

Abstract

Supporting a parent with dementia living in their own home is a challenging care issue which has potential for negative physical, emotional and psychosocial impacts. This research explores the experiences of adult daughters who sustain this arrangement as well as managing the competing demands of their lives. Using a qualitative approach, semi-structured interviews were conducted between March and October 2017. Eight adult females in the UK who were supporting a parent with dementia to remain living in their home were interviewed. Photo-elicitation was used as an aid to data collection and complemented the use of Thematic Analysis (TA) to analyse verbatim transcripts. Four themes were identified: (1) *Impact on identity*: impact of the participants' experience on their sense of identity; (2) *Continuity and change*: relationship re-definition and duality of roles; (3) *Stepping up to the challenge*: adjustment to and coping with competing demands and ethical dilemmas; and (4) *Finding help: "It's just a minefield"*: experiences of help-seeking and service provision. This study highlights the experiences and challenges for adult daughters who support a parent with dementia. Ethical dilemmas regarding autonomy and safeguarding concerns figure large along with the competing demands of multiple roles. Service providers should aim to be more proactive in offering timely practical and psychosocial support and guidance to avoid compassion fatigue and acknowledge the valuable unpaid service provided by these 'women in the middle'.

Key words: informal caregivers; dementia; qualitative; psychosocial impact of caregiving; community dwellers

What is known about this topic.

- Informal caregiving for people with dementia who live in their community is a global concern.
- Female adult daughters predominantly take on the informal caregiving role for a parent.
- Dementia caregiving impacts physical and psychosocial health of the caregiver.

What this paper adds.

- Distinct challenges were noted for adult daughters who take on this role relating to psychological impact of responsibility and inter-role conflict.
- Additional ethical and safeguarding concerns compounded the distress for the informal adult daughter caregiver.
- This paper highlights the inadequacies of healthcare services in addressing the distinct needs and supporting the informal community caregiver.

Main text

Introduction

Worldwide evidence suggests that most people with dementia live in the community and their primary support is from their families, thus the dependency on informal community care is increasing (Eccleston et al., 2019).

About ten percent of the British population are known to be informal caregivers (White, 2013). We recognise that there are multiple views and debates concerning the term ‘informal carer’; in line with Totsika and colleagues (2017), we view informal carers as people who provide unpaid care to relatives, friends or partners who are disabled or have a long-standing

illness or condition. Informal caregivers provide an invaluable service, and it has been suggested by Buckner and Yeandle (2011) that the economic value of informal caregiving exceeds the overall annual budget of the entire UK health system.

In the UK, there are an estimated 850,000 people with a diagnosis of dementia, two thirds of whom live in their own homes (Dawson et al., 2015). Many are enabled to remain at home because of their informal caregiver support. Whilst informal caregiving makes a positive contribution to the health system and to the individuals receiving the care, the psychosocial and physical health of the caregiver is negatively impacted (Sörensen & Conwell, 2011). The combination of dementia-related cognitive impairment and behavioural problems exacerbates this impact (Brodaty & Donkin, 2009; Dupuis, 2002; Ory et al., 1999)

Dementia caregiver burden is moderated by characteristics of the care recipient, the care situation, coping style and social support (e.g. Sörensen & Conwell, 2011). Furthermore, care experiences vary according to age, gender and the caregiver-care recipient relationship (Chappell et al., 2015; McKibbin et al., 1999). For example, negative psychological effects may be exacerbated for adult children caring for elderly parents due to other family and work demands (Gordon et al., 2012; Peacock et al., 2020; Stephens et al., 2001). Research has shown that daughters most commonly support their ageing parents, whereas sons generally become involved only in the absence of an

available female sibling (Giusta & Jewell, 2014; Hoff, 2015). Explanations for this include gender and cultural norms which affect daughters and sons differently (Haberkern et al., 2015).

Consequently, it has been noted how inter-role conflict is especially associated with daughters who take on this responsibility, and who are often referred to as “women in the middle” (Brody, 1981). This term alludes to the challenge of juggling multiple roles, including partnerships, parenting and working; often in a socio-cultural climate of ambivalence and expectation (Aneshensel et al., 1995; Horowitz, 1985; Stephens & Franks, 1999). Similarly, recent research which explores the phenomenon of compassion fatigue confirms distinct challenges facing adult daughters who support a parent (Day et al., 2014).

A recent meta-analysis of what works to support people with dementia living at home highlighted a failure to focus on perspectives and experiences of informal carers (Dawson et al., 2015). Sustaining and supporting people with dementia to remain living at home is a challenging care issue for both formal and informal carers which raises ethical dilemmas of how to balance the autonomy of a person with their safety and well-being (Lord et al., 2015; Smebye et al., 2016). These dilemmas impact particularly on the adult daughter experience (Giusta & Jewell, 2014; Hoff, 2015).

