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Dementia is defined as the deterioration of cognitive function beyond that which is expected (World Health Organisation, 2017). It is estimated that 850,000 people are living with dementia in the U.K., and this figure is expected to increase to one-million by 2025 (Alzheimer's Society, 2014). Furthermore, it is proposed that the total health and social care costs for dementia almost match the combined costs of cancer, heart disease and stroke (Alzheimer's Disease International, 2014). Despite the large healthcare costs associated with Dementia care, those living with dementia, and their families, cover two-thirds of this cost (Alzheimer's Society, 2014).

Informal caregiving is defined as unpaid care provided by a relative or friend (Bremer et al., 2015). However, whilst essential to health and social care provision, it is reported that almost half of caregivers for people living with dementia feel they do not receive the support they need (Alzheimer's Society, 2014) and evidence suggests that over 80% of informal dementia caregivers experience elevated levels of stress with nearly 50% reporting that they suffer from depression (Alzheimer's Society, 2014). Caregiver burden is defined as '*a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience*' (Kasuya, Polgar-Bailey, & MPH Robbyn Takeuchi, 2000, p. 119). Evidence has shown that caregiving for a relative living with dementia can lead to negative health outcomes for informal caregivers (Bremer et al., 2015), including increased risk of anxiety (Joling et al., 2010) and depression (Mahoney, Regan, Katona, & Livingston, 2005; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006), as well as decreased physical wellbeing and quality of life (Schulz et al., 2006).

The Caregiver Stress Process Model was developed by Pearlin, Mullan, Semple, and Skaff (1990) and brings attention to the various relationships between variables that lead to caregiver stress and the development of these relationships over time. The model constitutes of four domains; background and context, primary and secondary stressors, mediating conditions, and manifestations of stress and provides understanding of how caregiving develops from a reciprocal activity between two people to an unequal distribution of burden (Pearlin et al., 1990). This model argues that caregiver stress is a mixture of circumstances, experiences, reactions and resources, which impact upon health and behaviour in various ways. This is supported by systematic review evidence which stated that gender, relationship, culture and personal characteristics all influence carer burden, and is associated with negative effects on health (Etters, Goodall, & Harrison, 2008). Evidence suggests that caregivers of people living with dementia suffer from higher levels of burden and depression than caregivers of other chronic illnesses (Pinquart & Sörensen, 2004). Factors including impairment of daily activities, number of hours caregiving, coping strategies, co-residence, spousal status and gender are all evidenced as predictors of caregiver burden in dementia caregivers (Kim, Chang, Rose, & Kim, 2012). According to Ayres (2000) this is due to the fact that carers' experiences seem to be vastly different, owing to the nature of dementia and how the caregiver interprets and constructs meaning in their caregiving experience. Furthermore, the perceptions of caregivers for people living with dementia vary considerably (Shim, Barroso, & Davis, 2012), and it is argued that dementia caregiving experiences are grounded in culture (Ivey et al., 2013; Simpson, 2010; Simpson & Carter, 2010).

Some studies have utilised Interpretative Phenomenological Analysis (IPA) in examining individual differences of caregivers for individuals living with dementia (Lockeridge & Simpson, 2013; Quinn, Clare, Pearce, & Van Dijkhuizen, 2008; Stokes, Combes, & Stokes, 2014). The studies generated evidence around coping strategies (Lockeridge & Simpson, 2013; Quinn et al., 2008), adjustment, including feelings of losing control and loss (Lockeridge & Simpson, 2013; Quinn et al., 2008; Stokes et al., 2014), stigma (Lockeridge & Simpson, 2013), lack of information (Stokes et al., 2014), emotional strain (Quinn et al., 2008), and isolation (Stokes et al., 2014). However, all three studies only included participants' partners only, excluding other family members. Another qualitative study including caregivers with other relationships to care-recipients stated that differences were found between spousal and adult-child caregivers (Melunsky et al., 2015). However, they did not explicitly discuss these differences. Additionally, the study uses a heterogeneous group of caregivers and was not supported with demographic information, meaning it is difficult to identify differences between the subgroups. Melunsky et al. (2015) acknowledge these limitations, suggesting that research would benefit from qualitative exploration through comparison of particular groups of carers to support subgroups effectively and efficiently.

