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Positive experiences in dementia care-giving: findings from the IDEAL programme

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(Accepted 5 April 2022)

Abstract

There is a growing evidence base that identifying positive experiences in providing care can have a beneficial influence on carer wellbeing. However, there is a need to better understand what carers identify as the positive aspects of care-giving. The aim of this study is to explore the satisfying aspects of providing care to people with dementia. This study utilised Time 1 data from 1,277 carers of people in the mild-to-moderate stages of dementia taking part in the IDEAL (Improving the experience of Dementia and Enhancing Active Life) cohort study. Responses from 900 carers who answered the open-ended question 'What is your greatest satisfaction in caring for your relative/friend?' were analysed using thematic analysis. From the responses, 839 carers detailed satisfactions. Eight themes were identified, pertaining to three groups of beneficiaries: carers, people with dementia and the dyad. Perceived benefits for carers included identifying aspects of personal growth, seeing glimpses of the person, feeling they were making a difference and doing their duty. For the person with dementia, these included retaining independence, receiving good quality care and being happy. Dyadic benefits concerned the continuation of the relationship between carer and person with dementia. The findings highlight the need to take a dyadic approach when conceptualising positive experiences in providing care. Further research is needed to understand the role these positive experiences play and to develop interventions. Professionals working with carers should identify and validate these experiences.

Keywords: benefit-finding; gains; meaning; qualitative; satisfaction; uplifts

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Introduction

Carers are often the family members or friends of the care recipient. They play a crucial role within society. Estimates for the United Kingdom (UK) quantify the economic contribution made by carers at £132 billion a year (Yeandle and Buckner, 2015). Those providing care specifically for people with dementia are often providing more extensive assistance than for other chronic health conditions (Alzheimer's Association, 2018). Such carers provide a myriad of supports to the person with dementia, including assistance with basic and instrumental activities of daily living, and emotional and social support. These tasks can be time-intensive and care is often provided over a long duration, both in terms of daily hours and the long course of the disease (Alzheimer's Association, 2018). Not surprisingly, care-giving can have a significant negative impact on the health and wellbeing of carers (Carers UK, 2019; Alzheimer's Association, 2018). Yet despite this, amongst other financial and social factors, many carers are motivated to undertake and persist with their care-giving role due to their pre-existing relationship with the individual, feelings of duty and a desire to reciprocate past help (Quinn *et al.*, 2010). These factors have also been identified as some of the ways in which carers identify satisfactions and meaning in their role (Quinn *et al.*, 2010, 2015).

Positive psychological approaches have explored the role of positive emotions, from which may be derived positive experiences, in response to challenging circumstances. In the 'broaden-and-build' theory, Fredrickson *et al.* (2003) proposed that positive emotions have an adaptive role in dealing with stressful circumstances. Positive emotions lead to broadened attention and cognition and, over time, this broadening effect can lead to an expansion in patterns of decision-making. Longitudinally this fosters the building of a range of adaptive and durable personal resources in response to stress (Fredrickson, 2004). Other theories have posited that positive emotions constitute a form of coping. For example, the adapted stress and coping model (Folkman, 1997) proposed that in response to challenging circumstances, both positive and negative emotions can co-occur. A process of searching for and finding positive meaning could help the person to cope by enabling them to make sense of and accept the situation. Similarly, theories of benefit-finding suggest that people can report benefits and gains from adversity. However, it has been proposed that rather than being an explicit form of coping, benefit-finding is more an implicit adaptational process (Tennen and Affleck, 2002).

The notion that positive emotions, such as gratitude and hope, can have a role in helping people during challenging circumstances can be applied to care-giving. Despite a plethora of studies exploring the negative outcomes of providing care (*e.g.* Collins and Kishita, 2020), there is growing evidence that carers also identify positive experiences in providing care (*e.g.* Quinn *et al.*, 2019; National Alliance for Caregiving and AARP, 2020). However, the role of positive experiences in care-giving is unclear. In the Stress Process Model (Pearlin *et al.*, 1990), gain is conceptualised as a mediator of the care-giving process. Viewed as being related to the carer's self-concept, feelings of gain are linked to the enhancement of the self and inner growth. In the Stress Process Model, barriers to the development of or diminishment of this self-concept result in 'secondary intrapsychic strains'. Other studies

have conceptualised positive experiences as akin to a positive outcome of care-giving, linking it to more positive wellbeing (e.g. Lawton *et al.*, 1991).

An increasing number of studies have explored carers' positive experiences in providing care for people with dementia (e.g. Kramer, 1997; Carbonneau *et al.*, 2010; Quinn *et al.*, 2010; Lloyd *et al.*, 2016; Quinn and Toms, 2019). A systematic review of 53 quantitative studies (Quinn and Toms, 2019) found that identifying positive experiences in providing care is associated with better carer wellbeing which highlights the important role positive experiences can have. It was notable that the reviewed studies used a variety of terms to encompass these positive experiences, such as 'uplifts', 'gratification' and 'meaning'. This may have influenced the choice of quantitative measure employed in the study. It has been identified that there is a lack of conceptual clarity around the definition of positive aspects of care-giving (Kramer, 1997; Lee and Li, 2021). Studies focusing on specific domains may have neglected to explore other facets of positive experiences. A more qualitative approach may better capture the multi-dimensional nature of positive experiences of care-giving.