Using a qualitative approach, this study explored the experiences of adult daughters who were providing informal care for a parent with dementia. The aim was to better understand a) how daughters navigated the competing

demands of their situation and b) their perception of the impact of this role on their physical and psychological well-being.

Method

Participants and recruitment

Eight adult daughters of a parent with dementia were recruited opportunistically through the first author's personal contacts and gatekeepers in the health and social care sector. Following eight interviews no new themes were identified and recruitment ceased (Braun & Clarke, 2013, p 55). All participants met the criteria: adult daughter who was supporting a parent with dementia to live at home. All participants lived separately to their parent. One parent was male, and all were aged between 69 and 95 years. Three of the participants had additional paid home care support arrangements in place for their parents, which included personal care, medication and meal assistance. At the time of interview their caregiving roles were ongoing and had lasted for a minimum of 12 months. See table 1.

TABLE 1 HERE

Design

Data collection employed semi-structured interviews and photo-elicitation. Photo-elicitation is a research method which uses photographs to encourage comments from participants about the issue being studied. Previous studies

using this combined approach have noted the benefits in terms of empowering the participants and facilitating the narrative (Bates et al., 2017; Burton et al., 2017; Meo, 2010; Williams et al., 2014). In this study participants were invited to take photographs that represented their informal carer experience. Their photographs were not analysed in this study but were used to elicit and stimulate participants' narrative about their experiences. See figure 1 for some examples of the photographs taken.

Procedure

Ethical approval for this study was granted by [anonymised while being reviewed for publication] University Ethics Committee. Participants were sent information sheets and gave written consent to be interviewed and audio-taped prior to interviews. Prior to the interview, they were invited to take and submit electronic copies of between three and six photographs which represented their experience prior to the interview.

A semi-structured interview schedule was developed guided by thematic analysis recommendations and previous research (see table 2). The first author then conducted the semi-structured interviews. Each participant was given a document containing debrief advice and suggestions for accessing support. The interviews were recorded digitally and later transcribed verbatim and anonymised for the purpose of analysis.

TABLE 2 HERE

Analysis

Transcripts were analysed using inductive Thematic Analysis. This involves identifying, analysing, and reporting patterns or themes across a data set (Braun & Clarke, 2006). Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data (Braun & Clarke, 2006). The inductive approach to the analysis ensures that the themes identified are strongly linked to the data themselves (Patton, 1990).

The analytical steps recommended by Braun and Clarke (2006) were followed. The cyclical process of analysis involved immersion in the data by the first author reading and re-reading the transcripts, searching for patterns, noting semantic content and following a coding process. The second author independently analysed the transcripts. Notes were confirmed between the two authors, themes and sub-themes identified, and after further careful interrogation of the data, the final overarching themes were agreed upon.

Findings

Prior to presenting the themes, in order to provide context we briefly describe the types of photographs participants chose to represent their experiences.

Participants wanted to show their motivation to care as well as the impact of the caring role. Photographs of phones and washing machines symbolised the strain of their caregiving role as they tried to manage constant phone calls and additional domestic chores. Keys, locked doors and medication dosette boxes represented their safeguarding concerns. Old and current family photographs were included to symbolise the importance of family.

Four key themes were identified: *Impact on identity*, *Continuity and change*, *'Stepping up to the challenge'* and *Finding help: 'It's just a minefield'*. The themes and associated sub-themes are summarized in table 3.

TABLE 3 HERE

1. *Impact on identity*

This theme characterizes the physical and psychological impact of the participants' experience on their sense of identity. They all described a range of emotions as they tried to make sense of and manage the changing relationship and the competing demands of their lives.

1.a. I'm not just mum's carer

The unremitting nature of their supportive role took its toll. Participants described '*constant little things*' (Abigail) which impacted on their physical health and their sense of personal identity, often leaving them feeling disempowered. Maintaining a sense of self separate from the caring role was important to them all. For example, Karen described how work 'protected her identity from being reduced to that of carer':

'...so I'm not just mum's carer, I'm a teacher. Umm, I think part of my identity as well is that I'm a wife, I'm a mother and trying to support all those things'. (Karen)

Misty reflected on her self-identity when contemplating the difficulty she experienced reconciling her response to her mum's changing dementia-related behaviour. Her pre-morbid relationship with her mum was difficult and as a child, she had built a protective wall around herself: *'because emotionally she could be quite hurtful'* (Misty):

'And while my wall was down a little bit I didn't know what to do with it because it's not me, it's not me and my mum'. (Misty)

The metaphoric 'wall of defence' highlights Misty's vulnerability as she tries to protect herself from emotionally reacting to her mum. Tentatively allowing an empathetic response when her 'wall was down' challenged her own sense of identity and the only relationship with her mum that she had ever known. This highlights the ways in which former relationships can impact on the caring role.

