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Quality of life on the views of older family carers of people with dementia

Abstract

Older family carers of people with dementia represent an increasing but overlooked population of family carers. This research aimed to explore how these individuals make sense of their own quality of life and to identify the factors that enhance or compromise this. Four focus groups were conducted in 2014 with 19 older family carers in community-based support groups in Nottinghamshire, United Kingdom. Data was transcribed verbatim and analysed using Interpretative Phenomenological Analysis. Thirty-three subthemes emerged and were collated into three superordinate themes: 1) aspects of care and caregiving, 2) feelings and concerns, and 3) satisfaction with life and caregiving. This study identified a broad range of aspects that are of particular importance to the QoL of older family carers of people with dementia. These findings are expected to inform future research as well as health and social care providers with the aim of improving life quality for this population.

Keywords

Caregivers, dementia, quality of life, ageing, Alzheimer's disease, interpretative phenomenological analysis, qualitative research, focus groups

Background

Family members are considered to be the most important support resource available to people with dementia (Age UK, 2010; White, 2013). There are around 6.5 million people in the UK who are carers and this number is expected to increase to 9 million by 2037 (Carers UK, 2015). Older people who are carers (aged 60+) currently constitute a group of around 1.5 million people in the UK (White, 2013) and this number is also expected to increase, particularly among those aged 85 and over (Carers UK & Age UK, 2015).

Because caregiving can have a huge impact on carers' lives, family carers currently represent a major concern for governments and public services (Hoff, 2015; NICE, 2016; Parker, Arksey, & Harden, 2010). Older carers often have reduced incomes, may be living with long-term conditions themselves and have reduced social networks.

Moreover, these carers frequently provide intensive care for their loved ones with more than half of those aged over 85 providing 50 or more hours a week of care (Jopling, 2015). This can have a huge impact both on these individuals' quality of life (QoL) (Carers UK & Age UK, 2015) and on the quality of care they are able to provide (Lima, Allen, Goldscheider, & Intrator, 2008). Given that people living with dementia are encouraged to live in the community for as long as possible (HM Government, 2009), it is paramount to maintain life quality for older people who are responsible for providing this care.

The UK Care Act (HM Government, 2014) and the UK National Dementia Strategy also state that family carers have a right to assessment of their needs, particularly their QoL (HM Government, 2010). Considering the increasing population of older carers, a recent report from Independent Age and Carers UK pointed out the importance of focusing research on this particular age group (Jopling, 2015). It has also been argued that there is a need for age-specific interventions to allow us both further understand and meet the needs of older carers (Age UK, 2010; Carers Trust, 2011; NICE, 2015). However, it has been recently demonstrated that the QoL of older family carers is widely overlooked (Carers UK & Age UK, 2015), especially in dementia (Moniz-Cook et al., 2008; Oliveira, Vass, & Aubeeluck, 2015).

There is non-consensus in the literature with regards to the definition of QoL (Fayers & Machin, 2016) . However QoL is understood and accepted as a “multidimensional concept which incorporates physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship with the environment in which they live” (WHO, 1995 p.1405). As such, QoL can provide a holistic perspective on the impact of family caregiving for the individual. For example, low QoL in older family carers of people in multiple disease contexts has been associated with high levels of strain (Roth, Perkins, Wadley, Temple, & Haley, 2009), long-term caregiving, and the female gender (Kim & Spillers, 2010; Steptoe, Shankar, & Snorri, 2015). It is also associated with increased age (Clay et al., 2013; Godwin, Ostwald, Cron, & Wasserman, 2013; Kim & Spillers, 2010), number of illnesses (Godwin et al., 2013), poor economic situation and the demand for social and practical support (A. Ekwall, Sivberg, & Hallberg, 2004; A. K. Ekwall, Sivberg, & Hallberg, 2007; Ratcliffe, Lester, Couzner, & Crotty, 2013). Those with poor health, low social support, perceived stigma (Chou, Pu, Lee, Lin, & Kroger, 2009), living alone (Ratcliffe et al., 2013), feeling lonely, and with a small or non-existent network (A. Ekwall et al., 2004) are also more likely to be affected. In contrast, high QoL in carers is often associated with better coping abilities and a high sense of coherence (A. K. Ekwall et al., 2007).

