

*“I know who I am; the real me, and that will come back.”* **The importance of relational practice in improving outcomes for carers of people with dementia**

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## **Abstract**

Effective support to carers of people with dementia can be critical to maintaining quality of life for people with dementia, their families and to sustaining the future of health and care systems. Qualitative interviews were undertaken with 14 carers of people with dementia across Scotland, and the data analysed to identify the outcomes important to the carers. The importance of relationships emerged as the core theme, including relationship with the person with dementia, family members, other carers, and professionals. Although not evident in the literature, the authors noted the concept of self-relationship was important to carers in the context of changing relationships with others. A multi-layered approach to understanding relationships, and an approach to engagement that enables carers to define and express their priorities, is necessary to fit with the relational nature of care.

## **Key words**

Carers, dementia, personal outcomes, relationship-centred practice, self-relationship

## **Caring and dementia as a global public health priority**

Dementia has been defined as a global public health priority by the World Health Organisation (WHO) and Alzheimer's Disease International (ADI) (2012), who highlight the immense impact on the families involved, and particularly for the primary caregiver. They identify the stressors carers experience are physical, emotional and economic (WHO & ADI, 2012). The WHO estimate that 47.5 million people worldwide are living with dementia. The total number of people with dementia is projected to increase to 75.6 million in 2030 and 135.5 million in 2050, with the majority living in low- and middle-income countries (WHO, 2016).

With regard to carers and dementia, the WHO caution against assumptions being made about their role. Thus, it should not be assumed that health and social care systems play the primary role in higher income countries, and conversely, in developing countries the reliability and universality of the family care system is often overestimated: "Mythologizing the caring role of the family evidently carries the risk of perpetuating complacency" (WHO, 2006, p49). In the context of dementia as a global concern, it is clear that supporting carers of people with dementia is critical to the quality of life of people with dementia and their families, and sustaining health and care systems (Bailey, Kingston, Alford, Taylor, & Tolhurst, 2016). Yet, there is still much to learn about carer experiences, including how best to support individuals in relation to their sense of self and maintaining relationships with those involved in the caring experience. In the European context, with reference to carers of the growing older population, Eurocarers (2015) identifies a need to more actively involve carers in evaluating services, and for the development of outcome measures incorporating a strengths based approach. Further, holistic assessment is proposed as an important step in providing timely,

responsive information, advice and support to match the preferences and situation of the carer (Eurocarers, 2015).

### **Dementia, the carer experience and relationships**

There has been a tendency in literature on caring generally, and caring for people with dementia specifically, to focus on negative aspect of caregiving, with reference to 'burden' (Donellan, Bennett & Soulsby, 2015; Etters, Goodall & Harrison, 2008), 'struggle' or 'uphill fight' (Sutcliffe, Roe, Jasper, Jolley & Challis, 2015). Difficulties in navigating services have been identified, particularly in relation to residential or day service support (Georges, Jansen, Jackson, Meyrieux, Sadowska & Selmes, 2008), with the 'battle' involved increasing carer strain (Peel & Harding, 2014). Manthorpe and Bowling (2016) identified that notions of carer stress are most prevalent in literature on caring for people with dementia. Consistent with the WHO and ADI (2012) report, the impact of caring for people with dementia is described in terms of the physical, social, psychological and financial stressors of caring (Alzheimer's Research UK, 2015; Newbronner, Chamberlain, Borthwick, Baxter & Glendinning, 2013; Georges et al., 2008).

A common theme is the impact on the relationship between the carer and the person with dementia, with carers identifying complexities in sustaining the relationship, due to the loss of the person they knew, with particular reference to the wellbeing of spousal carers (Evans & Lee, 2014; Gillies, 2011). Wider relational consequences of caring include the negative psychosocial impact of loneliness (Charlesworth, Shepstone, Wilson, Thalanany, Mugford & Poland, 2008; Gruffydd & Randle, 2006).