1.b. I'm almost her parent

Finding themselves in a relationship where the parent-child role had over time gradually and irrevocably reversed resulted in an overwhelming sense of sadness and loss. In particular, participants who had previously had a strong bond with their mum missed the emotional relationship they once had. The loss of opportunity to confide and be supported themselves was mourned:

'Well, people go to their mum for support and advice and we've always had quite a good relationship, an emotional relationship, and that's just gone'. (Abigail)

Nostalgic reflections generated profound feelings of loss. For example, Abigail was angry and felt [dementia] had '*taken even more away*' of her mum leaving her with an exaggerated sense of loss.

The participants found the shift in roles '*tough*' (Misty) and indicative of major change as they tried to make sense of their new life. One participant reflected on how her role had changed not only to that of a parent but also in a more complex way which required sensitive management:

'... I'm almost her parent but also the person trying to make sure she's got the best life she can have and it's not sometimes ... so it's an advocate role rather than a daughter role'. (Karen)

1.c. Trying to get the balance

It was difficult at times for the participants to '*juggle*' (Abigail) their responsibilities which included working and family life as well as supporting their parent and this impacted on their sense of self. For those without the support of others, '*trying to get the balance*' (Karen) was more challenging. They often had to make major adaptations to their own life in order to find time for their supportive role. Many of these adaptations had significant consequences, practically, emotionally, physically and financially. For example, Karen was forced to reduce her working hours:

'One of the things that I did quite early on was to give up full time work and go part-time because trying to do the things that were needed, umm, it was impossible. Trying to balance the responsibility

there [work] with the responsibility of looking after mum, was just, well it made me ill'. (Karen)

Trying to get the balance right was difficult. There was a sense that participants became more overwhelmed as time went on. Libby described being “*totally out of her depth*” and of things “*spiralling out of control*”.

2. *Continuity and change*

Participants spoke of managing the parallel nature of their relationship with their parent. First there was the established ongoing relationship, but at the same time, the fluctuating nature of their changing role within that. However, this balancing act did have some positive aspects for some who discovered unexpected benefits, personal resilience and ways to manage.

2.a. Not the person that I know at all

The participants described progressive changes in their parent and the impact of this on their relationship which they struggled to reconcile. This often left them feeling ‘*uncomfortable*’ (Misty) with behavioural changes and suggested not only a sense of embarrassment at how their parent may present to others but also noting their own emotional responses:

‘Yeah, it irritates me [if she giggles]. Umm, and that just signifies mum’s childlike behaviour that’s coming through ... and that’s not my mum’. (Misty)

Examples of duality can be seen in the way some participants respond to their changing relationships. Assuring themselves that their loved one is ‘*unrecognisable*’ or ‘*gone*’ (Abigail) and yet applying their current thinking and behaviour to the pre-morbid parent.

Although some of the participants struggled to accept the changes in their parent, others were able to appreciate the continuing features which represented an emotional bonding separate from established roles. One participant described how the ‘new’ relationship allowed her ‘*a massive amount of [emotional] closure*’ following their earlier relationship which was not always ‘*smooth sailing*’. (Karen):

‘It’s like we love each other because we know each other rather than because we have to. Does that sound a bit...[?]? I don’t know. And we spend a lot of time laughing and a lot of time relating as women’.

(Karen)

Despite the struggle to reconcile the dementia-related change in their loved ones, some of the participants supporting their mother could appreciate a bond of female unity which transcended family roles and former attachments.

2.b. My life is different

The participants described a number of ways in which their lives were different. One felt her life had changed ‘*ten-fold*’ (Libby) since her mum’s dementia had deteriorated. Others described the change as rendering their parent as ‘*unrecognisable*’ (Misty). For the participants who did not have any

external formal support (for example from a care agency), this meant additional worry and daily contact to check on their parent's welfare. This extra burden weighed heavily and triggered complex responses to their situation. For example, Carolyn noticed that she began to resent the obligations imposed by the carer role, and then felt guilty for feeling resentful:

'So, you're at times tied up with going there and then you feel guilty thinking, oh God I begrudge going'. (Carolyn)

Similarly, Kath said *'we don't really have one [life]'* as she described the twice daily visits as being *'like running two homes'*. (Kath).

Whilst acknowledging their lives were *'not normal anymore'* (Libby), some participants were able to find comfort in maintaining previous routines, such as shopping and trips out in the car, which represented continuity of their former lives.