It is evident that caregiver burden is related to the subjective experience of individuals and it is important to study the lived experience of caregivers of dementia for a more holistic understanding of the challenges caregivers deal with (Shim et al., 2012). This study aims to explore the subjective lived experience of informal caregivers supporting an individual with dementia.

Method

Design

This study uses the IPA (Smith, 2009)utilising the method of photo-elicitation. Photo-elicitation is a method of data collection for which participants are given the opportunity to capture photographs and reflect on the content of these images as part of a semi-structured interview. This verbal narrative, produced in conjunction with photographs, enables an individual to provide a deep, detailed description of their own lived experience (Pilcher, Martin, & Williams, 2015). Furthermore, using photographs within research can be a particularly powerful tool for the researcher as it can challenge participants, provide nuances, trigger memories, lead to new perspectives and explanations, and help to avoid researcher misinterpretation (Hurworth, 2004).

Participants

Six participants took part in this study (aged 53-90 years; 2 females, 4 males). Three participants were currently caregivers for a parent with dementia, and three participants were spousal ex-caregivers of which, two spouses were recently deceased and one spouse was residing in a care home. Participants' experiences of care ranged from six months to 15 years. Participants were contacted through various dementia service charities in the North of England. A purposive sampling strategy was used, according to IPA in order to involve individuals with a wide range of caring experiences (Smith, 2009). Participants were included if they were over 18 years old, and identified themselves as an informal caregiver supporting, or having recently supported, an individual diagnosed as having dementia. Participants were excluded if they did not have capacity to provide full, informed consent. A small sample was recruited according to IPA in order to provide detailed accounts of individual experience (Smith, 2009).

Ethical approval

Ethical approval was attained [xxx]. The confidentiality and anonymity of participants, and others was of upmost importance throughout this project. Participants were fully informed of how, and when, to use the camera prior to collecting these images. Participants provided written consent to use unidentifiable photographs as part of publication.

Materials

Participants were given a Kodak© disposable camera, and instructed to capture photographs of anything they believed depicted their everyday experiences of being a caregiver. The camera was specifically chosen due to image quality, and all participants were given the same model. Participants were given verbal instructions of how to use the camera prior to use. Participants were given one disposable camera and were instructed to take as many photographs as they wanted to, with the only restriction being the number of photographs able to be captured on the camera (N=27).

Procedure

Identified representatives of various dementia service charities were contacted via email. Charities that were interested in being involved in participant recruitment then arranged for one member of the research team to attend support groups and discuss participation in the project with service users. Interested individuals were given an information sheet and had the opportunity to ask questions. Only those wishing to continue with the study were asked to provide written informed consent. Participants were issued a disposable camera to use over a two to four-week period, and as part of this, participants were given the option to take photographs of themselves and others. If participants wished to take photographs of others, they were informed that they must provide that individual with a participant information sheet and consent form.

At the end of the study period, photographs were developed, and a semi-structured interview was carried out at each participant's home (interview length between 30-70 minutes) using the photographs to guide discussion. Interviews were recorded using an Olympus digital voice recorder and transcribed verbatim. Once the interview was completed a debrief form was given to each participant reiterating the aim of the research and detailing further contact information and support.

Data Analysis

Photographs were not directly analysed by the research team but were described and interpreted by the participants during the interviews. Accordingly, the photographs were used as tools within the in-depth interviews used to broaden the interview around the significance of the images for the individual (Pauwels, 2015), and are also used for illustration of themes. Interview transcripts were analysed using IPA (Smith, 2009). IPA is most appropriate when exploring individual experiences and their understanding, or sense-making, of these experiences (Smith, 2009). Each text was initially read line-by-line and themes related to the subjective lived experiences of dementia caregivers were identified for each participant, then across the sample, before interpreting the coded data (Smith, 2009). The analysis involved the 'double hermeneutic' in that the analysts interpreted the participants' own interpretations (Smith, 2009). Transcripts were read multiple times through the reciprocal activity of the analysis to identify and highlight themes relating to the whole, such as the underlying meaning, and parts, to identify themes specific to the individual to retain subjectivity and understanding. Findings were discussed between the research team. Pseudonyms replaced participant names during analysis to retain anonymity.

