Submitted in partial fulfilment of the

Lancaster University Doctorate in Clinical Psychology

September 2022

Doctoral Thesis

The experiences of working sons caring for a parent with dementia

Samuel Hughes

Trainee Clinical Psychologist

Division of Health Research, Lancaster University

Statement of total word count for the Thesis

	Main Text	**Appendices (Including references, tables & figures)**	**Total**
Thesis Abstract	248	-	248
Section 1: Literature Review	6,622	6,316	12,938
Section 2: Research Paper	7,997	5,550	13,547
Section 3: Critical Appraisal	3,089	611	3,700
Section 4: Ethics Section	2,738	6,676	9,414
Total	20,694	19,153	39,757

Thesis Abstract

This thesis explores the lived experiences of people living with a diagnosis of dementia or caring for someone with a diagnosis of dementia from a qualitative perspective. It includes a literature review, research paper, critical appraisal and ethics section. The literature review is a meta-synthesis of the experiences of LGBTQ+ people living with or caring for dementia. Data from 8 papers were synthesised using a meta-ethnographic approach. Three resultant themes were discussed to contextualise the experiences across papers: (1) LGBTQ+ identity in heteronormative environments; (2) Families of origin; and (3) Families of choice. Findings contribute to existing literature by identifying the experiences of LGBTQ+ people and making suggestions for future research. The review makes suggestions for clinical services, emphasising the importance of making services more inclusive as well as discussing therapeutic implications such as cultural competency training. The Research paper explores the experiences of working sons caring for a parent living with dementia. 7 working sons were recruited to the study who acted as primary caregivers to their parent and took part in semi-structured interviews. Their data was analysed using Interpretative Phenomenological Analysis (IPA) and resulted in five themes: (1) A journey into the unknown; (2) The leader of the band; (3) Pride and purpose; (4) "Like all the best comedies, it's pretty tragic"; and (5) Workplace context matters. Findings contribute to the existing literature by emphasising the impact of the evolution of gender roles in caring, indicating clinical implications and suggesting specific areas worthy of further investigation

Declaration

This thesis describes research carried out between April 2021 and September 2022 for the Doctorate in Clinical Psychology Programme at the Division of Health Research, Lancaster University. The work presented here is my own, except where due reference is made. This thesis has not been submitted for the award of any higher degree elsewhere.

Name: Samuel Hughes
Date: 14th September 2022

Acknowledgements

My main thanks go to the men who agreed to share their stories with me. Thank you for your time and honesty, I hope that I have been faithful to your accounts and that the bravery you demonstrated by sharing your experiences may benefit others.

I would like to thank; Dr Clare Dixon and Dr Fiona Eccles for your guidance, knowledge and support (both academic and emotional) throughout this process. The understanding and encouragement you offered me throughout this process has been invaluable and will forever be appreciated; Dr Sarah Butchard for being a fountain of resources and inspiration; John Barbrook, faculty librarian, thanks for your support with the literature review; Dr Elizabeth Caldwell, learning developer, thank you for helping me to do justice to this thesis; my wonderful cohort of fellow Trainee Clinical Psychologists for your support throughout; my family and friends, particularly my lovely Mum and Dad, without whom I wouldn’t be in the position I am today.

And finally, my little family – Isabella and Zuzu. My darling wife, Isabella, your name belongs on this thesis just as much as mine. Thank you for the sacrifices you have made and the endless love, support and patience you have gifted me. Zuzu, thank you for your beautiful smile and reminding me, amongst all the late and sleepless nights hard at work, that this really is a wonderful life. I am so grateful for you both.

Thesis Contents

Section One: Literature review

Figure Legends

Section One Appendices

Section Two: Research Paper

Section One: Literature Review

How do LGBTQ+ people experience dementia?

Samuel Hughes

Lancaster University

Doctorate in Clinical Psychology

Prepared in accordance with the journal guidelines for

Dementia

Word count: 6622 (Excluding tables, appendices and reference lists)

All correspondence should be sent to:
Samuel Hughes
Doctorate in Clinical Psychology
Health Innovation One
Sir John Fisher Drive
Lancaster
Lancaster University
LA1 4AT
Email: S.hughes5@lancaster.ac.uk

Abstract

This paper reviews literature on the experiences, attitudes and needs of LGBTQ+ people caring for someone with dementia or living with dementia. A meta-synthesis was conducted based on a meta-ethnographic approach (Noblit and Hare 1988). A systematic search identified eight articles for review. All eight studies used a qualitative methodology. The review identified several themes: (1) LGBTQ+ identity in heteronormative environments; (2) families of origin; and (3) families of choice. Findings contribute to existing literature by identifying the experiences of LGBTQ+ people and making suggestions for future research. The review makes suggestions for clinical services, emphasising the importance of making services more inclusive as well as discussing therapeutic implications such as cultural competency training.

KEYWORDS: Dementia; Qualitative; Literature review; LGBTQ+; Meta-ethnography

Introduction

Dementia is an umbrella term for a variety of diseases categorised by progressive cognitive decline that interferes with the ability to function independently (Duong et al., 2017). It is non-curable and primarily managed through medication and behavioural treatment plans (Sink et al., 2005; Zucchella et al., 2018). The aim of treatment is to delay progression of the disease and to promote the independence Globally, around 55 million people have dementia and, as the proportion of older people is increasing worldwide, this number is expected to rise to 139 million by 2050 (World Health Organisation, 2021).

The impact of stigma in dementia

People living with dementia can experience many difficulties including in maintaining relationships, identity, and sense of purpose and may also feel marginalised by loved ones, healthcare services and wider society (Gorska et al., 2018). In addition to experiencing difficult symptoms, dementia can be experienced as an illness with significant social and personal consequences and this emphasises the importance of understanding the social context of people living with dementia.

Kitwood's (1997) seminal work on social context in dementia established the term 'personhood' which relates to treating people with dementia with dignity and respect in a way that supports their sense of self. However, a review into the way in which people living with dementia view the attitudes of people around them found themes including being treated as an 'other' or 'lesser', and reported people need to employ strategies to manage this (Patterson et al., 2017). The authors indicated that people living with dementia felt the effects of societal stigma and made active steps to avoid this such as by withholding their diagnosis. A review of public attitudes similarly found limited knowledge, as well as stereotyping, prejudice and discrimination. (Nguyen & Li, 2020). The impact of stigma and discrimination is particularly important to understand as people living with dementia have reported hopes of feeling valued by others and having a sense of social integration (Harding et al., 2019).

Caring for dementia

Of course, people living with dementia are not the only people who experience the illness. There are also informal caregivers (most commonly family and close friends) who provide an average of 5 hours per day providing care for people living with dementia (World Health Organisation, 2021). Caregiving for dementia is thought to be significantly different than general caregiving in that it requires more time and has been found to have a greater impact on caregiver mental and physical health (Ory et al., 1999). Changes to the care recipient’s personality, cognitive ability and mood can leave carers grieving their loved ones and the premorbid relationship they shared as well as being a source of stress (Chan et al., 2012). In the UK the National Institute for Health and Care Excellence (2018) recommend that caregivers of people living with dementia should be offered psychoeducational support. However, there appears to be a pervasive feeling amongst caregivers of feeling unsupported both by the wider family and by health and social care services (Laparidou et al., 2019).

A common theme in the experience of people living with dementia and their carers is the effect of others (through stigma and relationships) on their experience. It is therefore worthwhile to consider this in the context of people living with ‘difference’ and how this may create a different experience of living with dementia. One specific group for whom this could be important are people who identify as lesbian, gay, bisexual, transgender, queer/questioning plus other sexual identities (LGBTQ+).

Living as a sexual identity minority

A recent cross-country report found that globally, on average, 3% of people identify as gay, lesbian or homosexual, 4% as bisexual, 1% as pansexual or omnisexual, 1% as asexual and 1% as 'other' (Ipsos, 2021). Furthermore, each new generation is more likely to identify as a sexual identity minority than the previous generation. . However, despite international laws enshrining the right of LGBTQ+ people to enjoy their human rights 'without distinction' the United Nations regularly report violent attacks including assault, kidnap, rape and murder and discriminatory curbs on freedom of speech and expression (Tudor, 2021).

Even in countries in which rights have progressed the current cohort of older people living with dementia will have lived during a time in which their sexual identity was illegal. For example, the partial decriminalisation of homosexuality in the UK only began with the

Sexual Offences Act (1967). Same sex marriage was not legal anywhere in the world until September 2000 when the Netherlands became the first country to legalise it, however in the years that have passed only a further 31 countries have followed suit (Human Rights Campaign, 2022; Pentaris, 2019). The first country in the world to provide legal access to sexual reassignment surgery was Sweden in 1972 however, as of 2022, only 96 countries allow trans people to change gender legally (Chiam et al., 2017). Even in countries which recognise these rights trans people are reported to experience discrimination in all walks of life, including workplaces, universities and healthcare (Stonewall, 2021). The societal and legal legacy that LGBTQ+ people face is one which included harsh judgement of differences in sexual orientation, at best, and judicial punishment or violence at worst – this remains a reality in many countries around the world.

Sexual identity and ageing

LGBTQ+ older adults have reported facing dilemmas in whether to disclose their identities through fear of discrimination from those outside of their community (Fredriksen-Goldsen et al., 2016). One study has reported that the more open LGB older adults are about their sexual orientation the more prone to victimisation and physical assaults they are (D'Augelli & Grossman, 2001). Furthermore, the authors found that following an assault LGB people were more likely to report lower self-esteem, loneliness and poorer mental health. Concealing an identity in order to protect one’s self would have consequences for transgender older adults who experience negative mental health outcomes in the absence of group-level coping and open gender identity expression (Hoy-Ellis & Fredriksen-Goldsen, 2017). LGBTQ+ older adults appear to still be experiencing discrimination and violence and this can even come from within their immediate family. Breder and Bockting (2022) report that homophobia within the family can contribute to the individual becoming isolated, unsupported and to having poor psychological well-being. The legislation, societal homophobia and the associated effects on the LGBTQ+ community will be important for both people living with dementia and their caregivers.

To summarise, the number of people expected to experience dementia is rising, as is the number of people who identify as LGBTQ+. Both groups have experienced stigma and discrimination, and the impacts for older people may be particularly salient, given the historical contexts. Thus it is important to understand the specific LGBTQ+ experience of living with dementia.

Consequently, this paper reviews and synthesises the current research available regarding the experiences of people who identify as LGBTQ+ who have a diagnosis of, or care for somebody with, dementia. Qualitative methods are recognised as being better placed than quantitative to capture identity-based experiences (Fredriksen-Goldsen & Muraco, 2010). Therefore, the review will focus on qualitative research in this area. The research question is “How do LGBTQ+ people experience dementia?”.

Method

The review was conducted using the meta-ethnographic approach proposed by Noblit and Hare (1988). Meta-ethnography is recommended in order to develop higher order interpretations of the account of particular communities or ‘ethnographies’ (Atkins et al., 2008). It was thought that this would be an appropriate approach to reviewing and synthesising the experiences of the LGBTQ+ community with regards to their interaction with dementia**.** Additionally, meta ethnography has already been utilised successfully to explore, develop and create new bodies of knowledge of the LGBTQ+ experience in other topic areas and so has an appropriate precedent (Dahl et al., 2013; Moolchaem et al., 2015; Kearns et al., 2021). In contrast, alternative approaches considered such as thematic analysis are not as widely used in the literature base.

Literature search

A systematic literature search was conducted in November 2021. The following databases were searched: PsycInfo, Medline, CINAHL and Socindex. These were chosen as they were thought to be inclusive of a relevant and diverse range of research, for example, medical and care experiences through Medline and CINAHL and psychological and sociological experiences through Psychinfo and Socindex.

The systematic search included two main concepts: dementia and LGBTQ+ and was developed in consultation with an academic librarian. For the purposes of this review, the term LGBTQ+ is used as the most recent phrase to capture all sexual identity minorities. The finalised search terms (Table 1) were generated using individual database subject headings (e.g. APA thesaurus and MeSH headings) combined using Boolean operators with free text terms. The only filter used was to exclude any papers not published in English. No date or other restrictions were applied on the search. The resultant papers were drawn from the databases, duplicates were removed and then screened by title and abstract to remove irrelevant papers. Following this, the remaining papers were read in full and further irrelevant papers were removed resulting in the remaining 8 papers which were included in the review.

[Insert Table 1 about here]

Screening criteria

Inclusion

Qualitative studies published in English were included. They must have included a substantial focus (e.g. at least a complete theme or similar portion of text) on the experience of either LGBTQ+ people living with dementia or LGBTQ+ people caring for somebody with dementia.

Exclusion

Papers were excluded that focused on healthcare workers/services experiences of caring for people living with dementia who identified as LGBTQ. This was due to the scope of the research question specifically pertaining to the experiences of LGBTQ+ people experiencing dementia.

The final papers were examined for quality using the Critical Appraisal Skills Programme (CASP, 2018). The papers were read and analysed through the lens of the 10 quality appraisal items and rated based on their relative performance in each domain.. The appropriateness of quality appraisal tools are disputed due to the lack of calibration with meaningful real-world data and openness to subjectivity (Crowe & Sheppard, 2011; Petticrew & Roberts, 2006) and therefore the tool results were not used to exclude papers, particularly given the sparse literature However, the broad consensus is that critical appraisal tools provide valuable context to the findings of literature reviews (Tod et al., 2021). Therefore, this process was used to draw attention to strengths and limitations which might contextualise the findings. Furthermore, no theme contained only the weaker papers

Analysis and synthesis

The process of Noblit and Hare's (1988) seven step approach to meta ethnography is as follows: getting started; deciding what is relevant to the initial interest; reading the studies; determining how the studies are related; translating the studies into one another; synthesising translations; and expressing the synthesis. To do this a topic was selected to start with and primary studies were collected through a stringent search strategy. These were then read and re-read with an analytical lens specifically searching for areas related to the research question. Following this, each study was coded into key themes, ideas and concepts, an example of which can be seen in Appendix A; this was done by analysing Schutz' (1962) concept of first-order (participant's experiences) and second-order (researcher's interpretation) constructs resulting in third-order constructs (the author's interpretation of these constructs). These third-order constructs were then reviewed across studies to establish any relationships between them by cutting them out into pieces of paper and aligning those related into separate groups. Once relationships amongst groups were identified they were allocated into superordinate themes. Table 4 indicates the contribution of each paper to the theme. The resultant relationships were collated into a line of argument (Noblit & Hare, 1988) and presented in the review.

[Insert Table 4 about here]

Results

The initial search retrieved 1112 articles of which duplicates were then removed, leaving 782 papers. Titles and abstracts were then screened for relevance. Finally, 97 papers were reviewed in full against the inclusion and exclusion criteria resulting in 8 papers being included in the final meta-synthesis. Figure 1 shows the full search and screening process in the form of a PRISMA flowchart.

[Insert Figure 1 about here]

The majority of experiences explored in the papers were that of caregivers, and most involved a dyad of a person living with dementia and their carer. A summary of the final studies included can be found in table 2.

[Insert Table 2 about here]

The papers generally scored moderate-high quality on the CASP with only mild variances except for Marshall et al., (2015) which was relatively weaker than the other papers on most domains. For this reason no theme relied solely on this paper but instead the themes, at least, drew on a selection of the stronger papers. See table 3 for CASP scores.

[Insert Table 3 about here]

Three core themes emerged from this meta-ethnography which were: LGBTQ+ identity in heteronormative environments, families of origin, and families of choice. Here, these core themes are discussed with supporting excerpts from the eight reviewed papers. It is important to note that of these eight papers, three of them came from the same project with the same participants however with different research questions, focussing on subsections of the sample (Price, 2010; Price, 2011; Price, 2012).

LGBTQ+ identity in heteronormative environments

Many studies reported a general trepidation and lack of trust in services to respect and embrace their sexual identity (Barrett et al., 2015; Putney et al., 2018; Price, 2010; McParland & Camic, 2016). There appeared to be multiple factors across the papers explaining why this may be, ranging from systemic heteronormative biases to acute demonstrations of homophobia: ‘Tim reported that five services provided ‘trumped up’ reasons for not accepting his partner after identifying they were a gay couple’ (Barrett et al., 2015, p.37). One carer explained that their doctor had focused on medical issues and never asked how the couple were coping, leaving them feeling as though they had a problem with their sexual identity and as if their personhood and couplehood had been undermined (McParland & Camic, 2016). Many had experiences of healthcare professionals making assumptions that care providers or recipients were family members rather than romantic partners and felt their status as same-sex couples was not as important as their heterosexual counterparts: 'I'm afraid my partner had been referred to as my brother or something like that' (Price, 2010, p. 163; person living with dementia). Some participants reflected on these experiences and expressed a desire for more inclusive services: 'My dream is to have a kite mark so that LGBT people can see, at once, if a service provider is LGBT friendly. A kite mark that would indicate that staff have been made aware of LGBT clients and would indicate that prejudice of any kind would not be tolerated. That would make me feel safe and confident.' (Price, 2012, P. 528; carer).

Some LGBTQ+ caregivers expressed fears about an eventuality in which they themselves developed dementia and the care that they may receive. This fear appeared to be partially borne of a concern of the way in which they had experienced services be presumptuous and heteronormative by nature. There was a lack of confidence in services' abilities to care sensitively for sexual identity minorities or be attentive to their needs: 'But what if I have Alzheimer's? Will it be assumed I'm heterosexual and I don't need my friends to come and talk to me about my past?' (Westwood, 2016). Consequently, many didn't trust healthcare services with their wellbeing or even their physical safety (Putney et al,. 2018). Within this fear was an insight that LGBTQ+ people may need to plan further ahead than their heterosexual counterparts in order to protect their identity and wellbeing. One participant explained that she had started making photo memory books with appropriate labels detailing that the person in them was a romantic partner rather than just a friend 'because that's what would happen if anybody else was labelling them' (Price, 2012, P. 521).

These biases appeared to be made sense of in the context of the societal discrimination and expectations that the generation of participants had experienced: 'I don't think older people are allowed a sexuality, per se, you know, that's irrespective of gay/heterosexual, and I think, if you add sort of LGBT stuff to it, then it just becomes even more increasingly taboo and invisible' (Price, 2012, P. 522). Barrett et al., (2015) reported that many of the generation currently experiencing dementia had lived through a time in which invisibility was a protective mechanism from violence, discrimination and even punishment. This legacy resulted in care environments in which it was difficult to express an authentic sexual identity and influenced whether people would feel comfortable disclosing that they are gay (Westwood, 2016). Putney et al., (2018, P. 897) reported that transgender people living with dementia experience a double-edged sword when it comes to disclosure vs concealment: 'That fear is real and it will cause us to hide and do things that we wouldn't normally do, i.e., take your own life'. It is suggested that fear of violence and discrimination can cause LGBTQ+ people to conceal their identity from services to protect themselves but that this can cause psychological distress and suicide ideation/completion. Although many acknowledged the concerns around being open about sexual identity in care settings, some carers, in particular, rebuked the idea of concealing their identity: 'I am not going back in the closet. I spent my life fighting to get out of the closet'. (Price, 2012, P. 526).

Although, many of the participants cited difficulties within heteronormative environments and services, others spoke about positive experiences and how safety signals from clinicians, including not making assumptions about relationships or giving verbal and non-verbal acceptance, made them feel safe (McParland & Camic, 2016). These experiences were reported to have a positive outcome and helped carers and people living with dementia to express their authentic identities. However, this appeared to be the exception rather than the rule, with all papers citing concerns surrounding the way in which identity is treated within what are perceived to be heteronormative services. As a result, some advocated for LGBTQ+ specific care facilities in which they could be free to be themselves without fear of discrimination from fellow care-recipients or staff (Price, 2012; Putney et al., 2018).

Family of origin dynamics

Families of origin were a consistent topic of discussion throughout the studies. Varying dynamics were presented in the participants' narratives, however the way in which people were treated by, or relate to their family of origin, appeared to have an impact on the way in which they experienced dementia. There was a duality in this whereby sexual identity had an impact and a dementia diagnosis compounded these difficulties. Some family members reduced contact with their LGBTQ+ relatives due to their sexuality and this became even worse when a diagnosis of dementia was given (McParland & Camic, 2016).

One study detailing the case of a transgendered female who lived with dementia reported her daughter would remove more effeminate clothing from her closet when visiting the care home and not be tolerant of her gender identity. This woman's daughter had been estranged for years until a diagnosis of dementia was given and she started to visit her again (Marshall, Cooper & Rudnick, 2015). Conflicts with adult children of trans parents living with dementia was often triggered by difficulties in accepting the parental transition and even led to some children giving ultimatums to parents to live as their gender assigned at birth (Putney et al., 2018).

Family of origin was often a source of contention for LGBTQ+ people experiencing dementia: 'For myself… family is very often a great deal more problematic' (Price, 2011, P. 128). Some lesbian carers felt obliged to re-organise their lives to accommodate caring responsibilities due to a gendered and stigmatised expectation that their lives and personal relationships were less important than their heterosexual siblings (Price, 2011). However, some carers reported that the dementia experience had brought them closer to their families who were previously intolerant of their sexual identity through either shared bonds created by caring or the people living with dementia forgetting about the strains in the relationship (Price, 2011). 'There's a long history, I've had a huge long relationship with my sister about my sexuality. I know she still feels it would be better if I was heterosexual. In her heart she still thinks.. So interestingly, the point at which mum went into hospital … was the point at which we [respondent and her sister] started doing much better together. 'Cos I was doing the sleep deprivation and falling apart thing and she was, she was very supportive actually, and I remember coming away thinking how strange, that something as awful as that should bring us to a place where, you know, it, I mean, it felt like it kind of cut through.' (Price, 2011, P. 1295).

Family of choice

A seemingly protective factor in the experiences of LGBTQ+ people living with or caring for someone with dementia was safe and nurturing relationships. Reference was often made to the families LGBTQ+ people choose and to communities of other people with shared identities. Connecting to these communities helps people feel a sense of belonging and understanding with one carer exemplifying this: ‘I’ve just been out on my first trip with the Gay birdwatching club… There’s something about being in a majority, sharing a culture, not having to explain, having the same reference points etc.’ (Price, 2012, P. 527). People who shared a sexual minority identity often stepped in to provide support where a family or origin was lacking or provided a level of support that healthcare services simply did not: ‘There was never any question for me that I'd have gone to blood family to do that, it was absolutely my social family that I was going to do that with.’ (Price, 2011, P. 1299). It also appeared to be important for LGBTQ+ caregivers to maintain links with other gay and lesbian people both in the caregiving journey and if they were to rely on support in the future due their own cognitive health.