2.c. Stronger for it

Despite the rigours of the supporting role, participants were able to identify positive aspects which made them feel stronger, wiser and more resourceful as they navigated their changing lives. They shared the benefits of spending more time with their parent. Pre-diagnosis, visiting parents was a habit, however, the diagnosis made the time spent together tangibly different:

'So for me it's nice I'm spending more time with my dad, umm, than before when I just went round once a week and it just became something I did'. (Juliette)

As the dementia progressed some participants spoke of the need for them to become more involved in their parents' personal care. This was a difficult shift in role, which was approached with reluctance at first, followed by surprise at their own ability to take on the extra duties. For example, Karen spoke about how she would never have thought she was capable of taking on such a role, but with hindsight felt that supporting her mum had left her feeling '*stronger for it*'. (Karen).

The informal carer experiences were complex, illustrated by the apparently paradoxical nature of a role that left them feeling '*exhausted*' (Jess) but which also empowered them:

'...it's quite exciting and exhilarating but it's terrifying at the same time'. (Karen)

3. Stepping up to the challenge

Participants were worried about the future and how they would navigate the practical and ethical dilemmas they now faced. Issues of safeguarding whilst maintaining their parents' autonomy for as long as possible was a challenge. Additionally, trusting formal care providers was a big concern; caution and anxiety were common.

3.a. What are we going to do?

All participants described practical dilemmas (e.g. parents leaving appliances on and doors unlocked) which led to fears about the current (and future) safety and well-being of their parents, which in turn left the participants feeling guilty and anxious:

'You do feel really guilty locking your dad in, but it's something you have to do'. (Juliette)

The pervading sense of responsibility reflects the impact on their psychological well-being. Even when protective behaviours could be justified, a residual sense of guilt remained.

Future care management was a major concern as participants worried about the impact of the deterioration of their parent's dementia. One participant wondered *'at what point do you make that [formal care] decision?'* (Jess). Another became emotional when she described how she was *'petrified'* and *'absolutely dreading'* what the future might bring. (Abigail):

'So that's a big worry too. What are we going to do? We know that's coming but how's that going to work out?' (Jess)

3.b. It's not my decision it's hers

Difficult decisions sometimes had to be made which often created conflict and compromised their parent's sense of autonomy. Whilst some participants saw this as an opportunity to *'step up to the challenge'* (Jess), others found the dilemma more complicated:

'We keep her at home because she won't go in a [residential] home and she's adamant. And you don't like leaving her and I feel really really bad'. (Kath)

The dilemma was challenging because it required participants to make decisions based on their parents' wishes whilst recognising their parents' changing cognitive capacity. Further layers of complexity were added when

issues relating to the care and financial arrangements for their parent caused conflict as they grappled with the idea of decision-making by proxy:

'I'm making that [financial] decision for her because I know she's not able to. But I know I'm doing it for the right reasons'. (Misty)

Highlighting the dissonance of her position one participant openly reflects:

'Where are my mum's rights?'. (Karen)

3.c. Trusting others

A continuing dilemma for the participants was the need to trust outside agencies to help with the care support arrangement. Those who already had formal care in place valued the homecare workers and recognised how this support gave them *'breathing space'* (Karen), and an opportunity to retain a sense of identity. Those considering care options were more cautious and anxious about the suitability of an arrangement which allowed *'strangers coming in'*. (Juliette)

It is possible that a reluctance to trust others related to the difficulty in partly relinquishing their involvement in the first place and again highlights the complex emotions involved for the participants. This was a highly emotive topic for one participant who recognised that her pre-existing good relationship with her mum allowed her to see beyond behaviour which could be labelled difficult. Kath was concerned that a stranger without an emotional connection could provide a lower standard care. For this reason she disclosed a firm distrust of outside agency care:

'Because I think what we've seen on television. I don't think I could settle not knowing if someone was abusing my mum ... because they will. I mean I know how I feel. I would never hurt ... never, never, never ..., but I can imagine a stranger thinking, oh for God's sake woman, shut up.' (Kath)

4. *Finding Help: "It's just a minefield"*

For those participants who had sought external support, or who were in the process of doing so, the experience was frustrating. Finding time and emotional energy to seek formal support was difficult; all participants were coping with the dual responsibility of running their lives and providing support for their parent. None had had help to find formal support, nor guidance for how to access it. Once they had reached out for support, their frustration mounted and they felt that they were 'going round in circles'.