There is, however, a dearth of research on the QoL of older family carers of people with dementia, with only four publications identified in a recent literature review (Oliveira et al., 2015). These studies showed that the QoL of individuals in the carer group were lower in older carers, those with more dependent care recipients, those who spent more time caring and also those who are female. These carers also experienced higher levels of burden and depression than carers in a younger age bracket. These risk factors are also evident in dementia caregiver of any age group (Broe et al., 1999; Leggett, Zarit, Taylor, & Galvin, 2010; Moon & Dilworth-Anderson, 2014; Pinquart & Sörensen, 2003, 2007; Vitaliano, Zhang, & Scanlan, 2003; Wang, Robinson, & Carter-Harris, 2014) and are also likely to be associated with higher levels of burden in a younger caregiver population (Abdollahpour, Nedjat, Noroozian, Salimi, & Majdzadeh, 2014; Adelman,

Tmanova, Delgado, Dion, & Mark S. Lachs, 2014; Harwood et al., 2000; Leggett et al., 2010).

To date, no research has been carried out that specifically seeks the views of older family carers of people with dementia with regards to what QoL means to them.

Moreover, there is no consensus as to how QoL is defined by this population, i.e. what QoL means to them. In order to bridge this knowledge gap, this current study therefore aimed to explore the particular aspects of QoL that are relevant to older carers of people with dementia, as well as the factors that decrease or enhance their QoL. Understanding these individuals' needs and perceptions of QoL will address future research and the support provided for them. Consulting with older family carers on their QoL allowed for a person-centred care approach, in which the focus of care is on the needs of the person, rather than the needs of the service (Brooker, 2004; NICE, 2016).

Method

This research was approved by the Research and Ethics Committee of the Faculty of Medicine & Health Sciences, University of Nottingham (D10072014 SoHS), and of the National Health Service, UK (15/IEC08/0041).

This is a qualitative investigation which is part of a larger sequential and exploratory mixed-methods project aimed at developing an age and dementia specific QoL scale for use with older family carers - the Dementia Quality of Life Scale for Older Family Carers (DQoL-OC) (Oliveira, 2016). Focus groups were carried out in the community of Nottinghamshire, UK, in 2014. This method is widely used to assess people's experiences of disease and health, and is a good strategy for exploring individuals' feelings, attitudes, and needs (Kitzinger, 2013). The study followed an interpretivist epistemological approach aiming to explore relevant aspects of QoL for older family carers of people with dementia living in the community. The objectives were to explore how these individuals make sense of their own QoL through their experiences, meanings and understandings of QoL, as well as to identify the factors that enhance or compromise their life quality. Group discussions were guided by three semi-structured research questions: 1) What

does QoL mean to you as a carer? 2) How do you experience QoL on a day-to-day basis?
3) What caregiving factors enhance or reduce your QoL?

Sample and recruitment

Older family carers are defined in this study as being individuals aged 60 years old or above, currently providing unpaid care for a family member with dementia at home, supervising or helping them with activities of daily life that they can no longer perform independently. Participants were initially approached by local community leaders and by support workers within voluntary organizations, such as the Alzheimer's Society. Individuals who were interested in the study were then directly approached by the researcher. Reasons for declining participation or not attending the scheduled meeting were predominantly due to the full time nature of their caregiving role and no other available source of support. Other reasons were generally related to their own physical health impairments that limited their access to the venue. A total of 19 older carers took part in the study and were divided in four focus groups with two to six participants in each group. Their age ranged from 60 to 81 years old, with the majority aged 70 or over (n=11). They were mostly married (n=18), female (n=13), had attended school for 9 years or more (n=17). Three of the carers reported having a job outside of their caregiving role. Participants were mostly co-residing spouses (n=16) or children living in different houses (n=2), providing care to their family members 24 hours a day (n=15), seven days a week (n=18). Their relatives were diagnosed with dementia for up to three years (n=7), from four to six years (n=7) or more than seven years before the study (n=5), mostly with Alzheimer's disease, vascular dementia, or both (n=12).

Data collection and analysis

The researcher read the Participant Information Sheet and the Consent Form with the carers and answered their questions about the study. After giving their consent, participants were accommodated in a private room at one of the support centres, when they were invited to answer a socio-demographic and caregiving questionnaire. The

focus groups followed procedural guidance from (Kitzinger, 2013) and sessions were tape recorded. Each group took between 50 and 112 minutes of duration.

Data was analysed using Interpretative Phenomenological Analysis (IPA) with the aim of capturing the older family carers' lived experiences and understanding of QoL (Smith, 2011). This method enables the capture of the subjective experience from the perspective of individuals, and includes a certain level of interpretativism in trying to make sense of what participant's think and feel about their own experiences, allowing a detailed exploration and in depth understanding of subjective meanings, experiences, opinions and needs (Smith, Flowers, & Larkin, 2009). Within focus groups, this method of analysis allows the exploration of the complexity of shared experiences in the groups' dynamics and the multiple voices that are embodied with a set of complex social and relationships contexts. This helps to develop a meaningful analysis of the participant's experiences, while considering social cultural factors involved in the group constructions (Palmer, Larkin, Visser, & Fadden, 2010; Tomkins & Eatough, 2010). After the transcription of the focus group data, the researcher carried out the steps proposed by Smith et al. (2009) for effective IPA. Data analysis was carried out in NVivo® package by two independent researchers.