There have been several qualitative studies focusing on the positive experiences of carers of people with dementia. A review by Lloyd *et al.* (2016) identified 14 studies, many of which collected qualitative data as part of a larger mixed-methods study. Key positive experiences identified here were role satisfaction, relationship gains, reciprocity, emotional rewards, personal growth and competence, highlighting the wide range of factors that may be identified as positive experience. In terms of the existing evidence base, some qualitative papers did not specifically focus on positive experiences but identified pertinent themes as part of the data analysis (e.g. Jansson *et al.*, 1998; Narayan *et al.*, 2001; Acton and Miller, 2003; Shim *et al.*, 2012). Therefore, it is not clear whether carers identified these as positive experiences. Other studies are informative but strategically focus on case studies (Butcher and Buckwalter, 2002), samples comprising specific groups of carers such as spousal carers or male carers (Rubinstein, 1989; Murray *et al.*, 1999; Ribeiro and Paúl, 2008; Shim *et al.*, 2013) or have small samples of participants (Rubinstein, 1989; Sterritt and Pokorny, 1998; Duggleby *et al.*, 2009; Netto *et al.*, 2009; Peacock *et al.*, 2009; Donovan and Corcoran, 2010; Shim *et al.*, 2013). Whilst small samples are acceptable in qualitative research, there can be a value in collecting data from larger samples. Some research has been done with larger samples of carers. For instance, Sanders (2005) collected data from 85 carers focusing on how carers felt they had changed since taking on the care-giving role. Whilst this taps into the personal growth dimension of positive experiences, a further development of this research is needed to specifically focus on positive experiences. Similarly, Cohen *et al.* (1994) collected data from 196 carers, asking them to focus on the enjoyable aspects of care-giving, but it may be difficult for carers to consider care-giving as 'enjoyable' and this might explain why 45% of participants identified no enjoyable aspects. Farran *et al.* (1991) collected data from 94 carers with open-ended questions on the negative and positive aspects of care-giving, identifying themes such as valuing positive aspects of the care-giving experience, provisional meaning and ultimate meaning. In the years since this study was conducted, policies to support the care-giving situation have continued to develop. For example, national dementia strategies have focused on raising awareness of dementia and

the provision of better support for carers (Alzheimer Europe, 2018): these may have brought about changes in the care-giving landscape.

There is still a need to increase our knowledge in this area, particularly as being able to identify the positive aspects of providing care has been associated with better carer wellbeing (Quinn and Toms, 2019). Specifically, further research is needed to gain a comprehensive understanding of the satisfactions that carers gain from caring from a large cohort of carers. Accordingly, the aim of this study is to explore the satisfying experiences of care-giving for a person with dementia as reported by carers.

Method

Design

This study used data from Time 1 of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study (Clare *et al.*, 2014; Silarova *et al.*, 2018). The IDEAL study is a longitudinal cohort study exploring factors linked to the capability to 'live well' with dementia for both people with dementia and carers. This study focuses on data collected during the first wave of data collection (baseline), Time 1. Participants were identified from 29 National Health Service sites within Great Britain (England, Scotland and Wales) between June 2014 and August 2016. IDEAL was approved by the Wales Research Ethics Committee 5, the Scotland A Research Ethics Committee and the Ethics Committee of the School of Psychology, Bangor University. The study is registered with the UK Clinical Research Network (UKCRN registration number 16593).

Participants

The IDEAL study involved people with dementia and their carers, this paper focuses on the carers. Carers were eligible to take part if the person with dementia they cared for consented to take part in the study. People with dementia were eligible to take part in Time 1 of IDEAL if they were residing in the community, had a diagnosis of dementia (any sub-type) and a Mini-Mental State Examination (Folstein *et al.*, 1975) of 15 or above, indicating that they were in the mild to moderate stages of dementia. The exclusion criteria for people with dementia were a co-morbid terminal illness, inability to provide informed consent and if there were any risks to researchers conducting home visits. For carers to take part they had to be the primary carer and provide practical or emotional unpaid support to the person with dementia.

Data collection

Participant recruitment and assessment was done through researchers employed by the UKCRN: National Institute for Health Research (NIHR) Dementias and Neurodegeneration Specialty (DeNDRoN) in England, the Scottish Dementia Clinical Research Network (SDCRN), and Health and Care Research Wales. These researchers identified participants from a variety of sources such as memory clinics or Join Dementia Research, which is a registration service where people can indicate their interest in taking part in research. Identified potential participants

were approached about the study either through post or telephone contact. Those who expressed an interest in taking part in the study were visited by a researcher, often at their own home, who completed eligibility checks and obtained informed consent. Data were collected in the form of questionnaire packs that were completed over three visits. The carers self-completed their assessments but could seek support from the researcher if necessary. Details of the measures included in assessments administered in IDEAL are reported in the protocol (Clare *et al.*, 2014). The assessments also contained some open-ended questions. This study analysed data from one open-ended question to carers: 'What is your greatest satisfaction in caring for your relative/friend?'