Despite a tendency to focus on negative aspects of caring, there is evidence highlighting the positive aspects of caring. For example Keady and Nolan (2003) summarise literature that

identifies carers finding meaning in and motivation for the caring role related to the quality of the relationship prior to the onset of dementia. More recent literature also discusses enthusiasm in caring for the person with dementia (Skaalvick, Norberg, Normann, Fjelltun & Asplund, 2016) and satisfaction with the role (Lloyd, Paterson and Muers, 2014; Sano, Dahlman, Sewell & Zhu, 2013). Other research has linked positive experiences with factors that sustain carers, including support from friends, family and professionals, that help to maintain health and well-being (Evans, Harrison-Denning & Read, 2016; Lin, Macmillan & Brown, 2011). More generally, it has been identified that caring can positively impact relationships between the carer and the person with dementia (Alzheimer's Research UK, 2015).

The ways that carers adapt to the caring role and how this impacts on identity has been conceptualised in various ways. Carers' sense of self has been identified as central to adapting, managing conflicting emotions and sustaining the caring relationship (Skaalvick et al., 2016). While resilience is a theme (Donellan et al., 2015) associated with notions of 'bouncing back' from adverse circumstances (Windle 2011) there is as yet no integrated, fully operationalised definition of resilience (Donellan et al., 2015). Related concepts such as managing, competency and self-efficacy are also prevalent, linked to the continuing capacity of the carer to cope (Nolan, Ingram & Watson, 2002a). Skaalvick et al. (2016) focused on the impact of particular relationship effects, which can vary by gender, type of relationship, or both.

Assumptions cannot be made about the outcomes important to individual carers, or about the influence of interventions. For example, although information about dementia can help to improve understanding and confidence, competence and a sense of security and achievement for carers, it can also complicate caring practices in ways that reinforce previously difficult

relationships (Barnes, Henwood & Smith, 2014). These authors emphasise the importance of responsiveness to the carer, in the context of relational practice. Further, several authors caution against conceptualising caring as a one way street, preferring the concept of interdependence, (Fine & Glendinning, 2005; Nolan, Ryan, Enderby & Reid, 2002b) allowing for reciprocity for everyone involved.

From this perspective, it is critical that a conversation takes place with the carer, which might require building trust over time, in order that the carer is supported to understand and articulate their perspective and priorities in the context of changing relationships within the caring situation. One approach to promoting this type of engagement is through a personal outcomes approach.

### **Personal outcomes and carers**

Personal outcomes have become an increasingly important focus of health and social care policy in Scotland., emphasised for example by the Christie Commission report (Scottish Government, 2011), 8 Pillars model of community support (Alzheimer's Scotland, 2012), Focus on Dementia (2015) and the Carers (Scotland) Act (2016). A personal outcomes approach involves working collaboratively with people to identify what matters to them, and then planning how best to work towards those personal outcomes (Cook and Miller, 2012). The personal outcomes framework is rooted in extensive fieldwork with people who use services and their carers. A personal outcomes approach to carer engagement and support planning has been promoted in several countries, including the UK and in Sweden for many years, starting with early work at York University (Nicholas, 2003), which showed that the approach could support shared and responsive decision-making. Recent work from Wales argues that renewed efforts are required to promote narrative and outcomes focused approaches to support planning with carers, promoting 'the importance of practitioner-carer

interactions and the building of relationships' (Seddon & Robinson, 2015, p21). This concurs with earlier work from Sweden (Hanson, Magnusson & Nolan, 2008), promoting strengths based and outcomes focused planning. Work to embed outcomes based support planning has been promoted for several years in Scotland, where there is evidence of improved partnership between carers and services, and stronger links between maintenance of carer identity and decision-making (Jarvis, 2009; Miller, 2012; Miller & Barrie, 2016; Tsegai & Gamiz, 2014). The exchange model of assessment, which promotes partnership between the person being cared for, the carer, practitioner and organisation has been critical to underpinning the principles of the approach (Miller, 2012). A personal outcomes approach focussing on what matters to people has more recently been brought to the forefront by the Carers (Scotland) Act (2016) which emphasises the requirement to develop an adult carer support plan that incorporate carers' identified personal outcomes. The findings of this study are therefore particularly pertinent at this time, with a renewed focus and emphasis in several countries on a personal outcomes approach to practice.