The two sets of analysis were compared in order to enhance the robustness of the study findings. Inter-coder reliability was then established by correlating the two sets of analysis using Kappa coefficient. The independent examination of participants' accounts by another researcher helped to preserve the rigour of this qualitative investigation (Creswell, 2016). Even though inter-rater reliability is not often used within IPA studies, the researcher was non-native English speaker and had potential different cultural perceptions about quality of life and caregiving. This method therefore allowed for ensuring that participants' views were truly represented through the researcher interpretations.

Findings

Thirty-three subthemes emerged from the data analysis and were collated into three superordinate themes as outlined in (Table 1). Very good inter-coder reliability was established ($r=0.839$). The most frequent subthemes across all focus groups were daily conflicts ($n=111$), sense of burden of care and responsibility ($n=97$), and living a limited and restricted life ($n=102$). Subthemes were highly interrelated and therefore results from each superordinate theme are presented as a unit.

(Table 1)

Practical aspects of care and caregiving

More important than receiving support from health and social services was the extent to which this help was appropriate or adequate for older carers' needs. Carers had to face battles with the system to get a dementia diagnosis, with professionals who did not seem prepared to help, meaning that older carers' QoL may have been affected some time before the diagnosis.

P17: And, I told my daughters [about her husband's unusual swearing behaviour] and we went to the doctor, and he said 'I'll put sticky-tapes over your ears'. (Husband)'s got a neurol., ahm, a neurologist, at (hospital's name), for his brain haemorrhage. And I asked if I could go and see him, and he said 'no', he [husband] didn't need it.

As some participants were frail and had their own physical limitations, they found it very difficult to provide care. In this scenario, inadequate support from Social Services became an added source of stress and burden to their already difficult situation.

P4: Well, for me, what, what would improve my quality of life mostly is to have better support from health-care professionals, because (husband) is a very big man, a very heavy man, and just keeping him clean is extremely challenging, I can't clean his groins and his private parts, because I can't bend down. I can't do it. I can't kneel on the floor; I'll never get up if I kneel down. And the [formal] carers, just don't do that sort of thing, you know?

Some older carers had serious health problems themselves, such as Parkinson's disease, AD, cancer, and stroke, and being a carer interfered with them looking after their own health.

P3: I had to go to having two operations [cancer], one to diagnose and the second time, to have it out and then go through [inhale] various treatments [...] and I didn't feel there was a time for me to truly recover, I had to keep trucking in.

In addition, because the older person affected by dementia often had other co-morbidities, older carers' demands were significantly increased. They felt unsupported by the public system and frustration in not being able to provide good care.

P4: I am 72, (husband) is a very strong man, and, he has diabetes, he has hypertension, he has glaucoma, he has AF, he has all sorts of things, but he is actually a very strong man. [...] I do all of his, well I call the medical caring. I have to crush up his tablets, I have to give him his insulin, I have to apply, make sure he has his warfarin, I have to look after his feet, his legs, and there is very, very little help from the NHS for doing that.

They were also worried about the fact that their health issues would eventually prevent them from caring for their relatives. This was a constant worry for some of them.

P13: You can't be able to be ill when you're looking after someone with dementia [...] Because who is going to look after the person you're looking after?

Daily conflicts and symptoms also appeared to be hugely stressful and caused feelings of helplessness, frustration, and sadness for older carers, which significantly affected their overall QoL. Daily conflicts were mostly associated with the need for people with dementia to attend day centres or to accept paid carers in the home environment, as well as with all their day-to-day care needs (e.g. getting up in time, showering, etc.).

P4: He has day care two days a week in (day centre's name), which sounds great, but, 'a' is getting him organized, because he doesn't want to get up in the morning, and this morning was a nightmare!

While some carers of people in the early stages of dementia whose relatives only had memory problems appeared to have good QoL, carers of people in advanced stages of dementia demonstrated having their psychological well-being impacted by the disease stage. However, for some this situation was easier, because their relatives with advanced dementia were more passive and less confrontational, which reduced their stress.

P6: Because she is so far gone, she can't do anything. She doesn't argue, she doesn't, she doesn't get nasty, she doesn't.

P13: He's on the advanced stages now. But, you still have a laugh, and if you don't have a laugh, you cry.