4.a. Nobody's reached out

Participants often felt '*undervalued*' (Misty) and '*let down*' (Libby) by supporting services. They felt that they were '*not being listened to*' (Misty). Inadequate signposting to services required them to '*do loads of research*' (Libby) which was confusing and exhausting when they simply wanted answers to their questions:

'Yeah, I think people should come and say to you, you know, show you different things like a nursing home, like a warden-controlled flat, what different options there are. Can she go in any of them because

she's got dementia? I don't know. There are a lot of questions to be asked'. (Carolyn)

Quests for help also focused on siblings. Some participants spoke of their central role in the care arrangement and felt that family members were not helping as much as they might. This caused resentment and sometimes resulted in former parental attachment arrangements being explored and current roles dissected. For example, participants described *'not feeling supported'* (Abigail) and having *'arguments'* (Carolyn) with siblings regarding their role in the care arrangements. Karen highlighted a more complex resentment as she described how she felt her brother, who was always the *'blue-eyed boy'*, failed to confront the care situation and continued to *'bury his head in the sand'*.

4.b. Going round in circles

The process of seeking help in addition to the already competing demands of their life, left participants feeling helpless and stressed:

'Ringin' up when you haven't got time to be on the phone every day, you know'. (Jess)

Seeking extra help took time away from their other roles and further impacted on their psychological wellbeing:

'It's hard work mentally, you know, you're sat at a phone and while you're sat at a phone you're not doing your job at work are you? You're not looking after your parent who needs care, you're on the

phone and you're coming off stressed, so it just doesn't do you any good does it really? You're just going round in circles'. (Juliette)

Metaphors were commonly employed to emphasise a sense of helplessness as they described *'bobbing along underneath'*, getting *'knocked down'* and *'knocked into oblivion'* whilst trying to navigate support and guidance. (Juliette)

Discussion

This study explored the impact of the experiences of daughters as caregivers and supporters of parents with dementia. Although these processes were unique for each participant, shared features and similarities were evident.

Accounts note the physical and psychological impact of their role, in particular the overwhelming sense of responsibility they all felt. The impact related to their own personal identity as well as the identity of their relationship with their parent. Indeed, the concept of shared identities has been noted in the family caregiving context, which describes the difficulty in separating disruption to the self from that of close others (Hasselkus & Murray, 2007). The prevailing sense of burden in these accounts was often related to the inter-role conflict experienced whilst trying to balance the demands of their supporting role with other roles as mothers, wives, and, as one participant suggested, advocate. Furthermore, they had all taken primary responsibility for caregiving, with other siblings and family members being notably more peripheral. This finding concurs with existing literature which

has noted the distinct challenges and detrimental effects on physical and psychological well-being for this cohort (Brody, 1981; Aneshensel et al., 1995).

For all the participants the conflict was clearly exacerbated by the emotional relationship between them and their parent. In most cases a former positive relationship and emotional attachment motivated the participants to care for their parent, a finding which corroborates recent cross-cultural evidence (Greenwood & Smith, 2019).

Overall, it is clear that re-definition of the relationship was both challenging and invigorating for the participants. For some, the caregiving role itself was an experience of self-discovery which had given new life to the pre-morbid relationship, whilst for others reconciliation of old and new relationships was more problematic. Similar themes are evident in other qualitative research, identifying the importance of relationship quality to successful adaptation within changing relationships (Quinn et al., 2008; Williams et al., 2014).

The analysis in this study illustrated both positive and negative effects of the experience in terms of well-being. Many examples were shared which fortified the participants, not least their own sense of value, resourcefulness and capacity for emotional resilience. This finding was paradoxical in light of the burden clearly expressed in the study. However, relevant research has noted similar inconsistencies when seeking explanation for outcomes of dementia caregiving. Overriding factors relating to adult daughters appear to

be relationship quality, sense of reciprocity and the desire to uphold traditional values (Lloyd et al., 2016; Stephens & Townsend, 1997).

The concept of compassion fatigue has been explored in the caregiver burden literature and refers to prolonged exposure of caregivers to stress and suffering (Joinson, 1992). It was interesting to note how, despite accounts of the deleterious effects of juggling their multiple roles, the features of compassion fatigue were not fully demonstrated in this study. Although participants reported a sense of helplessness, hopelessness and isolation at times, thought to be characteristic of compassion fatigue, their emotional reservoir of empathy appeared to buffer the adverse effects. Research has noted how the buffering effect can be compounded by other factors, including changes to care recipient behaviour and longevity of situation and should be examined within the context of the caregiver's changing lives (Day et al., 2014).

Sustaining and supporting care at home presented distinct challenges for our participants. The analysis highlighted dilemmas faced when making decisions on behalf of their parent, and it was evident in all these cases that balancing autonomy with safety and well-being was paramount and required sensitive management. Concerns related to the possibility of physical harm befalling their parent due to dementia-related confusion. These safeguarding concerns were commonly shared and it was often difficult for participants to feel that they had achieved a satisfactory compromise. A recent study noted how people with dementia had to accept dependency on others to maintain their independence in order to remain living in their own homes and upholding this

was considered an ethical obligation of the adult children when involved (Smebye et al., 2016). For our participants, the dilemma continued when considering the suitability of outside agencies to provide care or delegating existing services to maintain that support effectively. Although those who had such support services in place were satisfied with them, trusting others remained an issue they had to learn to manage. The literature in this area notes the important role of domiciliary care in supporting both the person with dementia and their family carers and recommends robust measures to address progress in this area (Rothera et al., 2008; Dawson et al., 2015).