Families of choice represent a break from other environments which are often experienced as heteronormative. This may partially explain why some people expressed a desire for specialist gay and lesbian long-term care facilities which may be more sympathetic to lifestyle choices and needs.

Although mostly positive experiences were assigned to friendships, some couples explained that the dementia diagnosis caused social isolation and friends to withdraw from them. Some added that this was due to the duality of a dementia diagnosis and a gay identity (McParland & Camic, 2016). Further to this, some who were carers held stigmatised preconceptions of dementia which caused anxiety about social situations and how best to manage the condition: ‘I want to avoid the situation of him mixing too much with people who are in the same situation as him. I prefer him to lead as normal a life as possible’ (McParland & Camic, 2016). These preconceptions appeared to be shaped by external negative attitudes or being ostracised due to the individual or couple’s sexuality and the dementia diagnosis (Barrett et al., 2015; Price, 2012). These negative attitudes and the resultant social consequences, such as not accessing services or being estranged from family, may result in greater reliance on intimate partners for care and increase social isolation (Barrett et al., 2015).

LGBTQ+ persons are often supported by people who share their identity however the risk of such a group ageing together is that they may develop care needs at similar times and be unable to reciprocate support for each other (Westwood, 2016). Westwood (2016) argued that it may be beneficial to have an intergenerational support network in order to avoid this eventuality. Some carers who did not have children feared who would care for them as they aged: ‘We took care of him for the last two years of his life. I said to him, ‘Daddy, what am I going to do? I don’t have three daughters.’ He said, ‘God help you, sweetheart’. (Putney et al., 2018, P. 896).

Discussion

This review synthesised qualitative findings of the way in which LGBTQ+ persons experience dementia. Findings detailed how identity, familial relationships, relationships of choice and anxieties about the future form a crucial part of this experience. These themes interplay to inform the researchers and participants hopes for the future.

Identity

Care services were perceived as heteronormative at best and homophobic at worst. Westwood (2014) reported that this means service provision can compound the difficult experiences of, in particular, lesbian and bisexual women living with dementia in ways which do not affect their heterosexual counterparts. The authors report that this is due to this group being least likely to have an intergenerational support network. Although underrepresented in the research transsexual people have been reported to be marginalised and suffer iatrogenic harm as a result of heteronormative healthcare services (Newman-Valentine & Duma, 2014). Marshall, Cooper and Rudnick (2015), as above, reported a case in which a transgender people living with dementia was experiencing gender dysphoria and passed away leaving staff reflecting on how they could have approached the situation more appropriately. This demonstrates a lack of training and understanding from healthcare staff and illustrates that often people will live their entire care journey without receiving LGBTQ+ sensitive support. Dementia services are framed in ways which emphasise and rely on normative biological genders and family focussed assumptions which do not represent older LGBTQ+ adults (De Vries, Gutman, Soheilipour, Gahagan, Humble, Mock & Chamberlain, 2020). This can be seen through intimate partners often being disputed in their claim for legal decision-making powers and a lack of support from services within this (Barrett et al., 2015). The description of services as 'heteronormative' could be perceived as tame to some who described explicit homophobia from healthcare providers who were intolerant of their sexual identity (Westwood, 2016; Price, 2011). The lack of understanding combined with the possibility or reality of homophobia and discrimination are a threat to LGBTQ+ people's psychological safety in the context of their personhood (McParland & Camic, 2016). Furthermore, the cohort of people living with dementia will have experienced societal demonisation, discrimination and even have had their sexual identities be pathologized and penalised. It is therefore not surprising that the dilemma of whether to conceal an LGBTQ+ identity was established within a theme in the present review.

Dementia can affect recent autobiographical memory and identity, and people can often recall more personal semantic and personal incident memories from childhood and middle life than the recent past (Naylor & Clare, 2008). It is therefore interesting that the case reported by Marshall, Cooper and Rudnick (2015) detailed a transgender woman who had been living as a woman since her 70s having previously lived as a man in a heteronormative lifestyle. More research would be needed to ascertain whether a later life gender identity transition leads to gender uncertainty or regression as a result of the cognitive effects of dementia. It should also be noted that Barrett et al. (2016) disputed the idea that gender identities are susceptible to dementia but instead attributed changes in identity to external pressures such as family and the earlier issue of concealment. This presents an alternative explanation to the aforementioned transgender woman who had an unaccepting and involved daughter.

Family of origin

The present review found that families of origin and the dynamics through which they exist influence the experiences of LGBTQ+ people living with or caring for dementia. Generally, fractured relationships were reported which is consistent with literature discussing older LGBTQ+ adults in wider contexts (Fokkema & Kuyper, 2009; Boggs et al., 2016; Cummings et al., 2021). People reported a lack of tolerance from their families with regards to their sexual and/or gender identity. When family members hold these intolerant views and care for their LGBTQ+ relative, it can lead to problematic care outcomes (Marshall, Cooper, Rudnick & Abraham, 2015).

Fractures within the family of origin or not having children meant that many older LGBTQ+ people experiencing dementia did not have an intergenerational support network. This puts them at a disadvantage in receiving care as currently services and people living with dementia rely on informal carers and families to provide the bulk of support (Kasper, Freedman, Spillman & Wolff, 2015; Alzheimer's Society, 2015). Further to this, LGBTQ+ people's support network tends to be intragenerational and so as they age together, they may not be able to provide the level of care each member of the system needs (Westwood, 2016). Older LGBTQ+ adults are more likely to be single and without children than their heterosexual counterparts and this leads directly to experiencing less positive care outcomes and more comorbidities (De Vries et al., 2020). It is therefore possible that families of origin and the quality of relationships within them may compound the difficulties of dementia and should therefore be considered by healthcare services. This is of particular importance given the crucial role of family or systemic working when working with people experiencing dementia (Albinsson & Strang, 2003; Moyle et al., 2011; Thompson et al., 2021). It is further important to note that LGBTQ+ people's constructionist definition of family is not limited to biological relative but extends to 'family of choice' (Hull & Ortyl, 2018). It is therefore important for healthcare professionals to consider this in order to provide appropriate and inclusive care.

Family of choice

Relationships which people choose appeared to be generally positive experiences whether they be intimate relationships, friendships or families 'of choice'. Generally, it has been reported that LGBTQ+ people rely on friends for support whereas heterosexual people tend to rely on family (Dewaele et al., 2011). Relationships of choice provide a space of safety, non-judgement and acceptance which is not otherwise provided by familial relationships or healthcare services (Price, 2012; Ward et al., 2012).

The additional strains which LGBTQ+ significant others experience and the reduced validity they are given compared to heterosexual counterparts may compound the difficulties these couples experience. For example, LGBTQ+ significant others are generally not given the same rights as heterosexual partners globally. This is particularly when it comes to navigating the legal frameworks surrounding obtaining legal power of attorney (Harper, 2019). Research suggested some families disputed the rights of significant others to make decisions on behalf of the people living with dementia despite their wishes (Barrett et al., 2015). The validity which same-sex relationships are given by legal frameworks, healthcare services and families are not equitable and is based on heteronormative or homophobic beliefs.

Anxiety about the future

Participants who were caring for a people living with dementia expressed anxieties about the future should they develop dementia. Their concerns varied and included cognitive deterioration, fear of discriminatory services and uncertainty over who would provide informal care (Price, 2012; Westwood, 2016; Putney, Keary, Hebert, Krinskey & Halmo, 2018). The current experiences of people living with dementia is shaping the expectations of possible future cohorts who will experience the condition. Healthcare services should be cautious of this and the impact it may have on future generations' in the event they are diagnosed with dementia.

Limitations and future research

Only 8 studies were included in the final review, 3 of which were from the same project (Price, 2010; Price, 2011; Price, 2012). This reveals a paucity in research pertaining to the qualitative experiences of LGBTQ+ people living with dementia and caring for dementia. The limited amount of research gathered (and limited number of participants within) should be considered when reflecting on the results of the review. Only one study outlined the qualitative experiences of a transgender individual living with dementia. All other study participants were exclusively lesbian, gay or bisexual. Although the search terms aimed to include perspectives of all sexual identity minorities the voices of many were missing. Future research should aim to explore the experiences of all sexual identity minorities with a particular need in focussing beyond just those who are lesbian, gay or bisexual.

Most of the research participants were white and from western societies. There was a lack of cultural diversity within the research. Future research may aim to address this and explore further intersections in the form of minority ethnic people's experiences of living with dementia and as an LGBTQ+ person.

Further to this, the review was unable to comment on younger LGBTQ+ people's views on dementia either through caring or in considering their future cognitive health and care needs. Price (2010) suggested that younger gay and lesbian people may be accustomed to more liberal approaches to their sexual identity. Therefore, research hoping to plan for the future of LGBTQ+ appropriate dementia services may focus on exploring the experiences and concerns of younger cohorts.

Bandara et al., (2015) reported that using tools such as NVIVO can enhance the rigor of literature reviews. Should this be repeated, thought may be given to the use of supportive tools and software to enhance rigor. However, reference management software was used as well as tools such as the CASP (2018) in order to ensure quality and rigor was highlighted and particular attention was paid to ensuring this was properly presented within the main body of the results so as to add important context.

Implications for clinical practice

The recommendations are made based on the synthesis drawn from the selected studies and with an attempt to sensitively address the needs identified within the studies. Furthermore, the recommendations are primarily based on participant's direct suggestions and there should be an understanding that not all participants agreed on these just as not all people who identify as LGBTQ+ will. Some studies referred to LGBTQ+ specific services and the responses from participants were mixed ranging from positive to some believing this may be further stigmatising and separating rather than addressing difficulties within heteronormative services (Price, 2012). However, two particular areas of need were expressed: LGBTQ+-inclusive settings and LGBTQ+ trained and sensitive staff (Putney, Keary, Hebert, Krinskey & Halmo, 2018). People expressed fears about their privacy, identity and lifestyles being respected however acknowledged that safety signals from clinicians and services such as LGBTQ+ friendly kite marks and explicit verbal acceptance would be helpful in allowing them to feel safe disclosing their identities (Price, 2012; McParland & Camic, 2016).

There is a clear need for dementia services to be co-constructed with members of the LGBTQ+ community. Services are currently heteronormative in their structure and a difficulty in designing them to be appropriate in meeting the needs of LGBTQ+ people is the lack of understanding of their experiences and needs. Therefore, it would be beneficial for services to directly recruit people to construct a valuable and safe service. This idea of co-

construction within dementia has been modelled by Kenny et al., (2016) who found that setting up service user groups of people living with dementia can help facilitate an expert by experience approach to teaching and training healthcare professionals.

Generally, the findings reported a picture of unconscious and conscious bias presented towards LGBTQ+ people from service structures as well as individual staff. Issues such as concealment and fear of not having a sexual identity respected appeared to be due to this. Education surrounding these topics, the legacy of the LGBTQ+ cohort who may be experiencing dementia and unconscious biases may therefore be helpful in improving services as they are now. LGBTQ cultural competency training has been shown to significantly improve the knowledge, attitdes, self-efficacy and intentions of health care staff (Rhoten et al., 2021).With regards to Clinical Psychology, clinicians have a large role to play in the care of LGBTQ+ people living with dementia. They provide neuropsychological assessment as well as therapy for issues discussed such as family dynamics and adjustment (Davison et al., 2020). It has been shown that training in LGBTQ-affirmative cognitive behavioural therapy has positive effects on cultural competency and minority stress knowledge (Pachankis et al., 2022). Therefore, cultural competency training may have wide-ranging positive effects on healthcare services as well as the field of Clinical Psychology.

Conclusion

The present review synthesises qualitative findings of people who identify as a sexual identity minority and are experiencing dementia either through diagnosis or through caring. The review draws on individual studies in order to expand upon the needs and anxieties expressed by participants and found that LGBTQ+ people struggle with their identity in heteronormative environments, may have complex family of origin dynamics and have a constructional definition of family which importantly includes ‘family of choice’. The results of the synthesis have implications for the future of research into LGBTQ+ people and dementia and how services can be reconstructed in order to more appropriately and sensitively meet the needs of this group.

References

Albinsson, L., & Strang, P. (2003). Differences in supporting families of dementia patients and cancer patients: a palliative perspective. *Palliative Medicine*, *17*(4), 359-367. https://doi.org/10.1191/0269216303pm669oa.

Alzheimer's Society. (2015). *Alzheimer's Society – Family Doctor Survey*. Retrieved from https://www.bluebirdcare.co.uk/east-devon/news/6817/alzheimer-s-society-family-doctor-survey.

Barnet, Enfield and Haringey Mental Health NHS trust. (2021). *History of LGBTQ+ rights in the UK*. Retrieved from https://www.beh-mht.nhs.uk/news/history-of-lgbtq-rights-in-the-uk/1750.

Barrett, C., Crameri, P., Lambourne, S., Latham, J. R., & Whyte, C. (2015). Understanding the experiences and needs of lesbian, gay, bisexual and trans Australians living with dementia, and their partners. *Australasian journal on ageing*, *34* Suppl 2, 34-38. https://doi.org/10.1111/ajag.12271

Boggs, J. M., Dickman Portz, J., King, D. K., Wright, L. A., Helander, K., Retrum, J. H., & Gozansky, W. S. (2017). Perspectives of LGBTQ Older Adults on Aging in Place: A Qualitative Investigation. *Journal of Homosexuality*, *64*(11), 1539-1560. https://doi.org/10.1080/00918369.2016.1247539

Breder, K., & Bockting, W. (2022). Social networks of LGBT older adults: An integrative review. *Psychology Of Sexual Orientation And Gender Diversity*. https://doi.org/10.1037/sgd0000552.

Chiam, Z., Duffy, S., & Gonzalez, G. (2017). *Trans Legal Mapping Report 2017: Recognition before the law*. Geneva: International Lesbian, Gay, Bisexual, Trans and Intersex Association.

Critical Appraisal Skills Programme. (2018). CASP Qualitative Checklist. Retrieved from: http://www.casp-uk.net/checklists.

Crowe, M., & Sheppard, L. (2011). A review of critical appraisal tools show they lack rigor: Alternative tool structure is proposed. *Journal of Clinical Epidemiology*, *64*(1), 79–89. https://doi.org/10.1016/j.jclinepi.2010.02.008

Cummings, C. R., Dunkle, J. S., Mayes, B. C., Bradley, C. A., Petruzzella, F., & Maguire, K. (2021). As we age: listening to the voice of LGBTQ older adults. *Social Work in Public Health, 36*(4), 509-525. https://doi.org/10.1080/19371918.2021.1904081.

Dahl, B., Fylkesnes, A. M., Sørlie, V., & Malterud, K. (2013). Lesbian women's experiences with healthcare providers in the birthing context: a meta-ethnography. *Midwifery, 29*(6), 674–681.

D'augelli, A. R., & Grossman, A. H. (2001). Disclosure of sexual orientation, victimization, and mental health among lesbian, gay, and bisexual older adults. *Journal of Interpersonal violence*, *16*(10), 1008-1027. https://doi-org.ezproxy.lancs.ac.uk/10.1177%2F088626001016010003

Davison, T., Koder, D., Helmes, E., Doyle, C., Bhar, S., & Mitchell, L. et al. (2017). Brief on the Role of Psychologists in Residential and Home Care Services for Older Adults. *Australian Psychologist, 52*(6), 397-405. https://doi.org/10.1111/ap.12209.

de Vries, B., Gutman, G., Soheilipour, S., Gahagan, J., Humble, Á., Mock, S., & Chamberland, L. (2020). Advance care planning among older LGBT Canadians: Heteronormative influences. *Sexualities*, *1363460719896968*. https://doi.org/10.1177/1363460719896968

Dementia UK. (2021). *What is Dementia?* Retrieved from https://www.dementiauk.org/about-dementia/dementia-information/what-is-dementia/#:~:text=There%20are%20over%20200%20subtypes,are%20commonly%20called%20mixed%20dementia.

Dewaele, A., Cox, N., Van den Berghe, W., & Vincke, J. (2011). Families of Choice? Exploring the Supportive Networks of Lesbians, Gay Men, and Bisexuals. *Journal of Applied Social Psychology*, *41*(2), 312-331. https://doi.org/https://doi.org/10.1111/j.1559-1816.2010.00715.x

Fokkema, T., & Kuyper, L. (2009). The relation between social embeddedness and loneliness among older lesbian, gay, and bisexual adults in the Netherlands. *Archives of sexual behavior*, *38*(2), 264-275.

Frary, M. (2019). Hiding your true self: LGBT people face particular discrimination at some international borders. *Index on Censorship*, *48*(3), 23-25. https://doi.org/10.1177%2F0306422019876455.

Frederiksen-Goldsen, K. I., & Muraco, A. (2010). Aging and sexual orientation: A 25-year review of the literature. *Research on Aging*, *32*, 372–413.

Fredriksen-Goldsen, K. I., Jen, S., Bryan, A. E. B., & Goldsen, J. (2016). Cognitive impairment, Alzheimer's disease, and other dementias in the lives of lesbian, gay, bisexual and transgender (LGBT) older adults and their caregivers: needs and competencies. *Journal of applied Gerontology, 37*(5), 545-569. https://doi-org.ezproxy.lancs.ac.uk/10.1177%2F0733464816672047.

Gender Recognition Act (2004). Retrieved from https://www.legislation.gov.uk/ukpga/2004/7/contents.

Gleeson, K. (2007). Discipline, punishment and the homosexual in law. *Liverpool Law Review, 28*(3), 327–347.

Greenland, K., & Nunney, R. (2008). The repeal of section 28: it ain't over 'til it's over. *Pastoral care in Education, 26*(4), 243-251.

Harding, A., Morbey, H., Ahmed, F., Opdebeeck, C., Lasrado, R., & Williamson, P. et al. (2019). What is important to people living with dementia?: the 'long-list' of outcome items in the development of a core outcome set for use in the evaluation of non-pharmacological community-based health and social care interventions. *BMC Geriatrics*, *19*(1). https://doi.org/10.1186/s12877-019-1103-5.

Harper, P. (2019). How healthcare professionals can support older LGBTQ+ people living with dementia. *Nurs Older People, 31*(5), 16-21. https://doi.org/10.7748/nop.2019.e1115

Hoy-Ellis, C. P., & Fredriksen-Goldsen, K. I. (2017). Depression among transgender older adults: general and minority stress. *American Journal of Community Psychology, 59*, 295-305. DOI 10.1002/ajcp.12138.

Hull, K., & Ortyl, T. (2018). Conventional and Cutting-Edge: Definitions of Family in LGBT Communities. *Sexuality Research And Social Policy, 16*(1), 31-43. https://doi.org/10.1007/s13178-018-0324-2.

Human Rights Campaign. (2022). *Marriage equality around the world*. Retrieved from https://www.hrc.org/resources/marriage-equality-around-the-world.

Ipsos. (2021). *LGBT+ pride 2021 global survey: A 27-country Ipsos survey*. Retrieved from https://www.ipsos.com/sites/default/files/ct/news/documents/2021-06/LGBT%20Pride%202021%20Global%20Survey%20Report_3.pdf.

Jowett, A. (2017). Representing the history of LGBT rights: political rhetoric surrounding the 50th anniversary of the Sexual Offences Act 1967. *Psychology & Sexuality, 8*(4), 306-317.

Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The Disproportionate Impact Of Dementia On Family And Unpaid Caregiving To Older Adults. *Health Affairs, 34*(10), 1642-1649. https://doi.org/10.1377/hlthaff.2015.0536

Kenny, J., Asquith, I., Guss, R., Field, E., Slade, L., & Bone, A. et al. (2016). Facilitating an evolving service user involvement group for people with dementia: what can we learn*?. The Journal Of Mental Health Training, Education And Practice, 11*(2), 81-90. https://doi.org/10.1108/jmhtep-09-2015-0046.

Laparidou, D., Middlemass, J., Karran, T., & Siriwadena, A. (2019). Caregivers' interactions with health care services - Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia - A qualitative study. *Dementia, 18*(7), 2526-2542.

Office for National Statistics. (2021). *Sexual orientation, UK: 2019*. Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2019.

Latham, J., & Barrett, C. (2015). *We're People First: Trans Health and Ageing-An Evidence-based Guide to Inclusive Services.* La Trobe University: Melbourne, Australia.

Lee, C. (2018). Fifteen years on: the legacy of section 28 for LGBT+ teachers in English schools. Sex Education, 19(6), 675-690.

Lewis, F., Schaffer, S. K., Sussex, J., O'Neill, P., & Cockcroft, L. (2014). *The trajectory of Dementia in the UK - Making a difference*. Retrieved from Office of Health Economics website: https://www.ohe.org/publications/trajectory-dementia-uk-making-difference#.

Local Government Act (1988). Section 28. Retrieved from http://www.legislation.gov.uk/ukpga/1988/9/contents.

Marshall, J., Cooper, M., & Rudnick, A. (2015). Gender dysphoria and dementia: A case report. *Journal of Gay & Lesbian Mental Health, 19*(1), 112-117. https://doi.org/10.1080/19359705.2014.974475

McParland, J., & Camic, P. M. (2018). How do lesbian and gay people experience dementia? *Dementia: The International Journal of Social Research and Practice, 17*(4), 452-477. https://doi.org/10.1177/1471301216648471

Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2013). Couples constructing their experiences of dementia: A relational perspective. *Dementia, 15*, 34-50.

Moyle, W., Venturto, L., Griffiths, S., Grimbeek, P., McAllister, M., Oxlade, D., & Murfield, J. (2011). Factors influencing quality of life for people with dementia: A qualitative perspective. *Aging & Mental Health, 15*(8), 970-977. https://doi.org/10.1080/13607863.2011.583620

National Institute for Health and Care Excellence. (2018). Dementia: assessment, management and support for people living with dementia and their carers. Retrieved from https://www.nice.org.uk/guidance/ng97

Ward, R., Rivers, I., Sutherland, M. (2012). *Lesbian, gay, bisexual and transgender ageing: biographical approaches for inclusive care and support.* Jessica Kingsley: London.

National Institute for Health and Care Excellence. (2018). Dementia: assessment, management and support for people living with dementia and their carers. Retrieved from https://www.nice.org.uk/guidance/ng97.