For those who had no other source of support with caregiving and had a full-time caring role, regular respite support was important to maintain their own mental and physical health, and helped them to continue providing care at home for their family members.

P17: Ahm, (husband) goes to [day centre's name] two, two days a week, which gives me five hours each day; that's great! I can do things I want to do in those five hours.

They also appreciated the help provided by children and other relatives with practical care, especially at the advanced stages of the disease, when the physical care needs were more intense.

P13: If your daughters aren't there to help you, when they get as advanced as (husband), you're shot!

Participants also emphasised the importance of maintaining their friendships while being carers. Their social networks were generally reduced, either because of the limitations imposed by the caregiving needs, or by society, which isolated the carer and their cared for. This brought feelings of loneliness and sadness to participants.

P7: I had a group of friends, you've got this camaraderie at work, and I am leaving all that, to be a full-time carer. I... I mean, friends have gone, the acquaintance has gone, it so seems; I get very bored. You know? Especially in the winter time.

*P17: You are left with a few good friends, just a handful. And the others sort of...
They don't like the atmosphere, so they keep away, don't they?*

Another concern and source of stress for participants was getting access to carers' services and the impact of caregiving on their financial situation. The social care system appeared to be quite complicated for the older carers and often did not provide the support that these people needed to have access to their benefits.

P17: They [social services] gave all these forms for you to fill in, knowing, how old you are, and knowing what sort of stupid questions they ask, and you've got to fill them in! And, the older you get, the worse it is to try!

Carers' Allowance was usually used to pay care costs, and as they were mostly pensioners, they were no longer entitled to receive this benefit, even though they were still providing care.

P13: Whatever money I get for Attendance Allowance, pays for his days' care [tearful].

P7: I get Carers' Allowance, and I'll finish it in a year's time. I am still a carer! Really! It's the money side that worries you as well.

Another factor that helped to improve the older carers' QoL was receiving information about dementia and caregiving. This helped to enhance their QoL and the quality of the care that they provided for their relatives. Having enough information about the disease and its symptoms helped them to not attribute dementia symptoms to the person, which helped to maintain their mental health and ability to cope, and to preserve their spousal/parental relationship. It also enabled them to identify the sources of support that they could access whenever they found themselves in a difficult situation, preventing further distress.

P2: I've got a bit of knowledge of, of that, and, obviously that impacts on my caring [...] and because I understood those [symptoms] they didn't confuse me or make me frustrated or angry.

Feelings and concerns

One of the main challenges for the older carers was to allow someone else to care for their relatives. This represented an important decision and often involved considerable emotional distress and strain. Barriers to accepting support were imposed either by the carers themselves, or by their relatives with dementia. This was often associated with some level of stigma in the use of these care services.

P3: I take the responsibility. I know it sounds we've got a bit out of these care things, but we've set all alone. There is some satisfactory thing that you are doing the right thing.

P22: I mean, (support worker) from social services rung me up and asked me if I'd persuaded him to go in or not and what's his attitude now, 'cause he turns round, you know, he gets so vicious about it, as if I'm trying to shove him away. I'm not trying to shove him away!

For others this difficulty in accepting support was due to views on love and marital commitment, which caring for each other should be part of. For this reason, accepting care from services did not feel right for them.

P12: He's... I didn't know he [husband] was going with the carers, because, when you've done, same as P13 said, when you've been married that long, when you've done everything...

In cases where the difficulty in accepting formal care came from the person with dementia, carers had to face extremely stressful situations. This represented an added burden and distress, as they felt guilty in forcing their relatives to stay in a place where they did not wish to be.

P22: I'm in such a state now, and he won't go; he just threatens me and he gets nasty tempered. I don't know what to do! I don't know what to do anymore. My daughters said it's up to me [sighs]. I just need help and I don't know how.

Participants therefore perceived the use of formal services as being "a trade-off", because even though they may get some respite, their emotional health could be extremely affected by guilt and distress.

P2: And it doesn't feel good, bringing, strangers in to care for Mum, and there is an emotional journey there. [...] And there is a trade-off [...] you get guilt. So you share the care, with, ah, in this case, the agencies, ah, but then you feel guilty because you are, sharing it and giving it to strangers and not doing it all yourself.

Older carers also suffered with anticipated grief. They struggled to cope with the memory loss of their loved ones, especially the older spouses.

P4: He's not, he's lost all his perception of what his grandchildren meant to him. [...] I find it extremely hard to say to (husband): 'Look, here is a picture of (grandchild) on a Shetland pony'. And he says 'Oh, good for her'. That's very hard to take; it really is.