Another issue with significant implications were experiences of professional support, and stories told of confusion, frustration and disappointment as participants attempted to navigate systems and services. Often this was simply knowing their entitlements and which agency to contact; issues are already noted in recent literature (Dawson et al., 2015). Consequently, their experience was described metaphorically to suggest a sense of isolation and abandonment: *'Nobody's reached out'*.

Strengths and limitations

We aimed to explore first-hand experiences of supporting a parent with dementia. The sample size of this study allowed a quality driven detailed account of individual experience which permitted careful and sensitive scrutiny of a small number of cases. The addition of photo elicitation allowed the participants to be more involved and empowered thus stimulating the narrative process. Illustrated themes were described with verbatim quotes to reflect participants' stories and to allow readers to assess the analysis process.

All participants were white British so findings are limited in terms of ethnicity. Furthermore, only one participant was supporting her father. Although research notes how adult children are more likely to provide care to the parent of the same gender (Lee et al., 1993), detailed experiential accounts comparing the two are limited. Finally, three of the eight participants had formal paid care support arrangements in place. Although this factor did not appear to differentiate their sense of responsibility and burden, a larger sample could reflect disparities.

Implications

It is worth noting that we set out to better understand the experiences of informal caregivers supporting a parent to remain in their own home. Therefore all our participants lived separately to the person with dementia and the implications of this should be considered. For example, research has shown that the partner or spouse living with the person with dementia is more vulnerable to carer burden due to the unremitting nature of the caring role and potential interrupted sleep (Chappell et al., 2015). However, recent research acknowledges the complexity of making such comparisons, and notes the impact of competing demands for the daughter, as have been highlighted in our study. Indeed Peacock and colleagues (2020) conclude that the shared experiences of wives and daughters are similar and are dominated by the caring demands of their role.

Our findings indicate the need to identify individuals at risk of excessive burden and compassion fatigue. Further, there is a need for the provision of

anticipatory guidance, information and support tailored to informal caregivers' needs. Our study is unique in highlighting the challenges associated with the competing demands of our participants' situation and suggests that services fall short in addressing their needs. The implications for healthcare commissioning and delivery are noteworthy, not least the need to establish and sustain cohesive working with all agencies whose role is to support these arrangements

Conclusion

This study presents valuable insight into the role of the adult daughter when sustaining parental care in the home, highlighting the psychological impact of responsibility and inter-role conflict. Our work extends existing literature and yields fresh insights about the experiences and needs of this group, not least the ethical dilemmas and safeguarding concerns. Of particular importance are the consistently expressed quests for help and the concomitant dearth of advice and support available. This study highlights the need for an enhanced understanding of dementia from the caregiver perspective, an increased person-centred approach by health professionals and improved collaboration between the services which support those living with dementia and those caring for them.

References

Aneshensel, C.S., Pearlin, L., Mullan, J.T., Zarit, S.H., & Whitlach, C.J.

(1995). *Profiles in caregiving: the unexpected career*. San Diego, CA: Academic Press.

Bates, E., McCann, J.J., Kaye, L.K., & Taylor, J. (2017) “Beyond words”: a researcher’s guide to using photo elicitation in psychology. *Qualitative Research in Psychology*, 14(4) 459-481.

Braun V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research Psychology*, 3:77–101. doi: 10.1191/1478088706qp063oa.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, 11(2):217. doi: [10.31887/DCNS.2009.11.2/hbrodaty](https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty)

Brody, E. M. (1981). Women in the middle and family help to older people. *The Gerontologist*, 38, 471-480.

Buckner, L., & Yeandle, S. (2011). Valuing carers 2011: Calculating the value of carers' support.: University of Leeds, Carers UK.

Burton, A., Hughes, M., & Dempsey, R.C. (2017). Quality of life research: a case for combining photo-elicitation with interpretative phenomenological analysis. *Qualitative research in psychology*, 14(4), 35-393. DOI: <https://doi.org/10.1080/14780887.2017.1322650>

Chappell, N., Dujela, C., & Smith, A. (2015). Caregiver well-being: intersections of relationship and gender. *Research on Aging*, 37(6), 623-645. <https://doi.org/10.1177/0164027514549258>

Dawson, A., Bowes, A., Kelly, F., Velzke, K., & Ward, R. (2015). Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. *BMC Geriatrics*, 15:59, 1-17. <https://doi.org/10.1186/s12877-015-0053-9>

Day, J. R., Anderson, R.A., Davis, L.L. (2014). Compassion fatigue in adult daughter caregivers of a parent with dementia. *Issues of Mental Health Nursing*, 35(10): 796-804.