Naylor, E., & Clare, L. (2008). Awareness of memory functioning, autobiographical memory and identity in early-stage dementia. *Neuropsychological Rehabilitation, 18*(5-6), 590-606. https://doi.org/10.1080/09602010701608681

Newman-Valentine, D., & Duma, S. (2014). Injustice to transsexual women in a hetero-normative healthcare system. *African Journal of Primary Health Care & Family Medicine, 6*, 1-5. http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S2071-29362014000100056&nrm=iso

Nguyen, T., & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia, 19*(2), 148-181. https://doi-org.ezproxy.lancs.ac.uk/10.1177%2F1471301218800122.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: synthesizing qualitative studies*. Newbury Park: Sage.

Pachankis, J., Soulliard, Z., Seager van Dyk, I., Layland, E., Clark, K., Levine, D., & Jackson, S. (2022). Training in LGBTQ-affirmative cognitive behavioral therapy: A randomized controlled trial across LGBTQ community centers. *Journal Of Consulting And Clinical Psychology*, *90*(7), 582-599. https://doi.org/10.1037/ccp000074

Pentaris, P. (2019) A constructive analysis of the formation of LGBTQ families: Where Utopia and Reality meet. *International Journal of Humanities and Social Sciences, 13*(1), 60-65.

Petticrew, M., & Roberts, H. (2006). *Systematic reviews in the social sciences: A practical guide*. Blackwell.

Price, E. (2010). Coming out to care: Gay and lesbian carers experiences of dementia services. *Health & Social Care in the Community, 18*(2), 160-168. https://doi.org/10.1111/j.1365-2524.2009.00884.x

Price, E. (2011). Caring for mum and dad: Lesbian women negotiating family and navigating care. *British Journal of Social Work, 41*(7), 1288-1303. https://doi.org/10.1093/bjsw/bcr015

Price, E. (2012). Aay and lesbian carers: ageing in the shadow of dementia. *Ageing & Society, 32*(Part 3), 516-532. https://doi.org/10.1017/s0144686x11000560

Putney, J. M., Keary, S., Hebert, N., Krinsky, L., & Halmo, R. (2018). "Fear Runs Deep:" The Anticipated Needs of LGBT Older Adults in Long-Term Care. *Journal of gerontological social work, 61*(8), 887-907. https://doi.org/10.1080/01634372.2018.1508109

Regan, B., & Varanelli, L. (2013). Adjustment, depression, and anxiety in mild cognitive impairment and early dementia: a systematic review of psychological intervention studies. *International Psychogeriatrics*, *25*(12), 1963-1984. https://doi.org/10.1017/S104161021300152X

Rhoten, B., Burkhalter, J., Joo, R., Mujawar, I., Bruner, D., Scout, N., & Margolies, L. (2021). Impact of an LGBTQ Cultural Competence Training Program for Providers on Knowledge, Attitudes, Self-Efficacy, and Intensions. *Journal Of Homosexuality*, *69*(6), 1030-1041. https://doi.org/10.1080/00918369.2021.1901505.

Sexual Offences Act 1967. Retrieved from https://www.legislation.gov.uk/ukpga/1967/60/pdfs/ukpga_19670060_en.pdf.

Stonewall. (2021). *Come out for Trans Equality*. Retrieved from https://www.stonewall.org.uk/our-work/campaigns/come-out-trans-equality.

Stonewall. (2021). *List of LGBTQ+ terms*. Retrieved from https://www.stonewall.org.uk/help-advice/faqs-and-glossary/list-lgbtq-terms.

Thompson, G., Hack, T., Rodger, K., St. John, P., Chochinov, H., & McClement, S. (2020). Clarifying the information and support needs of family caregivers of nursing home residents with advancing dementia. *Dementia, 20*(4), 1250-1269. https://doi.org/10.1177/1471301220927617

Tod, D., Booth, A., & Smith, B. (2021). Critical Appraisal. *International Review of Sport and Exercise Psychology, 15*, 52-72.

Tudor, S. (2021). *Human rights of LGBT+ people worldwide*. Retrieved from https://lordslibrary.parliament.uk/human-rights-of-lgbt-people-worldwide/.

Wakefield, D., Kane, C. E. C., Chidiac, C., Braybrook, D., & Harding, R. (2021). Why does palliative care need to consider access and care for LGBTQ people? *Palliative Medicine, 35*(10), 1730-1732. https://doi.org/10.1177%2F02692163211055011.

Westwood, S. (2016). Dementia, women and sexuality: How the intersection of ageing, gender and sexuality magnify dementia concerns among lesbian and bisexual women. *Dementia, 15*(6), 1494-1514. https://doi.org/10.1177/1471301214564446

Withall, L. (2014). Dementia, Transgender and Intersex People: Do Service Providers Really Know what Their Needs Are? Alzheimer's Australia.

World Health Organisation. (2021). *Dementia*. Retrieved from https://www.who.int/news-room/fact-sheets/detail/dementia.

Figure legends

Table 1. Search terms applied to each database

Combined with AND	Search Terms
Sexual identity	DE "Lesbianism" OR DE "Male Homosexuality" OR DE "Same Sex Couples" OR DE "Bisexuality" OR DE "Homosexuality" OR DE "Lesbianism" OR DE "Male Homosexuality" OR DE "Sexual Minority Groups" OR DE "Asexuality" OR DE "Same Sex Marriage" OR DE "Gender Nonbinary" OR DE "Gender Nonconforming" OR DE "LGBTQ" OR DE "Bisexuality" OR DE "Transgender" OR DE "Transsexualism" OR DE "Androgyny" OR DE "Coming Out" OR DE "Intersex") OR TI (Lesbian* OR Homosex* OR (("Same Sex" OR samesex OR same-sex) N3 (Couple* OR married OR marriage* Or partner*)) OR Bisexual* OR (Sexual N2 Minority) OR Asexual* OR ((Gender OR identif*) N3 (Nonbinary OR fluid OR nonconform*)) OR LGBT* OR Bisexual* OR Transgend* OR Transsexual* OR Androg* OR "Coming Out" OR Intersex* OR queer* OR gay OR agender OR genderqueer OR pansex* OR "men who have sex with men" OR "women who have sex with women" OR non-heterosexual OR two-spirit* OR third-gender OR demisex* OR femme OR aromantic OR Abro OR ((Undetectable) N3 (HIV OR Viral*)) OR AB (Lesbian* OR Homosex* OR (("Same Sex" OR samesex OR same-sex) N3 (Couple* OR married OR marriage* Or partner*)) OR Bisexual* OR (Sexual N2 Minority) OR Asexual* OR ((Gender OR identif*) N3 (Nonbinary OR fluid OR nonconform*)) OR LGBT* OR Bisexual* OR Transgend* OR Transsexual* OR Androg* OR "Coming Out" OR Intersex* OR queer* OR gay OR agender OR genderqueer OR pansex* OR "men who have sex with men" OR "women who have sex with women" OR non-heterosexual OR two-spirit* OR third-gender OR demisex* OR femme OR aromantic OR Abro OR ((Undetectable) N3 (HIV OR Viral*))
Dementia	(DE "Dementia" OR DE "AIDS Dementia Complex" OR DE "Dementia with Lewy Bodies" OR DE "Pseudodementia" OR DE "Semantic Dementia" OR DE “Presenile Dementia” OR DE

	"Senile Dementia" OR DE "Vascular Dementia") OR TI (dementia OR alzheimer's) OR AB (dementia OR alzheimer's)

Figure 1: PRISMA diagram

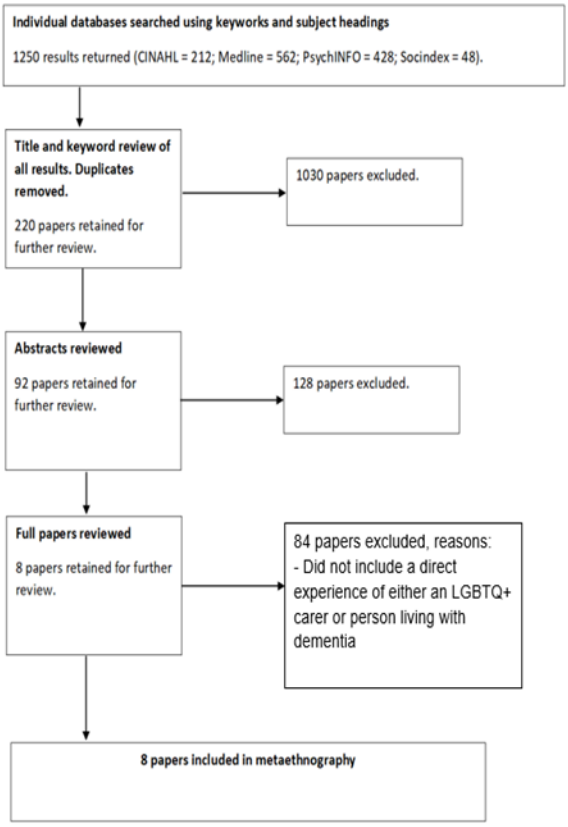

Table 2. Methodological summary of included papers

Author	Year	Country	Study aims	Participants	Data collection	Data analysis
Price	2012	England	To explore the experiences of gay men and lesbian women caring for a person with dementia through the lens of a persons sexuality.	21 participants; 10 gay men and 11 lesbian women. Carers.	Semi-structured interviews.	Constant thematic comparative method.

Price	2011	England	To explore how a persons sexual identity might impact the experience of providing care for a parent living with dementia. Particular focus on the experiences of lesbian women.	21 participants. Carers	Semi-structured interviews	Constant thematic comparative method.
Price	2010	England	To explore gay and lesbian carers experiences of 'coming out' to dementia service providers	21 participants. Carers.	Semi-structured interviews	Constant thematic comparative method
Westwood	2016	United Kingdom	To explore the significance of gender and sexuality for the experience of dementia and dementia care.	60 older LGB women.	Semi-structured interviews	Thematic analysis
Putney et al.,	2018	United States	To explore the anticipated needs and fears of LGBT older adults related to nursing homes and assisted living with a focus on dementia	50 LGBT adults aged 55 and over	7 focus groups	Thematic analysis
Marshall et al.,	2015	Canada	To explore gender dysphoria in a care home setting.	Case study with insights from care home staff and individuals	Case study	Case study

				family member.		
McParland & Camic	2016	United Kingdom	To explore what it means to experience dementia in the context of being lesbian or gay. To develop understanding of these experiences within dyadic relationships.	10 lesbian and gay individuals and 10 significant others of these individuals.	Semi-structured interviews	Interpretative Phenomenological Analysis
Barrett et al.,	2015	Australia	To outline the experiences and needs of lesbian, gay, bisexual and trans Australians living with dementia and their partners.	30 LGBT participants, 6 of whom were accompanied by a partner. No self-identified bisexual, trans or intersex individuals were recruited.	In-depth interviews	No specific analysis technique described. The transcripts were analysed to identify common themes and differences.

Table 3. Quality appraisal of included review papers

	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value	Total
Price, 2012	3	2	3	3	2	2	3	2	20
Price, 2011	3	2	3	3	2	2	3	2	20
Price, 2010	3	2	3	3	2	2	3	2	20
Westwood, 2016	2	2	2	3	2	1	2	2	16
Putney et al., 2018	2	2	3	3	3	3	3	2	21
Marshall et al., 2015	1	1	2	3	1	1	1	1	11
MacParland & Camic, 2016	2	2	3	3	2	3	3	3	21
Barrett et al., 2015	2	3	3	2	2	1	2	2	17

Table 4. The relationship between studies in the form of final themes

	LGBT+ identity in heteronormative environments	Families of origin	Families of choice
Price, 2012	X	X	X
Price, 2011	X	X	X
Price, 2010	X	X	X
Westwood, 2016	X	X	
Putney et al., 2018	X	X	X
Marshall et al., 2015	X	X	
MacParland & Camic, 2016	X	X	X
Barrett et al., 2015	X	X	X

Section one appendices

1-A An example of data extraction (Price, 2011)

1-B Manuscript preparation guidelines: Dementia

Appendix 1-A - An example of data extraction (Price, 2011).

Author themes	Author data (Interpretations, key phrases and metaphors)	Participant quotes	Initial thoughts and interpretations
Study: Price (2011)			
Negotiating care-giving relationships within the biological family. Support from within: the family of choice.	- Life-changing decisions required when faced with the prospect of caring for a person with dementia - A range of new physical and emotional responsibilities which participants were unprepared for - A sense of family pressure perceived to be as a result of gender or sexual orientation (lesbian women) - Participants felt that their personal relationships were perceived as of limited importance compared to heterosexual siblings	*My brother, who lived in England, couldn't cope and he opted out really. And my other brother was in America, so it very much fell to us as daughters. It was expected of us, certainly, by the rest of the family.* *I think we lesbian women pick up the pieces and clear up the crap—to put not too fine a point on it!* *I was caring for her because I wanted to, and because I was available. Yes, it was expected by other family members. But I would have wanted to whatever they said or did.* *I was told early on*	- Adjustment - Having to renegotiate life to provide care - Adapting to unexpected changes - Intersection of gender and sexuality influencing the experience of lesbian care-givers - Prior experience of not being accepted by care recipient and co-carers (siblings) - Identity forgotten and sometimes ignored within the caregiving relationship - Families not respecting the legitimacy of lesbian relationships may lead to increased caring

	- Obligation, expectation, love and reciprocity - Problematic and challenging biological family relationships, largely because of families difficulties in accepting sexuality. - Estranged siblings may find themselves forced to renegotiate the parameters of their relationship due to caring - Caring for parent became a catalyst for changing family relationships - Dementia may soften people's views towards sexual identity - There is a need to link into non-biological friendships networks for support (family of choice) - The family of choice was the principal source of support for many	*that I was a big mistake. So I did have this theory that we kind of made a bargain when I was still in the womb that, ok, if she was going to have me, then, you know, I'd better come up with the goods.* *There's a long history, I've had a huge long relationship with my sister about my sexuality. I know she still feels it would be better if I was heterosexual. In her heart she still thin So interestingly, the point at which mum went into hospital … was the point at which we [respondent and her sister] started doing much better together.* *'Cos I was doing the sleep deprivation and falling apart thing and she was, she was very supportive actually, and I remember coming away thinking how strange, that something as awful as that should bring us to a place where, you know, it, I mean, it felt like it kind of cut through.*	responsibilities - Some reports that sexual identity was more accepted by the person living with dementia as a result of their condition - Caring may be a tie that binds and may help repair previously ruptured relationships - Many people turned to friends and ex-lovers to form a 'family of choice' to support them in this experience. - Some couldn't rely on their biological family due to ruptures and unaccepting views. - Is turning to a 'family of choice' in the dementia caregiving experience exclusively a lesbian experience? - Heteronormative ideas regarding family and the relative importance attributed to heterosexual relationships influence caregivers experience.

	participants - Some respondents felt that support received from friends and ex-lovers was a particular feature of the ‘lesbian experience’ - Carers sexualities added a very specific dimension to adjusting relationships with family - Care-giving presents opportunities to re-evaluate previously difficult family relationships - The concept of family ought to be conceptualised more broadly to include family of choice.	*ks it's a bit sad.* *And for me, my experience of mum and her dementia was actually a lovely time to … not resolve issues because I could never say, ‘Mum, why are you such a bitch?’ … but I sorted it out with myself.* *We pretty much always go together to see him. She always comes with me and the staff at the home know that she's my partner and you know, he'll give her a hug and he's quite sweet.* *For myself and for a very large number of my gay friends, family is very often a great deal more problematic and, even if there's still the love there, there's the love, but maybe not necessarily the understanding, and so you do, you know, your friends become maybe more central to you than straight people's friends do* *There was never any question for me that I'd have*

	gone to blood family to do that, it was absolutely my social family that I was going to do that with.

Appendix 1-B Manuscript preparation guidelines: Dementia

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. Biomedical and overly clinical research articles will not be accepted.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at Sarah.Campbell@MMU.ac.uk and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should be placed on the title page. Your main text should include a Declaration of Conflicting Interests (if applicable), any notes and your References but should be completely anonymized.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

2.7 Research data

The journal is committed to facilitating openness, transparency and reproducibility of research, and has the following research data sharing policy. For more information, including FAQs please visit the SAGE Research Data policy pages.

Subject to appropriate ethical and legal considerations, authors are encouraged to:

- share your research data in a relevant public data repository
- include a data availability statement linking to your data. If it is not possible to share your data, we encourage you to consider using the statement to explain why it cannot be shared.
- cite this data in your research

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Dementia offers offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'.

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.5 Reference style

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Book reviews must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Sarah Campbell Sarah.Campbell@MMU.ac.uk

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be made available to the corresponding author via our editing portal SAGE Edit or by email, and corrections should be made directly or notified to us promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com

Section Two: Research Paper

The experiences of working sons caring for a parent with dementia

Samuel Hughes

Lancaster University

Doctorate in Clinical Psychology

Prepared in accordance with the journal guidelines for

Dementia

Word count: 7997 (Excluding tables, appendices and reference lists)

All correspondence should be sent to:
Samuel Hughes
Doctorate in Clinical Psychology
Health Innovation One
Sir John Fisher Drive
Lancaster
Lancaster University
LA1 4AT
Email: S.hughes5@lancaster.ac.uk

Abstract

This study explored the experiences of working sons who have cared for a parent with dementia. Individual, semi-structured interviews were conducted with seven sons living in North-West England. Data were analysed using interpretative phenomenological analysis resulting in five themes: (1) A journey into the unknown; (2) The leader of the band; (3) Pride and purpose; (4) "Like all the best comedies, it's pretty tragic"; and (5) Workplace context matters. Findings contribute to the existing literature by emphasising the impact of the evolution of gender roles in caring, indicating clinical implications and suggesting specific areas worthy of further investigation.

KEYWORDS: Qualitative; dementia; carer; sons; work

Introduction

Dementia is an umbrella term defining a range of neurodegenerative diseases which have a variety of consequences for the individual, family and on a wider socioeconomic level (Jones, 2015). The clinical symptoms of dementia vary widely by type, although, the diseases are connected by progressive deterioration of cognitive and functional ability and people can also experience a variety of psychological difficulties including apathy, agitation and depression (Van Der Flier & Scheltens, 2005). The functional impact of dementia progresses over time, increasing difficulties with activities of daily living and leading to increased care needs (Luttenberger et al., 2012). Recommended psychological approaches to caring for those experiencing dementia include cognitive stimulation therapy and psychoeducation and skills training for carers (Frias et al., 2020; Gibbor et al., 2021; National Institute for Health and Care Excellence, 2018). Around 55 million people are living with dementia globally with this number expected to rise (World Health Organisation [WHO], 2021).

In 2015 it was estimated that 82 billion hours of care was provided to people living with dementia by informal caregivers (defined as family or close friends); 29% of these hours were provided by males (Alzheimer's Disease International, 2015). The WHO (2021) has advocated for support to be provided by the health, social, financial and legal systems of respective global nations for informal carers who provide an average of 5 hours care per day, which often results in physical, emotional and financial stress. 91% of unpaid family carers feel ignored by the UK government with approximately half reporting using their personal savings to fund their caring role and giving up hobbies or personal interests due to lack of support (Carers Trust, 2022). Further to this, a scoping review encompassing informal carers from across continents, found that the COVID-19 pandemic saw governments suspend or restrict care services traditionally used by informal carers (Muldrew et al., 2021), further increasing the burden of caring.

The impacts of caring for someone with dementia have been well-researched. Meta-analyses have found that dementia caregivers reported negative effects of caregiving including family conflict, reduced working hours, reduction in personal/social time and adverse effects on physical and mental health and finances (Brodaty et al., 2003; Cross et al., 2018). Data have shown that dementia caregiving differs from other types of caregiving in that it requires more hours per week and has greater impacts on employment, mental and physical health, and family conflict (Ory et al., 1999). However, there can be positive aspects of caring for somebody with dementia and these may include gratification, increased family cohesion and personal growth and life purpose (Yu et al., 2018). Furthermore, positive aspects of caregiving, such as gratification and feelings of satisfaction, are strongly associated with positive caregiver wellbeing outcomes (Wu et al., 2022).

Despite care being provided by a variety of family members, much of the research in dementia focusses on carers in general. However, specific family members may have specific needs and experiences which may not be universal. For example, adult children can be forced into caring roles due to a sense of obligation, however, this can lead to feelings of loss of freedom and guilt, especially if they have children and/or a career (Conde-Sala et al., 2010). There is an impact of changing family roles in adult children of those living with dementia, with some feeling they need to take the parental role and find this a difficult transition, missing the way they communicated with their parent in the past (Kjallman-Alm et al., 2013). This group can also experience conflict with their siblings due to differences in understanding of behavioural symptoms, an inability to accept the diagnosis and difficulties in negotiating carer responsibilities and how best to help the parent (Tatangelo et al., 2018).

As much of the research has had a majority female sample, there is a relative lack of discussion surrounding the nuances of the male experience of caring for somebody with dementia (Robinson et al., 2014). Perhaps this is a consequence of the majority of care hours being provided by women (Alzheimer’s Disease International, 2015). However, men still provide care and indeed in the UK an estimated 40% of informal carers are male (New Policy Institute, 2016; Carers UK, 2019). Male caregivers are said to ‘masculinize’ caring behaviours by ‘taking control’ and showing autonomy and independence in how they take on tasks which helps them maintain a sense of self-efficacy (Mott et al., 2019). Furthermore, Baker and Robertson (2008) suggest that although literature has suggested women experience more burden as a result of caregiving this is likely a result of men being less likely to report burden to protect their masculinity. Male carers are less likely to seek support, particularly when managing stress, and are also more likely to be isolated from social support when they are in paid employment (McKenzie et al., 2018). Men are also less likely to reduce their working hours than women and the most significant predictors of distress in adult child caregivers not living with their parent are the impact on schedule, health and finances (Wawrziczny et al., 2020). This may mean that men are less likely to seek support for caregiver-related stress and experience greater stress if they have a busy schedule. Thus, it is important to understand men’s experience in more depth.