Results

Three main themes were generated from the data; 'conceptualising the role of informal caregiver', 'support for the informal caregiver', and 'the caregivers own needs'.

Conceptualising the role of informal caregiver

Participants considered their role as caregiver in varying ways. Individuals discussed their transition to the role of caregiver, and also highlighted the impact that it had on themselves as individuals. Three participants describe their role of caregiver as being a natural transition.

> *"I never really considered myself as a carer it just sort of slowly happened. Erm slowly crept…I'm officially a carer but I never thought that way it just happened" (Josef, Spouse)*
>
> *"I've always been the carer, and the carer has been in my work. Erm it is a kind of a natural role" (Susan, daughter)*
>
> *"It's no chore at all it's just like, it's just what I would do, it's just natural you know" (Alison, daughter)*

These three participants conceptualised their changing role as progressive and natural, Susan understands her role as a caregiver for her mother as natural due to her life experience working in the care profession. Alison also highlights her own past lived experiences as having an impact on the role of caregiver, as her mother had taken on the caring role in the past, helping her raise her child, and because of this she feels she '*owes*' her mother. Whereas, for Josef as a spouse there was no moment of realisation but simply a slow and natural process. Other carers expressed a different understanding, Graham perceives his caring role as his '*duty*' to care for his mother, whilst acknowledging the self-reward gained from caring.

> *"It's a duty, I love my mother and you know it's a duty you do. Like coming back from Australia, I didn't want to come back, I loved it over there, but you know you have to sacrifice things. But it is rewarding in a way because you know you're doing good, you're helping somebody. And we all like to help." (Graham, son)*

By conceptualising his caring role as his duty Graham is able to justify the *'sacrifice'* he has made to his own life. He rationalises this sacrifice through the difference he is making to his mother's life, describing the caring role as *'rewarding'.* Peter, as a spouse caregiver, describes the reward in caregiving through the satisfaction derived from his role as caregiver.

> *"I think I think it's very fulfilling oh yes. It's a sense of achievement you know that you're doing something that will really help someone. It just gives you a nice glow, a nice feeling yeah" (Peter, spouse)*

The role of being an informal caregiver was viewed as rewarding and delivering a sense of achievement for some individuals, but for others it was difficult within other aspects of their lives.

The concept of responsibility and the burdens involved with this responsibility influenced all caregivers understandings of their role. Despite describing her role as "*natural*", Susan repeatedly used tense language, such as the use of the metaphor "*juggling"* her responsibilities to make sure that everyone was "*kept happy*". The pressure of the responsibility of caring for her parent was clear, and evidently influenced her daily living physically but also emotionally.

> *"I do yeah I have to kind of soak up those negatives and its awful because they stay with me it's almost as if their emotional baggage is just dumped on you… you just kind of get on with it." (Susan, daughter)*
>
> *And at the same time you do feel a bit resentful, um that er nobody else offers. Or volunteers to. And then you just feel guilty if you've even thought that. *Laughs* so it's kind of a cycle of guilt, anxiety, worry cos you constantly worry about it (Susan, daughter)*

Susan describes the *'cycle'* of negative emotions she experiences as the main caregiver and conceptualises the emotional strain from the caring role as *'baggage'*. This conflict between her "*natural role*" and the physical and emotional struggles are evident.

Particularly evident for those caring for a parent was the newly acquired intimate responsibilities which also exacerbated the emotional challenges of the new role, with carers having to re-conceptualise their relationship with their significant other when taking on these additional duties. Alison took a photograph of her mother's shower to illustrate the upsetting experience when she first took on the responsibility of intimate care (figure 1).

Figure 1: Alison took a photograph of the shower representing her upsetting experiences when first showering her Mother.