### **The study**

This study was part of The Focus on Dementia Programme in Scotland (NHS Education for Scotland [NES], 2016), which now sits within Healthcare Improvement Scotland as part of the Improvement Hub – an improvement resource for Health and Social Care in Scotland. Understanding the experience of carers for people with dementia was key to the programme to develop an evidence base that could shape development and improvement of local services. (Scottish Government, 2013) This paper reports on one element of this study that aimed to explore the experiences of caring for a person with dementia.

### **Sampling/participants**

A sample of 14 individuals who identified themselves as a carer for a person with dementia, from five localities across Scotland (North Lanarkshire, Glasgow, Midlothian, Highland and Moray), were recruited to take part in the study (see table 1). The Focus on Dementia programme worked with five different health and social care partnerships, with each site being managed by a Test Site Study Manager whose role in this service improvement initiative included identifying carers, inviting them to take part in the study and gaining written informed consent.

**Table 1: Participants in relation to pseudonyms, locality and relationship to the person with dementia:**

| <b>Participant pseudonym</b>     | <b>Relationship to person with dementia</b> |
|----------------------------------|---|
| Theresa                          | Cares for husband                           |
| Mandy                            | Cares for father                            |
| Ken and Daisy (husband and wife) | Care for Ken's mother                       |
| Diane                            | Cares for mother                            |
| Diana                            | Cares for father                            |
| Lorna                            | Cares for sister                            |
| Kevin                            | Cares for wife                              |
| Tina                             | Cares for son's mother-in-law               |
| Norma                            | Cares for husband                           |
| Katherine                        | Cares for mother                            |
| Edith                            | Cares for husband                           |
| Violet                           | Cares for husband                           |
| Jennifer                         | Cares for husband                           |
| Chris                            | Cares for husband                           |

## **Methodology/Methods**



A qualitative approach was employed, with the aims of understanding and giving meaning to experiences as opposed to measuring outcomes such as quantity and intensity (Denzin & Lincoln, 2011). Interviews were carried out by two researchers using the methods of emotional touchpoints and photoelicitation. Emotional touchpoints, originally developed by Bate and Robert (2007) represent an interview technique that helps explore an individual's experience in a structured way, by focussing on emotions (Dewar, Mackay, Smith, Pullin & Tocher, 2010). It focuses on 'touchpoints,' or neutral points in an experience journey, whereby participants are asked to select from a range of emotional words those that sum up what the experience felt like, and explain why they felt that way. The three core 'touchpoints' co-created with staff and carers in localities involved in this study were: caring together, my life and the future.

Photoelicitation is a method that uses images during the interview process. It can capture different, deeper and more meaningful information than questioning alone (Dewar, 2012; Harper, 2002). At the end of each interview participants were invited to select an image that summed up how they felt about the experience of caring from a selection of 70 generic images taken from the NES Envision cards (NES, 2012). This enabled the participants to review their caring experience overall and articulate key aspects of this experience. The methods of emotional touchpoints and photoelicitation were specifically selected for this study to enable participants to tell their story with the aim of gaining richer and more meaningful information.

## **Ethical Considerations**

The Scottish Government contacted the study managers at each site and gained permission to do this work, as part of a wider initiative to explore the experiences of people with dementia and their carers, it represented quality improvement within service provision contexts, and was not deemed as requiring formal ethical approval. Ethical principles of informed consent, anonymity and confidentiality were adhered to throughout the study.

### **Data Analysis**

A modified version of immersion crystallisation was used to analyse the data (Borkan, 1999). This process involved two researchers initially immersing themselves in the data, pausing to reflect on findings to consider hunches, openly code data and identify patterns and exceptions. From this initial analysis a set of themes and subthemes were developed. While the interviews were loosely structured around touchpoints about the life of the carer, their caring experience and the future, the researchers analysed the data through the lens of personal outcomes for carers, generated through years of research about what matters to carers (Hanson et al., 2008; Nicholas, 2003,) with particular reference to the model developed in Scotland, as set out in table 2 (Cook & Miller, 2012).