Data analysis

Data from the IDEAL Time 1 dataset, version 5 were imported into NVivo 12 for analysis. We used thematic analysis to identify, analyse and explore patterns within the qualitative data. An inductive approach was taken whereby the coding of the responses is data driven rather than being influenced by a pre-existing coding frame, theoretical perspective or the researchers' pre-conceptions (Braun and Clarke, 2006). Analysis occurred at the surface level, but also sought to identify latent themes. Data analysis was conducted in a recursive process, going back and forth between the various stages of the analysis process. A preliminary stage involved becoming familiar with the data, which involved reading all the carers' responses. The first stage of coding involved recording whether the carers had responded to the question and, if so, whether they had been able to identify a satisfaction in providing care or not. When carers had responded and identified a satisfaction, their responses were analysed and coded by a researcher (CQ). During this process, notes were kept about the initial codes being generated. Once this process had been completed, similar codes were clustered together to identify sub-themes. Related sub-themes were then grouped together under theme headings. The contents of the themes were checked by CQ to ensure that they had coherence. In a further stage of coding, the themes were further encompassed under higher-order themes. This process involved discussion with two other researchers (IR and GT), who acted as 'critical friends' on the structure of the themes (Smith and McGannon, 2018). The 'critical friends' approach does not strive to achieve consensus but instead encourages reflectivity by challenging assumptions and considering alternative interpretations of the data (Smith and McGannon, 2018).

Several steps were taken to enhance the credibility of the analysis. The descriptions of the themes provided in the Results section are illustrated with extracts from the accounts of a range of participants to ensure the findings are grounded in the data (Whittemore *et al.*, 2001). Three female researchers (CQ, IR, GT), educated to PhD level, were involved in discussions about the analysis to ensure the analysis does not reflect one person's viewpoint. However, due to the interpretative nature of data analysis, it is important to also acknowledge the researchers' preconceptions and knowledge of the topic that could influence their approach. Both CQ and GT are familiar with the wider literature on positive experiences in providing care and so expected that some carers would identify satisfactions, though GT and CQ had no preconceptions about what these would be. None of the researchers who were

involved in the data analysis were involved in the data collection process, and so the analysis is purely based on participants' responses to the question.

Results

Out of the 1,277 carers taking part in IDEAL, 900 responded to the question about satisfaction and their characteristics are described in [Table 1](#). Seventy-two per cent of these carers were female and 79.2 per cent were spousal/partner carers. Of these carers, 839 respondents detailed satisfactions from care-giving, 49 stated that there were 'no satisfactions' to be derived from care-giving and 12 were unsure.

The analysis identified eight themes which could be grouped under three overarching themes: perceived benefits for the carer, perceived benefits for the person with dementia and dyadic benefits. [Table 2](#) provides an overview of the themes and the number of extracts encoded under these themes. The most dominant theme pertained to the relationship between the carer and person with dementia.

Perceived benefits for the carer

Personal growth and achievement

Carers identified elements of personal growth through providing care. Some carers described it as a learning process and found themselves becoming more patient and understanding. Some learnt that they needed to enjoy their lives now, rather than putting things off to the future. Through competently dealing with challenges, carers identified increased confidence in their own abilities. They identified that through care-giving they had learnt new skills, such as learning to cook, but also felt they were having the opportunity to use their pre-existing skills:

I also feel more valued as I have a science and admin [administration] background and feel my reasoning skills and communication skills are being put to good use again. (Female carer ID: 945)

Carers felt a sense of achievement through being able to cope with both the situation and care-giving for the person with dementia. They identified satisfactions from being able to fulfil the care-giving role and felt they were in control of the situation. They recognised that, so far, they had been fit and well enough to manage the care-giving role:

I am happy that I feel mentally and physically well enough to cope at the moment. (Female carer ID: 228)

They identified that by being able to cope, they were bringing benefit to the person with dementia. Carers found it rewarding that the person with dementia knew they could 'rely' and 'depend' on their support. Through this they also felt 'needed' and 'wanted' by the person. Carers identified that the person with dementia trusted them and felt 'safe' with them:

Knowing that she relies upon me and trusts me implicitly to look after her best interests. (Male carer ID: 404)

Table 1. Characteristics of the care-givers and people with dementia for whom they care

Demographics	N (%)
Care-givers (N = 900):	
Sex: female	648 (72)
Age:	
<65	275 (30.6)
65–69	163 (18.1)
70–74	192 (21.3)
75–79	147 (16.3)
80+	123 (13.7)
Kin-relationship:	
Spouse/partner	718 (79.8)
Other family/friend	182 (20.2)
Education: ¹	
No qualification	161 (17.9)
School leaving certificate aged 16	207 (23.1)
School leaving certificate aged 18	267 (29.8)
University/college	262 (29.2)
Hours of care (provided on an average day): ²	
<1	185 (20.8)
1–10	355 (40)
>10	348 (39.2)
People with dementia (N = 900):	
Sex: female	355 (39.4)
Diagnosis:	
Alzheimer's disease	502 (55.8)
Mixed dementia	189 (21)
Vascular dementia	98 (10.9)
Frontotemporal dementia	32 (3.6)
Parkinson's disease dementia	30 (3.3)
Dementia with Lewy bodies	32 (3.6)
Unspecified/other dementia	17 (1.9)

Notes: MMSE: Mini-Mental State Examination score. 1. Missing data for three participants. 2. Missing data for 12 participants.