<https://doi.org/10.3109/01612840.2014.917133>

Dupuis, S.L. (2002). Understanding ambiguous loss in the context of dementia care. *Journal of Gerontological Social Work*, 37:2, 93-115.

https://doi.org/10.1300/J083v37n02_08

Eccleston, C., Doherty, K., Bindoff, A., Robinson, A., Vickers, J. & McInerney, F, (2019), Building dementia knowledge globally through the Understanding Dementia Massive Open Online Course (MOOC). *NPJ, Science of Learning* 4(1), 3. doi:10.1038/s41539-019-0042-4

Giusta, M. and Jewell, S. (2014). *Unpaid work and conformity: Why care?* Cambridge Journal of Economics, doi: 10.1093/cje/beu061.

Gordon, J.R., Pruchno, R.A., Wilson-Genderson, M., Murphy, W.M., & Rose, M. (2012). Balancing caregiving and work: role conflict and role strain dynamics. *Journal of Family Issues*, 33(5), 662-689.

<https://doi.org/10.1177/0192513X11425322>

Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatrics*, 19(1), 169.

<https://doi.org/10.1186/s12877-019-1185-0>

Haberkern, K., Schmid, T., & Szydlik, M. (2015). Gender differences in intergenerational care in European welfare states. *Ageing & Society*, 35, 298-320. doi: 10.1017/S0144686X13000639

Hasselkus, B.R., & Murray, B.J. (2007). Everyday occupation, well-being, and identity: The experiences of caregivers and care receivers in families with dementia. *American Journal of Occupational Therapy*, 61, 9-20. <https://doi.org/10.5014/ajot.61.1.9>

Hoff, A. (2015). *Current and future challenges of family care in the UK. Future of an ageing population: evidence review*. Foresight, Government Office for Science: London.

Horowitz, A. (1985). Sons and daughters as caregivers to older parents: differences in role performances and consequences. *The Gerontologist*, 25(6), 612-617. <https://doi.org/10.1093/geront/25.6.612>

Joinson, C. (1992). Coping with compassion fatigue. *Nursing*, 22(4), 116-120.

Lee, G.R., Dwyer, J.W., & Coward, R.T. (1993). Gender differences in parent care: demographic factors and same-gender preferences. *Journal of Gerontology*, 48(1), S9 - S16 <https://doi.org/10.1093/geronj/48.1.S9>

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>

Lord, K., Livingston, G. & Cooper, C. (2015). A systematic review of barriers and facilitator to and interventions for proxy decision-making by family carers of people with dementia. *International Psychogeriatrics*, 27(8), 1301-1312.

McKibbin, C.L., Walsh, W., Rinki, M., Koin, D., & Gallagher-Thompson, D. (1999). Lifestyle and health behaviours among female family caregivers: A comparison of wives and daughters. *Aging and Mental Health*, 3:2, 165-172. <https://doi.org/10.1080/13607869956334>

Meo, A. I. (2010). Picturing Students' Habitus: The advantages and limitations of photo- elicitation interviewing in a qualitative study in the city of Buenos Aires. *International Journal of Qualitative Methodology*, 9 (2), 149-170 <https://doi.org/10.1177/160940691000900203>

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 non-dementia caregivers. *The Gerontologist*, 39, 177-185. <https://doi.org/10.1093/geront/39.2.177>

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.

Peacock, S., Bayly, M., Duggleby, W., Ploeg, J., Pollard, L., Swindle, J., Jung Lee, H., Williams, A., Markle-Reid, M., & McAiney, C. (2020). Women's caregiving experience of older persons living with Alzheimer's disease and related dementias and multiple chronic conditions: Using Wuest's theory. *Open Nursing*, 6, 1-11. DOI: 10.11.77/2377960820974816

Quinn, C., Clare, L., Pearce, A. & van Dijhuizen, M. (2008). The experience

of providing care in the early stages of dementia: an interpretative phenomenological analysis. *Aging & Mental Health*, 12(6), 769-778.

<https://doi.org/10.1080/13607860802380623>

Rothera, I., Jones, R., Harwood, R., Avery, A.J., Fisher, K., & James, V.

(2008). An evaluation of a specialist multi-agency home support service for older people with dementia using qualitative methods. *International Journal of Geriatric Psychiatry*, 23(1), 65-72.