**Table 2- Outcomes important to carers (Cook & Miller, 2012)**

| <b>Quality of life for the cared for person</b> | <b>Quality of life for carer</b>  | <b>Managing the caring role</b>                   | <b>Process (relate to the experience that individuals have seeking, obtaining and using services)</b> |
|---|-----------------------------------|---|---|
| Quality of life for the cared for person        | Maintaining health and well-being | Choices in caring, including the limits of caring | Valued/respected and expertise recognised   |
|   | A life of my own                  | Feeling informed/skilled/equipped                 | Having a say in services  |
|   | Positive                          | Satisfaction in                                   | Flexible and  |

|  |  |                           |   |
|--|--|---------------------------|---|
|  | relationship with the person cared for | caring                    | responsive to changing needs                        |
|  | Freedom from financial hardship        | Partnership with services | Positive relationship with practitioners            |
|  |  |                           | Accessible, available and free at the point of need |

## **Findings**

The salience of the outcomes framework for carers of people with dementia (table 2), was confirmed when applied retrospectively to the data generated in this study. Between them, carers referred to all of the outcomes. The strongest overarching theme was the importance of relationships, which were often linked to other outcomes in the framework. Subthemes included emphasis on the relationship between the carer and the person with dementia and with other family members, relationships with other carers, the importance of the carer's relationship with self and with practitioners. Therefore we present the findings under these themes.

### **Relationship between the carer and the person with dementia**

As our core focus is the carer situation and experience, we will not expand on carer concerns about the outcomes related to quality of life for the cared for person, other than to say that core carer priorities were knowing that their relative with dementia was happy, retained a sense of purpose in life, and was safe. These outcomes had a bearing on the quality of life of the carer, and as will be demonstrated in the following sections, carer quality of life interacts with relationships with others. Although material circumstances were not mentioned by all participants, they did have a bearing on several caring situations. Regarding availability of

services, variations were apparent across health boards, with particular issues in the North of Scotland, where transport, care homes and day care were identified as gaps in provision. Financial security had an impact both on the present caring situation in terms of being able to maintain quality of life, and in terms of worries about the future and being able to plan continuing management of the situation as the illness progressed.

In considering the relationship between the carer and person with dementia, it is important to acknowledge the pressures which can arise. Previous research, describing the ‘burden’ and ‘struggle’ involved, have identified the challenges faced by carers of people with dementia, including sleep deprivation, incontinence, changes in behaviour and concerns about risk taking in the person with dementia, which were replicated in this study.

*We got a good night's sleep last night because she slept all night but the previous two nights we did not get much sleep. This is when I get frustrated and tired. This impacts more than all of the other things that I have told you; the lack of sleep. (Tina)*

In this context, unsurprisingly, a key theme relevant to the relationship with the person with dementia, was how this changed as a direct result of the illness, with some describing having ‘lost the person’ they once knew:

*You're living with a person you don't know, a shadow/ghost of someone, so you feel completely cut off. (Jennifer)*

Changes in how the person behaved as a result of the dementia could be frustrating for the carer, particularly as the illness might present barriers to communication about the impact.

The following carer felt that she couldn't share her feelings with her mother:

*What she sees is I am tetchy but I try not to get angry with her. I can't tell her how I feel. (Diane)*

This was not always the case however. The following female carer described how as the disease progressed, her father's dementia had a more positive impact on their relationship:

*Our relationship has got better since he stopped drinking; it is more relaxing for me ... things have improved when the dementia had progressed and paid carers came in to support my dad. (Mandy)*

Feelings about the relationship between carer and the person with dementia varied according to how the historical relationship had been. The female carer who identified that she couldn't speak to her mum about her frustrations about caring, also noted that the relationship prior to the dementia had not been particularly positive:

*I could never tell her how I felt, we were never close enough. (Diane)*

Despite the range of challenges described by interviewees, all but one talked about satisfaction they got from caring for the person with a dementia, using expressions such as feeling 'proud' and 'privileged' to be able to care:

*I'm proud that I'm doing something for somebody else. It makes me feel good about me. Sometimes you could just go "oh no, I could see this far enough" but ..... once you've done the task you feel good. It's worth getting through to the other end of it. I feel good about me. (Lorna)*