One previous study found adult son caregivers experience stress but also feelings of satisfaction associated with their role (Grigorovich et al, 2015). However, the participants in this study tended to be ‘care managers’ involved in administrative and management tasks for their parent rather than primary caregivers (Grigorovich et al, 2015). Another study found that sons were more likely to assume caring responsibility for their mothers than their fathers, an act described as ‘reciprocity in kind’ as a sense of obligation to repay the care they received as children (McDonell & Ryan, 2013). The study further highlighted the level of commitment and motivation sons have in their caregiving role as well as holding a perspective of ‘getting on with it’ despite the emotional challenges. However, this study focussed on a purposeful sample of adult sons in rural Ireland, some of whom were farmers, and the authors acknowledged the limitations of the findings in terms of generalisability beyond the culture they were living in.

Consequently, the aim of this study will be to explore the experiences of working adult sons caring for a parent who is living with dementia in England. It is hoped that findings may have useful clinical applications both in increasing the understanding of a carer’s perspective and to inform service delivery and support. This is particularly important given the disruption to service delivery during the COVID-19 pandemic and the hope of constructing services with a knowledge of the experience of service users (Muldrew et al., 2021).

Method

Design

The methodological approach taken was interpretative phenomenological analysis (IPA; Smith, Flowers & Larkin, 2009). IPA is concerned with the detailed examination of personal lived experience. It is idiographic, in that it is interested in participants’ individual meaning-making. However, at the same time it recognises the role of the researcher in interpreting the meaning-making processes of participants, making it particularly useful when examining topics which are complex and/or emotionally laden and involve sense-making (Smith & Osborn, 2015). The researcher is required to immerse themselves in the lived experience of the participants and concludes with interpretations being taken to a deeper level importing theories as a lens with which to view them (Smith et al., 2009). As such, IPA was felt to be a particularly appropriate methodology for exploring the lived experiences in depth of working sons caring for a parent living with dementia.

Semi-structured interviews were utilised, as recommended within the seminal work of Smith et al., (2009) on IPA. The flexibility of semi-structured interviews allows for the researcher to listen and probe where necessary (Smith & Osborn, 2008).

When designing the interview schedule, consultation took place with an expert by experience, who recommended that the interview should start with, ‘Could you tell me a little bit about your mum/dad…who were they as a person’. The expert by experience felt this was a positive way to establish rapport and to ease participants into the interview and help them feel comfortable. The interview guide included open questions guided by previous literature (Grigorovich et al, 2015; McDonnell & Ryan, 2013). It was further informed by discussions with research supervisors and the expert by experience.

Participants

IPA is concerned with perspectives rather than with populations and aims to capture in depth the experiences of particular samples and so focuses on homogenous groups (Smith et al., 2009). In alignment with this, purposive sampling was used to recruit seven participants. Although it has been argued that "there is no right answer to the question of...sample size" (Smith et al., 2009, page 57), it has been suggested that 4-10 participants are appropriate for a professional doctorate (Clarke, 2010). Therefore, seven was both intentional as well as the point at which recruitment efforts were exhausted.

Participants were required to be sons, aged 18 or over, who have cared or currently care for a parent living with dementia whilst also working a minimum of 10 hours per week. Average part time hours in the UK was 11.7 hours during May-July 2020 (Office for National Statistics, 2022). As the aim was to examine the experience of working sons, 10 hours was decided as a minimum criterion in conjunction with research supervisors as a threshold which would widen the recruitment criteria whilst also not losing the salient experience of being a working man. The participants were required to provide or have provided support with at least one activity of daily living (ADL) (such as cleaning, cooking, bathing, managing finances etc). IPA requires a homogenous sample (Smith et al., 2009) and the aim was to capture participants caring for individuals with moderate stage dementia, so that the level of care needed and types of difficulties experienced by the care recipient would be similar. The support with IDL criterion was guided by indicators of moderate dementia (e.g. the Functional Assessment Staging Test (FAST) scale (Reisberg, 1988)). Participants were also required to speak English and to have been a primary carer for at least six months; all participants were required to have provided care within the last two years, so that their experience was recent.

Those who cared for a parent living with early-onset dementia were excluded from the study due to IPA being concerned with homogenous groups and the experience of this group was felt to differ. All participants were white-British and all were still working a minimum of 10 hours per week at the time of interview. Five of the participants were self-employed. All participants reported that their work was flexible regarding their care commitments. Participants' demographics are provided in Table 1.

[Insert Table 1 about here]

Recruitment

Recruitment was conducted using a research poster which was shared on a dedicated social media page, all participants who responded were recruited through this method. Further stages of recruitment involved sharing information with the organisation Age UK and with a service user group of carers in North-West England, however neither of these stages resulted in further participants.

Data collection

Semi-structured interviews were conducted between October 2021 and April 2022; six of these took place via Microsoft Teams (video-conferencing software) and one took place over the telephone. All of these were audio recorded using Microsoft Teams. Interviews were transcribed verbatim by the researcher and anonymity was protected by allocating pseudonyms and removing any other identifying information. Interviews began by revisiting the information sheet, giving space for questions to be asked and answered followed by a separate audio file being recorded of verbal consent. Interviews lasted between 45 and 80 minutes.

Analysis

The analysis followed the methodology of Smith et al. (2009). The analysis was conducted by me ('the researcher') by hand. The first four stages were completed on a case-by-case basis allowing for the researcher to fully immerse himself in the individuality of the experiential data being considered. As such the first stage of analysis involved repeatedly reading the first transcript to aid familiarity. Secondly, the transcript was printed with a margin for notes and interpretations to be made. Notations varied between paraphrasing the participant's experience (e.g. 'Judgements by others don't matter'), using the participant's language (e.g. 'I'm the leader of the band') and the researcher's interpretations (e.g. 'Risking self to protect Dad'). An example of this level of analysis can be found in appendix 2-A. Thirdly, emergent themes for the individual participants were developed by focusing on sections of transcript, being informed by these notations. Fourthly, the researcher searched for connections across the emergent themes, clustering them, resulting in superordinate themes for that participant (see appendix B). A narrative summary of each cluster was written in order to enhance the researcher's interpretation and understanding of their meanings. Following the completion of this process for each participant, the researcher looked for and drew patterns across cases (whilst noting any idiosyncrasies) and finally took interpretations to deeper levels via the use of metaphors and by importing theory. The final analytic stage involved developing five final themes (See appendix C) for which a narrative summary was written about each with evidence in the form of participant quotations (see results).

Reflexivity is thought to be protective of quality and rigor in qualitative studies (Johnson et al., 2020) and as such the researcher kept a reflective log when analysing studies to keep track of thoughts and assumptions that arose. Furthermore, the researcher used supervision to enhance transparency and consider sensitivity to context (Yardley, 2000).

Ethics

Formal ethical approval was granted by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University. Participants were informed of their right to withdrawal and confidentiality prior to commencement of interviews.

Findings

All participants were white-British and all were still working a minimum of 10 hours per week at the time of interview. Five of the participants were self-employed. All participants reported that their work was flexible regarding their care commitments. Six out of the seven participants are represented by direct quotes. Hugo's voice is represented in the overall narrative, but the tight word count meant it was not possible to include his longer responses. Participants' demographics are provided in Table 1.

[Insert Table 1 about here]

Five overarching themes describe participants' experiences of caring for a parent living with dementia whilst also working. (1) A journey into the unknown; (2) The leader of the band; (3) Pride and purpose; (4) "Like all the best comedies, it's pretty tragic"; and (5) Workplace context matters.

A journey into the unknown

A consistent theme throughout the participants' narratives was a feeling of 'not knowing' that remained pervasive throughout their caregiving journey and a resultant frustration with systems and services. Participants explained that this frustration was borne out of a lack of ongoing support and information-providing from service they perceived to be there to "help".

The feeling of "not knowing" often started with the sons noticing gradual changes in their parents' cognition, mood and behaviour. . Initially, with the less-pronounced symptoms such as early changes to memory, participants tried to make sense of this as a normal, shared human experience or normal in the context of ageing:

> The memory loss we didn't really notice very quickly because people forget things, I forget things, if somebody forgets something until there is a pattern you don't realise. (John)

However, as changes became more pronounced and unusual behaviours were noticed, they had a feeling that something was not right and sought medical assistance. For Hugo this was when he came to his mother's house and noticed she had left the taps on and flooded the house. His mother subsequently started leaving the gas cooker hobs switched on without a flame prompting Hugo to disconnect all her appliances. These symptoms and the lack of certainty surrounding their causes was a cause for concern and anxiety in the sons; feelings which persisted throughout the caregiving journey.

Following seeking help from healthcare providers, the sons discovered that their parent had developed dementia. However, the diagnosis on its own did not alleviate the feeling of 'not knowing' and it was reported that health and care professionals were either not able or not willing to provide further education on what this meant:

> they diagnosed him as being asymptomatic Alzheimer's so I don't fully understand it, they don't understand it, we don't fully understand it, I don't think anyone fully understands it. (Jason).

Jason went on to explain that no one initiated support or offered any further guidance on what dementia was, what his caregiving journey may look like or what support was available to him. This was mirrored by Owen who reported he did not know he could access carers' allowance until several years into caring for his father after having experienced significant financial strain. There was a conflicted view of seeking carer support, such as respite, day centres, carers' allowance, or carer support sessions. Some felt angry that they had not been told about avenues of support available to them and others felt guilty for even considering it, in particular financial support, as they felt others may need it more. Some of the offers of support, both financial and care, were viewed as paltry and insulting in comparison to the level of need and effort expended:

> [In response to being told that the carer's allowance he was requesting was £169] I said "well, can I make a suggestion? Well, I'd like to apologize 'cause I think I've wasted your time and my time," she said "why?" I said "I'm not doing this for £169"… I said that out of pride, not because I didn't need the money 'cause I did (Owen).

Not knowing what support was available to them led to some participants taking extra action to either educate themselves or force health and care services to sit down with them and offer further information. Joe would spend hours in the evenings trawling the internet and

Facebook support groups. However, he acknowledged that he could fall down a ‘rabbit hole’ with this leaving his mind feeling cluttered and him struggling to sleep. Hugo recalled how he had to get his niece who was a senior healthcare professional to come to meetings with him in order to have a knowledgeable advocate as he felt his ignorance was being taken advantage of by social workers and doctors. Ultimately, participants felt let down and unsupported by services through their whole caregiving journey:

> Don’t get me wrong… this isn’t about not wanting to put the effort into caring for dad. This is about yeah absolutely I want to put that effort in but what is there to support me in putting that caring effort in? (Jason).

‘The leader of the band’ – The challenges of responsibility

Being a primary caregiver appeared to result in a caregiver identity in which a great deal of responsibility was adopted by or placed on the participants. Sons spoke about how they came to become primary caregivers for their parent and the challenges associated with being ‘*the leader of the band’* noting the potential detrimental effects it can have on wellbeing.

Some participants became carers due to their relative geographical closeness to their parent and some felt obliged by circumstance such as Jason who took the lead as he was the only one of his siblings without young children or a partner. The effort and hours required to care for their parent resulted in participants sometimes neglecting their personal lives and hobbies. The role balanced with working responsibilities meant that participants had very little time or personal resource left for other things. John, who would regularly write and contribute to magazines, unpaid as a hobby commented:

> I just didn’t have time to write and when I did have time to write I didn’t have energy so that took a huge hit. (John)

Alan had a similar experience; however, he was the only participant working two full-time jobs. He reported that his paid role and caring took priority and so the voluntary company that he worked for combined with the stress of being a carer became an “enormous source of stress and depression”. All participants discussed having periods of adverse mental health as a result of caring, although only Alan explicitly labelled depression.

As their parents' condition progressed participants grappled with the responsibility of being decision-makers in terms of involving social care services. This was usually in the form of involving carers to assist with daily activities such as taking medication. Some of the participants struggled to discuss this aspect of caregiving, becoming tearful and ruminating when reflecting on their choices:

I'm consistently saying to my sister "did we make the right decision?" (Jason).

Being assigned or adopting the primary caregiver role led to some difficulties within the family system. Joe reported that he suffered fractured relationships with his siblings due to demands placed on him by them and a feeling of not being understood or appreciated for his efforts. Others felt that their siblings did not contribute as much as they would have liked leading them to feel isolated in their caregiving efforts. This sometimes culminated in tensions spilling over into arguments about roles:

> [Speaking as if to his brother] "I'm gonna' tell you this and I'll tell you this once and you can either accept it and walk away and accept it and support me and it's this. I'm the leader of the band and you're not playing your instrument." (Owen).

However, for some participants families could also provide support which helped participants cope and feel like part of a team. For example, although Jason was the primary caregiver for his father and reported trying to go it alone for as long as he could, when his father's needs increased, he was able to recruit support from his sister and brother-in-law. Furthermore, he was able to talk with his son about the core difficulties he experienced such as his father's incontinence, which helped him cope with these experiences. The context of the family was an important variable; close-knit, local and supportive families appeared to work cohesively and leave participants feeling grateful and content with their caregiving achievements:

> We are just a very, very loving family… between me, my sister, my brother, my mum and you know… I'd even say my own girlfriend, and my brother in law we all did as much as we possible could for him. You know, when he passed there was no one who thought, "I could have done more". (Alan).

Pride and purpose

Despite the challenges of caring for a parent with dementia, participants gave an insight into why they cared and what they gained from their experiences. All participants demonstrated a sense of pride in their parent and a sense of purpose accompanied the role.

Participants proudly reported their parent’s achievements as people and in parenthood such as Owen’s father’s sporting achievements and John’s mother forming a committee in her accommodation to secure funding for her fellow residents. This was demonstrative of positive pre-dementia relationships and participants reflected on this being a motive for caring:

> Because he has always been a lovely, lovely warm welcoming and good father. (Joe).

Some reflected positively on their parent’s roles as parents and grandparents to their own children. John fondly recalled how his mother wasn’t a ‘typical granny’ but would spend hours playing video games and watching mafia films with his children. When reflecting on their caregiving efforts the participants felt that it paled in comparison to what their parent did for them growing up:

> Yeah, we do whatever we can for him he did so much for us and through hard times… its nothing what we are doing, nothing. (Jason).

As well as an evident sense of pride, participants reported gaining from their caregiving experiences. For example, when asked about coping Daniel reported that he didn’t think about it and that it was his father who was making him alright and helping him cope even though he was the care recipient. Daniel added that he gained a sense of satisfaction from caring for his father:

> Helping any family member just gives you that bit of a kick doesn’t it and you just feel good about it. (Daniel).

Similarly, most participants reported that an important coping mechanism in their journey was the time that they got to spend with their parents. Most participants reported that they had shared interests with their parent such as rugby, football or music and that they would value the time they got to spend with their parent sharing these things. John exemplified this by explaining that for the first few years of caring it didn’t feel like a burden but rather a highly valued opportunity to get to spend more time with his mother.

Although, the caregiving journey has evident difficulties, all participants reported gaining a sense of purpose. Some participants were reflecting in hindsight, following their parent's passing, and this sense of purpose is perhaps best captured by Owen:

> And I grieved his death four years ago…[when dad was diagnosed, now] I'm grieving the loss of being a carer. (Owen).

"Like all the best comedies, it's pretty tragic" – Trying to cope with the changing parent

Participants reported the difficulty of witnessing their parent 'change' and deteriorate. They attempted to cope with this by using humour and trying to maintain an optimistic approach to their roles. However, despite their best efforts, participants appeared to be forced to acknowledge the 'tragedy' of their situation.

The progress of dementia presented the participants with some difficult scenes to witness, which Jason described as 'heart-breaking'. Participants reported a difficulty with or an unwillingness to take part in personal care and were upset if their parents became incontinent. Joe reported that as his father's condition progressed, he became disinhibited and the banter that he highly valued in his relationship became annoying and at times aggressive. Daniel explained that his father was always a highly intelligent man however became unable to tell the time or dress himself. Participants explained how the symptoms and presentations that they found most difficult were the ones that exposed stark changes to their parent's pre-dementia personality. Sometimes agitation and delusions could manifest resulting in the parent acting aggressively and out of character:

> There are times when it is a little bit difficult because my mum would experience this paranoia where we were trying to keep her prisoner or lie to her about her condition. (Alan).

Despite these obvious challenges, a consistent theme throughout the participants' stories was in finding levity in otherwise difficult times. Some participants reported an almost taboo or dark sense of humour saying that they should not laugh however they needed to, in order to cope. Hugo reported that he and his mum would laugh together about the absurdity of some of the delusions she had temporarily experienced and that ultimately laughter was a highly valued way of helping her cope as well as him with the difficulty of them. Laughter and humour appeared to help participants cope with and adapt to difficult experiences as they happened:

> They [my siblings] say it's quite damning and not funny when actually at the time it was hysterical. I remember...we went to a restaurant and my dad was eating his soup with a fork. I remember mother falling out with me for what?...it doesn't matter. [they said] “Yeah, well people are looking at him.” None of that actually matters, is he enjoying it? Yeah, crack on. All that little fucking stuff, doesn't matter. (Owen).

Participants reported how getting stuck in ruminating about the negativity of their experience was unhelpful and instead focused on trying to reframe their experiences optimistically and stay in the present:

> Sometimes I look and I think “well he’s doing well now so just embrace it and just enjoy every single day while he is lucid”. Like I mentioned earlier on. And I think that's the sort of stage where I am at. I'm not looking further past today (Joe).

Despite these efforts and the relief the humour provided, ultimately, participants’ dominant experience in their stories was one of sadness and grief. Inevitably, there came times where it was impossible to find the levity in situations:

> There were times when it was enjoyable. But like the best comedy, it's quite tragic, isn't it...So there were funny times, but looking back it was quite tragic. (Owen).

Workplace context matters

Participants reflected on the relationship their work had on their caring role and vice versa. The context of the workplace appeared to be predictive of difficulties in the relationship between work and care. Those who were self-employed and/or had flexibility in their work reported no or minimal adverse interactions between working and caring, whereas rigidity or working multiple jobs appeared to result in heightened personal stress as well as negative outcomes in one of the workplaces.

Most of the participants reported that work did not affect their caring responsibilities and vice-versa and reported that these two roles were the non-negotiable parts of their lives. All participants continued to work all the way through their caregiving journey. However, most participants had an element of flexibility to their work. This was deemed to be invaluable while they were caring for their parent as Jason explained:

> I work about 50 hours a week but I work from home so that has been massively helpful I don't think I would've been able to do this if I had been working in an office the whole time. (Jason).

Daniel was a musician working specifically at night when his father was asleep or settled. The participants reflected on the context of their work and how they would have struggled had they been in different roles with different expectations. Participants altered their schedules or created their jobs based on their caring experiences in order to be able to fulfil the caregiving role. Hugo explained that he was a taxi driver and so he could select his own hours in order to accommodate his caregiving needs.

However, working more than one job role presented a challenge in maintaining both workplaces as well as caring for a parent. One participant had two jobs and when care needs were particularly intensive it could cause an inability to perform as usual in some of the roles Alan explained the impact of intense caring responsibilities on his second job as a promoter of a company:

> That was the only time I would feel that I was really not able to…not be available for my mum So it [My workplace] was not being promoted and there wasn't much progress being made. We lost most of our volunteers during that time as well partly due to some of them moving on to other jobs and placements but I think also partly due to me just being a bit rubbish a bit neglectful and not very good with my correspondence (Alan).

Alan elaborated that he worked two roles, one paid and one unpaid as the director of a community interest company and when more time was needed for his caregiving role, it would ultimately be the unpaid position that he would spend less time in. Similarly, Owen experienced some difficulties during his experience of caring for his father. He felt he needed to spend a significant amount of time with him and in order to free himself to do that he established his own business so that he could be flexible in his hours. Although this worked in the end there was a time when he struggled financially, even declaring his business 'bankrupt'.

Discussion

The aim of this research was to understand the experiences of working sons who had cared for a parent living with dementia. The themes highlight how the journey of being a son caring for a parent with dementia is very much relational. Participants highlighted how their relationships with themselves, their parents, services, their family and their work interplayed to inform their appraisals of their caregiving experience.

This relational understanding of sons' experiences is similar in parts to previous research into the experiences of sons in rural Ireland (McDonell & Ryan, 2013). The authors concluded that caring sons developed a rigid caring identity borne from a strong parental bond and a sense of duty to establish 'reciprocity' in the relationship. Interestingly, despite both the McDonell and Ryan (2013) study and the present study focusing on a particular gender, there were limited experiential accounts of the perceived impact of gender on caring. However, in both papers the participants discussed how caring meant that their hobbies and interests were interrupted. This is in contrast to a recent literature review which concluded that men generally recognised the importance of having time for themselves and as such engaged in personal activities (Xiong et al., 2021). This finding appears to be unique in the literature, however, also unique is that the men in the present study were primary caregivers which was not an exclusive inclusion criteria for the above literature review. It would be worthwhile considering how the experience of caregiving may be different for men if they take on the primary caregiver role.

Journey into the unknown

Participants wove a narrative throughout their answers of their experience as a 'journey'. This is a common metaphor used to discuss the dementia caregiving experience (Peacock et al., 2010; Peacock et al., 2014). It is a longstanding theory that caregivers utilise story-telling as a method of coping with and processing their experiences and supported story-telling can assist this further (Clark & Standard, 1997; Matta, 2021).

The 'journeys' that the participants outlined were shrouded in uncertainty, having to make rapid adaptations and feeling unsupported by the 'experts'. Often, when making the transition to caregiver, individuals feel ill-prepared for the role and journey that lie ahead (Ducharme et al., 2011). In the present study this resulted in feelings of being let down by and frustrated with healthcare services who they expected to provide more information and support throughout their journey. Laparidou et al. (2019) suggested that carers feel that healthcare services provide paltry, if any, education of dementia to them and have an unrealistic expectation of carer knowledge. The present study similarly reported that sons felt that not enough education was provided to them on the dementia prognosis both in clinical terms and in caregiving journey expectations. This was consistent throughout the experiences, from pre-diagnosis to caring for a parent with moderate stage dementia. Previous research has mirrored these findings with caregivers consistently reporting a lack of information and support provided to them by care services (Francis & Hanna, 2020; Gibson & Anderson, 2011; Van Wijngaarden et al., 2018). It would therefore appear that this experience is not unique to sons but rather something that many caregivers of people living with dementia (people living with dementia) face.

