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## **The positive aspects of caregiving in dementia: A critical review of the qualitative literature**

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# **The positive aspects of caregiving in dementia: A critical review of the qualitative literature**

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## **Abstract**

Positive aspects of caregiving in dementia have been identified as important in understanding the experiences of carers, yet the research base lacks clear definitions of key concepts. Qualitative research explores carers' experiences of positive aspects of caregiving in rich detail which lends itself to supporting theory development. The aim of the present review was to critically evaluate the empirical findings of qualitative studies that have explored positive aspects of caregiving in dementia. A systematic search of the literature revealed 14 studies that met this aim. Carers described multiple positive dimensions of caregiving and identified several factors that were important in supporting their positive caregiving experience. The present review evidences a solid base of understanding of the positive aspects of caregiving in dementia from which concepts and theories can be further developed. Clinical and research implications are discussed.

**Keywords:** *Carers, caregiving, dementia, positive aspects, qualitative*

## **Introduction**

### ***Caregiving context***

In the context of a growing elderly population, dementia has been identified as an international priority (Department of Health (DoH), 2013). It is estimated that around 35.6 million people worldwide currently have dementia and this figure is set to double every 20 years reaching 115.4 million by 2050 (Alzheimer's Disease International, 2009). The majority of care and support for people with dementia is provided by family members, friends or neighbours (Knapp & Prince, 2007; Tremont, 2011). With the global cost of dementia in 2010 reaching 400 billion pounds, these informal carers of people with dementia have been recognised as an increasingly valuable resource (Wimo et al., 2010).

### ***Caregiver burden***

Over recent decades, a large volume of research has explored the negative impact of caregiving on informal carers (Etters, Goodall & Harrison, 2008). Studies indicate that caring can place a significant level of burden on caregivers resulting in poorer physical and psychological wellbeing (Bell, Araki & Neumann, 2001; Gallagher-Thompson & Powers, 1997). This in turn can affect the care they provide, sometimes leading to premature institutionalisation of the person with dementia (PWD) (Bédard, Pedlar, Martin, Malott & Stones, 2000) or even elder abuse (Wolf, 1998).

It has also been recognised that caring for a PwD can be more stressful than caring for a physically frail older adult (Schulz, O'Brien, Bookwala & Fleissner, 1995). Carers have to contend with the challenging behaviours and distressing changes to personality that dementia can cause. Furthermore, the progressive nature of the illness means that over time, the caregiver is faced not only with increased care demands but also the gradual loss of the person they once knew (Clipp & George, 1993).

### ***Positive aspects of caregiving in dementia***

In comparison to caregiver burden research, there is a relative paucity of literature examining the positive aspects of caregiving (PAC). The research that has been conducted demonstrates that many carers cope well with the challenges they face and experience caregiving as a rewarding and satisfying experience (Cohen, Colantonio & Vernich, 2002; Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991).

Carers who report higher levels of PAC report lower levels of depression and anxiety as well as fewer feelings of being affected by the behaviour of the PwD (Mausbach et al., 2006; Pinquart & Sorensen, 2004). Additionally, the ability to find meaning in and derive gratification from the caregiving experience is associated with increased morale and a feeling of being more able to manage (Hirschfield, 1983). Importantly, those who reported higher satisfaction with caring were also less likely to institutionalise the PwD (Roff et al., 2004). Therefore, gaining an understanding of the factors that predict a more positive caregiving experience is important and could contribute to the development of interventions to support carers who are struggling (Rapp & Chao, 2000).

### ***Conceptualisations of positive aspects of caregiving***

The main body of research has attempted to integrate PAC into the same stress-coping model used to understand negative aspects of caregiving (Pearlin, Mullan, Semple & Skaff, 1990; Roff et al., 2004). However, other research has found that positive and negative aspects of caregiving are not opposite ends of the same continuum. Correlations between the two tend to be modest at most (Kinney & Stephens, 1989; Rapp & Chao, 2000) and predictors of positive and negative aspects are often not the same, with far fewer predictors of positive aspects being identified (Kramer, 1997b; Pinqart & Sorensen, 2004). Therefore PAC appear to be a separate dimension of the caregiving experience.