> *"In the beginning it was awful to shower your mum and just quite upsetting really but embarrassing for my mum and she didn't want us to do it. But she didn't want the carers to do it" (Alison, daughter)*

As a result of undertaking these intimate jobs, there was an internal struggle between her responsibility as a caregiver and as a daughter. Whereas, for spouse caregiver Peter he described the uptake of household chores as leading to a change in his relationship with his wife as it lessened the time they spent together and made him feel guilty (figure 2).

Figure 2: Peter took a photograph of the washing machine representing the responsibility of housework.

> *"I've managed quite well really I think. It's just a part of what, you can either suppose you could get somebody in to do all the housework but I've done it all my myself really […] sometimes you feel that you could be giving more time possibly to seeing to [my wife] erm and sitting with her, it does take away some of the time but I decided I would do the house work and carry on with it." (Henry, Spouse)*

Henry "*managed"* the housework, but felt that, in doing so, time was being taken away from being with his wife.

The transition to caregiver was difficult for individuals, however, it is evident that this transition, and the difficulties experienced, differ considerably between the type of caregiver and individual caregivers within this study. This transition is complex, and based on the current and past relationship between the caregiver and loved one, the new roles acquired as caregiver, as well as other responsibilities that the caregiver has in their own life.

Support arising for caregivers themselves

The theme of support arose as an important aspect of the caring role. Often support was received indirectly through support provided for the individual living with dementia, and participants also identified the support, or lack of support, received for themselves within their role as caregiver. The way in which the participants discussed support was diverse, ranging from information received about dementia, practical aids, social support, and support for co-morbidities also experienced by their loved one. Susan described one of her photographs as the "*masses*" of information available about dementia, and the support and services available to her Mother (figure 3).

Figure 3: Susan photographed information sheets available about dementia and the services available.

However, rather than the availability of this literature increasing perceived support, Susan felt overwhelmed by the realisation of her new responsibilities.

> *"That triggered something in me about the advice, it's almost saying well you've gotta be a carer, and this is what you've got to do"* (Susan, daughter)
>
> *"The overwhelming responsibility of it that hits you when you get all of this [information]"* (Susan, daughter)

Once more, Susan's internal conflict surfaces. Graham took photographs of adaptations used to increase his mother's mobility including, adapted seating, a walking frame, bathroom aids, a stair lift, and an adapted pillow (figures 4-6).

Figures 4-6: Graham took photographs of aids and adaptations used by his mother.

Graham describes the many benefits of these aids and adaptations, not only for his mother, but for himself as caregiver.

> *"The better she functions the better it is for me, the easier it is for me" (Graham, son)*
>
> *"We got the wheelchair because she was getting a bit slower you know she's getting older she's 89 […] I said we'll get a wheelchair and then*

> *we can zip round quicker and she's still getting out and it gives you a life line you know, she can walk a bit and all that…well it gives me freedom, I can push her round" (Graham, son)*

Graham describes the aids as a "*lifeline"* and a "*godsend*" as they allowed him more freedom and the ability to carry out the caring role more easily.

Social support was another important aspect discussed by participants. Three individuals (Peter; Henry; Josef) took photographs of social groups especially for individuals living with dementia, and their caregivers.

> *"You got chatting to other caregivers and er as well and er yeah enjoying day… just to talk over things really it's been a big help chatting about anything not always about your problems but sometimes yeah but er and er yes, so I found it worthwhile to go" (Josef, spouse)*
>
> *"We go along for the chat and the and I get on I find that you have an affinity to people with dementia you can quite easily get on with them you know" (Peter, spouse)*

Josef explains how the carer's groups act as place to socialise with others. All three spouse carers expressed the importance of the social groups for meeting others in a similar position, discussing their experiences and providing continued emotional support. Peter also discussed the opportunity the groups gave him, allowing him to help other caregivers due to his own knowledge.

> *"The fact that erm I had quite a bit of knowledge of what is required in the treatment and I could understand people's problems I just felt that that was probably the sort of thing that I could help with" (Peter, spouse)*

It was evident from participants that caregivers' experiences differ but having a place to meet and talk with others is an important form of support. Alison also describes how going along to the group and being around other carers provides emotional support by giving her a space to offload. .