Especially for older spouses, the feeling of loss also means loss of lifelong companionship, as they will no longer be able to enjoy activities together or share their past memories.

P12: What do I miss? What I was saying, as I say, doing things, a lot of things together and doing things, you know? I mean, (husband), we always did everything together.

Much of the sense of loss that older carers felt was accounted for by the loss of identity of their relatives, particularly in spouses. They felt that their relatives had become strangers to them, which often generated emotional distress. For cohabiting spouses, this sense of loss had a severe impact on their marital relationship and identity as a couple, as well as on their own self-identity, causing feelings of loneliness, sadness, and helplessness.

P5: He was 'the most gentle' considerate gentleman. And he is suddenly, or gradually, is becoming a very obstreperous, cantankerous, difficult man! Nothing like the man I married!

P17: But that [memories] slowly goes out of your mind, and you forget the person as well because it's so dominant the person that you've got now, he is so full in in your mind, and in your thinking, that it's hard to go back and pick that up all those years ago.

One method some older carers found to cope with losses was to focus on positive memories from the past. These individuals were often those who reported better levels of QoL. They tried to reassert the activities that they were still able to do together and sometimes even started doing new ones in a way that meant they could both still enjoy life together.

P18: You've got to think about all the good times you had. I mean, and if the bad times come up, you've got to deal with them. You want to be thankful to what you've had, and not what you've missed. You know? You've got to look on the positive side.

Others found meaning or a purpose in life through caregiving. By reframing how they saw their everyday problems, they were able to see benefit from being a carer.

P6: I don't look at any problems as problems; I look at problems as a challenge. When you successfully complete a challenge, you feel good.

Caregiving also meant a constant worry about their relatives with dementia. Being apart from their cared for made them feel anxious, which impacted on a range of aspects of their lives, such as sleep quality and psychological well-being.

P2: When I wasn't there [with the cared for], I was just so worried. And calls in the night, and jumping over, at two o'clock in the morning...

Carers, and particularly spousal carers, also felt responsible for making their relatives happy and enabling them to have a high QoL, as it seemed to be part of their marital commitment.

P10: I mean, we do things together, and my wife is happy, and she'll laugh, and she's not sad. So that's good; I mean, I forfeit my bits and bobs to keep going as it is. [...] That's all, that's all my task is, to keep her happy.

Advances in dementia meant lower levels of reciprocity in spousal relationships. Feeling unable to make their cared for happy generated frustration and a sense of failure as carers or partners.

P4: And you just, is such a sense of, just, failure, to, to look after him properly in the sense of making him happy. But I... I... I can't make him happy.

Older carers were also constantly worried about keeping their relatives healthy and felt that they did not receive enough support with this aspect of their caregiving role.

P4: My concerns are about everything, but (husband)'s health, that I find it very hard to keep him healthy and that I am unable to get what is the support that I feel that I need. [...] because I want him to be healthy; I don't want him to have soreness and infections...

The older carers also demonstrated feeling concerned and responsible for their family members' safety, which was intimately associated with how satisfied they were and how much they could trust Social Services to care for their relatives. Feeling that their relatives were in a safe environment gave them a sense of psychological well-being.

P3: So I would say that quality of life [...] is having that confidence that she is safe in the setting she is in [...] just made us, I think, far more in peace.

This sense of responsibility towards their relatives' well-being also made participants feel that caregiving became dominant and that they lost control over their own lives, as they felt subjugated to their relatives' needs.

P4: I... I can't take (husband) with me to see him [grandson] because (husband) doesn't want me looking at other people or talking, he wants me looking after him [...] (husband) dominates my whole life [...]

Because participants felt that they had to preserve their relatives' independence as much as possible, they felt obliged to do what this relative wanted to do all the time, putting aside their own expectations and wishes in life in order to keep their relatives active for longer.

P19: I mean, as far as, you know, on the whole, quality of life isn't too bad, at the moment, 'cause we can still go out and, you know? But it's all about what he wants to do. I feel as I should be, doing things that he likes to do, while he can still enjoy it, you know?

A sense of control was also associated with feeling of safety. If carers were able to have control over caregiving and over their lives, they felt safe.

P6: I think if you feel in control, you feel safe. If you don't feel in control, you'll be wobbly.

The older carers also had negative expectations about the future not only related to the disease progression, which is uncertain, but also about their own QoL prospects. Carers referred to not being able to envisage any QoL for the future.

P15: Note what quality of life we are going to have for the next years or whatever it is. I don't; you can't have a quality of life. We don't know what's going to happen.

Because most participants were spouses, they felt that they had a duty of marriage, which implied being a carer for their spouses with dementia.