Table 2. Categories identified from the analysis

Higher-order theme	Theme	Number of extracts coded in the care-giver data
Perceived benefits for care-giver	Personal growth and achievement	67
	Glimpses of the person they used to be	38
	Making a difference	201
	Doing my duty	65
Perceived benefits for person with dementia	Helping to retain their independence	98
	Receiving good quality care	135
	They are happy and enjoying life	195
Dyadic benefits	Our relationship	262

Notes: The counts equate to the number of extracts coded for each theme. Participants' responses may have been coded under more than one theme.

Glimpses of the person they used to be

Carers recognised that they still had the person with dementia in their lives. Some carers did not think that the person's personality had radically changed, identifying that they may be more dependent but remained a good 'companion'. Some recognised their role in enabling the individual to remain the 'same' person:

That she is still the companion I have known for 50 years, because physical and mental stimulation keeps her going. (Male carer ID: 9)

Others had noticed changes but were able to identify retained aspects of the person such as the person still being 'kind', 'generous' and 'good company'. For those who had noticed a change in the person, it was instances when they seemed like they 'used to be', that were rewarding for carers:

When he is in a good spell, sometimes he is completely normal as he used to be and that is great. Give[s] me hope and happiness. (Female carer ID: 804)

There could be glimpses of the person with dementia being 'their old self' when they were able to perform certain tasks or when aspects of the person would emerge in situations, such as their sense of humour. For instance, sometimes they could have a laugh together and enjoy each other's company like the 'old times'. Linked to this, the person with dementia having retained memories was important in demonstrating the person was still there. Carers described being able to sit and discuss the past with the individual:

Listening to him when he remembers something and the boost it brings. (Female carer ID: 1074)

Carers thought having conversations about memories was helpful for the person with dementia. This might also involve the person with dementia remembering their shared life with the carer. However, there was a recognition that this source of satisfaction might not continue:

She is still the person I love, but will she still remember me in years to come? Satisfying now but will it continue? (Male carer ID: 283)

Making a difference

Carers identified fulfilment from feeling that they were making a difference to the life of the person with dementia. Carers derived satisfaction from knowing that they were helping the person, being able to offer comfort and support. Positive changes in the person's health and wellbeing were perceived as indicators that their support was effective. They felt they were enabling the person to keep going and retain their independence. They had a role in helping the person to cope, have a better life and enabling them to live well for longer:

Knowing I am making a significant difference in helping my wife to have the best quality of life that is possible. (Male carer ID: 539)

By identifying that they were making a difference by helping the person, they felt that they were doing something worthwhile. It was identified that they were doing their 'best' for the person to make their lives easier and help them as much as they could. Knowing that they were doing 'all I can' gave the carers a sense of satisfaction:

The knowledge that I am doing my best for her and hopefully am making her life a little easier all the time. (Male carer ID: 850)

Carers found it rewarding to be there for the person when they were needed and when, through their efforts, the person had a 'good' day. 'Good' days could involve seeing the person enjoying activities such as going out for a walk or socialising with others. Having a 'good' day made the carer feel like they were doing a 'good job'.

Carers received appreciation from the person with dementia for doing specific tasks or other activities such as taking the person out in the car or taking them to lunch. Recognition also came from other family members and friends, through the person with dementia telling others how much the carer helped them. This appreciation was also apparent when the person with dementia recognised all 'they do':

My wife's appreciation of what I may have done to help her, albeit it could only be something insignificant I may have done. (Male carer ID: 528)

This appreciation could be expressed through the person verbally thanking them or through non-verbal means such as a smile. Although some carers described the person thanking them 'every day', for others it was just the 'occasional word'. For some, this appreciation was a continued demonstration of love:

When he says love you and thank you for doing little things for him. (Female carer ID: 597)

Doing my duty

Being able to repay past help or fulfil marital vows brought a positive element to providing care. This was intrinsically linked to the long-standing relationship between the carer and person with dementia. Providing care was an act of reciprocating past help and support. This could include paying back past love and affection from the person with dementia. It was felt that the person with dementia would have done the same for them if they had needed care. Some believed it was now their turn to provide care for that individual:

It is an opportunity for me to repay to some extent all the things she has done for me. (Male carer ID: 24)

Perceptions of duty were also linked to the carer's kin-relationship to the person with dementia. For adult child carers, providing care was an opportunity to repay their parents:

He is my dad and, for me, he's the best dad ever! We have always been close and looked after each other. (Female carer ID: 889)