The leader of the band

The experience of being a primary caregiver for a parent came with a set of experiences including identity change, caregiver burden and complicated family dynamics. Salient to this was the idea that the sons perceived themselves as the ‘leader’ of the caregiving efforts and with this came a sense of responsibility and pressure. However, ‘taking control’ is thought to be a masculinization of carer behaviour common in men which is protective of a sense of self-efficacy (Mott et al., 2019). This self-perception represents a change to their identity and self-concept which is consistent with the caregiver identity theory (CIT) (Montgomery & Kosloski, 2009). CIT posits that the more the pre-existing relationship with a care-recipient changes (due to progressively intensifying needs) so to does the caregivers self-identity leading to an imbalance in self-care and burnout. Enright et al. (2018) furthered this by proposing a dementia-specific model through which increasing identity changes in the people living with dementia triggers a change in their carer’s self-identity. The authors argue this subsequently impacts caregiver burden and mental and physical health outcomes. Similarly, participants in the present study experienced adverse mental health outcomes and a sense of caregiver burden following self-identity changes, especially when they considered the relative lesser caring efforts of their family.

Participants in the study had a diverse experience of familial support. What was consistent however was the perceived quality of the support and relationship to siblings appeared to relate to caregiver burden and identity changes. Those with positive relationships and a teamwork approach to caring did not report frustrations or arguments with their siblings as opposed to those who felt their siblings were critical or did not sufficiently contribute.

Identity theorists suggest that individuals may employ strategies to maintain an identity in the face of feedback that threatens that identity, allowing them to alleviate or avoid psychological distress (Stets et al., 2020). One study found that 98% of caregivers who felt their siblings were critical of the care they provided tried to maintain their identity as a good caregiver despite these criticisms (Rurka et al., 2020). Perhaps, adopting the role of 'the leader of the band' is protective of such criticisms and threats to caregiving identity.

Central to CIT is the idea that as a carer's identity changes and caregiving responsibilities are perceived to become ever more all-encompassing, the ability for the caregiver to take care of their own needs decreases. Participants reported a lack of time to engage in their usual hobbies and passions.

Pride and purpose

Pride was evident in the participants when reflecting on their parent's past and life story and they detailed positive pre-dementia relationships. This positive pre-dementia relationship was a motivating factor behind the decision to become a primary caregiver. Pre-dementia relationship quality has long been shown to be predictive of lower caregiver burden (Steadman et al., 2007). This would suggest that the sons in the present study would have lower levels of caregiver burden. However, although no measure of caregiver burden was taken in this study, participants did qualitatively report high levels of caregiver burden. The participants in the Steadman et al., (2007) study were predominantly female and older than those in the present study; perhaps this represents a difference in the way that caregiver burden manifests amongst the genders or working age carers do not experience the prior relationships as completely protective from burden.

Participants also reported gaining something from their caregiving experience whether it was time with their parents including participating in shared interests or a sense of purpose and satisfaction with the role. The use of shared activities has been shown to be a way of improving family care visits to people living with dementia in care homes (Munoz et al., 2021). However, caregivers often report that the disease and role have an impact on their ability to engage in these shared activities (Blaike, 2002; Di Lauro et al., 2017). In the present study sons were able to engage in these shared activities despite previous literature suggesting that caregivers (both men and women) generally find it difficult or impossible.

Central to the participants' experience was a sense of purpose and satisfaction gained from caring for their parent. This is commonly cited in the literature with multiple reviews pertaining to the positive aspects of caregiving in dementia finding that meaning, satisfaction and purpose can be gained from the role despite the challenges it presents (Lloyd et al., 2016; Quinn & Toms, 2019).

Like all the best comedies, it's pretty tragic

Participants reported that despite the challenges of their caregiving experiences, they attempted to find humour even in the most difficult circumstances. This ranged from having a 'dark' sense of humour surrounding the symptoms of their parent's dementia to sharing laughs about and minimising symptoms of memory loss with their parent. Dark humour can act as a coping mechanism in the face of adversity (Üngör & Verkerke, 2015). There is minimal research pertaining to the use of dark humour as a coping mechanism in dementia caregivers, however Ugwu (2020) reported that it can be helpful in mediating caregiver stress in this group. Similarly, the humour reported in participants appeared to act as a way of ameliorating the impact of difficult experiences.

Workplace context matters

The aim of the study was to explore the experiences of working sons who have cared for a parent living with dementia. Participants reported little to no effect of work on caring or vice versa for the most part. However, all the participants reported some sort of flexibility in their work schedules, with some working from home and others self-employed, meaning that they were able to allocate time to fulfil their caregiving responsibilities. Supportive employment practices such as flexible working and working from home have been found to be helpful in reducing caregiver strain and in improving caregiver health outcomes (Wang et al., 2018). It therefore makes sense that most participants in this study did not report adverse outcomes in the relationship between work and care.

Interestingly, participants made little reference to the balancing of care with other family responsibilities or relationships, which are sometimes referenced in the literature pertaining to the experiences of female and spousal dementia caregivers (Toepfer et al., 2014; Wadham et al., 2015). However, the differences observed here may be understood by the family contexts in that none of the participants had children under 18 or living at home. Further gender differences have been reported by Grigoryeva (2017) who reviewed national questionnaire data in the United States and concluded that sons reduce their relative caregiving efforts when a sister is present, whereas daughters increase theirs when a brother is present. This is a finding which is consistent with historical research (Matthews, 2002; Wolf et al., 1997).

However, the results of the present study would suggest otherwise as most sons in the present study had sisters and still assumed the role of primary carer, even reporting sisters who were less than helpful. Furthermore, the paper by Grigoryeva (2017) was based on questionnaire data from 2010 and was discussed in the context of relatively outdated papers. More recent research reports that male representation in caregiving is increasing as gender expectations and roles are modernising (Comas-d'Argemir & Soronellas, 2019).

Clinical implications

The ‘Journey into the unknown’ theme outlines feelings of ignorance about dementia and the caregiving experience and the anxiety and guilt this ignorance results in. Participants detailed services and professionals who were unhelpful in providing answers or access to information about resources. This has consistently been shown in the literature to be a problem for caregivers on a wider scale (Gibson & Anderson, 2011; Laparidou et al., 2019; Lethin et al., 2016). Services and professionals should consider this from the point of diagnosis onwards and consider how they can offer education to sons on dementia, what a caregiving journey may look like and accessible community, care and financial resources. Services should be mindful of the amount of power they have and make efforts to address this to enable sons to feel like they are being fully informed and treated in the way they wish to be. It should also be noted that although information interventions can have some benefit, the way in which they are delivered will predict whether they help carers (Corbett et al., 2011). Services should therefore ascertain the individual requirements of caregivers and respond appropriately. This is reflective of guidance issued by the National Institute for Health and Care Excellence (NICE) (2018) which recommends individually tailored packages of support, education and skills training to be delivered to carers.

The results show that family can be a help or a hinderance to the experiences of sons caring for a parent with dementia. It would therefore be helpful for services to explore the family contexts of sons caring for a parent with dementia to help determine the level of need and support required for them. Similarly, working context is important to explore as the results suggest sons with an element of flexibility to their work may find their roles easier to balance but participants acknowledged this would be more difficult with a more rigid work environment. Ultimately, Clinical Psychologist may find themselves best-places to use their skillset, namely formulation, to assist in addressing these issues and meeting NICE (2018) guidelines. Formulation can

Limitations and future research

All participants were white, heterosexual men from North-West England. The experiences of other demographics are likely to be different, particularly those with an LGBTQ+ identity. LGBTQ+ people are likely to experience more significant complex family dynamics and discrimination or a lack of inclusivity from services (McParland & Camic, 2016; Price, 2011; Price, 2012;). Therefore, it would be useful for future research to explore the experiences of sons from who identify as LGBTQ+.

Similarly, all participants had an element of flexibility to their work whether it be flexible hours, working from home or being self-employed. This meant that the group could construct their work routines to accommodate their caring responsibilities. Participants acknowledged this could be more difficult if they had a rigid work schedule and therefore future research should look to recruit sons with a more varied experience of working pressures or could recruit participants who can talk retrospectively about these experiences. Given the challenges of reaching this group, perhaps future researchers should consider alternative methods of data collection such as a questionnaire with open questions which could be accessed at a convenient time.

The study was wholly qualitative which allowed for deeper exploration of the participants' experiences. However, in producing the results it may have been helpful to have had some quantitative data to further contextualise the results within the pre-existing literature. Measures such as the caregiver burden scale (Zarit et al., 1980) and the positive aspects of caregiving scale (Tarlow et al., 2004) would have been helpful in exploring the identity, humour and purpose elements of the participant's experiences. Future research may benefit from employing a mixed methods analysis.

Later experiences of dementia care, such as moving into a care home and end of life care, were beyond the scope of this study, but during interviews stories were inevitably told by participants who were reflecting in hindsight following their parent passing away. The theme of the unknown was consistent even in these answers leaving people feeling a significant level of guilt, anxiety and doubt surrounding the phase of dementia care in which they become ‘decision-makers’. Exploring this aspect of caring in sons in more detail could also be an area for future research

The limitations discussed here are primarily related to the groups which were not able to be explored in this project due to the need for homogeneity in IPA research. Homogeneity is a core facet of IPA and allows for rich, rigorous and detailed exploration of the experiences of well-defined groups (Smith et al., 2009). However, it appears to also be a limitation of the approach as the adherence to this rule has meant that in this project many groups of potential participants were not able to be represented

Conclusion

Overall, this study presents the phenomenological experiences of sons caring for a parent with dementia. Five themes were identified from the data which showed how sons relate to their parents, services and their families. The results show that sons experience their caregiving journeys in similar but also in highly individual ways. The findings were similar to the wider literature of caring, which has been predominantly female based, demonstrating that the needs of these caring men are similar to those of caring women and the current sample do not conform to outdated gender roles cited in the older literature. Clinical services need to understand individual needs and offer a tailored package of support to better support men caring for their parent.

References

Alzheimer's Association (2016). 2016 Alzheimer's disease facts and figures. *Alzheimer's & dementia: the journal of the Alzheimer's Association*, *12*(4), 459–509. https://doi.org/10.1016/j.jalz.2016.03.001.

Alzheimer's Disease International. (2015). *Global estimates of informal care*. Retrieved from https://www.alzint.org/u/global-estimates-of-informal-care.pdf.

Baker, K.L., & Robertson, N. (2008). Coping with caring for someone with dementia: Reviewing the literature about men. *Aging and Mental Health, 12*, 413–422

Barclay, L., & Lupton, D. (1999). The experiences of new fatherhood: A socio-cultural analysis. *Journal of advanced nursing*, *29*(4), 1013-1020. https://doi.org/10.1046/j.1365-2648.1999.00978.

Blaike, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy*, *3*, 289-299. https://doi.org/10.1080/14681990220149095.

Brodaty, H., Green, A., Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of American Geriatric Society, 51*, 657-664.

Carers Trust. (2022). *Over 90% of adult unpaid carers feel ignored by the government.* Retrieved from https://carers.org/news-and-media/news/post/169-over-90-of-adult-unpaid-carers-feel-ignored-by-the-government#:~:text=91%25%20of%20unpaid%20family%20carers,carers%20for%20a%20long%20time.

Carers UK. (2014). *Caring & Family Finances Inquiry: UK report*. Retrieved from https://www.carersuk.org/for-professionals/policy/policy-library/caring-family-finances-inquiry

Carers UK. (2019). *Facts about carers.* Retrieved from https://www.carersuk.org/images/Facts_about_Carers_2019.pdf

Clark, M., & Standard, P. (1997). The Caregiving Story: How the Narrative Approach Informs Caregiving Burden. *Issues In Mental Health Nursing*, *18*(2), 87-97. https://doi.org/10.3109/01612849709010326.

Clarke, V. (2010). Review of the book "Interpretative Phenomenological Analysis: Theory, Method and Research". *Psychology Learning & Teaching*, *9*(1), 57-56.

Comas-d'Argemir, D., & Soronellas, M. (2019). Men as carers in long-term caring: Doing gender and doing kinship. *Journal of Family Issues*, *40*(3), 315–339. https://doi-org.ezproxy.lancs.ac.uk/10.1177/0192513X18813185.

Conde-Sala, J. L., Garre-Olmo, J., Turro-Garriga, O., Vilalta-Franch, J., & Lopez-Pousa, S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: an exploratory comparative design. *International Journal of Nursing Studies*, *47*, 1262-1273. http://dx.doi.org/10.1016/j.ijnurstu.2010.03.001.

Conde-Sala, J. L., Garre-Olmo, J., Turro-Garriga, O., Vilalta-Franch, J., & Lopez-Pousa, S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: an exploratory comparative design. *International Journal of Nursing Studies*, *47*, 1262-1273.

Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R., ... & Ballard, C. (2012). Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *International journal of geriatric psychiatry*, *27*(6), 628-636. https://doi.org/10.1002/gps.2762.

Cross, A. J., Garip, G., & Sheffield, D. (2018). The psychosocial impact of caregiving in dementia and quality of life: a systematic review and meta-synthesis of qualitative research, *Psychology & Health*, *33*(11), 1321-1342, DOI: 10.1080/08870446.2018.1496250

Department of Health & Social Care (2018). *Carers Action Plan 2018-2020: Supporting carers today*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf.

DiLauro, M., Pereira, A., Carr, J., Chiu, M., & Wesson, V. (2017). Spousal caregivers and persons with dementia: Increasing participation in shared leisure activities among hospital-based dementia support program participants. *Dementia*, *16*(1), 9–28. https://doi.org/10.1177/1471301215570680.

Ducharme, F., Lévesque, L., Lachance, L., Kergoat, M., & Coulombe, R. (2011). Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: A descriptive study. *International Journal Of Nursing Studies*, *48*(9), 1109-1119. https://doi.org/10.1016/j.ijnurstu.2011.02.011.

Eagly, A., & Wood, W. (2012). *Social role theory*. (Vols. 1-2). SAGE Publications Ltd, https://dx.doi.org/10.4135/9781446249222.

Enright, J., O'Connell, M. E., Branger, C., Kirk, A., Morgan, D. (2018). Identity, relationship quality, and subjective burden in caregivers of persons with dementia. *Dementia, 19*(6), 1855-1871. https://doi.org/10.1177%2F1471301218808607.

Epstein-Lubow, G., Gaudiano, B., Darling, E., Hinckley, M., Tremont, G., Kohn, R., Marino, L., Salloway, S., Grinnell, R. and Miller, I. (2012). Differences in Depression Severity in Family Caregivers of Hospitalized Individuals With Dementia and Family Caregivers of Outpatients with Dementia. *The American Journal of Geriatric Psychiatry*, *20*(9), 815-819.

Francis, N., & Hanna, P. (2020). Informal carer experiences of UK dementia services—A systematic review. *Journal Of Psychiatric And Mental Health Nursing*, *29*(1), 116-129. https://doi.org/10.1111/jpm.12698.

Frias, C. E., Garcia-Pascual, M., Montoro, M., Ribas, N., Risco, E., & Zabalegui, A. (2020). Effectiveness of a psychoeducational intervention for caregivers of people with dementia with regard to burden, anxiety and depression: a systematic review. *Journal of advanced nursing*, *76*(3), 787-802. https://doi.org/10.1111/jan.14286.

Gibbor, L., Yates, L., Volkmer, A., & Spector, A. (2021). Cognitive stimulation therapy (CST) for dementia: a systematic review of qualitative research. *Aging & Mental Health*, *25*(6), 980-990. https://doi.org/10.1080/13607863.2020.1746741.

Gibson, A. K., & Anderson, K. A. (2011). Difficult diagnoses: family caregivers' experiences during and following the diagnostic process for dementia. *American Journal of Alzheimer's Disease and other Dementias*, *26*(3), 212-217.

Grigorovich, A., Rittenberg, N., Dick, T., McCann, A., Abbott, A., & Kmielauskas, A. et al. (2015). Roles and Coping Strategies of Sons Caring for a Parent With Dementia. *American Journal Of Occupational Therapy*, *70*(1), 1-9.

Grigoryeva, A. (2017). Own Gender, Sibling's Gender, Parent's Gender: The Division of Elderly Parent Care among Adult Children. *American Sociological Review*, *82*(1), 116–146. https://doi.org/10.1177/0003122416686521.

Johnson, J. L., Adkins, D., & Chauvin, S. (2020). A Review of the Quality Indicators of Rigor in Qualitative Research. *American journal of pharmaceutical education*, *84*(1), 7120. https://doi.org/10.5688/ajpe7120.

Jones, R. (2015). Dealing with Dementia. *British Journal of General Practice*, *65*(637), 387.

Kjällman-Alm, A., Norbergh, K. and Hellzen, O. (2013). What it means to be an adult child of a person with dementia. *International Journal of Qualitative Studies on Health and Well-being*, 8(1), p.21676.

Laparidou, D., Middlemass, J., Karran, T., & Siriwadena, A. (2019). Caregivers' interactions with health care services - Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia - A qualitative study. *Dementia*, *18*(7), 2526-2542.

Lethin, C., Hallberg, I. R., Karlsson, S., & Janlov, A. C. (2016). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Sciences*, *30*, 526-534

Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*, *15*(6), 1534–1561. https://doi.org/10.1177/1471301214564792.

Luttenberger, K., Schmiedeberg, A. & Gräßel, E. (2012). Activities of daily living in dementia: revalidation of the E-ADL test and suggestions for further development. *BMC Psychiatry* **12,** 208.

Matta, T. (2021). Treating Caregiver Grief With Narrative Therapy. *Innovation In Aging*, *5*(Supplement_1), 1050-1051. https://doi.org/10.1093/geroni/igab046.3750.

Matthews, S. H. (2002). *Sisters and brothers/daughters and sons: Meeting the needs of old parents*. Unlimited Publishing LLC.

McDonnell, E., & Ryan, A. A. (2013). The experience of sons caring for a parent with dementia. *Dementia, 13*(6), 788-802.

McParland, J., & Camic, P. M. (2018). How do lesbian and gay people experience dementia? *Dementia: The International Journal of Social Research and Practice*, *17*(4), 452-477. https://doi.org/10.1177/1471301216648471.

Montgomery, R. J. V., & Kosloski, K. (2009). Caregiving as a process of changing identity: implications for caregiver support. *Generations*, *33*, 47-52.

Mott, J., Schmidt, B., & MacWilliams, B. (2019). Male caregivers: shifting roles among family caregivers. Clinical Journal of Oncology Nursing, 23, 17-24.

Muldrew, D. H. L., Fee, A., & Coates, V. (2021). Impact of the COVID-19 pandemic on family carers in the community: A scoping review. *Health & Social Care in the Community*, 00, 1– 11.

Muñoz, D., Favilla, S., Pedell, S., Murphy, A., Beh, J., & Petrovich, T. (2021). Evaluating an App to Promote a Better Visit Through Shared Activities for People Living with Dementia and their Families. *Proceedings Of The 2021 CHI Conference On Human Factors In Computing Systems*. https://doi.org/10.1145/3411764.3445764.

National Health Service. (2018). *Looking after someone with dementia*. Retrieved from https://www.nhs.uk/conditions/dementia/carers/.

National Institute for Clinical and Health Excellence. (2018). *Dementia: assessment, management and support for people living with dementia and their carers*. Retrieved from https://www.nice.org.uk/guidance/ng97/chapter/recommendations

New Policy Institute. (2016). Informal carers & poverty in the UK: An analysis of the family resources survey. Retrieved from https://www.npi.org.uk/files/2114/6411/1359/Carers_and_poverty_in_the_UK_-_full_report.pdf.

Office for National Statistics. (2022). *Average actual weekly hours of work for part-time workers (seasonally adjusted)*. Retrieved from Average actual weekly hours of work for part-time workers (seasonally adjusted) - Office for National Statistics (ons.gov.uk).

Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, *39*(2), 177-185.

Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., Leipert, B. D., & Henderson, S. R. (2010). The Positive Aspects of the Caregiving Journey With Dementia: Using a Strengths-Based Perspective to Reveal Opportunities. *Journal of Applied Gerontology*, *29*(5), 640–659. https://doi.org/10.1177/0733464809341471.

Peacock, S., Hammond-Collins, K., & Forbes, D. (2014). The journey with dementia from the perspective of bereaved family caregivers: a qualitative descriptive study. *BMC Nursing*, *13*(1). https://doi.org/10.1186/s12912-014-0042-x.

Price, E. (2011). Caring for mum and dad: Lesbian women negotiating family and navigating care. *British Journal of Social Work*, *41*(7), 1288-1303. https://doi.org/10.1093/bjsw/bcr015

Price, E. (2012). Aay and lesbian carers: ageing in the shadow of dementia. *Ageing & Society*, *32*(Part 3), 516-532. https://doi.org/10.1017/s0144686x11000560.

Quinn, C., & Toms, G. (2019). Influences of positive aspects of caregiving on caregivers' well-being: A systematic review. *Gerontologist*, *59*(5), 584-596. https://doi.org/10.1093/geront/gny168.

Reed, C., Belger, M., Dell'Agnello, G., Wimo, A., Argimon, J., & Bruno, G. et al. (2014). Caregiver Burden in Alzheimer's Disease: Differential Associations in Adult-Child and Spousal Caregivers in the GERAS Observational Study. *Dementia And*

Geriatric Cognitive Disorders Extra, *4*(1), 51-64. https://doi.org/10.1159/000358234.

Reisberg, B. (1988). Functional Assessment Staging (FAST). *Psychopharmacology Bulletin, 24*, 653-65.

Robinson, C. A., Bottorff, J. L., Pesut, B., Oliffe, J. L., & Tomlinson, J. (2014). The male face of caregiving: a scoping review of men caring for a person with dementia. *American Journal of Men's Health*, *8*(5), 409-426. https://doi.org/10.1177/1557988313519671

Robinson, L., Tang, E., & Taylor, J. (2015). *Dementia: timely diagnosis and early intervention*. Retrieved from https://www.bmj.com/content/350/bmj.h3029.

Rurka, M., Jill Suitor, J., & Gilligan, M. (2020). The Caregiver Identity in Context: Consequences of Identity Threat From Siblings. *The Journals Of Gerontology: Series B*, *76*(8), 1593-1604. https://doi.org/10.1093/geronb/gbaa099.

Schütz, A. (1962). *Collected Papers 1.* The Hague: Martinus Nijhoff.

Smith, J. A., & Osborn, M. (2008). *Interpretative Phenomenological Analysis. In J. A. Smith, (Ed.), Qualitative psychology: A practical guide to research methods*. London: Sage

Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain, 9*(1), 41-42.