P4: Obviously part of that is that you married some one that, for better or for worse... And you, that's something that you just have to take on board.

In other cases, this duty of care came from their cared for, especially in parental care. P2 explained how her mother expected her daughters to provide full-time care for her, not accepting other sources of support. This feeling of duty may explain why some carers struggled to accept support with caregiving or felt guilty for doing so.

P2: She [mother] did actually say to one of the carers, in front of my sister, 'You shouldn't be here. I have daughters; they should be doing this. That's what I have daughters for!'

The older carers reported a huge amount of burden generated by several factors related to caregiving. This was expressed in several parts of the focus groups, by for example their inability to cope and increased family and house responsibilities as a result of dementia progression. Carers also felt forced to choose between their own lives and their relative's needs and provision of intensive physical care. These situations led participants to feel extremely exhausted (such as P5 below), having a dramatic impact on their mental and physical health, as well as social relationships, which invariably affected the quality of their lives.

P5: I feel that I can't manage, I ca... I can't, you know, there is [sighs deeply] there is just so much that I just can't do it.

One aspect impacting specifically on spouses' QoL, which may be particular to this generation of older carers, is the fact that they found themselves having to take over their partner's role. Male carers found themselves having to cook and clean their homes, which in the past had been their wives' role, and older women had to deal with finances and fix problems around the house, which used to be their husbands' role.

P19: I've got to make all the decisions now, you know, and (husband) can't make a decision. You make the decision for everything and you take over everything.

While some of the participants found ways of coping, such as appealing to faith, religion, or spiritual beliefs, others felt resentment and anger towards their situation.

P17: Well, I sort of pull on to my religion [...]

P3: Ahm, and, it felt resent. Resentment. Because, it was a black hole just sucking you dry [mother/dementia].

Satisfaction with life and with caregiving

One of the major challenges for the older carers was the limited and restricted life that they had resulting from the need to adapt their lives to their caregiving. Some participants adapted to the limitations in order to cope; others did not feel that they had any choice and therefore felt very sad and frustrated. These older individuals did have their own physical impairments but had arrived at later life with relative independence and energy. However, they felt forced to limit their expectations of life because of their relatives' limitations, thus gradually becoming less active.

P10: Well, it changes, it changes your quality of life, your own quality of life [...] I used to walk, I used to do a lot of garden, I used to do all these, but you have to pack it up because it takes too much time up, 'cause she cannot cope with me being away to long [...] You can't leave them. So you've got to accept; you've got to say you've packed up.

Mostly, older carers felt that their expectations for retirement had not been achieved.

They felt unable to travel and enjoy their pension, to share memories with their partners, and be part of their grandchildren's lives. Participants who struggled to accept

these changes suffered living a life that they did not wish to live and were very dissatisfied with it.

P4: I... I would say I have actually no quality of life, at all. I... I... In terms of the expectations that I had of my retirement, none of that is, is available to me. I can't see my grandchildren, I can't go anywhere, in particular, I can't do anything [...] This is not what I expected and, to be honest, it's not what I want. I do want to look after (husband), but I want to... It isn't what I wanted in my old age, to be, tied 24 hours a day into the house, not able to do the things that I wanted to do, and above all, not being able to see my grandchildren and see them grow.

Because their interests were limited by their caregiving needs, these older carers' self-identity was also affected. In addition, the loss of identity of the cared for was also intimately related to the identity of their carers, especially in spouses. Their identity as a couple and as life partners slowly became substituted by their identity as carer and cared for. This was quite sad for carers and appeared to have a great impact on their psychological well-being.

P17: [...] and who is me? And who is (husband)? Who is (husband)?! And, you slowly forget what they've been, 40 years ago to you, because it's taken out of your mind by what you are doing now!

Participants perceived their own selves and those of their relatives with dementia as a unit and so the limitations caused by dementia not only affected the person with the disease but also limited how much the older carer felt he or she was able to accomplish. The more dependent the person with dementia became, the less the older carers perceived themselves as able to do or learn. When asked about her own QoL, P18 spoke as if her husband's QoL was part of her own QoL.

P18: We like dancing. We go dancing two or three times a week, but we don't learn; we only learn what we can cope with.

Those who were able to preserve their own interests and keep their own identity acknowledged that this enhanced their QoL.

P2: [I] separate my sense of well-being as a carer, as opposed to my sense of well-being in the rest of my life. [...] So, there is the other side of that which I try to put all on a separate shelf; otherwise, I just get totally, I get lost in, in, in negativity [...] that's how I cope with it.

Due to a shifting of identities, older couples found their closeness was also gradually eroded and their intimacy was largely affected. For this reason, older carers felt very lonely, even though they did not live alone.