Some carers felt pleased about being able to give something back – a feeling of reciprocity, with one female carer identifying she was only repaying 'a fraction' of what her parents had given her. Particularly powerful was a recognition from the cared for person:

*When people say to my wife 'do you get on alright with Kevin?' she says: 'I couldn't do without him, I'd be lost without him'. And that gives me a boost, knowing that she knows. (Kevin)*

Some carers spoke about how their relationship helped them be aware of their knowledge about the person they cared for and how they used this to help them in their caring role:

*When my dad gets confused I say to him let's sit down and try and put your jigsaw together, you're trying to take pieces from different parts of your life, and we try together to make sense of things. (Diana)*

In the face of changing relationships between the main carer and the person with dementia, it might be assumed that the main carer would seek support from other family members. However, this was not always straightforward.

## **Relationship between the carer and other family members/friends**

Although some carers discussed the importance of maintaining positive relationships with, and involving other family members, there were complexities involved. Sometimes the main carer felt they should protect the person with dementia, which could mean concealing the extent of the difficulties faced as a result of the illness. However, there could be a sense of relief when the carer did share the realities, particularly where family responded by offering support:

*My family have been great – when they realised how bad things had got. I hadn't told them how bad it was – he's their Dad after all and I didn't want to run him down. I didn't want to be saying things about Harry. (Violet)*

Another carer described her reluctance to talk to her daughter, expressing conflicted feelings about her daughter's involvement. Instead, she confided in a close friend, and even then only talked about 'some of the things.'

*I only told a close friend some of the things...I was missing the family and had nobody here 'of my own' to really open up to. You don't want to worry the family because they are so far away but then again, it is her dad, I only have the one daughter, and she must know what is going on. So I was worried about that..... (Edith)*

Another carer had a different perspective. She seemed to be aware that caring in general could impact on other relationships, and although she had experienced 'clashes' through caring, she seemed clear about her priorities and was determined to maintain positive family relationships:

*My caring role is not impacting on any other relationships in my life but it can happen. There have been clashes, but ..... I have made it very clear that my children and my grandchildren come first and they are my priority. But my two girls are very understanding. They have got good jobs and they don't depend on me for a lot but my grandchildren like to see me. And I enjoy spending time with them as well. (Lorna)*

Thus maintaining positive relationships with other family members and friends could involve complex, even conflicting feelings, relating to progression of the disease and the behaviour of

the person with dementia. It also appeared that the carer's sense of self in face of the changing relationship with the person with dementia, could influence whether they were prepared to be open with and involve other relatives.

### **Relationship with other carers**

Relationships with, or peer support from other carers was discussed less than relationships with others in these interviews. However, several carers identified contact with other carers as helpful. In the following example, the carer places value on attending groups with her spouse who has dementia. She identifies that as a couple, they obtain different benefits from these opportunities, impacting on their relationship with each other, and relationship with self:

*I am very fortunate with the Alzheimer's Scotland groups. They are brilliant. .... He goes to football memories groups ..... Singing groups, we've got one tomorrow..... we go to allotment groups every week. .... I can talk sense there as there are a lot of carers there. They're very educated people so it's great for me and it's great for him... We would have gone completely bananas without them.  
(Norma)*

Being able to talk to people who have shared experiences of caring for a person with dementia seemed beneficial to several carers, with one describing this as 'supportive' and the following carer similarly enjoying the peer support:

*It was nice to sit and listen to individuals who are in the same situation as I am.  
(Katherine)*

Reflecting the diverse geographical settings of the carers involved in this research, these opportunities were not necessarily available to everyone however, and identified as a gap in some cases:

*We would like more help, for example, a class or a group where people could sit down and share experiences. This would also help us feel less isolated and less like we are the only people in this situation. (Ken and Daisy)*

Thus, for several carers the opportunity to interact with others in a similar situation was valued or sought out in order to feel supported and less isolated in their role.