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*

Steadman, P., Tremont, G., & Duncan Davis, J. (2007). Premorbid Relationship Satisfaction and Caregiver Burden in Dementia Caregivers. *Journal of Geriatric Psychiatry and Neurology*, *20*(2), 115–119. https://doi.org/10.1177/0891988706298624.

Stephens, M. A. (2009). *Gender differences in parenting styles and effects on the parent-child relationship* (Unpublished thesis). Texas State University-San Marcos, San Marcos, Texas.

Stets, J. E., Savage, S. V., Burke, P. J., & Fares, P. (2020). Cognitive and behavioral responses to the identity verification process. In R. T. Serpe, R. Stryker, & B. Powell (Eds.), *Identity and symbolic interaction: Deepening foundations, building bridges* (pp. 65–88). Springer. doi:10.1007/978-3-030-41231-9.

Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive Aspects of Caregiving: Contributions of the REACH Project to the Development of New Measures for Alzheimer's Caregiving. *Research on Aging, 26*(4), 429–453. https://doi.org/10.1177/0164027504264493.

Tatangelo, G., McCabe, M., Macleod, A., & Konis, A. (2018). I just can't please them all and stay sane: Adult child caregivers' experience of family dynamics in care-giving for a parent with dementia in Australia. *Health & Social Care in the Community, 26*(3), 370-377.

Toepfer, N. F., Foster, J. L., & Wilz, G. (2014). 'The good mother and her clinging child': Patterns of anchoring in social representations of dementia caregiving. *Journal of Community & Applied Social Psychology*, *24*(3), 234-248. https://doi.org/10.1002/casp.2164.

Ugwu, E. N. (2020). *Laughter therapy and coping strategies for dementia patient caregivers* (Doctoral dissertation). https://www.proquest.com/openview/f9db0324f1fb611aa7cbbf45ef142a1a/1?pq-origsite=gscholar&cbl=18750&diss=y

Üngör, U. U., & Verkerke, V. A. (2015). Funny as hell: The functions of humour during and after genocide. *The European Journal of Humour Research*, *3*(2/3), 80–101. https://doi.org/10.7592/EJHR2015.3.2.3.ungor

Van Der Flier., W. M., & Scheltens, P. (2005). Epidemiology and risk factors of Dementia. *Journal of Neurology, Neurosurgery & Psychiatry, 76*, 2-7.

Van Wijngaarden, E., Van der Wedden, H., Henning, H., Komen, R., & The, A. M. (2018). Entangled in uncertainty: the experience of living with dementia from the perspective of family caregivers. *PLoS ONE, 13*(6), 1-21.

Wadham, O., Simpson, J., Rust, J., & Murray, C. (2016). Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood. *Aging & mental health*, *20*(5), 463-473.

Wang, Y., Hsu, W., Yang, P., Yao, G., Chiu, Y., & Chen, S. et al. (2018). Caregiving demands, job demands, and health outcomes for employed family caregivers of older adults with dementia: Structural equation modelling. *Geriatric Nursing*, *39*(6), 676-682. https://doi.org/10.1016/j.gerinurse.2018.05.003.

Wawrziczny, E., Duprez, C., & Antoine, P. (2020). Predictors of caregiver distress among spouses, adult children living with the person with dementia, and adult children not living with the person with dementia. *Psychogeriatrics*. doi:10.1111/psyg.12553.

West, C., & Zimmerman, D. (1987). Doing gender. *Gender & Society : Official Publication of Sociologists for Women in Society.*, *1*(2), 125–151.

Wolf, D. A., Freedman, V. A., & Soldo, B. J. (1997). The division of family labor: Care for elderly parents. *Journals of Gerontology Series B*, *52*, 102-109.

World Health Organisation. (2021). *Dementia*. Retrieved from https://www.who.int/news-room/factsheets/detail/dementia#:~:text=Worldwide%2C%20around%2055%20million%20people,and%20139%20million%20in%202050.

Wu, Q., Yamaguchi, Y., & Greiner, C. (2022). Factors associated with the well-being of family caregivers of people with dementia. *Psychogeriatrics*, *22*(2), 218-226. https://doi.org/10.1111/psyg.12805

Xiong, C., Biscardi, M., Astell, A., Nalder, E., Cameron, J. I., et al. (2020). Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. *PLOS ONE*, *15*(4): e0231848. https://doi.org/10.1371/journal.pone.0231848

Yardley, L. (2000) Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215-228. https://doi.org/10.1080/08870440008400302

Yiannopoulou, K. G., & Papageorgiou, S. G. (2013). Current and future treatments for Alzheimer’s disease. *Therapeutic advances in Neurological Disorders*, *6*(1), 19-33.

Yu, D. S. F., Cheng, S. T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: an integrative review of research literature. *International Journal of Nursing Studies*, 79, 1–26. https://doi.org/10.1016/j.ijnurstu.2017.10.008.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, *20*(6), 649–655. https://doi.org/10.1093/geront/20.6.649.

Table 1

Participant demographics

Pseudonym	Age	Who did they care for?	Currently caring?
Daniel	30	Father	No
Joe	50	Father	Yes
Alan	37	Mother	Yes
Hugo	62	Mother	No
Owen	48	Father	Yes
John	54	Mother	No
Jason	50	Father	No

Section 2 Appendices

2-A Initial analysis of data: An extract from Jason’s interview

2-B An example of the clustering of themes from Jason’s interview

2-C Illustration of how initial clusters led to final themes

2-D Manuscript preparation guidelines: Dementia

Appendix 2-A Initial analysis of data: An extract from Jason’s interview

Participant quotes	Initial notes	Emergent themes
Got to the point where they diagnosed him as having what they called asymptomatic alzheimers which it was strange that he was able to get 38 out of 40 questions right and he wasn’t a typical alzheimers patient and it was only when they did the scans and they measured what they called the wastage on his brain and they diagnosed him as being asymptomatic alzheimer’s so I don’t fully understand it we don’t fully understand it I don’t think anyone fully understands it but we know that he is not himself so then maybe 3 years ago we took the decision to move him in with me at my suggestion because I have a brother and sister with young families and my lad is 18 now and im divorced and he lives with his mum so it made sense for him to come live with me and we moved him in with me 3 years ago and to be fair up until Christmas last year we didn’t to be fair we could obviously notice a change in his behaviours and memory and things but it was gradual it wasn’t significant deterioration yano last year we had a great year where I took him out we used to go the park and I took him to costa coffee a lot and he used to stay at redacted a while yano go for his tea on a Sunday and things and Christmas came round everything was similar and since then he has literally fell off a cliff	Dad diagnosed with ‘aysmptomatic alzheimers’ despite scoring well on cognitive tests. confusing time for P and his family. Lack of insight and answers provided to him starting his caring role. *‘it was strange…I don’t fully understand it…we don’t fully understand it..i don’t think anyone fully understands it..’ – repetition of ‘not understanding’.* Uncertainty, confusion, not knowing? Dealing with the unknown? A feeling that even professionals can’t shed a light on this? How would P deal with this uncertainty? Dad moved in with P as his family had grown whereas his siblings had young families. Caring due to family convenience? Primary carer due to other siblings familial obligations? Having to care as he is divorced and has older children, how does this feel? Initially, upon moving Dad in with P, they had a good year. P described the ‘deterioration’ as gradual. They were able to enjoy shared time together. *‘fell off a cliff’ – falling down, complete downfall, deterioration beyond recognition?* Sudden and drastic deterioration? P appears	Confusion The experts don’t have answers Journey into the unknown Uncertainty Confusion The experts don’t have answers If the experts don’t know, how should we? Caring due to family convenience Forced to care The only child who could care Finding ways to stay connected Rapid deterioration Sacrifice (personal)

2-B An example of the clustering of themes from Jason's interview

Emergent themes	Superordinate themes
- Confusion	A journey into the unknown
- The experts don't have answers	
- Uncertainty	
- Confusion	
- If the experts don't know, how should we?	
- Anxiety	
- Feeling let down by care	
- Needing help but not getting it	
- Defeated by the system	
- Sacrifice (personal)	I'll do it myself, until I can't
- Labour intensive	
- Disgust/upset at personal care	
- I'm not strong enough to do this	
- Recruiting support from within the family	
- Feeling unsafe in caring	
- Teamwork within the family	
- Realising you can't do it alone	
- I'll do it myself	
- Love	
- Heartbreaking	
- Rollercoaster journey	
- Flexible working	Working flexibly is key
- Cared for Dad between meetings	
- Working from home	
- 'I couldn't do this if I worked in the office'	
- Caring didn't affect work	
- Work didn't affect caring	
- Caring due to family convenience	The only sibling that 'could'
- Forced to care	
- The only child who could care	
- Finding ways to stay connected	
- Desperation	
- Guilt	
- Intense pressure/responsibility	
- Am I strong enough for this?	
- Best relationship with Dad	
- Proud of Dad	
- This…This is nothing	

2-C Illustration of how initial clusters led to final themes

Pseudonym	Theme 1: A journey into the unknown	Theme 2: The leader of the band	Theme 3: Pride and purpose	Theme 4: “Like all the best comedies, it’s pretty tragic”	Theme 5: Workplace context matters
Daniel	I just had to work it out for myself	We all pitched in but I was the favourite	Family values	Finding the light in the dark	Easy to juggle roles
Joe	Seeking answers	Strained sibling relationships	The proud son repaying his debt	Finding the light in the dark	Working around Dad
Alan	Trial and error	Making sure everyone gets a break	Keeping the memories of my childhood alive	Anxiety and stress	Trying to keep my paid job, my volunteering suffers
Hugo	They haven’t got a clue	My brother is useless	She’s my mam, she brought us up on her own	We could always have a laugh, even at the end	Being self-employed, I could work around mums needs
Owen	No one tells you anything	‘I’m the leader of the band and you’re not	Grieving the loss of being a carer	“Like all the best comedies,	I created my own business so that I

		playing your instrument’		it’s pretty tragic”	could care for Dad
John	No one tells you what to expect	My sister was no help whatsoever	Extra quality time because of care	It’s funny, but it’s really not	I had flexi-hours so I could work around Mum
Jason	A journey into the unknown	I’ll do it alone, until I can’t	“To me, this is nothing”	Sweat, tears and not coping	Working flexibly is key

.

Appendix 2-D Manuscript preparation guidelines: Dementia

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. Biomedical and overly clinical research articles will not be accepted.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at Sarah.Campbell@MMU.ac.uk and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer’s name is withheld from the author and, the author’s name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should be placed on the title page. Your main text should include a Declaration of Conflicting Interests (if applicable), any notes and your References but should be completely anonymized.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

2.7 Research data

The journal is committed to facilitating openness, transparency and reproducibility of research, and has the following research data sharing policy. For more information, including FAQs please visit the SAGE Research Data policy pages.

Subject to appropriate ethical and legal considerations, authors are encouraged to:

- share your research data in a relevant public data repository
- include a data availability statement linking to your data. If it is not possible to share your data, we encourage you to consider using the statement to explain why it cannot be shared.
- cite this data in your research

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Dementia offers offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'.

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.5 Reference style

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Book reviews must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Sarah Campbell Sarah.Campbell@MMU.ac.uk

5.1 ORCID

> As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports

automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be made available to the corresponding author via our editing portal SAGE Edit or by email, and corrections should be made directly or notified to us promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com

Section Three: Critical Appraisal

Reflections on a qualitative analysis of the experiences of working sons caring for a parent living with dementia

Samuel Hughes

Lancaster University

Doctorate in Clinical Psychology

Prepared in accordance with the journal guidelines for

Dementia

Word count: 3089 (Excluding tables, appendices and reference lists)

All correspondence should be sent to:
Samuel Hughes
Doctorate in Clinical Psychology

Health Innovation One
Sir John Fisher Drive
Lancaster
Lancaster University
LA1 4AT
Email: S.hughes5@lancaster.ac.uk

Introduction

Section Two of this thesis presents qualitative research into the experiences of working sons who have cared for a parent living with moderate-stage dementia. The results reveal what challenges are involved within this role and how sons navigate them. The results also suggest the motivations behind sons becoming a primary caregiver for a parent as well as the secondary gains that exist within the role. Using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) five themes were identifies: 1) Journey into the unknown; 2) 'Leader of the band'; 3) Pride and purpose; 4) 'Like all the best comedies, it's pretty tragic; and 5) Workplace context matters. The research enabled sons, who are significantly underrepresented in the research, to share stories about a significantly emotional phase of their lives.

Much has been learned through the process of planning, conducting and finalising the research. Accordingly, this critical appraisal represents a reflection on key elements of learning, strengths and areas for development which will be discussed in the context of recommendations for future research.

Selecting a Research topic and Methodology

My interest in this area of research developed several years ago when I was an Assistant Psychologist working in an Older Adult Mental Health team and memory clinic. I worked with and alongside many female informal caregivers however most of the male caregivers I worked with were husbands or partners. I reflected on the difficulties of engaging caregivers who were sons of the people living with dementia, often due to their work schedule conflicting with the business hours of the service. It was evident from my own professional experiences that caregiving can be an intense period in an individual’s life resulting in both difficulties and rewards. Such consequences are reflected in the research with caregiving for a people living with dementia being found to result in isolation, multiple adverse mental health outcomes such as anxiety and depression, and financial distress (Benbow & Kingston, 2014; Epstein-Lubow et al., 2012; Laparidou et al., 2019; Tatangelo et al., 2018). Despite this, caregivers also report rewards of caregiving such as an appreciation of the sense of purpose the caregiving role gives them (Clemmensen et al., 2019; Van Wijngaarden et al., 2018). My clinical supervisors and I would reflect on these consequences and wonder what effect, if any, they had on sons of a people living with dementia. National Institute for Clinical Health and Excellence (2018) guidelines on supporting dementia caregivers are not gender discriminative, and we often wondered whether son caregivers were being afforded the same care as other caregivers.

Therefore, an interest in the experiences of sons was piqued, particularly working sons, with the view that research may shed a light on the experiences of those not traditionally captured by the existing literature. Upon entering training, my research supervisors encouraged me to conduct scoping reviews of the literature to ascertain the quantity and quality of the literature in this area. Although, this ‘review’ was by no means a systematic review, only one study was found pertaining to the experiences of sons caring for a people living with dementia. This was a study by McDonnell & Ryan (2013) who explored the experiences of rural Irish sons caring for a mother living with dementia. The authors found that sons cared for their mother through a sense of duty and reciprocity for the role their mother played in their upbringing. The authors acknowledged limitations within their study including the limited geographical base, lack of ethnic diversity and the sample being limited to those caring for a mother living with dementia. The research also used an older methodology for phenomenological analysis proposed by Colazzi (1978), however there are more modern approaches such as Interpretative Phenomenological Analysis (IPA; Smith et al., 2009). Upon discussion of this study’s findings and limitations with my research supervisors, it was agreed that a study focusing on the experiences of working sons caring for a parent living with dementia would represent an addition to an otherwise paltry literature base.

Similarly to the McDonnell & Ryan (2013) study a qualitative approach was chosen to enable exploratory investigation of this topic with the focus being on the participant's experience rather than answers to pre-constructed questionnaires (Barker et al., 2015). Initially, a narrative inquiry methodology was considered to facilitate the participants to use storytelling, an approach which is reported to enable deeper and more honest reflections (Mertova & Webster, 2019). However, there were potential limitations to this. Firstly, my research supervisors had not had experience in supervising narrative research methods which would have potentially lessened the effectiveness of supervision in ensuring the quality of the project. Secondly, disadvantages of narrative inquiry included blurred lines between the role of researcher and therapist as well as difficulties in setting boundaries to ensure the research question and scope is maintained (Ntinda, 2018). The research project was concerned with people's experiences of caring up to the point of their parent having 'moderate-stage' dementia. However, participants with retrospective experience of this were included and so the disadvantages of narrative inquiry became too difficult to consider with the participant group we were considering. Therefore, the attention switched to other methods resulting in the selection of IPA. IPA was a methodology with which my supervisors had a significant level of experience with, which felt containing as I was embarking on my most significant research project to date. Furthermore, IPA is concerned with the phenomenological experiences of homogenous groups of people (Smith & Osborn, 2008) and so was relevant to the well-defined group of participants with which the study was concerned. IPA has also been used before to explore the experiences of caregiving in dementia (Lockeridge & Simpson, 2013; Mwendwa et al., 2021; Quinn et al., 2015). Therefore, IPA has greater utility to researchers interested in such populations. The study was guided by the framework proposed by Smith et al., (2009).

Recruitment and homogeneity

Recruiting participants for the study was challenging. This had been anticipated given that the participant sample I had selected were not previously well-represented in the literature. In order to mitigate the anticipated difficulties a staged approach to recruitment was taken starting with social media recruitment before moving on to seeking support from Age UK and then finally circulating the poster amongst a service user group external to the NHS. All stages of recruitment were carried out due to low initial interest, however, in the end all participants were recruited through the first stage of social media recruitment. It was hoped that social media recruitment and seeking national campaigns and charities to share the project would mean that a more geographically diverse population would be reached. Although this was the hope, all participants lived and worked in one region of England.

One issue with the sample obtained was that they were all either self-employed or had flexible working conditions which allowed them to care and work relatively cohesively. This may represent a skewed sample as only 15.3% of the working population in the United Kingdom are self employed (Office for National Statistics, 2022). On reflection, I wonder whether the social media recruitment strategy may have influenced this. Generally, active recruitment was conducted during traditional working hours. I wonder whether this meant that sons with more flexibility in their working day were more likely to see the recruitment campaign. Another possible explanation is that sons with flexibility found research more accessible than those with rigid working schedules. Future research would benefit from making efforts to recruit a more balanced sample of participants with a variety of working conditions or even focus on those with rigid work schedules to ascertain the relationship of this type of work and caring. I wonder whether seeking NHS ethical approval would have been an effective way to recruit participants with a more diverse experience of working conditions. This was initially considered due to my professional links in NHS Older Adult services and the potential benefits it would have for ease of recruitment. However, following discussion with my supervisors and consideration we felt that social media recruitment would allow for a more geographically diverse sample of participants.

Due to difficulties in recruiting participants, the initial inclusion criteria were widened to include those with retrospective experience of caring for a parent with moderate-stage dementia. Ethical approval was granted for this amendment. This was beneficial to the project in that it meant that recruitment was fulfilled, and the project was able to be completed. However, a predicted difficulty was that participants may discuss experiences which were beyond the scope of the study. This felt like an important issue to navigate due to the potential ethical implications of a participant sharing stories which could not then be used in a meaningful way within the research. It was also important to maintain the scope of the research focus to protect the homogeneity of the experiences being discussed. Therefore, participants were briefed through the research and consent literature as well as prior to interviews on the scope of the study and what would be beyond that. I was guided on this by the British Psychological Society’s (2021) code of ethics for researchers as well as the University’s ethical requirements, particularly pertaining to informed consent. Although every effort was made to inform the participants of the scope of the research, inevitably, those with retrospective experiences discussed later life and even bereavement experiences related to their caregiving journeys. This left me feeling conflicted in my role as researcher. For the purposes of protecting the homogeneity of the experiences presented in the study as well as respecting the scope of the project which had been given ethical approval, I had to exclude those stories from the final analysis. I felt in doing this that meaningful and useful experiences had been lost and that the stories of those with retrospective experience would make for important research going forward.

The research and Me

A reflection of the research process was my relationship with it. Although I have no experience of caring for a parent with dementia, I have worked with hundreds of families affected by it. Furthermore, during the process of the project both my grandfather and grandmother were formally diagnosed with dementia. As a result, it has been important to reflect on my own experiences and attitudes both from a professional and personal standpoint. The research felt more important as I witnessed my father become a ‘working son’ who cares for a parent living with dementia. However, I was also conscious that such experiences may lead to biases in the interviewing and analysis process. In recognising my biases, I was able to reflect on them in supervision with my clinical and field supervisor and consider them in the design and delivery of the interview schedule as well as the analysis to ameliorate any effects they may have.

I became aware of further assumptions during the interviewing process. I realised I was expecting work to have a greater significance on the experiences of sons caring for a parent with dementia. This was due to my clinical experience of witnessing sons struggling to attend appointments, the literature surrounding financial difficulties in caregivers and my personal experience of seeing my father become a working son and caregiver. However, the participants in the study reported that their work was flexible and so they had created a work schedule which accommodated their caring responsibilities. Upon reflection, I wonder whether my assumption that work would have a bigger impact led to other more salient experiences being missed in the interviewing process.

Further to this, I noticed that I was sometimes holding interpretations that were beyond the scope of the stage of Smith et al’s., (2009) seven stages of IPA I was currently working at. At the stages of initial noting and developing emergent themes I would inevitably make comparisons across the data set as I was familiar with all the transcripts. However, at this stage Smith et al., (2009) report that it is important to take each transcript as an individual and to not search for connections until all transcripts have been analysed individually. In order to reduce the impact of my premature interpretations I wrote them down separate to the analysis and returned to them only when I had finished the main stages of analysis to check whether they had re-appeared in the hope that this would maintain the accuracy with which the framework was followed.

Unexpected lessons I learned

Naturally, throughout the course of the research, alternative research interests have developed. When conducting the systematic literature review pertaining to the experiences of LGBTQ+ people living with dementia I gained a familiarity with the legacy of discrimination people belonging to a sexual identity minority have experienced. As a heterosexual person, this led to me acknowledging the privilege I hold and confronting my own ignorance surrounding the issues which different generations have experienced, particularly in my own country.

The current cohort of people living with dementia (excluding some of those with early onset dementia) will have lived during a time in which homosexuality was illegal. The partial decriminalisation of homosexuality began with the Sexual Offences Act (1967) however even this act prohibited public acts of intimacy or affection between two consenting men. This was indicative of a societal view towards homosexuality within which the current cohort of older adults experiencing dementia were brought up in their early years. A societal and legal view which included harsh judgement of differences in sexual orientation, at best, and judicial punishment or violence at worst. This cohort has also experienced the effect of section 28 (Local Governments Act, 1988), a piece of legislation designed to prevent the ‘promotion’ of homosexuality in schools. The effects of section 28 are thought to still be felt today by LGBTQ+ teachers who see their sexual orientation and teaching identities as incompatible and feel they cannot be open about their sexuality (Lee, 2019). Despite its repeal in 2003, section 28 was widely seen as a symbol of oppression of LGBTQ+ people and remains to have an effect on the cohort of individuals who may now be caring for a parent living with dementia or at risk of experiencing it themselves in later life.