Studies that have considered this broader interpretation have conceptualised PAC in a number of different ways. Some studies have looked at overall positive appraisal of, or satisfactions with the caregiving experience (Lawton et al., 1989) whereas others have considered discrete daily events that trigger positive outcomes in carers (Kinney & Stephens, 1989). Further studies have focused on positive aspects in terms of impacts upon the carers themselves on variables such as their self-esteem or mastery (Semiatin & O'Connor, 2012), while others have investigated the enrichment or rewards generated by the dynamic reciprocity of the caregiving relationship (Cartwright, Archbold, Stewart & Limandri, 1994). Nolan, Grant and Keady (1996) developed a matrix to draw together a number of these concepts. Using evidence from research looking at carers of people with a wide variety of physical and mental health issues they identified dimensions of PAC in terms of beneficiary of the reward or gain (carer, care recipient or shared aspects) and the nature of the satisfaction (interpersonal, intrapersonal or outcome gains). This matrix provides a helpful description of some of the differing concepts involved but further work is needed in order to better understand the specific processes involved in PAC within different groups of carers.

### ***Methodological Issues***

One reason for the lack of clarity within this body of research is the reliance on quantitative methodologies to explore and understand what is ultimately a subjective experience (Bryman, 2008). Quantitative methods are based on a positivist perspective which views the world as a formation of measurable and observable facts. Caregiving research within this paradigm has attempted to identify specific processes that underpin positive and negative caregiver outcomes (Pinquart & Sorenson, 2004). However, identifying the details of these processes requires clear definitions of the concepts involved, something that has not yet been achieved within the PAC research base leading to conflicting results (Kramer, 1997a).

Furthermore, in attempting to identify processes which can be generalised across caregiving situations many of the nuances of the caregiving experience are lost and as such these quantitative approaches have been criticised for ‘...constraining the capacity of health care workers to fully understand the caregiving experience...’ (Butcher et al., 2001, pp 34-35).

In contrast, qualitative methods are based on an interpretative perspective which views reality as socially constructed and constantly changing. Qualitative research seeks to understand experiences by discovering and reconstructing processes from an insider viewpoint (Creswell, 2005). They offer an opportunity to gain insight into caregiving experiences and the meanings carers attribute to their role. These insights can be of immense clinical value and can also support the process of defining clear concepts and the development of theories (Hasselkus, 1998).

### ***Rationale for the current review***

In growing recognition of the value of qualitative research, a number of qualitative studies have investigated PAC in dementia. These studies are likely to shed new light on the area through allowing a detailed exploration of the experiences of distinct groups of carers and are therefore worthy of review.

Two previous reviews of PAC have been conducted in previous years (Carbonneau, Caron & Desrosiers, 2010; Kramer, 1997a). Both of these reviewed studies involving carers of people with a variety of mental and physical difficulties. As has been noted, caring for someone with dementia presents a unique caregiving situation and therefore warrants a separate review.

### ***Aims***

The primary aim of the present review is to critically evaluate the empirical findings of qualitative studies that have explored PAC in dementia. Within this, particular attention will be paid to:

- How PAC in dementia have been conceptualised within the qualitative literature.
- How carers perceive the process of positive caregiving.
- Exploring the qualitative differences between the experiences of different groups of carers (e.g. spouses vs children, husbands vs wives).

### **Method**

#### ***Search strategy***

A systematic literature search for relevant studies was performed using the following internet-based bibliographic databases: PsychINFO, Web of Science, Cumulative Index of



Nursing and Allied Health Literature (CINAHL) and Scopus. The following search terms were used: care\* AND Alzheimer's OR dementia AND 'positive aspects' OR 'positive experiences' OR 'positive perceptions' OR reward OR gain OR 'satisfaction with care\*' OR 'care\* satisfaction' OR benefit OR uplift OR meaning OR enjoyment OR pleasure AND qualitative OR 'grounded theory' OR phenomenological OR narrative OR ethnographic. These are consistent with terms used by Kramer (1997a) but extended to capture qualitative methodologies. The term 'carer' or 'caregiver' refers to those who provide support to someone with dementia, without receiving payment, including partners, spouses, adult children, friends or neighbours. No date limit was put on the search. The articles included in the present review were used as the basis for the manual search to identify additional references. The reference lists were searched and where possible, articles that had cited them were traced.

The titles and abstracts of the references generated were screened to assess their relevance. References that did not focus on the experiences of caregivers of a PwD or were clearly quantitative were discarded. This was kept deliberately broad to maximise the chance of detecting relevant studies as it has been identified that qualitative articles can have misleading titles or abstracts (Emslie, 2005). The references that focused on this area were located and assessed for inclusion in this literature review in line with the inclusion and exclusion criteria.