### **Carer relationship with self**

The theme of relationship with self, related strongly to two of the personal outcomes identified by Cook and Miller (2012) under the heading of quality of life for the carer; ‘maintaining health and wellbeing’ and ‘a life of my own’. Maintaining health and wellbeing is a key concern for many carers, who do not want to compromise their capacity to care. As the following carer suggests, this requires that the carer remains aware of their wellbeing, and how to sustain it:

*Carers need to think of their own wellbeing and health as they can become worn out by their caring role. (Theresa)*

In order to maintain physical and mental wellbeing, some carers discussed the importance of having a positive mental attitude to help them stay hopeful and positive:

*You can go down the avenue of saying you have had enough and you'll bring your own health down. Or you can say "I'm in this, I'll need to get on with this" you've got to build yourself up... You need to keep cheerful otherwise you'd jump in the Clyde [a River]. (Theresa)*

Staying well was sometimes clearly linked to other factors promoting quality of life, such as relationships with others or maintenance of ‘ties,’ which for one carer were seen as essential in planning for life after caring. For the following carer, a positive outlook was linked to confidence and having lots of friends, in turn viewed as enhancing resilience:

*I look on the bright side rather than the down side of life, and I have a lot of good friends. I have always been quite confident so I think that helps. I am quite resilient. I am happy most of the time (Jennifer)*

While relationships with others were frequently referenced as contributing to the carer having a positive self-relationship, wellbeing was also regularly defined in the context of relationship boundaries with others:



*Time to myself is tops. That's my priority. Some people have an unhealthy relationship and are dependent on each other, but that's not me. I know who I am; the real me, and that will come back. If I had one day to myself – 2 days would be wonderful – but even one day then I could make a plan. (Norma)*

Some carers talked about particular pursuits that helped them maintain a positive relationship with themselves such as their faith:

*I have the outlets that are important to me such as my faith as a Christian, I regularly go to church, I pray and read the Bible. I also find reading positive books such as self-help books are important to me. (Theresa)*

For the following carer, doing his 'own things around the house' including playing the piano, were the priorities:

*You do your own things around the house if you're that sort of person, which luckily I am, I can go and play the piano, and I can cope with it. For someone who is desperate to get out and have their life, it would be very difficult. (Chris)*

The importance of having time and space from caring was illustrated starkly by the following carer:

*I can hardly breathe, she follows me everywhere. Cleaning the loo is the only time I get away from her. (Diane)*

As suggested by previous research, feeling informed about dementia was a common theme. However, this was influenced by carer's understanding of themselves and their own coping strategies. For several carers, the unpredictability involved could seem overwhelming, with one describing the lack of certainty as 'horrible'. For the following carer, the unpredictability was exacerbated by financial concerns:

*There has always been an uncertainty about the future, especially with dementia. About me, what am I going to do, what am I not going to do, what am I prepared to do? I don't know what's coming. How is it all going to end? She might be in a home. How much might that cost? ..... What about her house? Do we sell it/rent it? Will we be able to afford it? What happens if we run out of money? What about when she doesn't know me? How will I feel? I know it will be gradual. (Diane)*

Although similarly struggling with unpredictability, a few carers chose to avoid thinking about the future, with one commenting that she chose to focus on the 'here and now' and the following carer also preferring to avoid thinking too far ahead:

*I don't know about the future, I don't like to think about it. ...The idea that it's terminal and that you don't really know what you're facing.... 'It's like staring into the fog, you can't see or touch anything.'* (Chris)

Getting a break from caring was regularly linked to carers being able to maintain a life of their own, whether that involved day break opportunities or longer periods. This was described in relation to a sense of freedom and independence and 'time to be,' with one carer commenting on her sense of being 'a wee bird and free.' So the interaction between the carer's sense of self and ability to define priorities and boundaries, which varied considerably between carers, were strongly linked to having a life of their own and to maintaining wellbeing.