For spousal carers, there was recognition that providing care to their husband or wife was part of fulfilling their marital role. This was often linked to their marital vows and promises to look after each other:

I made a vow when I married him for better or worse, in sickness and in health, we have our good health and now we have sickness ... we love each other so we work together to get through it. (Female carer ID: 848)

Perceived benefits for the person with dementia

Helping to retain their independence

Carers identified satisfactions from enabling the person with dementia to retain some independence. This was often equated to the person still being able to live a relatively 'normal life'. Carers discussed being satisfied that, despite the diagnosis, the person with dementia was able to carry on as before and have a 'normal life-style' with their input:

Doing the best I can to maintain a 'normal' daily life. (Male carer ID: 19)

Related to this desire to maintain a normal life was ensuring the person was still involved in daily life. This could be through them actively participating in decision-making, family life and friendship groups. A normal life also involved the person maintaining some level of independence. Carers identified satisfactions from the person still being able to lead a relatively independent life. They identified their role in supporting the person to achieve this. They talked about the importance of keeping the person with dementia 'going' and doing as much as possible for

as long as possible. Carers had a role in giving the person with dementia assistance and encouragement to complete tasks independently, which they found very worthwhile as they could see the positive impact that this had on the person:

Seeing him completing a job and smile about it and him being happy with the result. (Female carer ID: 977)

Being able to live independently was also linked to the person being able to live at home. Carers were proud to have a role in facilitating the person living at home. For some, this was because they were aware that the person was happy living in a familiar environment where they were surrounded by family and friends. Carers felt reassured that through their care-giving they were able to help the person to stay at home:

Knowing that she can stay in the comfort of her own home. (Female carer)

Some carers felt that it was better for the person with dementia to remain in their own home than move to a care home; for instance, they had more 'freedom' at home. For others, this desire to keep the person at home related to the person's own wish not to go into a care home. Promises may have been made to the person with dementia that they would not go into a care home:

Keeping my promise to keep her going in her own place for as long as possible. (Female carer ID: 379)

Receiving good quality care

Good quality care could relate to the practical aspects of care and a pressing concern for many carers was ensuring the person was safe:

Making sure he is safe and cared for. (Female carer ID: 1088)

Some talked about 'knowing' the person was safe and others had a more active role in 'making sure' the person was safe through fostering an environment that protected them from harm.

Linked to safety was a satisfaction that the person was being well cared for. Carers described the reassurance of knowing that the person with dementia was being well looked after and had all the help that they needed. This could be having someone there to help them with practical tasks such as accompanying them to appointments or assisting with housework. Linked to this was providing support so that the person could maintain their previous standards of tidiness and cleanliness. It was also important that the person was emotionally supported during 'difficult times':

That they feel there is someone here for them and they don't feel alone with their problem. (Female carer ID: 668)

Many carers drew strength from believing that they were the 'best' person to provide care and did not want 'strangers' to take on this role. To some this related to their long-

standing relationship with that person and their belief that they best understood the person's needs and thus could provide care in a way that they would like:

I know him better than anybody else and, consequently, am more likely to help in the way that he would like it. (Female carer ID: 102)

They are happy and enjoying life

Carers identified that they were making a difference to the quality of life of the person with dementia. Some carers thought it was their role to 'give' the person a good quality of life, though, as illustrated in the quote below, there were different dimensions to what was referred to as 'quality of life':

That they are safe, fed, clean, comfortable and know that they are loved. (Female carer ID: 184)

Carers also identified that the wellbeing of the person with dementia was improved by them providing care. Carers attached importance to ensuring the person remained happy and enjoyed themselves. Seeing the person with dementia happy, laughing and smiling was very rewarding:

Seeing mum wakes up with a smile everyday. (Male carer ID: 715)

If the person with dementia was happy this meant that they were living a fulfilling life and enjoying themselves. Some carers were relieved as it meant that they were not dwelling on their diagnosis and prognosis. Equally for carers this was a sign that they were doing a good job in care-giving for the person with dementia.

The person with dementia enjoying themselves could also encompass seeing that the person was enjoying partaking in activities and spending time with family or friends. Some felt it was important that they identified and facilitated activities and opportunities for the person:

That we do things which means she can enjoy life as much as possible. (Female carer ID: 223)

This was linked to the carer wishing to make sure that the person was living a worthwhile life. This encompassed ensuring the person had a 'good life', with the onus on the carer ensuring this. This involved ensuring that the person could lead an active life, so they were satisfied with their life. They also discussed making sure that the person could live their lives 'to the full' and have a 'worthwhile life':

Trying to make his life as good as it can be in the circumstances. (Female carer ID: 682)

As well as seeing the individual happy and enjoying life, carers had to balance this against ensuring the individual was well. It was important that the individual was kept 'well' and healthy for as long as possible. Being healthy was linked to the person being well looked after:

Knowing he is well, is very important to me ... to us. (Female carer ID: 441)

In addition, carers also attached importance to the person being calm and contented. This reduced their worry and concern. This may have been because carers were keen to ensure the person had the best quality of life whilst they still had the capabilities to enjoy their life. Whilst some carers talked about 'seeing' the individual calm and content, others talked about 'keeping' the individual calm and contented.