### ***Selection criteria***

#### *Inclusion criteria:*

- Studies in which at least one of the primary aims was to investigate PAC in dementia using a qualitative methodology;
- Participants were informal caregivers as opposed to voluntary or paid carers of people with dementia;
- Studies published in English.

*Exclusion criteria:*

- Quantitative studies with no qualitative data;
- Personal accounts of caring for someone with dementia with no analysis;
- Studies using discourse analysis;
- Studies in which it was not possible to separate carer data from data gathered from the PwD;
- Studies in which it was not possible to separate data from carers of people with dementia from carers of people with other physical or mental health difficulties;
- Studies that were not peer reviewed.

***Search Results***

Following the selection procedure, 14 studies were included in the present review. The study selection process is described in figure 1.

***Assessment of quality***

Following the systematic search, the 14 selected studies were appraised using a quality rating checklist. The checklist chosen was originally utilised by Greenwood, MacKenzie, Cloud and Wilson (2009) in their review of the qualitative literature on caring for someone

following a stroke and was developed from criteria outlined by Popay, Rogers and Williams (1998). Study scores can be found in table 1. These scores demonstrate that despite some variability, a number of quality criteria were consistently met across the studies. For example, all but two studies (Duggleby, Williams, Wright & Bollinger, 2009; Netto, Jenny & Philip, 2000) demonstrated the use of more than one researcher in the analysis and all but one (Netto et al., 2009) included a broad range of participants including cases of participants who did not experience PAC.

However, the assessment process highlighted a number of factors impacting on the quality of studies. Firstly, the majority of the studies reported on qualitative data collected as part of larger, mixed-method studies. In some cases, opportunity or convenience sampling was used to collect the large volumes of data required for the quantitative aspects of the studies as opposed to purposive sampling preferred in qualitative methodologies (Farran, et al., 1991; Murray, Schneider, Banerjee & Mann, 1999; Narayan, Lewis, Tornatore, Hepburn & Corcoran-Perry, 2001).

Furthermore, those studies that formed a part of a larger piece of research tended not to report as much detail of the data collection method, particularly in terms of who collected the data, their training and potential influence they may have had on the process (Butcher & Buckwalter, 2002; Farran et al., 1991; Jansson, Almberg, Grafström, & Winblad, 1998; Jarvis, Boland & Fickenscher 2010; Peacock et al., 2010; Ribeiro & Paúl, 2008; Shim, Barroso, Gilliss & Davis, 2013). Even in cases where interviewer information was provided, in all but one study - Netto et al., 2009 - it was not the author of the study that carried out the interviews. As a result, important qualitative nuances that develop in the dynamic between participant

and interviewer may have been missed, which could affect the quality of the results presented in these studies.

With regard to analysis, the majority of studies made a good attempt to describe the techniques used to analyse the qualitative data. However, what was lacking in terms of quality was appropriate justification and theoretical underpinning for the methods chosen. The theoretical underpinning of the method enables the reader to understand the lens through which the data was analysed and therefore adds transparency to the findings. Some studies described using a range of 'common qualitative techniques' (Farran et al., 1991, p. 485) or reported engaging in different levels of coding with no theoretical basis (Narayan et al., 2001). Further studies utilised techniques from a particular theoretical position, most commonly grounded theory, but did not follow through with this approach to develop a theory grounded in the data (Jervis et al., 2010; Murray et al., 1999; Netto et al., 2009; Ribeiro & Paúl, 2008).

### ***Analysis***

The analysis in the present review employed techniques initially described by Britten and colleagues (Britten et al., 2002; Campbell et al., 2003) and adapted by Emslie (2005). Each paper was read to identify the main concepts of the study, study setting and participants, starting with those studies that scored most highly on the quality rating checklist. These details were compared systematically to detect common and recurring concepts. From this, similarities and differences in scope and findings were established. Only findings relevant to the aims of the present review are presented here.

### **Findings**

General study characteristics are displayed in table 1. Study findings will be presented in terms of themes relating to the aims of the present review. The first aim sought to explore how PAC have been conceptualised within the qualitative literature. The findings of eight of the studies reviewed primarily met this aim. The second aim was to investigate how caregivers perceive the process of positive caregiving. The findings of six of the reviewed studies met this aim, although there was some overlap. Within these two sections, particular attention will be paid to the experiences of individual groups of carers (spouses vs adult children vs other relatives, husbands vs wives, sons vs daughters) where possible, thus meeting the third aim of the present review.