<https://doi.org/10.1002/gps.1841>

Smebye, K. L., Kirkevold, M., & Engedal, A. (2016). Ethical dilemmas

concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study. *BMC Health Services Research*, 16:21,

1-12. <https://doi.org/10.1186/s12913-015-1217-1>

Sörensen, S. & Conwell, Y. (2011). Issues in dementia caregiving: effects on

mental and physical health, intervention strategies and research needs.

American Association for Geriatric Psychiatry, 19(6), 491-496.

DOI:<https://doi.org/10.1097/JGP.0b013e31821c0e6e>

Stephens, M.A.P., Townsend, A.L., Martire, L.M., & Druly, J.A. (2001).

Balancing parent care with other roles: Interrole conflict of adult daughter caregivers. *Journal of Gerontology: Psychological Sciences*, 56B(1), 24-34. <https://doi.org/10.1093/geronb/56.1.P24>

Stephens, M.A.P., & Townsend, A.L. (1997). Stress of parent care: positive and negative effects of women's other roles. *Psychology and Aging*, 12(2), 376-386.

Stephens, M.A.P., & Franks, M.M. (1999). Parent care in the context of women's multiple roles. *Current Directions in Psychological Science*, 8, 149-152.

Totsika, V., Hastings, R.P., & Vagenas, D. (2017). Informal caregivers of people with an intellectual disability in England: health, quality of life and impact of caring. *Health and Social Care in the Community*, 25, 951-961. doi: 10.1111/hsc.12393

White C. (2013) 2011 Census Analysis: Unpaid care in England and Wales, 2011 and Comparison with 2001. Office of National Statistics. Available

at: http://www.ons.gov.uk/ons/dcp171766_300039.pdf

Williams, K.L., Morrison, V., & Robinson, C.A. (2014). *Exploring caregiving experiences: caregiver coping and making sense of illness*. *Aging and Mental Health*, *18*(5), 600-609.

<https://doi.org/10.1080/13607863.2013.860425>

Additional documents

Table 1. Participant characteristics

Pseudonym	Age	Parent pseudonym	Age	Parent status	Support status
Abigail	36	Dorothy	69	Dorothy lives with husband	Primary unpaid caregiver for both parents. Peripheral sibling support.
Carolyn	59	Peggy	90	Peggy lives alone	Primary unpaid caregiver. Sibling support.
Kath	63	Joan	95	Joan lives alone	Primary unpaid caregiver. Formal paid care support also in place*.
Juliette	55	Miles	91	Miles lives alone	Primary unpaid caregiver. Sibling support.
Karen	56	Jenny	79	Jenny lives alone	Primary unpaid caregiver. Formal paid care support also in place*.
Libby	47	Nell	81	Nell lives with husband	Joint unpaid caregiving role with father. Sibling support and formal paid care support also in place*.
Misty	50	Lil	76	Lil lives alone	Primary unpaid caregiver. Granddaughter supports.
Jess	53	Milly	81	Milly lives alone	Primary unpaid caregiver. Peripheral sibling support.

*Formal paid care support refers to domiciliary care company support arrangement

Table 2: Interview schedule

1. Can you tell me about your life at the moment with regard to supporting your mother/father to remain in their home? *Prompt: How do you feel? How do you cope?*
2. What are your reasons for supporting the current arrangement? *Prompt: Are you able to understand your mother's/father's perspective?*
3. How about any challenges you have encountered? *Prompt: can you describe a recent example?*
4. How has the arrangement affected your relationship with your mother/father? *Prompt: Do you feel different towards him/her?*
5. How has the arrangement affected your relationship with your family? *Prompt: how does the family feel - your spouse/partner/children?*
6. How would you describe yourself as a person? *Prompt: How do you feel about yourself now? Prompt: Do you feel different to how you used to feel? If so, why do you think that is?*
7. What do you think the health care service needs are for people like yourself? *Prompt: Adequate? Do you feel supported?*
8. What would be a positive development for you?

Table 3. Overview of themes and sub-themes.

-
- 1. *Impact on identity***
 - a. I'm not just mum's carer (*issues of identity*)
 - b. I'm almost her parent (*emotional impact of role reversal*)
 - c. Trying to get the balance (*competing demands*)

 - 2. *Continuity and change***
 - a. Not the person that I know at all (*relationship redefinition*)
 - b. My life is different (*changing aspects of new life*)
 - c. Stronger for it (*positive aspects of caregiving experience*)

 - 3. *Stepping up to the challenge***
 - a. What are we going to do? (*worry about the future*)
 - b. It's not my decision, it's hers (*maintaining autonomy*)
 - c. Trusting others (*to care and support*)

 - 4. *Finding help: 'It's just a minefield'***
 - a. Nobody's reached out (*quest for help*)
 - b. Going round in circles (*navigating health care support*)
-

Figure 1. Examples of photographs taken by participants

