had previous experiences of having cleaners steal from her house. Their care navigator, who they regarded as "like a son"(int 1) to them, was incredibly helpful during the interview process by occupying Rahul so that Radhika and I could speak directly.

Their care navigator was their biggest source of support. He had helped them to arrange to have the same health care assistant to come every morning for an hour to help with cooking and getting Rahul ready. While their son lived in the same city, Radhika explained that he and his wife were busy with work, so she only saw them occasionally. From our conversations, it appeared that her son likely provided important instrumental and financial supportive background roles. Radhika and Rahul were closely linked in with their local G.P., and Rahul attended day centre three times a week. Radhika was also attending a computer course.

Radhika centred her first interview on her care routine that she had carefully curated for them both. As she put it she was Rahul's "full day carer" (int 1):

> ***I: What kind of activities do you do to care for your husband?***
>
> *R: Actually only one thing is there because when he is doing yoga I keep an eye but only. And one thing I take him for the walk also. The days he is home. And this thing I ask him to fill the sudoko, we get the paper so we both do that in the evening.*
>
> ***I: And what is the Suduko for?***

R: Me? To keep him company and it is also a nice thing (int 1)

Radhika focused her second interview more specifically on the physical toll of caring, bemoaning that “I am old, I am sick” (int 2). Her ailments included her deafness and arthritis, which coupled with her husband’s declining cognition was making it difficult to maintain the fine balance they had structure through their daily care routine. Illustrative of this was the breakdown in her arrangement where Rahul would listen to her phone calls and loudly repeat back what the caller was saying so she could respond:

I: So I came a month ago has there been any changes?

R: No but I thought cos he has been coming less now. So I told you not when telephone used to come I used to do the talking and when they talk I ask him to listen now he is also not getting that so it is becoming impossible and our this thing, some people they send me some video clipping. Or talking videos and they are becoming useless but I don’t want to disappoint those people. So I say thank you. What to do?(int 2)

Our third interview was not possible as Radhika’s mental health had declined, and the recruiter felt that she was not up to another interview.

Couple 15: Barbara (P) and Scott

Barbara, 77, white British, was caring for her husband Scott, 82, white British who had end-stage Vascular Dementia. Barbara retired early to care for him due to his liver failure in 2001 relating to his alcoholism. However, it is only in the last seven months, with Scott’s declining cognition and incontinence, that she began to think of herself as a carer:

I: What made you feel like you became a carer then?

R: Because he wasn’t able to look after himself unwilling and unable he wouldn’t take responsibility for himself he was not aware of his own situation … (Interview one)

Barbara reported that she was deemed physically healthy at a recent G.P. visit except for having high blood pressure.

Barbara rang me directly to participate in the study, having seen the recruitment flyer via an email from a local carer charity. Our first two interviews took place at her house in the garden with the door shut so Scott could see but not hear us. The third interview was conducted at a local café, after which we went for a long walk.

Barbara provided daily care for her husband with support from social-service provided carers twice a day. Barbara was required to arrange them through a personal budget, which was particularly difficult as her health care assistants were not as consistent or reliable. She said that one of the key roles of being a carer was “learning to cope with [formal] carers”(int 1). However, she was reluctant to burden her two daughters. Though they rang to ask about their father, Barbara felt it was “too sad to tell them the full extent of his decline” (int 2).

The trajectory of our interviews was Barbara’s slow loss of faith in her abilities to keep care for Scott at home. In her first interview, she explained that she was “entering the worry stage" (int 1) because of difficulties managing his incontinence and health care assistants. By the second interview, Barbara felt that she was "driving blind" (int 2), no longer seeing what she could do to improve her situation. By the final interview, she suggested she should keep a “diary of the defeated”(int 3) as she recounted the dead ends she kept confronting in trying to get respite care for herself. Finally, Barbara explained ringing a mental health helpline during a low, expressing suicidal ideation to receive support. She was since then attending a well-being class to help get herself on track.

Couple 16: Guilia (P) and Arvind

Guilia, 89, Italian, was caring for her husband Arvind, 89, Indian, who had Lewy Bodies Dementia. She had been doing so since Arvind’s surprise admission to the hospital and subsequent end-of-life diagnosis three years prior (discussed in the prologue). Since returning home from the hospital, Arvind was confined to bed. Guilia was frail herself, having fallen three times in recent months, leaving her tentative to leave the house without a support person.

Guilia was recruited to the study by a carer’s organisation. The recruiter discussed the study with her and then arranged a visit. Her recruiter attended the first meeting, and we all agreed that I would interview by myself at the end of the first interview. I did not meet Arvind, who remained in his upstairs room through the interviews.

Arvind received social service funded carers three times a day. They had no children but were in close contact with her brothers in Italy. Her care navigator helped arrange the bureaucratic aspects required to facilitate their care, such as liaising with social services and arranging their pension payments.

The central storyline of Guilia's first interview was: "why cure the pain and not the damage" (int 1). This reflected her belief that her husband's condition had been made worse because of his treatment in the hospital and the subsequent issues with getting rehabilitative support in the house. Her following interview focuses on her poor physical health and the daily trails she faces getting up and down her stairs to provide care for her husband who can not leave the top level:

> …it has caused me the loss of 12 kilograms in weight, enormous physical stress. Last year I fell down and fractured my left ankle, it has been a hell up and down the stairs. This year I have fallen down again. To put the stair lift is vital for my husband to go out in the wheel chair and for me not to go up and down all the time, because my husband will only sleep upstairs (int 2).

Guilia and I agreed that she would not need a third interview as the central issues of her situation remained unchanged and that she needed her energies to pursue another matter not discussed here.

Couple 17: Charles (P) and Dolores

Charles, white British 80, had been caring for his wife Dolores, 87, for the last eight years since a severe stroke that left her wheelchair-bound, incontinent and able to communicate only through her facial expressions. One year into his remission from prostate cancer, Charles was continuing to care for Dolores in their spacious, well-decorated home with a team of three privately paid healthcare assistants. Dolores' two daughters were also hugely supportive, with each taking a day on the weekend so that Charles could have some time off. They were also involved in the local neurological organisation, and he attended an informal carers group.

Charles was recruited through snowballing by a friend, who had heard about the study from her friend involved in the PPI process. To not tire him out, we agreed on the phone ahead of the interview to complete one long interview instead of subsequent interviews. Dolores and her health care assistant arrived at the end of the interview at which point Charles explained to Dolores that he had been talking about how much he loved her and how much he appreciated the support of the HCA, who was "part of the family" (int 1).

The key storyline from his interview was "out of evil cometh good" (int 1). Charles described how he was trying to stay positive and make the most of their predicament whilst admitting care was taking an emotional toll. He shared that he felt "angry" that his wife was no longer about to speak. But, on the other hand, they remained emotionally close and that there "was only one occasion that I haven't been able to figure out what she needs" (int 1). Through association with a carers organisation he had "made a couple of really quite close friends". He continued "I say to Doloroes, part of us have been really lucky because we have met people who we would never have met if this hadn't happened so out of evil cometh good" (int 1). He explained that his military service, in the context of the Cold War, had in strange way prepared him for caring as in both instances; "you never knew when you'd be called into battle" (int 1). Such ambivalence extended to his views on the carer identity which is explored in Chapter 4.