### ***Conceptualisations of positive aspects of caregiving in dementia in the qualitative literature***

*Role satisfaction.* A sense of satisfaction with carrying out caregiving duties well was reported by carers in most studies. Feelings of satisfaction were particularly associated with doing a good job (Jervis et al., 2010), keeping the PwD safe (Peacock et al., 2010) or making them as comfortable as possible (Murray et al., 1999).

However, there also appeared to be a difference between carers in the quality of the satisfaction experienced. Studies reported that some carers approached their caregiving roles in a practical and unemotional way, deriving satisfaction from simply 'doing their best' (Murray et al., 1999, p665). Other studies suggested that some carers found a deeper satisfaction. Ribeiro and Paúl (2008) described carers experiencing a sense of pride in carrying out care-related activities to a high standard and reported that carers found a new sense of purpose in their caring role. Shim, Barroso and Davis (2012) further demonstrated that carers who were ambivalent about caring tended to find satisfaction in discrete activities, such as visiting friends; whereas positive carers reported a more overarching sense of pride and satisfaction in their role.

Studies that explored this further suggested that previous quality of relationship may be important in understanding these different experiences. Carers who derived less satisfaction from caring spoke about their previous relationship with their spouse or parent in negative terms and reported caring out of obligation, without enjoyment (Jansson et al., 1998; Ribeiro & Paúl, 2008; Shim et al., 2012). These carers were committed to their role, but did not express the same pride and satisfaction in the role as carers who reported having a positive prior relationship with their spouse or parent.

*Emotional rewards.* As well as job satisfaction, carers across the studies spoke of emotional rewards gained through caring. These were often related to feeling appreciated or successful and such comments were particularly poignant when they came from the PwD themselves (Jansson et al., 1998; Jervis et al. 2010; Netto et al., 2009; Ribeiro & Paúl, 2008). In addition, some adult child carers specifically described enjoying the company of elderly people (Jervis et al., 2010; Netto et al., 2009). For husbands in particular, there was an emotional reward in the perceived social honour of being a man caring for his wife (Ribeiro & Paúl, 2008).

*Personal growth.* Many of the studies reported that caregivers described having 'grown intrinsically' as a result of their role (Netto et al., 2009, p. 250). Particular areas of growth included increased patience (Peacock et al., 2010), self-respect (Jansson et al., 1998) and being more self-aware (Sanders, 2005). Some studies referred to a sense of peace that seemed to be present in those carers who spoke of personal growth (Peacock et al., 2010; Sanders, 2005). This growth appears to be separate from personal development achieved through learning new skills.

Male carers (husbands and sons) were more likely than female carers to describe personal growth in terms of becoming more humble (Netto et al., 2009; Ribeiro & Paúl, 2008).

Furthermore, personal growth may be more salient to adult child carers and husbands than to wives who care. In Sanders' (2005) study, husbands and daughters were more likely to report personal growth, whereas wives were more likely to report spiritual growth. In addition, studies that included predominantly adult child carers in their sample found personal growth to be the most consistently reported gain (Jansson et al., 1998; Netto et al.,

2009), whereas studies focusing on spousal carers tended to report relationship gains more consistently.

*Competence and mastery.* Alongside personal growth, studies reported that carers described gaining a sense of competency or mastery in the role as a positive aspect of caregiving (Netto et al., 2009; Narayan et al., 1999; Murray et al., 1999; Peacock et al., 2010; Ribeiro & Paúl, 2008; Sanders, 2005). They spoke of caregiving as providing an opportunity to learn new skills both in terms of caring specifically (Ribeiro & Paúl, 2008) and also transferable skills, such as problem-solving (Sanders, 2005). For many carers, the sense of competence went beyond simply mastering new skills to a feeling that they had achieved something they did not think they were capable of (Jansson et al., 1998; Sanders, 2005). Many spoke of wanting to share their skills and knowledge with others and some were even considering changing career to a caring profession (Peacock et al., 2010).

In particular, husbands reported increased confidence and self-worth as a result of learning new skills such as cooking or housework which had traditionally been the domain of their wives (Ribeiro & Paúl, 2008).

*Faith and spiritual growth.* Increased faith and spiritual growth was mentioned as a positive aspect across many of the studies, but was emphasised differently depending on the sample of carers. In some studies, spiritual growth was a strong and consistent theme among carers (e.g. Sanders, 2005). These studies tended to have taken place in the USA with caregivers identifying themselves as being of Christian faith. These carers described their faith as enabling them to take on the caring role and providing them with the strength to continue (Netto et al., 2009). This was particularly salient for wives caring for husbands (Sanders, 2005).