Perceived dyadic benefits

Our relationship

Identifying positive experiences in providing care was intrinsically linked to the relationship between the carer and person with dementia. This encompassed both the current and previous relationship.

Past relationships were often characterised as containing love and affection. Carers described their past relationship with the person with dementia as 'good' and said they were 'close'. The mutual love between the carer and person with dementia was often discussed. Carers identified how their long-standing love for the person with dementia remained unchanged and that care-giving was a way of demonstrating their love for that individual. Some described how the person with dementia still loved them:

Knowing at the moment that he truly loves me and although he may lose this at some point that knowledge will last me ... my lifetime. (Female carer ID: 572)

Care-giving was perceived to be a way of continuing this long-standing relationship and recognising a shared history. Many spousal/partner carers referred to their long-standing marital relationship and felt blessed that they were still together and wanted to be there to support the person with dementia:

Knowing I am doing something worthwhile and helping the person I love and to whom I have been married to for over 50 years. (Male carer ID: 317)

Carers also reflected on their current relationship with the person with dementia. They talked about the importance of still being together and being able to do things together, such as going places together. Carers also discussed how their relationship helped them and the person with dementia to cope with the situation. They described still being able to 'laugh together' and enjoy their time together. They also discussed working together as a team to support one another, managing the situation together:

That we stay strong together to cope with this very sad disease, and we make our life as pleasant as it can be which so far we are achieving. (Female carer ID: 869)

Some identified that they had grown closer through care-giving. This could be physically closer as the person had moved to be near them or had more contact

with them. It could also be emotionally closer as they felt the person was more affectionate towards them. By spending more time together some carers felt they had got to know the individual better:

That our relationship has improved since the diagnosis. Seeing my mum become more open, more relaxed and less focused on work. (Female carer ID: 1257)

Discussion

To our knowledge, this is the largest study exploring positive experiences in providing care in a group of carers for people with dementia. Most carers taking part in the IDEAL study were able to identify satisfactions from care-giving. These satisfactions encompassed perceived benefits for the carer, perceived benefits for the person with dementia and dyadic benefits. The findings support some of the themes identified in other qualitative research in this area but equally highlight novel areas for consideration.

The relationship between the carer and person with dementia emerged as the dominant theme in the analysis. This encompassed both the relationship before care-giving and the current relationship. Being able to identify satisfactions through the relationship is a common theme within other qualitative research in this area, with carers identifying a strengthening of the relationship, spending more time together and affection (*e.g.* Cohen *et al.*, 1994; Murray *et al.*, 1999; Narayan *et al.*, 2001; Lloyd *et al.*, 2016). The current findings provide some support for the conceptual model developed by Carbonneau *et al.* (2010) which identified that the quality of the relationship was a central domain in the positive aspects of care-giving. Other quantitative evidence has shown that finding positive aspects in providing care is associated with better pre-care-giving (*e.g.* Kramer, 1993; Gold *et al.*, 1995; Quinn *et al.*, 2012a, 2012b) and current relationship quality (*e.g.* Quinn *et al.*, 2012a, 2012b). Although many of the carers in the current study described their relationship with the person with dementia as good, some identified that care-giving had improved this relationship and brought them closer. Carers often feel motivated to take on the care-giving role because of this pre-existing relationship, but care-giving can occur in the context of a poor relationship as the carer may feel they have no other choice or feel obligated to provide care (Quinn *et al.*, 2010). Having a poor pre-care-giving relationship with the person with dementia can have a negative impact on the carer's wellbeing (Quinn *et al.*, 2012a). Interestingly, Motenko (1989) reported that it was the carers' perception of change within the marital relationship, rather than the actual closeness, that was associated with levels of gratification from care-giving. Those who identified a negative change in their relationship were less gratified; whereas continuity in the relationship, even for those who were not close, was associated with gratification. This partially supports the improved relationship finding from the current study. Thus, it is possible that those who may not have had a close relationship before care-giving may still be able to identify satisfactions if they identify an improvement in this relationship. Similarly, it is possible that those who identify a negative change in their relationship may struggle to identify any benefits.

Some carers derived satisfaction from fulfilling their spousal or filial duties. Care-giving was perceived as a way of reciprocating past help and affection. Other qualitative studies have identified feelings of reciprocity and duty in how carers experience satisfaction in providing care (e.g. Murray *et al.*, 1999; Shim *et al.*, 2012). These types of positive experiences are interlinked with carers' motivations for providing care (Quinn *et al.*, 2010). Interestingly, in the current study, this feeling of duty was not a particularly dominant theme and more extracts were coded under the theme of 'making a difference'. Carers identified both that they were making a difference to the life of the person with dementia and that the person appreciated their help. Although other studies have identified themes around appreciation (e.g. Jansson *et al.*, 1998; Murray *et al.*, 1999; Ribeiro and Paúl, 2008), this element around making a difference seems to be a novel finding. Although a sense of making a difference may have links to 'role satisfaction', an important element of the theme was that satisfaction was reinforced by the appreciation shown by the person with dementia.