Further to this, younger cohorts have experienced discriminative legislation with only slow and gradual steps towards equality being achieved in legislation over the last thirty years. As recently as the 1990s gay men were not allowed to serve as diplomats. Only in 2004 were civil partnerships legitimised legislatively. Until 2009 those in same-sex relationships were not allowed to register both parents' names on the birth certificate of their child. The government 1997-2010 introduced rights for same sex couples to adopt, introduced the gender recognition act, categorically stated that transsexualism is 'not a mental illness' and repealed section 28. Parliament only passed a bill allowing for same sex marriage in England, Wales and Scotland in 2014, with Northern Ireland following in 2020. Further to this, as of the time of writing, conversion therapy aimed at changing an individual's sexual orientation is still legal in the United Kingdom. (Gender Recognition Act, 2004; Civil Partnership Act, 2004; Marriage (Same Sex Couples) Act, 2013; Barnet, Enfield & Haringey Mental Health NHS trust, 2021). The focus of these legislation changes has primarily been in introducing rights for same-sex couples and lesbian and gay individuals. The rights of other sexual identity minorities however are even further behind, with trans people reporting that they experience discrimination in all walks of life including workplaces, universities and healthcare (Stonewall, 2021).

The above is a brief and far from all-encompassing outline of the legislative changes that the LGBTQ+ community have experienced since 1967. It outlines a society that has been hostile and punitive of people's identities. Recent 2019 UK population data, although limited, shows that the number of older adults identifying as LGBTQ+ is increasing and over 1.4 million people aged 16 or over in UK identify as such compared to 1.2 million in 2018, continuing a trend in recent years (Office for National Statistics, 2021). The legislation and the associated effects on the LGBTQ+ community are not just associated with the cohort of people experiencing dementia now but also LGBTQ+ caregivers. The legacy of this will also influence future generations of people from a sexual identity minority who will experience dementia. This outlines a genuine need for research to be conducted that is sensitive to the history of discrimination LGBTQ+ people have faced. Furthermore, the results of the review are suggestive of heteronormative services being problematic for people and a general lack of culturally sensitive care is highlighted. For these reasons, it is important that future health care services and Clinical Psychologists engage in education and research to ascertain the needs of LGBQT+ people in order to design and co-construct more appropriate services.

Implications for future research

Based on the reflections thus far, researchers may consider some suggestions for future work, specifically pertaining to areas such as sampling and scope. It would be beneficial for future research to consider a more diverse range of working experiences by seeking more efficient means of recruitment following which participants can be selectively chosen for participation based on demographic information collected. This may include obtaining NHS ethics and seeking support from multiple services from different geographical areas. This would be helpful in furthering our understanding of the experiences of working sons.

Furthermore, future research may benefit from focussing on areas which were present but beyond the scope of the study. For example, the retrospective experiences of sons who had experienced the loss of their parent may provide useful and meaningful insights. Additionally, alternative research topics may include exploring the experiences of LGBQT+ people who are living with dementia, specifically those from outside of the lesbian, gay and bisexual identity who are significantly underrepresented in the literature.

Moreover, when reflecting on the results of the study, it was tempting to consider the comparisons of the experiences of sons and daughters and was disappointing to lack the data set to be able to do this. Future research may consider the results of this study and recruit a sample of both sons and daughters in order to ascertain any differences in the caregiving experience to discuss potential clinical implications for this.

Conclusion

In reflecting upon key elements of the research process, this critical appraisal has discussed the challenges of conducting qualitative research with sons of those caring for a parent living with dementia. It has considered some of the practical, ethical and methodological issues I encountered in conducting this research. Researchers working with this population may therefore find this critical appraisal helpful in planning their future work.

References

Barker. C., Pistrang. N., & Elliot, R. (2015). *Research Methods in Clinical Psychology: An Introduction for Students and Practitioners: Second Edition*. Chichester: John Wiley & Sons Ltd.

Barnet, Enfield and Haringey Mental Health NHS trust. (2021). *History of LGBTQ+ rights in the UK.* Retrieved from https://www.beh-mht.nhs.uk/news/history-of-lgbtq-rights-in-the-uk/1750.

Benbow, S. M., & Kingston, P. (2014). 'Talking about my experiences...at times disturbing yet positive': Producing narratives with people living with dementia. *Dementia, 15*(5), 1034-1052.

Civil Partnership Act (2004). Retrieved from https://www.legislation.gov.uk/ukpga/2004/33/contents.

Clemmensen, T. H., Busted, L. M., Soborg, J., & Bruun, P. (2019). The family's experience and perception of phases and roles in the progression of dementia: An explorative interview-based study. *Dementia, 18*(2), 490-513.

Colaizzi, P. (1978). Psychological research as the phenomenologist sees it. In: Valle, R., King, M. (eds) *Existential-phenomenological alternatives for psychology*, New York, NY: Oxford University Press, pp. 48–71.

Epstein-Lubow, G., Gaudiano, B., Darling, E., Hinckley, M., Tremont, G., Kohn, R., Marino, L., Salloway, S., Grinnell, R. and Miller, I. (2012). Differences in Depression Severity in Family Caregivers of Hospitalized Individuals With Dementia and Family Caregivers of Outpatients with Dementia. *The American Journal of Geriatric Psychiatry, 20*(9), 815-819.

Gender Recognition Act (2004). Retrieved from https://www.legislation.gov.uk/ukpga/2004/7/contents.

Laparidou, D., Middlemass, J., Karran, T., & Siriwadena, A. (2019). Caregivers' interactions with health care services - Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia - A qualitative study. *Dementia, 18*(7), 2526-2542.

Lee, C. (2019). Fifteen years on: the legacy of section 28 for LGBT+ teachers in English schools. *Sex Education*, *19*(6), 675-690.

Local Government Act (1988). Section 28. Retrieved from http://www.legislation.gov.uk/ukpga/1988/9/contents.

Lockeridge S., & Simpson, J. (2013). The experience of caring for a partner with young onset dementia: How younger carers cope. *Dementia*, *12*(5):635-651. doi:10.1177/1471301212440873.

McDonnell, E., & Ryan, A. A. (2013). The experience of sons caring for a parent with dementia. *Dementia*, *13*(6), 788-802

Mertova, P., & Webster, L. (2019). *Using Narrative Inquiry as a Research Method: An Introduction to Critical Event Narrative Analysis in Research, Teaching and* Professional *Practice* (2nd ed.). Routledge. https://doi.org/10.4324/9780429424533

Mwendwa, P., Mutunga, E., Kroll, T., & De Brún, A. (2021). 'It is stressful, almost every hour…': Experiences of caring for people living with dementia in Kenya—An interpretive phenomenological approach. *Dementia*, *20*(8), 2916–2932. https://doi.org/10.1177/14713012211022989.

National Institute for Health and Care Excellence. (2018). Dementia: assessment, management and support for people living with dementia and their carers. Retrieved from https://www.nice.org.uk/guidance/ng97.

Ntinda, K. (2018). Narrative Research. In Liamputtong, P. (ed.), *Handbook of Research Methods in Health Social Sciences*. Springer Singapore. https://doi.org/10.1007/978-981-10-2779-6_79-1.

Office for National Statistics. (2021). *Sexual orientation, UK: 2019*. Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2019.

Office for National Statistics. (2022). *Self-employment*. Retrieved from https://www.ethnicity-facts-figures.service.gov.uk/work-pay-and-benefits/employment/self-employment/latest#:~:text=In%202019%3A,out%20of%20all%20ethnic%20groups.

Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia, 14*(2), 220–237. https://doi.org/10.1177/1471301213495863.

Sexual Offences Act 1967. Retrieved from https://www.legislation.gov.uk/ukpga/1967/60/pdfs/ukpga_19670060_en.pdf.

Smith, (Ed.), Qualitative psychology: A practical guide to research methods. London:Sage.

Smith, J. A., & Osborn, M. (2008). *Interpretative Phenomenological Analysis. In J. A.*

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research.*

Stonewall. (2021). *Come out for Trans Equality*. Retrieved from https://www.stonewall.org.uk/our-work/campaigns/come-out-trans-equality.

Tatangelo, G., McCabe, M., Macleod, A., & Konis, A. (2018). I just can't please them all and stay sane: Adult child caregivers' experience of family dynamics in care-giving for a parent with dementia in Australia. *Health & Social Care in the Community, 26*(3), 370-377.

Van Wijngaarden, E., Van der Wedden, H., Henning, H., Komen, R., & The, A. M. (2018). Entangled in uncertainty: the experience of living with dementia from the perspective of family caregivers. *PLoS ONE, 13*(6), 1-21.

Section Four: Ethics Section

Reflections on a qualitative analysis of the experiences of working sons caring for a parent living with dementia

Samuel Hughes

Lancaster University

Doctorate in Clinical Psychology

Word count: 2738 (Excluding tables, appendices and reference lists)

All correspondence should be sent to:
Samuel Hughes
Doctorate in Clinical Psychology
Health Innovation One
Sir John Fisher Drive
Lancaster
Lancaster University
LA1 4AT
Email: S.hughes5@lancaster.ac.uk

Introduction

Dementia is a clinical diagnosis categorised by a marked decrease in cognitive decline resulting in new functional dependencies for the individual (Cunningham, McGuiness, Herron & Passmore, 2015). An estimated 1.3% of the population of the United Kingdom are currently diagnosed with dementia and more prevalently 7.1% of those aged 65 and over (Prince, Knapp, Guerchet, McCrone, Prina & Comas-Herrera, 2014). The vast majority of informal carers for those living with dementia are either the spouse of the individual or adult children (Clay,2018), making up a large number of the estimated 706,000 informal carers in the United Kingdom (Lewis, Schaffer, Sussex, O'Neill & Cockcroft, 2014).

Dementia can cause both neuropsychiatric symptoms including apathy and depression as well as functional difficulties such as decreased ability in activities of daily living such as bathing, cooking, cleaning and managing finances (Brunelle-Hamann, Thivierge & Simard, 2015). These symptoms may evolve or be more common with certain types of dementia. In the latter stages of the disease difficulties can include delusions, aggression and irritability, causing potential risks to both the individual and others (Bjerre et al, 2018). These symptoms and the loss of functional abilities can often cause individuals living with dementia to require more support from their family members and this support can have an adverse effect on these carers.

There is significant literature detailing and exploring the effects of caregiver burden. A meta-analysis of this research, specifically relating to dementia caregivers, reported negative effects of caregiving including family conflict, reducing working hours, reduction in personal/social time and adverse effects on physical and mental health and finances (Brodaty, Green & Koschera, 2003). Adult child caregivers in particular are thought to be driven by external motivations, such as a sense of obligation, and this can result in feelings of loss of freedom and guilt, particularly, if they have other responsibilities such as children and a career (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch & Lopez-Pousa, 2010).

Despite care being provided by a variety of family members, much of the research in dementia focusses on carers in general, as opposed to focusing on specific members who may have specific needs. Furthermore, samples tend to be mainly female. One specific group that has not received much attention is working adult sons. Men are less likely to seek support, particularly when managing stress, and are also more likely to be isolated from social support when they are in paid employment (McKenzie, Collings, Jenkin & River, 2018). Men are also less likely to reduce their working hours than women and the most significant predictors of distress in adult child caregivers not living with their parent was the impact on schedule, health and finances (Wawrziczny, Duprez & Antoine, 2020). Given, the differences between men and women's experiences of caregiving, there is a paucity of literature pertaining to the experiences of working adult sons who are the primary caregivers for a parent living with dementia. One study has explored the experiences of adult sons. However, this noted that their participants tended to be 'care managers' involved in administrative and management tasks rather than primary caregivers (Grigorovich et al, 2015). A further finding was that sons were more likely to assume caring responsibility for their mothers than their fathers, an act described as 'reciprocity in kind' as a sense of obligation to repay the care they received as children (McDonell & Ryan, 2013). However, this study focussed on a purposeful sample of adult sons in rural Ireland, some of whom were farmers, and the authors acknowledge the limitations of the findings in terms of generalisability beyond the culture they were living in.

As there is a breadth of research exploring the experiences of caregivers and increasing research pertaining to adult caregivers, but a relative paucity of studies including solely the perspectives of working caregiving adult sons, the current study will focus on this group. As stated above, research has shown that having a career and spending time apart from the care recipient, due to career and children, can have adverse consequences on a caregiver's mental health and on feelings of guilt. However, there is no research to date that explicitly explores the experience of this cohort. Therefore, the aim of this study will be to explore the experiences of working adult sons caring for a parent living with dementia. It is hoped that findings may have useful clinical applications both in the understanding of a carer's perspective but also in the form of service delivery and support.

Method

Design

The proposed study is a qualitative design and I intend to use interpretative phenomenological analysis (IPA) methodolgy. IPA is concerned with participants' experiences of the world and meaning making in social interactions following a phenomenological event or significant life event (Antoine, Filinois, Nandrino, Dodin & Hendrickx, 2016). Furthermore, small sample sizes consisting of a well-defined homogenous group allow for a rich analysis of the data collected (Smith & Osborn, 2015) and therefore I propose to recruit 7-12 participants who are all working adult sons of people living with moderate stage dementia.

Data will be collected via individual semi-structured interviews which will be conducted over the phone or video call via Microsoft teams. The interview schedule was informed by input from an expert by experience who reviewed the document prior to submitting a final draft.

Participants

The aim will be to recruit 7-12 participants. The participants will be working sons ~~acting~~ who either currently or previously have acted as the primary caregiver for a parent living with moderate-stage dementia.

The inclusion criteria for participants will be as follows:

- Individuals over the age of 18, who are/were in employment and working at least 10 hours per week during their caregiving experience.

- Individuals who are male and ~~have been~~ have been or were the primary caregiver for at least 6 months for a parent who is living or lived with moderate stage dementia and was diagnosed after the age of 65.

- Individuals who speak English.

Being a primary carer for at least 6 months allows sufficient time to have passed for participants to have experienced what it is like to be a caregiver for their parent and for it to begin to influence their lives.

If the participant no longer provides care, their caregiving experiences must have been since March 2020 (to ensure that the experiences are easy to recall and that the social context will not have been substantially different). This will ensure that all participants will have cared during the COVID-19 pandemic.

According to the Functional Assessment Staging Test (FAST) scale (Reisberg, 1988), moderate stage dementia is defined as an individual who needs assistance with various activities of daily living including handling finances, travelling, planning events, cooking and choosing proper clothing. For this study, whether the family member is considered to be in a moderate stage of dementia will be determined by the caregiver's own report, that their parent needs help with these activities.

Those caring for (or who had previously cared for) parents with early onset dementia will be excluded (hence requiring age of onset to be 65). The rationale for not including those with a diagnosis of early-onset dementia is due to the methodology of IPA being concerned with a sample who have a homogenous experience and early-onset has a variety of confounding experiences which could potentially be different to an older parent experiencing dementia.

Recruitment

The study will involve purposive sampling through which a sample representing the specific cohort, i.e. working adult sons ~~caring~~ who are currently or who have previously cared for a parent living with dementia, will be recruited. There will be multiple stages to the recruitment process depending on how successful the initial stages are.

The first stage of recruitment will involve setting up an allocated social media research account to appeal for interested prospective participants. A poster will be disseminated (see appendix A) on social media with a brief description of the study and the inclusion criteria as well as contact details for the researcher (non-personal email). The second stage of recruitment, should insufficient eligible participants be identified, will be to circulate the poster to a local dementia and carer support group facilitated by Age UK, this will be circulated on behalf of myself by staff members who facilitate groups at Age UK. A further final stage will be to circulate the poster within the Service User Reference Forum (SURF) group. I will share the poster with a member of the group who will circulate it to the members

of the group. This group is comprised of people living with dementia and carers and is involved in dementia research and campaigns for improvements in rights for those living with the disease.
The researcher's details will be on the poster, and potential participants will be invited to contact the researcher in order to discuss their potential participation. Participants will be sent the information sheet once they have contacted the researcher and the consent form will be read aloud to them prior to commencing the interview. The information sheet and consent form will also be sent to participants to read in advance for information purposes.

Participants will be asked a range of demographics questions to ascertain their age, ethnicity, number of hours employed, job titles, living situation and whether they care for/cared for their mother or father and how often they currently or previously cared and what sort of care they provide/previously provided. This data will be used to ensure an even spread of demographics are represented within the sample, should more than the 7-12 participant be recruited for the study. Should there be too many potential participants, participants will be selected in a way which will represent a variety of job roles (this information will be collected when potential participants contact the researcher. If this is not possible, assuming all job roles are in similar sectors, they will be selected on a first come first served basis.

Data collection

Participants will be interviewed via telephone or via Microsoft Teams video call due to the ongoing unpredictability of the situation arising from covid-19. This is also due to the potential participants having regular contact with those in a particularly vulnerable group to the virus therefore physical contact would not be appropriate at this time.

Prior to the interview, participants will be asked to read an information sheet (see appendix B) which will be sent via email, and asked to verbally consent to participate (see appendix C for consent form) just before commencing the interview if they are comfortable to do so.

On the day of the interview, potential participants will be reminded of the information on the information sheet and they will be reminded of their right to withdraw from the study. Verbal consent will be sought before the interview commences. Consent will be recorded as a separate audio file.

After this the interview will commence (see appendix D for interview schedule).

It is anticipated that each interview will last approximately one hour, however, should more time be needed on the part of the participants a break will be offered or an alternative time and date will be negotiated. Following completion of the interviews, a debrief will be held in which the participant's welfare will be checked and space given for any questions to be asked. They will also be reminded of their right to withdraw their personal data (and the answers they have given in the interview) up to two weeks following completion of the interview. Participants will be redirected to the information sheet for the researcher's contact details should they have any questions they wish to have answered following their participation.

Analysis

Data will be analysed using IPA. To do this, interviews will be listened to and transcribed using the transcription function in Microsoft teams, this will then be quality checked and amended by the researcher to allow for full immersion in the data. After the data is transcribed the researcher will examine the transcripts one by one. First he will make notes and initial codes in the margin which will then be gathered into themes and super-ordinate themes, this will be repeated for each transcript and then the themes will be analysed across datasets as recommended by Pietkiewicz and Smith (2014).

Data Storage

All data will be stored in line with Lancaster University's policy. Audio files will be transferred from the device they are recorded (which will either be a camera recorder device with the lens closed or directly from Microsoft teams) on to a space on OneDrive or an equivalent cloud storage system approved by the university, as soon as is possible following completion of the interview. It will then be deleted from any external device. Audio recordings of the main interviews will be kept until the project has been examined and will then be deleted.

Any contact information will also be held in a password-protected file on the University server or on the researcher's OneDrive account until they are no longer needed to carry out the research, after which they will be deleted. If a participant wishes to receive a summary of the research, contact details will be retained until the summary is sent out and then will be immediately deleted. The raw data (transcripts) will be kept for 10 years in line with university policy. Furthermore, the contact details of those who are not selected to participate in the study will be deleted as soon as it is known that they are not needed anymore, only the contact details will be retained and will only be kept until they are no longer required following which they will be deleted.

Following completion of the research the data (transcripts and audio consent recordings) will be securely transferred to the Research Coordinator in the Lancaster Doctorate in Clinical Psychology for storage. Fiona Eccles and Clare Dixon, the research supervisors, will be the data custodians at this point. Data will be stored for a maximum of 10 years, or 10 years from data collection, whichever is the longer, after which the research co-ordinator will delete all data, under the direction of the research supervisors (Fiona Eccles and Clare Dixon).

Costs

There will be a cost, for participants, in terms of approximately one hour of their time. All efforts will be made to arrange the interview for a time that is appropriate for them. No financial reimbursement will be offered for their time which will be provided on an entirely voluntary basis.

Ethics

Pseudonyms will be used when writing up the study and the final report will not contain any identifiable data.

All participants will be informed prior to the commencement of the interview that should the researcher become concerned about any information which may suggest a risk to themselves or others then this will be shared with the research supervisors. They will also be informed that there may be a requirement for a further course of action if appropriate, however every attempt will be made to inform the participant of this prior to sharing this information.

The researcher and information sheet will acknowledge that the interview topic may be emotive and provoke a strong emotional response and that, although the researcher will try to remain sensitive to this, the participant can take a break or terminate the interview at any point should they feel uncomfortable. The participants will also be made aware that they do not have to answer any questions they find particularly difficult. Participants will also be informed that if they experience distress due to the interview, either during it or afterwards, they can contact the researcher or refer to the information sheet for signposting to access to further support.

Should a risk issue come up within the session, the researcher will try to contain the risk and signpost the participant to the appropriate service, whether this be GP or immediate crisis support pathway by advising them to attend their local Accident & Emergency department. The researcher will share this as soon as is possible with their supervisor and the participant will be made aware of this.

Timescale

October - December 2020

- Hand in and complete ethics form

January - March 2021

- Obtain ethical approval.

April - June 2021

- Draft introduction and method to Empirical paper
- Data collection
  - Begin analysis

July - September 2021

- Complete data collection

- Review literature for Systematic review

October - December 2021

- Complete analysis of data

March 2022

- Submit thesis

References

Antoine, P., Filinois, B., Nandrino, J., Dodin, V., & Hendrickx, M. (2016). Living as a couple with anorexia nervosa: A dyadic interprative phenomenological analysis. Journal of Health Psychology, 23(14), 1842-1852

Bjerre, L. M., Farrell, B., Hogel, M., Graham, L., Lemay, G., McCarthy, L., et al. (2018). Desprescribing antipsychotics for behavioural and psychological symptoms of dementia and insomnia. *Canadian Family Physician, 64*, 17-27

Brodaty, H., Green, A., Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of American Geriatric Society, 51*, 657-664.

Brunelle-Hamann, L., Thivierge, S., & Simard, M. (2015). Impact of a cognitive rehabilitation intervention on neuropsychiatric symptoms in mild to moderate Alzheimer's disease. *Neuropsychological Rehabilitation*, *25*(5), 677-707

Clay, A. D. (2018). The grief experience of spousal and adult child caregivers of individuals diagnosed with Alzheimer's disease or related dementias following facility placement. (Doctoral dissertation). Retrieved from https://search-proquest-com.ezproxy.lancs.ac.uk/docview/2213516447

Conde-Sala, J. L., Garre-Olmo, J., Turro-Garriga, O., Vilalta-Franch, J., & Lopez-Pousa, S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: an exploratory comparative design. *International Journal of Nursing Studies, 47*, 1262-1273.