Other studies with more spiritually and religiously diverse samples recognised faith as a valuable source of support for some carers, but acknowledged that it did not apply to all (Peacock et al., 2010; Ribeiro & Paúl, 2008). Further studies described carers as experiencing a broader positive change in philosophy rather than specific spiritual growth (Netto et al., 2009). These carers spoke of placing less value on material goods and focusing more on relationships. Regardless of religious background, caregivers appeared to have gained a broader perspective on life and found their lives to have new meaning as a result of caring.

*Relationship gains.* The majority of studies referred to relationship gains as a positive outcome of caring. Spousal carers described gains relating to companionship and simply being in the company of their husband or wife, even if the other could no longer reciprocate (Ribeiro & Paúl, 2008). They also referred to the onset of dementia and the associated growing dependency as strengthening their relationship and bringing greater emotional closeness (Murray et al., 1999). Both husbands and wives explained that engaging in caring tasks increased the intimacy in the relationship (Peacock et al., 2010; Ribeiro & Paúl, 2008).

For adult child carers, relationship gains often came in the form of strengthening a relationship with a parent that had become distant as a result of everyday life (Jansson et al., 2008; Netto et al., 2009). They spoke of the onset of dementia as an opportunity to spend time with and really get to know their parent or grandparent (Jervis et al., 2010). In addition, these carers reported gains in the relationships with their own immediate family. They identified that caregiving encouraged them to appreciate those around them more (Netto et al., 2009; Jervis et al., 2010).

Only one study, Sanders (2005), did not comment on relationship gains amongst their findings. It is likely that this is because participants were asked particularly about the

changes they had noticed in themselves as a result of their caregiving, leading to self-focused answers. Furthermore, they were asked to provide responses in written format, limiting the opportunity for any elaboration of responses.

*Sense of duty.* In many studies, spousal carers reported finding rewards in following through a sense of duty. They explained that there was an intrinsic reward in upholding their marital vows and expressed pride in being able to care for their lifelong spouse (Murray et al., 1999; Ribeiro & Paúl, 2008). Similarly to 'job satisfaction' (section 1.3.1.1.1), spouses with a prior positive relationship were more likely to report these feelings (Ribeiro & Paúl, 2009; Shim et al., 2012).

This intrinsic reward in fulfilling a sense of duty was reported less often by adult child caregivers. However, it featured in Jervis and colleagues (2010) study with American Indian caregivers. Both adult child and grandchild carers expressed pleasure in being able to uphold cultural values of caring for their elderly. They consistently commented that this commitment was diminishing within the community, but that they were proud to be following tradition.

*Reciprocity.* In addition to fulfilling a sense of duty, many studies reported that carers found satisfaction in the notion of reciprocity, or the opportunity to give back to their loved one (Jervis et al., 2010; Murray et al., 1999; Peacock et al., 2010; Ribeiro & Paúl, 2008). Carers spoke of wanting to repay the love and care they had received from their spouse or parent (Peacock et al., 2010; Jansson et al., 1998). It was noted across studies that husbands in particular were keen to pay back the love and care they had received whereas wives tended to view caring as a continuation of the relationship (Murray et al., 1999; Peacock et al., 2010; Ribeiro & Paúl, 2008).

In some cases this reciprocity was future focused, with adult child carers acknowledging the influence of the knowledge that they would be old one day and may be in need of care (Jervis et al., 2010). Some even highlighted that through caring for their parent, they were able to demonstrate to their children what may be expected of them in the future (Peacock et al., 2010).

However, similarly to satisfaction, reciprocity was more likely to be cited as a reward by carers who had a previous positive relationship with their parent or spouse (Ribeiro & Paúl, 2008). Those daughters who had previously had a difficult relationship with their mothers reported caring ‘...in the absence of either affection or reciprocity’ (Jansson et al., 1998, p. 279).

### ***Dementia caregiver’s perceptions of the process of positive caregiving***

Studies reviewed in relation to the second aim utilised different methods to explore carers’ perceptions of positive caregiving. Some took ‘uplifted’ carers and studied their thoughts on their caring role (Butcher & Buckwalter, 2001; Donovan & Corcoran, 2010), others asked carers how they find ‘hope’ or ‘meaning’ (Duggleby et al., 2009; Farran et al., 1991; Shim et al., 2013) and one compared negative, ambivalent and positive carers (Shim et al., 2012).