P17: But, at the end of the day, it sounds really awful for me to say this, you really lose the person that you knew! And they sort of become further away from you; the closeness becomes further way.

P4: It's, it's been very, very difficult [...] so, there is no conversation; there is no interaction.

Co-residing older spouses were also more likely to have their sleep quality affected, as they were greatly effected by their relatives' sleep disruptions. This impacted on how much carers could recover from a stressful day, rest mentally and physically, and preserve their own health and well-being.

P4: I get no sleep because I have to have a buzzer that wakes me up when he gets out of bed, and, ahm, because he can't manage toileting on his own, so, it's fine; he gets up, and I take him back into bed and [pretends to be snoring]. Then I'm awake for hours now and everything is going around... [thinking]

Another large part of how satisfied the older carers were with their life and their caregiving was related to how satisfied they were with the care they were able to provide for their family members.

P1: [my quality of life] depends upon how satisfied I am with what I do and how I do it. Feeling that whatever I'm doing, I've done it, to the best of my ability.

P5: I don't feel to be doing anything to the best of my ability (laugh)! I always thought I was a very practical, ahm, sensible sort of person, and, ahm, I am, now, a bit like you [points to P4], going downhill.

Discussion

Little is known about what is important to improve the QoL of older family carers of people with dementia in the UK. This study therefore aimed to investigate some of these unknowns by exploring how older family carers make sense of their own QoL through their experiences and understanding of what QoL means to them, and the factors that enhance or compromise their QoL. Three superordinate themes emerged from focus groups, namely practical aspects of care and caregiving, feelings and concerns, and satisfaction with life and caregiving. The older carers disclosed their intimate feelings, expectations, information, experiences, which has been considered therapeutic for older people (Powers & Wisocki, 1997) and suggests a strong 'group identity' (Barbour, 2007). Although inter-coder reliability tests are not commonly used within IPA studies, this test helped the authors ensure that the views of participants were truly represented through the identified themes.

The results of the current study corroborate highly with previous research carried out with older family carers in other disease contexts mentioned earlier. The most frequent aspect impacting negatively on the older family carers' QoL was the presence of daily conflicts, often resulting from dementia symptoms. Neuropsychiatric symptoms have also been identified in the literature as being important causes of stress and burden in family carers (García-Alberca et al., 2014; Pinquart & Sörensen, 2004; Svendsboe et al., 2016), which were also themes identified in this group of older carers.

Several research studies with family carers have also demonstrated how physical demands may have a high impact on carers' health and well-being (Dilworth-Anderson, 2015; Laks, Goren, Dueñas, Novick, & Kahle-Wroblewski, 2016; Steptoe et al., 2015). This is sometimes due to other co-morbidities (McCarron, Gill, McCallion, & Begley, 2005), which generate need for complex care in older carers (Samuelsson, Annerstedt, Elmståhl, Samuelsson, & Grafström, 2001). As with the study participants, the literature has demonstrated that older family carers often report more chronic illnesses when compared with young adult carers or older adults who are not carers (Shahly et al., 2013). Physical demands have been demonstrated to be especially harmful to older

carers, as their often compromised state of health and the presence of chronic and disabling diseases may impact greatly on their capacity to provide care (Schulz & Sherwood, 2008).

Due to the aforementioned challenges, participants highlighted the importance of having a strong informal support network in order to maintain their QoL. Other studies also demonstrate that support from family and friends indeed helps to decrease depressive symptoms (Moon & Dilworth-Anderson, 2015), burden (Coen, O'Boyle, Coakley, & Lawlor, 2002), and loneliness (Anna K. Ekwall, Sivberg, & Hallberg, 2005) in older carers. In contrast, having access to extensive social ties (Berkman et al., 2004) and having a productive role (Rozario, Morrow-Howell, & Hinterlong, 2004), strengthened social networks (Huang, 2012), and more general resources (Neri et al., 2012) are associated with more favourable health and psychological outcomes in this population. Participants reported that the quality of the support received, as well as their financial situation, negatively impacted on their QoL. This is also replicated by several other studies as contributing to older carers' QoL (Oliveira, Neri, & D'Elboux, 2016; Shurgot & Knight, 2005; Wiles, 2003).

Participants' high levels of perceived burden due to an increase in domestic chores and change of family roles have also been identified in previous qualitative research with older carers (Egdell, 2013; Steptoe et al., 2015). Participants' sense of loss and anticipatory grief, which had a major impact on their psychological well-being and overall subjective QoL, are also shown in the literature as impacting on carers' ability to cope with the stressors, leading to depressive symptoms and lower levels of subjective QoL (Garand et al., 2012; Shuter, Beattie, & Edwards, 2013).