> *"I think my mum had had a bit of a bad week and I went and had a little chat and cry" (Alison, Daughter)*

Social support was imperative, specifically that from other caregivers. However, it is important to note that two participants caring for a parent emphasised the importance of social support but this was not specifically from dementia support groups or other caregivers.

Although the focus of the photographs was the caregiver's lived experience of caring for an individual living with dementia, an unexpected finding emerged with regards to their lack of support with dementia, but also co-morbidities of care recipients. Various participants took photographs of pill dispensers, or medication, and described their overwhelming sense of responsibility in dealing with this. In some cases, the caregiver had become an 'expert' with their loved one's other needs, with Alison describing one of her mother's co-morbidities "*a bit like a little project of a job*".

Figure 7-8: Photographs of medication for co-morbidities, taken by various participants

> *"the blister pack for medication…they'd sent the blister packs in and they hadn't put the right medication in, so it's things like that that you're having to be on top of and ahead of them and just think oh I just feel you need to think all the time" (Alison, daughter)*

> *"That's the insulin and a chocolate, well a little piece of chocolate. It's actually diabetic chocolate…I go every day and I give her the insulin injection" (Josef, spouse)*

The caregivers had responsibility for medication relating to both dementia and co-morbidities.

The caregiver's own needs

The importance, and perceived neglect, of the caregiver's individual needs emerged from findings, with individuals feeling as though their own identity was often compromised due to their role as caregiver. Susan felt as though she had no choice in her role as informal caregiver. She described the role as being an "*identity forced on you*" and in doing so you "*lose yourself in it*". She repeatedly used language illustrating the challenging way in which it becomes part of the caregiver's identity, without any consideration to themselves as individuals.

> *"No one is really interested in what challenge it is. They are just happy that they've got somebody doing this" (Susan, daughter)*
>
> *"You're just expected to do it and nothing about your own life is taken into consideration" (Susan, daughter)*
>
> *"No one has ever asked me what other responsibilities that I have" (Susan, daughter)*

Susan described others making "*assumptions*" about her own responsibilities, and she felt that she often had to choose between caring for her mother, looking after her own grandchildren, or caring for her husband.

The caregiver's own needs were described by participants as a time of respite where the participants were able to focus on activities for their own enjoyment and the impact this had on their own wellbeing and ability to care. Henry took a photograph of his wife's respite activities in which a friend cared for his wife whilst he spent time doing activities such as walking and golf (figure 9).

Figure 9: Henry took a photograph of his wife's nail varnish, demonstrating time that he did not need to care for her

> *"It was a bit of a release it was a release really. Because your mind is always really on her all the time so erm if you know that she's safe and alright you know you can forget it can lose it for a bit and I loved sport*

> *so and fresh air and everything and so it was that sort of help really."*
> *(Henry, spouse)*

Henry describes time of respite as a "*release*" explaining how he is always thinking about his wife whereas in these afternoons he can "*forget*" his caring role and focus on his own needs. He describes the importance of taking time for himself and its impact on his own well-being. The importance of caregiver's individual needs is further evidenced by Alison who described the importance of her sewing activities for time to herself (figure 10).

Figure 10: Alison photographed her sewing activities showing time taken for herself

> *"I've been going to my sewing class so I've been learning things new things this is a Thursday night. So again it's giving me some something for me really. That's my pleats that I've learned how to do *laughs*"*
> *(Alison, daughter)*

Alison explains how going to her sewing classes gives her something for herself and her own enjoyment. However, Alison explains how allowing time for her own needs impacts upon her life and uses a photograph to highlight this (Figure 11).

Figure 11: Alison photographed her spare bedroom full of sewing materials

> *"Chaotic bedroom, chaotic is my home really and my life"*
>
> *(Alison, daughter)*

Alison illustrates how her own needs are in conflict with the needs of her mother, as she is unable to provide adequate time for both, creating an aspect of chaos in her life. Graham also describes how his own needs are interlinked with the needs of the care recipient (figure 12).