Cunningham, E. L., McGuiness, B., Herron, B., & Passmore, A. P. (2015). Dementia. *Ulster Medical Journal*, *84*(2), 79-87

Grigorovich, A., Rittenberg, N., Dick, T., McCann, A., Abbott, A., & Kmielauskas, A. et al. (2015). Roles and Coping Strategies of Sons Caring for a Parent With Dementia. *American Journal Of Occupational Therapy*, *70*(1), 1-9

Lewis, F., Schaffer, S. K., Sussex, J., O'Neill, P., & Cockcroft, L. (2014). The trajectory of Dementia in the UK - Making a difference. Retrieved from Office of Health Economics website: https://www.ohe.org/publications/trajectory-dementia-uk-making-difference#

McDonnell, E., & Ryan, A. A. (2013). The experience of sons caring for a parent with dementia. *Dementia*, *13*(6), 788-802

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using Interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, *20,* 7-14

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., & Comas-herrera, A. (2014). Dementia UK: Update. Retrieved from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf

Reisberg, B. (1988). Functional Assessment Staging (FAST). *Psychopharmacology Bulletin, 24*, 653-659

Smith, J., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology on the lived experience of pain. British Journal of Pain, 9, 41-42.

Wawrziczny, E., Duprez, C., & Antoine, P. (2020). Predictors of caregiver distress among spouses, adult children living with the person with dementia, and adult children not living with the person with dementia. *Psychogeriatrics*. doi:10.1111/psyg.12553

Appendices

Appendix 4-A: Recruitment poster

Appendix 4-B: Participant information sheet

Appendix 4-C: Consent form

Appendix 4-D: Interview topic guide

Appendix 4-E: FHMRec application form

Appendix 4-F: FMHRec Ethics approval letter

Appendix 4-G: FHMRec ethics amendment approval confirmation

Appendix 4-A – Recruitment poster

Dementia carers needed for research…

Doctorate in Clinical Psychology | Lancaster University

Study title: ***Experiences of working sons caring for a parent with dementia***

Are you:

- Over 18?
- Male?
- In employment for over 10 hours per week?

Do you:

- Care for a parent with dementia who needs regular support?

What would you need to do?

- Take part in an interview which will last up to one hour where we will discuss your experiences of caring for your parent with dementia.

If you know of somebody who may be interested in this research, please forward this poster on.

If you would like to participate in this research, please contact me (Sam Hughes).

This research will form part of my Clinical Psychology training.

Contact: s.hughes5@lancaster.ac.uk

Supervisors: Dr Clare Dixon and Dr Fiona Eccles

Appendix 4-B – Participant information sheet

Doctorate in Clinical Psychology | Lancaster University

Participant Information Sheet

Experiences of working sons caring for a parent with dementia

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Samuel Hughes and I am conducting this research as a student in the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the experiences of working sons who are caring or who have cared for a parent with moderate-stage dementia. It is hoped that this study can give a clearer understanding of the unique experiences of working sons and help inform healthcare professionals about these to improve communication and care.

Can I take part?

I hope to interview men who currently work or have worked a minimum of 10 hours per week as well as caring for a parent with dementia who requires or required assistance with daily tasks such as handling finances, travelling, planning events, cooking, cleaning bathing and/or choosing proper clothing.

Do I have to take part?

No. It’s completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to agree to an interview to be held either over the phone or via video call using Microsoft teams. This interview may last up to one hour during which time you will be asked questions about your experiences of caring for a parent with dementia whilst also working.

How will my data be kept secure and confidential?

The data collected for this study will be stored securely and only the researchers and the research supervisors involved in this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been examined
- The files stored on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and stored on the Lancaster University secure drive in a password-protected file or in a secure University cloud storage space.
- At the end of the study, audio copies of you consenting to participate in the study will be kept securely on a secure Lancaster University server for up to ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- The typed versions of your interview will be kept on a secure Lancaster University server for up to ten years or ten years from publication, whichever is the longer.
- All your personal data will be confidential and will be kept separately from your interview responses.
- Following completion of the interview you will have up to two weeks to withdraw your data.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of the supervisory team about this. If possible, I will tell you when I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal however this is not guaranteed. The results of this study may be submitted to conferences and may be shared in presentations however data will remain anonymous. Participants may have a copy of the results if they wish.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the organisation/draw on the resources provided at the end of this sheet. If you experience any distress as a result of the process you may cease your involvement at any point or take a break during the interview should you think this would be beneficial for you.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Samuel Hughes
s.hughes5@lancaster.ac.uk

Research Supervisors:

Dr Fiona Eccles
F.eccles@lancaster.ac.uk 01524 592807
Health Innovation One|Sir John Fisher Drive|Lancaster University|Lancaster|LA1 4AT|UK

Dr Clare Dixon
c.dixon3@lancaster.ac.uk 01524 593492
Health Innovation One|Sir John Fisher Drive|Lancaster University|Lancaster|LA1 4AT|UK

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Ian Smith Tel: 07507857069
Email: i.smith@lancaster.ac.uk
Health Innovation One|Sir John Fisher Drive|Lancaster University|Lancaster|LA1 4AT|UK

If you wish to speak to someone outside of the Doctorate of Clinical Psychology Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
Health Innovation One|Sir John Fisher Drive|Lancaster University|Lancaster|LA1 4AT|UK

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

- The first line of support in seeking support for any feelings of distress or deterioration in your mental health should be to speak to your General Practitioner (GP) in order to get appropriate support.

- You may also find it beneficial to seek support from the following helplines which are freely available to access:

Samaritans: You can telephone Samaritans on 116 123. This helpline is available 24 hours a day, 365 days a year. You can also visit the Samaritan’s website for further information: http://www.samaritans.org/

Mind: Phone: 0300 123 3393 (Monday to Friday, 9am to 6pm)
Website: www.mind.org.uk

You may also find it beneficial to access the **Men's Health Forum.**
24/7 stress support for men by text, chat and email.
Website: www.menshealthforum.org.uk

Appendix 4-C – Consent form

Doctorate in Clinical Psychology | Lancaster University

Consent Form

Study Title: Experiences of working sons caring for a parent with dementia

We are asking if you would like to take part in a research project to explore the experiences of working sons who are caring or who have cared for a parent with moderate-stage dementia. It is hoped that this study can give a clearer understanding of the unique experiences of working sons and help inform healthcare professionals about these to improve communication and care.

At the start of the interview I will ask if you have read and understood the information sheet and consent to participate in the research. This process will be audio recorded and stored separately to the main interview.

1. **Do you confirm that you have read the information sheet and fully understand what is expected of you within this study?**

2. **Do you confirm that you have had the opportunity to ask any questions and to have them answered?**

3. **Do you understand that your interview will be audio recorded and then made into an anonymised written transcript?**

4. **Do you understand that audio recordings will be kept until the research project has been examined?**

5. **Do you understand that your participation is voluntary and that you are free to withdraw at any time without giving any reason, without your medical care or legal rights being affected?**

6. **Do you understand that once your data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract your data, up to the point of publication?**

7. **Do you understand that the information from your interview will be pooled with other participants’ responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project?**

8. Do you consent to information and quotations from your interview being used in reports, conferences and training events?

9. Do you understand that the researcher will discuss data with their supervisor as needed?

10. Do you understand that any information you give will remain confidential and anonymous unless it is thought that there is a risk of harm to yourself or others, in which case the principal investigator will need to share this information with their research supervisor?

11. Do you consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished or 10 years from data collection, whichever is the longer?

12. Do you consent to take part in the study?

13. Can you confirm your name and today's date? (Here, I will also confirm my name)

Appendix 4-D – Interview topic guide

Introduction: The aim of my research is to provide a greater understanding of the experiences of sons who care for a parent with dementia whilst also working a minimum of 10 hours per week. The interview should last no longer than an hour and will be recorded using (Microsoft teams/a camera with the lens closed). Only audio will be recorded.

I am interested in your experiences and in your own words. As such there are no right or wrong ways to answer these questions, just answer them in a way that fits your individual experience. I will now check you have read the information sheet and consent form and ask if you have any further questions or are happy to proceed.

Introduction to the initial questioning:

I will start the questions by asking some initial questions about the participants experience to help build rapport and attempt to make the space feel comfortable and safe. I will ask for how long their parent has had a diagnosis of dementia, how long have they had caring responsibilities for their parent and have these caring responsibilities changed over time. I will also ask them to tell me a little about their mum/dad as recommended by an expert by experience to build rapport.

Core interview Question:

I will then ask the core interview question ‘Can you tell me about your experiences as a working son caring for a parent with dementia?’

Prompts:

<u>Personal experiences of caring:</u>

Can you tell me a little about your mum/dad?

Why did you become your parent’s primary caregiver?

What do you do for your parent?

Could you tell me about some of the decisions you have to make with, or on behalf of, your parent in your role as carer?

<u>Practical experiences of caring/support from others:</u>

Can you tell me about any support you have received in this role? (e.g from friends/family/services)

Could you tell me about your experiences of the healthcare system?

Have you had any formal support to help you with your role as caregiver?

Do you think you would have benefitted from formal support to help you cope with your role? (e.g psychological support), if so how

<u>Experiences of working and caring:</u>

Could you tell me about your experiences of working and caring for your parent?

How has your employer responded to your caring responsibilities, are they aware?

What challenges have you experienced in this role?

What challenges have you faced being a working man and caring for your parent?

Has work interfered in your caring responsibilities? If so, how did you manage this?

How do you feel your role is perceived by others?

Has your role had an impact on your life, work or relationships? If so how and how have you managed this?

<u>Outcomes of caring:</u>

What has helped you cope with any challenges you have experienced?

Have you learned anything from being in this role?

Has this role changed your life in any way? If so, how? If not, why do you think it has not?

Final questions

Is there anything you feel we have missed in our discussion today?
Do you feel we have captured your experiences of being a working son caring for a parent with dementia?
Have you got any final thoughts to add?

Is there anything you think I may have missed? Or is there a good question you think I could ask in the future to learn more?

Following this, I will thank participants and ask if they have any further questions. I will inform them that should they have any further questions after the interview they can refer to the information sheet and if this does not answer them they may wish to get in contact with myself. Contact details can be found on the information sheet.

Appendix 4-E – FHMRec application form

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

for additional advice on completing this form, hover cursor over 'guidance'.

Guidance on completing this form is also available as a word document

Title of Project: Experiences of working sons caring for a parent with dementia

Name of applicant/researcher: Samuel Hughes

ACP ID number (if applicable)*: **Funding source (if applicable)**

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychology, Doctorate in Clinical Psychology

2. Contact information for applicant:

E-mail: shughes5@lancaster.ac.uk **Telephone**: 07916094137 (please give a number on which you can be contacted at short notice)

Address: Clinical Psychology – Division of Health Research, Faculty of Health & Medicine

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster

LA1 4AT

3. **Names and appointments of all members of the research team (including degree where applicable)**

Dr Fiona Eccles, Lecturer (Lancaster Doctorate in Clinical Psychology)
Dr Clare Dixon, Clinical Tutor (Lancaster Doctorate in Clinical Psychology)
Dr Sarah Butchard (Clinical Psychologist/lecturer, Merseycare NHS Trust/Liverpool University doctorate in Clinical Psychology – Field supervisor)

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant:

Dr Fiona Eccles
Dr Clare Dixon
Dr Sarah Butchard

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:

Fiona Eccles, Lecturer
Clare Dixon, Clinical Tutor

(Lancaster University Doctorate in Clinical Psychology)

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' no

4c. If yes, where relevant has permission / agreement been secured from the website moderator? no

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? no

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? no

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

The study will explore the experiences of sons who have cared for a parent with dementia when they were/are also in paid employment. The study will focus on those who have previously cared for or currently care for a parent with dementia who requires assistance with daily activities such as cleaning, bathing, cooking and managing money. I will interview adult sons about their experiences by asking them questions and allowing a conversation to flow around that topic. I will ask about how their lives have been impacted by their caring experiences as well as their relationships, identities and work experiences. It is hoped that this study will give a clearer understanding of the experiences of employed sons in the context of them being a primary caregiver for a parent with dementia.

2. **Anticipated project dates (month and year only)**

Start date: January 2021 End date March 2022

Data Collection and Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

The aim will be to recruit 7-12 participants. The participants will be working sons acting/who have acted as the primary caregiver for a parent who is living/or lived with moderate-stage dementia.

The inclusion criteria for participants will be as follows:

- Individuals over the age of 18, who are/were in employment and working or worked at least 10 hours per week.

- Individuals who are male and are/were the primary caregiver for at least 6 months for a parent who is living or lived with moderate stage dementia and is over 65 years old.

- Individuals who speak English.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

The study will involve purposive sampling through which a sample representing the specific cohort, i.e. working adult sons caring for a parent living with dementia, will be recruited. There will be multiple stages to the recruitment process depending on how successful the initial stages are.

The first stage of recruitment will involve setting up an allocated social media research account to appeal for interested prospective participants. A poster will be disseminated (see appendix A) on social media (e.g twitter, facebook and Instagram) with a brief description of the study and the inclusion criteria as well as contact details for the researcher (non-personal email). The second stage of recruitment, should insufficient eligible participants be identified, will be to circulate the poster to a local dementia and carer support group facilitated by Age UK, this will be circulated on behalf of myself by staff members who facilitate groups at Age UK. A further final stage will be to circulate the poster within the Service User Reference Forum (SURF) group. I will share the poster with a member of the group who will circulate it to the members of the group. This group is comprised of people living with dementia and carers and is involved in dementia research and campaigns for improvements in rights for those living with the disease.

The researcher's details will be on the poster, and potential participants will be invited to contact the researcher in order to discuss their potential participation. Participants will be sent the information sheet once they have contacted the researcher and the consent form will be read aloud to them prior to commencing the interview. The reason for having this tiered approach to recruitment is to have a larger potential sample of participants initially in order to obtain participants who are less tied to organisations but represent a typical caregiving experience. The latter tiers are more focused methods of recruitment and it is predicted will yield more successful results for recruitment however will be of those who have links to organisations that provide support and so their experience may be influenced by this.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Participants will be interviewed via telephone or via Microsoft Teams video call due to the ongoing unpredictability of the situation arising from covid-19. This is also due to the potential participants having regular contact with those in a particularly vulnerable group to the virus therefore physical contact would not be appropriate at this time. Data will be analysed using IPA due to IPA being concerned with the meaning making of homogenous groups it is felt that this will be the most appropriate method of analysis. To do this, interviews will be listened to and transcribed verbatim by the researcher to allow for full immersion in the data. After the data is transcribed the researcher will examine the transcripts one by one. First he will make notes and initial codes in the margin which will then be gathered into themes and super-ordinate themes, this will be repeated for each data set and then analysed for relationships between data sets to explore and to identify themes emerging across the interviews as recommended by Pietkiewicz and Smith (2014).

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

All data will be stored in line with Lancaster University's policy. Audio files will be transferred from the device they are recorded (which will either be a camera recorder device with the lens closed or directly from Microsoft teams) on to a password-protected file on the researcher's personal file space on the University server or to a space on OneDrive or an equivalent cloud storage system approved by the university, as soon as is possible following completion of the interview. They will then be deleted from any external device.

The reason for some interviews potentially being recorded on a camera recorder device is to allow for those who cannot access Microsoft teams to still participate via telephone, this data will be immediately transferred to the University approved cloud storage server following completion of the interview.

Any contact information will also be held in a password-protected file on the University server or on the researcher's OneDrive account until they are no longer needed to carry out the research, after which they will be deleted. If a participant wishes to receive a summary of the research, contact details will be retained until the summary is sent out and then will be immediately deleted.

Following completion of the research the data (transcripts and audio consent recordings) will be securely transferred to the Research Coordinator in the Lancaster Doctorate in Clinical Psychology for storage. Fiona Eccles and Clare Dixon, the research supervisors, will be the data custodians at this point. Data will be stored for a maximum of 10 years, or 10 years from publication, whichever is the longer, after which the research co-ordinator will delete all data, under the direction of the research supervisors (Fiona Eccles and Clare Dixon). Prior to this transfer, data will be stored on a secure university server or on a secure university cloud storage.

7. Will audio or video recording take place? ☐ no ☒ audio ☐ video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

Audio files will either be recorded from Microsoft teams which will be transferred immediately to University secure cloud storage or via a camera on to an SD card which will be placed into a laptop and transferred immediately to the secure University server to a password protected file. Any remaining files on devices which are encrypted or not encrypted will be immediately deleted when the data is securely transferred. Following the recording being made available by teams it will be converted to an audio file immediately so that no video footage is being stored.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Following completion of the research the audio consent recordings will be securely transferred to the Research Coordinator in the Lancaster Doctorate in Clinical Psychology for storage. Fiona Eccles and Clare Dixon, the research supervisors, will be the data custodians at this point. Data will be stored for a maximum of 10 years, or 10 years from publication, whichever is the longer, after which the research co-ordinator will delete all data, under the direction of the research supervisors (Fiona Eccles and Clare Dixon). Audio interview data will be secured on the secure university server in a password-protected file or on the secure cloud and these will be deleted after the viva voce examination.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

Data (written transcripts and any accompanying notes) will be stored by the research coordinator of the DClinPsy under the direction of the supervisors Clare Dixon and Fiona Eccles

8b. Are there any restrictions on sharing your data?

Given the sensitive nature of the data, data will not be routinely shared and will not be publicly available. It will be made available to genuine researchers on request to the research supervisors, Clare Dixon and Fiona Eccles. Quotations from the interview may be shared with consent from the participants to which they belong.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Prior to the interview, participants will be asked to read an information sheet (see appendix B) which will be sent via email and read a consent to participate form (see appendix C) if they are comfortable to do so. The consent form will be sent to participants just for information purposes, however, they will give consent verbally. On the day of the interview, the information will be relayed back to the potential participants and they will be reminded of their right to withdraw from the study and verbal consent will be taken. Consent will be recorded as a separate audio file prior to commencing the interview.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

The researcher and information sheet will acknowledge that the interview topic may be emotive and provoke a strong emotional response and that, although the researcher will try to remain sensitive to this, the participant can take a break or terminate the interview at any point should they feel uncomfortable. The participants will also be made aware that they do not have to answer any questions they find particularly difficult. Participants will also be informed that if they experience distress due to the interview, either during it or afterwards, they can contact the researcher or refer to the information sheet for signposting to access to further support. Participants may withdraw their data from the study up to two weeks after completing the interview, this is due to the methodology of IPA being used as after this point the analysis will have commenced. It would be potentially difficult to remove data once the analysis process has begun so this gives some time between completion of interview and start of analysis for participants to consider their involvement.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

Should a participant experience significant distress during the phone call due to the emotive nature of the topic being discussed I will discuss this with my supervisors to ascertain an appropriate course of action. I will contact my supervisor following attempts to contain the participant during the interview and upon completion of the phone call, I will make it clear to the participant that I will contact them back as soon as I have spoken to my supervisor regarding the situation. I will also inform the participant of relevant pathways and signposting should it be necessary and appropriate.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There may be no direct benefit to participants in this study however they may find it beneficial to share their experiences.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

No payments will be offered to participants.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Pseudonyms will be used when writing up the study and every effort will be made to try to ensure that the final report will not contain any identifiable data however this cannot be guaranteed due to the nature of the experience being researched.

All participants will be informed prior to the commencement of the interview that should the researcher become concerned about any information which may suggest a risk to themselves or others then this will be shared with the academic supervisors. They will also be informed that there may be a requirement for a further course of action if appropriate, however every attempt will be made to inform the participant of this prior to sharing this information. This further course of action would depend on the situation and the recommendations of my supervisors.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

An expert by experience who is a working son caring for parent with dementia was consulted for their advice on the information sheet, consent form and interview schedule. Their input was considered and led to alterations being made to the interview schedule and reassurance that the information sheet and consent forms made sense in the context of the study.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The results and findings of this research will be shared with Lancaster University Doctorate in Clinical Psychology programme and will be collated to produce an academic thesis.

The findings may also be submitted for publication in an academic journal however publication cannot be guaranteed.

Findings may also be presented at appropriate conferences, special interest groups and meetings.

Participants will be sent a copy of findings if they wish this. These will also be sent, should they be wanted, to the organisations who help with recruitment for the study and experts by experience who assisted in the design of the research.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

No.

SECTION FOUR: signature

Applicant electronic signature: Samuel Hughes Date 03.10.2020

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review ☐

Project Supervisor name (if applicable): Date application discussed ☐

Dr Fiona Eccles ***14.10.2020***

Dr Clare Dixon ***16.10.2020***

Submission Guidance

1. Submit your FHMREC application by email to Becky Case (fhmresearchsupport@lancaster.ac.uk) as two separate documents:
    - i. **FHMREC application form.**
      Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
    - ii. **Supporting materials.**
      Collate the following materials for your study, if relevant, into a single word document:
        - a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
        - b. Advertising materials (posters, e-mails)
        - c. Letters/emails of invitation to participate
        - d. Participant information sheets
        - e. Consent forms
        - f. Questionnaires, surveys, demographic sheets
        - g. Interview schedules, interview question guides, focus group scripts
        - h. Debriefing sheets, resource lists

   Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:
    - i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to Becky Case **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
    - ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:

   a. existing documents/data only;
   b. the evaluation of an existing project with no direct contact with human participants;
   c. service evaluations.

3. **<u>You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application</u>**

Appendix 4-F – FMHRec Ethics approval letter

Applicant: Sam Hughes
Supervisor: Fiona Eccles, Claire Dixon, Sarah Butchard
Department: DHR FHMREC
Reference: FHMREC20037
21 April 2021
Re: FHMREC20073
Experiences of working sons caring for a parent with dementia

Dear Sam, Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project. As principal investigator your responsibilities include: - ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained; - reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress); - submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.
Please contact me if you have any queries or require further information.
Email: fhmresearchsupport@lancaster.ac.uk
Yours sincerely,

Dr. Elisabeth Suri-Payer

Research Ethics Officer,

Secretary to FHMREC

Appendix 4-G – FHMRec ethics amendment approval confirmation

FHM-2022-2121-AmendPaper-1 The experiences of working sons caring for a parent with dementia

Dear Sam Hughes,

Thank you for submitting your ethics amendment application in REAMS, Lancaster University's online ethics review system for research. The amendments have been approved by the FHM REC.

Yours sincerely,

Faculty Research Ethics Officer on behalf of FHM