Another novel finding was that carers found it rewarding when they saw 'glimpses' of the person with dementia as they used to know them. Although this was the smallest theme, in terms of the number of extracts coded, it was clear some carers identified a role in maintaining the person's identity, for instance by keeping the person occupied or talking about old times. This theme of maintaining a person's identity supports the work of Kitwood (1997), who wrote about the importance of maintaining personhood in dementia and the role of others in conferring identity when someone has dementia. Out of the existing literature, only Quinn *et al.* (2015) have described carers finding it rewarding when the person seemed like their 'old self'. In comparison, although it is a common category in other qualitative research (e.g. Lloyd *et al.*, 2016), few carers discussed personal growth, focusing more on their achievement in being able to provide care. Similarly, none of the carers discussed spiritual growth, which has been found in other studies (Lloyd *et al.*, 2016). It may be these issues are less salient for this group of carers, or it may be that personal growth may not occur till later in the care-giving process. Carers in the current study were supporting people with mild-to-moderate dementia and as dementia is a progressive degenerative condition personal growth may emerge later. Theories on growth following adversity suggest that perception of personal growth may occur later as part of the coping process where it emerges as part of an effortful rumination activity (Joseph and Linley, 2006).

Although other studies have identified positive gains for the carer, there has been less evidence on the perceived benefits for the person with dementia. There appeared to be some form of positive feedback cycle whereby perceiving benefits for the person with dementia acted as a way of enabling carers to see their role in this as rewarding. Carers perceived that they were the best person to provide care and that they were providing good quality care. This is similar to themes concerning competence which have been described in other studies (e.g. Farran *et al.*, 1991; Jansson *et al.*, 1998) and it raises the question of whether care-giving competence is a separate entity or a component of positive aspects of care-giving. Studies have found that care-giving competence can influence carer quality of life (Farina *et al.*, 2017) and living well in people with dementia (Quinn *et al.*, 2019).

Competence was not the sole source of carer satisfaction as this theme also highlighted that carers found it satisfying that the person was receiving good practical and emotional care. For some carers, this related to their self-identified role in enabling the person to retain their independence. Whilst a few studies have identified similar themes around enabling the person to live at home (Cohen *et al.*, 1994; Shim *et al.*, 2013), carers in the current study also identified their role in supporting the person to lead a relatively normal life. Similarly, carers found it satisfying to see the person with dementia happy and enjoying life. This is a novel finding with only the case study by Butcher and Buckwalter (2002) describing the carer wishing to ensure the person has a happy life.

In considering the findings of the study, it is necessary to reflect on its strengths and imitations. This study involved a large cohort of carers from different regions within Great Britain. The data were collected through an open-ended question as part of a wider survey study and as such we were unable to ask participants follow-up questions on their responses. Whilst the format limited the depth of responses, the large number of respondents does provide breadth. In addition, this approach of collecting data through an open-ended question has been used in other large-sample qualitative studies in this area (*e.g.* Murray *et al.*, 1999; Sanders, 2005). This was an optional open-ended question towards the end of the survey, and it is likely this resulted in some participants opting not to answer the question. It is also possible that carers who did not identify any satisfactions decided not to answer this question, but there were 49 carers who indicated no satisfactions in their response. Although this study involved a large sample of carers, the theme 'glimpses of the person they used to be' was only endorsed by a small number of extracts from carers. However, as Braun and Clarke (2006) identify, the important thing is that the theme makes an important contribution to the research question and this theme contained novel findings that were worth highlighting.

Overall, in contrast to previous research, the findings point to a need to take a dyadic approach when conceptualising positive experiences in providing care. Carers in this study identified benefits for themselves but equally perceived the benefits of their care-giving for the person with dementia. The relationship between the person with dementia and carers was an important source of care-giving satisfactions. These findings have some important implications. The majority of measures of positive experiences in providing care have focused on the benefits for the carer (*e.g.* Tarlow *et al.*, 2004; Yap *et al.*, 2010; Faba *et al.*, 2017). Some have included a small number of items on the benefits for the person with dementia, focusing on the care recipient 'appreciating help' (Lawton *et al.*, 1989; Farran *et al.*, 1999), and on care being beneficial for the care recipient (Strawbridge, 1991; Abdollahpour *et al.*, 2017). Thus, some of the themes identified in this study may not be represented in existing measures. Potentially this is because item generation for existing measures seems mainly to have been informed through consultation with experts and the existing literature (*e.g.* Abdollahpour *et al.*, 2017; Faba *et al.*, 2017), through interviews with small samples of carers (*e.g.* Yap *et al.*, 2010) or through a mix of these techniques (*e.g.* Strawbridge, 1991). Whilst these measures have been subsequently validated with carers, there would be advantages to developing measures through interviews with a large cohort of carers to ensure

questionnaire items fully encompass the broad range of care-giving satisfactions identified in this paper.