Figure 12: The caregiver's hobby of playing the piano

> *"I: So then would the photo of the piano and stuff and also the crossword how do you think you'd feel if you didn't have that time?*
>
> *P: well, well it's all work and no play then isn't it? Really, I mean I have to keep myself in tip top condition to look after mother. You know physically and mentally as well you know if I start missing out on tablets and all that then she's no good. She'd have to go in a home or we'd have to get help for me as well. So yeah, the better I am the better she is." (Graham, son)*

The caregiver describes how his own needs are important as it enables him to stay in "*top condition".* He explains how his own needs are intertwined with his ability to care, and explains the importance of remaining functional outside of his caring responsibilities.

Caregivers often felt that the role was thrust upon them, sometimes without consideration of other aspects of their life. Maintaining the caregivers' own identity, meeting their own needs, as well as participation in their own hobbies was clearly important for maintaining their caregiving role effectively. However, for some carers the ability to meet their own needs and provide time for themselves was not possible.

Discussion

Overall findings

Three main themes were generated from the data: ‘conceptualising the role of informal caregiver’, ‘support for the informal caregiver’, and ‘the caregivers own needs’. The complexity of the transition from family member to informal caregiver was evident with this transition evidently having both a physical and emotional impact on caregivers. The importance of the relationship between the individual and caregiver was illuminated as part of this transition, and could perhaps explain some of its complexity, specifically differences between the adult child as caregiver and the spouse as caregiver. This is demonstrated in wider literature as adult-children acting as dementia caregivers have reported greater effects in terms of employment complications, role strain and mental health problems (Ory, Hoffman III, Yee, Tennstedt, & Schulz, 1999).

It was evident that experiences of support also varied across the sample, as well as the type of support differing. Interestingly, support encompassed educational support, physical support aids, formal support, and social support. Variation in caregiving experiences are supported by previous literature which reported caregivers’ perceptions of dementia as having an impact on the health of the caregivers themselves, with caregivers that report greater consequences of dementia negatively having an impact on levels of burden, physical health, and depressive symptoms (Lo Sterzo & Orgeta 2017). Previous research has demonstrated that caregivers of individuals living with dementia feel as though they do not receive sufficient support, and experience barriers to seeking this information due to their own knowledge gaps (Peterson, Hahn, Lee, Madison, & Atri, 2016). Furthermore, there is a lack of success of professional support for caregivers, with Brodaty, Green, and Koschera (2003) finding that informal carers generally report feelings of satisfaction and gratefulness with professional support, yet, this did not reduce their depression or caregiver burden. Within this study, social, peer, support was evidently important, and wider literature identifies that support specifically tailored to help caregivers cope with their changing demands has a larger effect on caregiver wellbeing (Andrén & Elmståhl, 2008). Therefore, findings highlight the importance of providing support for the caregiver rather than just to the care recipient, with caregivers stating the importance of focusing on their own individual needs in order to maintain wellbeing and expressed positive experiences of informal support in the form of dementia charity support groups.

The perceived neglect of the caregiver’s individual needs was evident, with individuals feeling as though their own identity was often compromised due to their role as caregiver. The findings demonstrated that the caregiver’s own needs were a time of respite where caregivers were able to focus on activities for their own enjoyment and the impact this had on their own wellbeing and ability to care. The impact of working whilst being a caregiver has been shown to have adverse effects on caregivers’ physical, social and emotional health (Bullock, Crawford, & Tennstedt, 2003). Research indicates that although many family caregivers want to work and care for family members (Arksey, Kemp, Glendinning, Kotchetkova, & Tozer, 2005) the strain from completing care responsibilities means caregivers often reduce work hours or stop working entirely (Laczko & BA, 1993). These findings are supported by previous research highlighting that a lack of time to devote to the caregiver's own personal needs contributes to negative physical and mental health outcomes for the caregiver (Richardson, Lee, Berg-Weger, & Grossberg, 2013). Research also suggests that a lack of time for caregiver's individual needs is related to a number of factors such as care recipients functional and cognitive dependence, lack of social support (Pinquart & Sörensen, 2004), caregiver's working status and resource availability (Wolfs et al., 2012). The findings accordingly lend support for the Caregiver Stress Process Model (Pearlin et al., 1990) in that a mixture of personal circumstances and characteristics, caregiver role, experiences of support, and interpretation of the caregiving experience can be seen to influence caregiver burden and the impact on carers' health and wellbeing.