### **Relationships with practitioners / services**

While the carer sense of self and their approach to caring was strongly linked to how close personal relationships changed and were managed, relationships with practitioners and services also had a strong bearing. Interactions with skilled professionals helped people to feel valued, heard and able to have open conversations. One carer described contrasting interactions with doctors, and their different effects:

*I felt as though the doctor thought I was exaggerating, overreacting and that he didn't understand where I was coming from. I wanted to say that this is my experience; you're not listening to me. So then I just kept quiet and didn't speak to him about it anymore. One of the doctors took the time to sit and speak with me and explain things and I had found this really helpful.* (Edith)

The following couple who were carers, described how feeling listened to and supported by practitioners ameliorated their feelings of loneliness:

*I feel more hopeful than before. I feel people are coming together more now to listen and support us.... we felt lonely before. Loneliness is a terrible feeling. (Ken and Daisy)*

Several carers talked about how much they appreciated acknowledgement that they are 'doing a good job'. For some carers, this was related to recognition that they were managing the caring role:

*Any time that I have attended with Nancy and been interviewed by Sara and the doctor they've always shown me the utmost respect. They are very courteous, saying "you're doing a good job" and I suppose in that way I felt respected. (Lorna)*

The following example illustrates the complexities involved in skilled interactions. In this case one carer comments on another carer's interaction with a doctor. While George interpreted the doctor asking how he was, as implying he was not coping, Lorna interpreted this interaction as a helpful enquiry about carer wellbeing, based on the understanding that carers can easily 'forget about their own needs':

*The doctor asked him "how are you" and I can understand what the doctor means because, when you are looking after somebody your needs take third and fourth place. But George says "oh, I'm alright". He said afterwards that he thought the doctor thought he was incapable. But I said no George I think it's more that because you are caring for somebody so much you forget about your own needs. (Lorna)*

The importance of positive relationships between the person with dementia and paid carers, was identified by three carers, including the following:

*We had difficulty getting a carer mum liked - if you know the carers and if you like them then you feel confident... that's why I would like to meet them; to feel reassured (Diane)*

Continuity of contact with professionals and paid carers was important. One carer expressed concern about whether her link worker would be removed after the end of the year of post-diagnostic support, while others were concerned about the disruption to the 'teamwork' when paid carers changed:

*There is a real problem when there are new people or people who you don't know and also, the carer doesn't know the house or where things are and it doesn't allow for 'teamwork' between myself and support coming into the house. (Chris)*

The importance of working in partnership was a common theme in discussing relationships with practitioners and services.

*It's about us all working together and sharing the load (Diane)*

Working in partnership could mean the carer being supported to accept that the time might come for the person with dementia to be cared for primarily by others. One carer talked about the relief this brought her:

*I'm relieved that I don't have to do everything for Harry that I had to do. I couldn't do all that I did in the past. I'm too tired at times now to go to bed. If Harry was here he would be up and down. I couldn't do that now. When I see the care he is getting in the hospital I just couldn't do all that I did in the past. I feel relieved. (Violet)*

There was a sense of hopefulness among some carers that things could get better, but that they might need support to find answers:

*The solutions are there somewhere I just don't know what they are yet (Norma)*

Working in partnership with professionals and services was consistently emphasised, and associated with process outcomes such as being listened to and respected, and linked to feelings of confidence, reassurance and relief. One carer couple described how feelings of 'terrible' loneliness were ameliorated through working in partnership with practitioners. Partnership with services included the carer being effectively supported to maintain their quality of life and self-relationship whilst caring, and define limits if and when they became less able to manage the caring role.

### **Summing up the Experience of Caring**

Overall the participants in the study described the experience of caring as multifaceted evoking a range of positive and negative emotions. The importance of maintaining

relationships with self and others was an important theme articulated both through the use of emotional touchpoints and photoelicitation. At the end of the emotional touchpoints interview participants were asked to select an image that summed up their experience of caring overall (photoelicitation) with some examples of responses provided in Figure 1:



**Figure 1. Summing up the experience of caring using photoelicitation**

Original images by kind permission of NHS Education for Scotland (2012) adapted for the project by authors.