Participants' constant worry, as well as sense of failure, guilt, frustration, distress, and resentment are also considered important aspects of psychological well-being in the literature (Carers Trust, 2011; Steptoe et al., 2015) (McDonnell & Ryan, 2014; Santos, Sousa, Ganem, Silva, & Dourado, 2013). Older carers coping strategies, such as having positive view about their situation or having increased spirituality, were also been identified in other qualitative investigations as mitigating factors of negative feelings

(Villareal-Reyna, Salazar-González, Cruz-Quevedo, Carrillo-Cervantes, & Champion, 2012; Zhang, Edwards, Yates, Ruth, & Guo, 2012) and have shown to reduce levels of burden (Spurlock, 2005) and improve mental health outcomes (Hebert, Dang, & Schulz, 2007) in other studies.

Another highly relevant theme relating to older family carers' QoL was the feeling of being limited in terms of their own interests, which is confirmed by the literature (Dilworth-Anderson, 2015; Lavela & Ather, 2010). This can lead to loneliness and limited social networks resulting in isolation and has been considered a strong predicting factor of low QoL levels in older carers (Anna K. Ekwall et al., 2005). Moreover, as older people are more likely to value close and meaningful relationships in their lives, as opposed to general and short-term relationships (Carstensen, Pasupathi, Mayr, & Nesselroade, 2000), older family carers may find their close relationships disrupted by their caregiving role.

Added to the reduced access to positive social relationships, older family carers can also lose their sense of self-identity, which is often the result of intense caregiving demands, and may hinder their own interests and desires. Participants' self-identity was also affected when the person with dementia no longer recognised the older carers as being their spouses or their children, or when the older carers needed to assume a different role in the relationship with their cared for (e.g. husband vs wife roles). This has been described in the literature as a factor affecting closeness between carer and cared for, as well as the quality of marriage and intimacy (for older spouses in particular) (Hayes, Boylstein, & Zimmerman, 2009).

Higher levels of well-being in older people help to maintain life control during periods of stress (Hansen & Slagsvold, 2012). When external factors are ideal (e.g. strong social support, good financial situation, positive relationships) and accessible, it has been suggested that older people have greater life satisfaction than younger people. However, in the face of inevitable and prolonged stress, such as experiencing a negative situation as a carer, this psychological regulation suffers, and these individuals may struggle to cope. When compared with the general older population, older family carers may not be

able to compensate for stress and daily challenges and therefore may not be able to protect themselves from them. Participants in the present study had their well-being reduced considerably and their QoL greatly affected. Most of the older carers were not able to compensate for the negative impact of caregiving and therefore to cope and protect their well-being from this experience. Those participants with better capacity to cope had various situations which allowed them to compensate, such as strong family support, healthy financial situation, or their cared for were at the early stages of the disease, with almost no dementia symptoms present.

Older people who are carers may therefore be at higher risk for adverse outcomes if they are not able to maintain well-being and satisfaction with life and prevent such outcomes (Newsom, Mahan, Rook, & Krause, 2008; Reishardt, Boerner, & Howrowitz, 2006). This may explain why several studies show older carers with worse health and psychological outcomes when compared with young adult carers or older people who were not carers, even though the majority of studies still show higher life satisfaction in this population when compared with young adult carers (Anderson et al., 2013; A. K. Ekwall & Hallberg, 2007; Harwood et al., 2000; Tang, 2011).

Conclusion

This qualitative research explored how older family carers of people with dementia in the UK make sense of their own QoL through their experiences and understanding of what QoL means to them, as well as identified the factors that enhance or compromise their life quality. Focus groups with 19 older family carers helped to identify three broad areas of QoL, namely practical aspects of care and caregiving, feelings and concerns, and satisfaction with life and caregiving, which were associated with participants' QoL. The 33 subthemes composing each of these major groups were described and analysed using a detailed and interpretative approach, which helped to shed light on the particular caregiving issues associated with these individuals life quality. The most frequent themes emerging from participants' narratives were daily conflicts, sense of burden of care and responsibility, and living a limited and restricted life. Even though this is a small

qualitative study, it included older family carers of people with dementia from various sociodemographic backgrounds, representing the wider population of older carers. Findings corroborated highly with studies carried out with older family carers in other disease contexts. In addition, findings were in line with the available literature related to QoL of family carers and the QoL of the general older population. Considering that little is known about the QoL of older family carers of people with dementia, this study has the potential to inform future qualitative and quantitative research in this area aiming to expand the knowledge in this field. It can also help inform the day-to-day support provided to these individuals.

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