Methodological Reflections

The use of photo-elicitation as a method of qualitative investigation was a key strength of the current study. A main characteristic of this approach is analysing how participants ascribe meaning and values to these images and allows exploration of a phenomena within a social context (Ruby, 1995). It is suggested that additional methods to interviews in qualitative inquiry, allows for richer more nuanced data (Black, 1994). Furthermore, photo elicitation can overcome some of the problems faced with qualitative interviewing in that the understanding of both participant and researcher is grounded in the photograph (Harper, 2002). However, previous qualitative research into the lived experiences of caregivers of dementia has only utilised interviews. Photo elicitation has been used as an innovative method to capture lived experiences in other clinical and community settings with different populations, for example, experiences of recovery in a hospital setting (Radley & Taylor, 2003), men's' experiences of living with prostate cancer (Oliffe & Bottorff, 2007), and women's experiences of chemotherapy (Frith & Harcourt, 2007). To the researchers' knowledge the current study is the first of its kind to utilise photo-elicitation when investigating the experiences of caregivers of dementia; thus, providing a unique insight into these experiences. The photographs provided an innovative way of capturing the lived experiences of formal dementia caregivers and allowed the interview data to be grounded in their daily living, centring around their own lived experiences. When participants discussed the experience of using the camera the response was positive, and participants anecdotally felt that it was a good way of capturing and remembering their thoughts.

This study specifically utilised photo-elicitation, as opposed to more participatory photography methods such as photovoice, as the interview was led by the researcher whilst considering and being led by the research aims, rather than being truly participant led. Within more participatory approaches, the verbal narrative, produced in conjunction with photographs, enables an individual to provide a deep, detailed description of their own lived experience (Pilcher et al., 2015). Using photo elicitation interviews still allows individuals to express themselves within the research (Harper, 2002; Pauwels, 2015).

A key limitation of the research related to timescale and demographics, with all participants recruited from a small area in the North East of England. This has implications for the transferability of findings due to a lack of diversity between participants, as well as similarity of provision by the local authority and local third-sector services.

Future Research and Practice Implications

Future research would benefit from recruiting a wider, diverse sample, spanning multiple local authority sites. Furthermore, the differences identified between spousal caregivers and adult-child caregivers within themes suggests that future research should look into the differences in the caregiving experience between spousal and adult-children caregivers of people living with dementia.

Conclusions

Through qualitative investigation the study found three key areas of dementia caregiving that related to the lived experience. The themes highlight aspects of caregiving that is specific to caregiver's experiences. The caregiver's own needs were found to be important for their own wellbeing and continuation of care. Whilst positive experiences of informal assistance emphasise the value of carer focused support. Finally, a notable difference was found between experiences of spousal caregivers and adult-child carers, particularly in their conceptualisation of the role. Further exploration of these differences is essential for understanding carers of dementia in the UK and providing appropriate services. Findings demonstrate the importance of implementing countrywide emotional support for caregivers focusing on their individual needs and employing suitable coping strategies. In conclusion, by understanding the day-to-day experiences, findings have illuminated the lived experience of carers of dementia in the UK, adding to the small body of existing literature and highlighting important issues for both future intervention programs and research.

Declaration of Conflicting Interests: The Authors declare that there is no conflict of interest.

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Figure 1: Alison took a photograph of the shower representing her upsetting experiences when first showering her Mother.

Figure 2: Peter took a photograph of the washing machine representing the responsibility of housework.

Figure 3: Susan photographed information sheets available about dementia and the services available.

Figures 4-6: Graham took photographs of aids and adaptations used by his mother.

Figure 7-8: Photographs of medication for co-morbidities, taken by various participants

Figure 9: Henry took a photograph of his wife's nail varnish, demonstrating time that he did not need to care for her

Figure 10: Alison photographed her sewing activities showing time taken for herself

Figure 11: Alison photographed her spare bedroom full of sewing materials

Figure 12: The caregiver's hobby of playing the piano