It is not clear what role positive experiences of care-giving had for the carers taking part in this study. The Stress Process Model (Pearlin *et al.*, 1990) conceptualised positive experiences as part of inner growth, yet our findings imply their role for carers is greater than this. Tennen and Affleck (2002) have questioned whether benefit-finding is a form of emotion-focused coping. They perceive this to be a conscious process; however, benefit-finding could also be more an implicit adaptational process. This argument can be applied to our own findings as to whether care-giving satisfactions could be a form of coping. The data do not give a clear answer as to whether carers were consciously or unconsciously using their positive experiences as a form of coping. For some, these experiences may help to reframe and positively understand the care-giving role. For others, positive experiences may have a role in sustaining care-giving, for instance if carers are finding the role rewarding. Certainly, understanding the role of positive experiences is an area that requires further research as it has implications for how we support carers.

This study has identified novel themes which have been missing from previous reports. Future research is needed to understand how carers can be supported to identify and benefit from positive experiences in their role. For example, interventions that acknowledge and validate positive experiences of care-giving could build self-efficacy in carers (*e.g.* Tang and Chan, 2016). Interventions could be developed to enable carers to appraise their role positively and identify their own positive experiences in providing care. Given the role that the relationship between the person with dementia and carer plays in these positive experiences, it is feasible that relational interventions might also help carers to identify positive experiences in their caring role. It is also important that these positive experiences are acknowledged and validated by health and social care professionals working with carers. Carers assessments may be an appropriate opportunity to recognise carers' positive contributions (Alzheimer's Society, 2020). Acknowledging these positive experiences and the value that carers place on the relationship with the person with dementia may help challenge the stigma around dementia and have wider benefits for the community.

In conclusion, this study provides evidence that some carers have positive experiences in providing care. Carers identified benefits for themselves but equally perceived the benefits of their care-giving for the person with dementia. Researchers should consider a dyadic approach to conceptualising positive experiences of care-giving. Further research is needed to understand the role that these positive experiences play, whether they are a consciously adopted form of coping or a more implicit adaptational process. This understanding will support the development of interventions to reinforce these positive experiences. Professionals working with carers should identify and validate these experiences to ensure the full range of care-giving experiences are acknowledged.

Data. IDEAL data were deposited with the UK Data Archive in April 2020 and will be available to access from April 2023. Details of how the data can be accessed after that date can be found at <http://reshare.ukdataservice.ac.uk/854293/>.

Acknowledgements. We are grateful to the IDEAL study participants for their participation in the study, and to members of the ALWAYS group and the Project Advisory Group for their support throughout the study. We would like to acknowledge the support of the following research networks: NIHR Dementias and Neurodegeneration Specialty (DeNDRoN) in England, the Scottish Dementia Clinical Research Network (SDCRN), and Health and Care Research Wales. We gratefully acknowledge the local principal investigators and researchers involved in participant recruitment and assessment within these networks. CQ acknowledges that preliminary work for this paper was undertaken at a writing workshop funded through the European Union Erasmus+ Programme (2018-1-UK01-KA103-046908) awarded to the University of Bradford. LC acknowledges support from the NIHR Applied Research Collaboration South-West Peninsula.

Author contributions. Conception and design: CQ, EvH, IR, RGM, CV, SMN, JMR, JMT, CH, LC. Analysis and interpretation of data: CQ, GT, IR. Drafting the manuscript: CQ, GT. Critical appraisal and review of the manuscript: CQ, GT, EvH, IR, RGM, CV, SMN, JMR, JMT, CH, LC. Final approval of the manuscript: all authors.

Financial support. ‘Improving the experience of Dementia and Enhancing Active Life: living well with dementia. The IDEAL study’ was funded jointly by the Economic and Social Research Council (ESRC) and the National Institute for Health and Care Research (NIHR) (grant number ES/L001853/2); Investigators: L. Clare, I. R. Jones, C. Victor, J. V. Hindle, R. W. Jones, M. Knapp, M. Kopelman, R. Litherland, A. Martyr, F. E. Matthews, R. G. Morris, S. M. Nelis, J. A. Pickett, C. Quinn, J. Rusted and J. Thom. ESRC is part of UK Research and Innovation (UKRI). ‘Improving the experience of Dementia and Enhancing Active Life: a longitudinal perspective on living well with dementia. The IDEAL-2 study’ is funded by the Alzheimer’s Society (grant number 348, AS-PR2-16-001); Investigators: L. Clare, I. R. Jones, C. Victor, C. Ballard, A. Hillman, J. V. Hindle, J. Hughes, R. W. Jones, M. Knapp, R. Litherland, A. Martyr, F. E. Matthews, R. G. Morris, S. M. Nelis, C. Quinn and J. Rusted. The views expressed in this publication are those of the authors and not necessarily those of the ESRC, UKRI, NIHR, the Department of Health and Social Care, the National Health Service or Alzheimer’s Society. The support of ESRC, NIHR and Alzheimer’s Society is gratefully acknowledged. The funders had no role in the design, execution, analysis and interpretation of data, or writing of the study.

Conflict of interest. The authors declare no conflicts of interest.

Ethical standards. IDEAL was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405), the Scotland A Research Ethics Committee (reference 14/SS/0010) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014-11684).

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