## **Discussion**

This study set out to explore the experiences of carers of people with dementia, using specific qualitative approaches, in diverse geographical locations within one country. The wider context is one in which dementia has been identified as a global public health priority, with

recognition both of the ‘immense’ impact on the carers involved, and that the role played by these carers is essential to increasingly stretched health and care systems (WHO, 2006; WHO and ADI, 2012). This study highlighted the complex and varied relationships impacting on the caring situation. Understanding and supporting the multi-layered relationships involved, emerged as central to supporting quality of life of both the carer and the person with dementia, and to sustaining the caring situation. This requires engaging with the complexity of existing relationships and how they change in response to the caring situation, including the carer’s self-relationship. At the same time, attentiveness to the potential impact of new relationships with practitioners and services, in turn influences the carer’s ability to manage existing relationships.

The application of a personal outcomes framework to the data gathered in this study provided a means of exploring carer priorities and some of the complex interactions between different relationships. Application of this framework is of particular importance at this point in time following publication of the Carers (Scotland) Act (2016) that focusses on a personal outcomes approach in relation to develop adult carer support plans. The findings of this study support previous research which advocates a conversational approach, based on an exchange of views, rather than a tick list approach to developing carer support plans (Miller & Barrie, 2016). This supports the exchange model of assessment (Smale, Tuson, Biehal & Marsh, 1993), which emphasises the importance of bringing expertise and priorities together and the value of working in partnership. Whilst carers in our study appreciated and valued being told they were ‘doing a good job’ and wanted their understanding of the person with dementia to be acknowledged, they also valued, and sought out the expertise of professionals to support them as required. The professional role is to ‘negotiate a shared solution about who should do what for whom’ (Smale et al., 1993, p.16). Smale et al. (1993) also highlight the complexity

of interactions required to ensure open dialogue and avoid decisions being made on the basis of flawed assumptions.

Having conversations with people about their lives involves complexity, and the priorities, or outcomes, which emerge can be multifactorial and overlapping. A personal outcomes approach has been advocated for some years, and current health and social care policy strongly advocates this approach with potential for significant benefits for people using services, practitioners and organisations. Benefits also include improved partnership and collaboration and the capacity to focus on strengths as well as challenges (Miller & Barrie, 2016; Nicholas, 2003; Nolan et al., 2002b; Seddon & Robinson, 2015). However, implementation of such approaches can be patchy. This research suggests that systems need to allow for complexity in the recording of carer priorities, rather than assuming linear and tick box frameworks as promoted by the more ‘procedural’ approach described by Smale et al. (1993).

## **Conclusion**

Previous studies have explored interactions between carer resilience, self-efficacy, competency (e.g. Donellan et al., 2015), with carer quality of life and ability to sustain the caring situation. There is a lack of definitional clarity around these concepts. In considering the multi-layered relationships which were fundamental to the outcomes for carers of people with dementia, the concept of self-relationship seemed to capture some of the complexity involved. The experiences of carers seemed less consistent with the idea of ‘bouncing back’ implied by resilience (Donellan et al., 2015), than with the development of self-knowledge and an ability to define boundaries in face of changing and new relationships with others.

Many carers in this study were striving to nourish their self-relationship, and hold on to the 'real me,' often with reference to their relationship with others.

The WHO cautions against making assumptions about carers of people with dementia, which risks complacency (WHO, 2006). Caring for a person with dementia is a complex and varied experience. The circumstances of each caring situation are unique, and there are also variations in how circumstances interact with the range of relationships involved. Effective support starts with meaningful engagement, which enables the carer to reflect on and articulate what matters to them most. Further, acknowledging and building on what is already working well enables a strengths based approach to supporting carers. Photoelicitation and emotional touchpoints are amongst a range of approaches which can facilitate this (Dewar, 2012), and in this study enabled carers to reflect on their own changing circumstances and priorities, supporting Bushe and Kassam's (2005) assertion of inquiry as intervention. Using different methods such as emotional touchpoints and photoelicitation can help to open up dialogue (Dewar et al., 2010). Stickley and Freshwater (2002) highlight the importance of discussing emotions to promote meaningful engagement. Additionally photoelicitation can facilitate a deeper understanding of experiences, gaining more, or a different kind of information than questioning alone (Dewar, 2012; Harper, 2002). Effective engagement with services requires that relevant organisations embrace this type of conversational and relational culture, valuing the perspective of each participant, and the outcomes important to people which are in turn essential to sustaining the services involved.



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