*Acceptance.* A key factor in experiencing caregiving as positive was acceptance of or coming to terms with the situation (Donovan & Corcoran, 2010; Duggleby et al., 2009; Shim et al., 2012; 2013). Carers reported having to relinquish previous plans, focus on living day by day and accept the limitations of the PwD (Duggleby et al., 2009; Shim et al., 2013). Coming to terms with the situation was seen to involve gaining an understanding of what they were

dealing with (Duggleby et al., 2009) and through this they could be compassionate and empathic towards the PwD (Shim et al., 2013).

*Choosing a positive caregiving attitude.* In addition to accepting the situation, carers across studies spoke of choosing the attitude they took towards their caring role. There was an acknowledgement that resentment could develop, but that they could choose whether or not this dominated their outlook (Farran et al., 1991; Shim et al., 2013). In particular, carers described making an active choice to look at the positives in the situation. Uplifted carers in Donovan and Corcoran's (2010) study spoke about 'practicing a positive attitude' (p. 592) by dwelling on positive thoughts and avoiding negative ones. In other studies carers described counting blessings (Butcher & Buckwalter, 2001), cherishing what remained (Shim et al., 2012) or choosing to use humour to make a positive situation out of a negative one (Donovan & Corcoran, 2010; Farran et al., 1991; Shim et al., 2013). By making this personal choice to focus on the positives, carers seemed to be empowered to continue to face the challenges of their role (Butcher & Buckwalter, 2001).

In terms of specific caregiving groups, Farran and colleagues (1991) noted that spouses were more likely to report actively making this choice than adult child carers. Few other studies looked at different groups of carers.

*Commitment to relationship.* Spousal carers across the studies described how commitment to their relationships enabled them to maintain positive attitudes towards caring (Donovan & Corcoran, 2010; Farran et al., 1991; Shim et al., 2013). They spoke of the love they still had for their partner and the love they received in return. This love helped them to put their partner first and be compassionate towards them at times of difficulty (Shim et al., 2013).

The uplifted carers in Donovan and Corcoran's (2010) study described how maintaining their commitment to their spouse enabled them to maintain their stamina for caring.

Similarly to some of the PAC discussed above, carers who described their relationship prior to the onset of dementia in positive terms were more able to draw upon their commitment to their marriage to empower them to continue caring (Ribeiro & Paúl, 2008; Shim et al., 2012). Butcher and Buckwalter (2001) highlight the importance of cherished memories as part of this process. Being able to find joy in memories of the PwD prior to the onset of dementia can inform how carers view them in the present.

*Creating opportunities.* The majority of studies reported that carers created opportunities for the PwD to engage in meaningful activities. Carers suggested that if the PwD were happy and comfortable then they could be too (Butcher & Buckwalter, 2001). Furthermore, as with adopting a positive attitude, carers described this as an active choice. The carers in Duggleby and colleagues (2009) study spoke of hope arising through setting goals with the PwD.

*Drawing strength from faith/past challenges/others.* Carers also described drawing strength from various sources in order to remain positive. Some spoke about drawing strength from faith (Duggleby et al., 2009), some from past challenges (Shim et al., 2013) and others from supportive friends, family or services (Donovan & Corcoran, 2010). Utilising these sources of strength enabled carers to maintain a balance in their lives and continue caring in the face of hardship. Of note, Sanders (2005) reported that carers who struggled to report gains in their caregiving experience were more likely to be caring in isolation.

## Discussion

The primary purpose of the present review was to critically evaluate the empirical findings of qualitative studies on the PAC in dementia. Specifically, the aims were to explore the contribution of qualitative research to the conceptualisations of PAC, carers' perceptions of the positive caregiving process and to gain an understanding of the experiences of different groups of carers.

Positive aspects for all groups of carers arose from two broad areas: those gained from the caring itself and those derived from the dynamic between the caregiver and the PwD. The former included satisfaction, emotional rewards, personal growth, competence and mastery and increased faith and spiritual growth while the latter encompassed relationship gains, satisfactions in reciprocity and fulfilling a sense of duty. Interestingly, these dimensions echo those described by Nolan et al (1996) in their caregiving satisfaction matrix.

Studies that explored caregiver perceptions of the process of positive caring highlighted a number of significant factors that appear to contribute to this. Primarily, the positive aspects described by carers did not simply appear, but were achieved through the choices and strategies adopted by the carers. In particular, acceptance of the situation and the ongoing implications of this appeared to be an important step. This enabled carers to make a choice to view the situation with a positive attitude and be compassionate and empathic towards their loved one. Furthermore, choosing to commit to the relationship whilst drawing upon sources of strength and creating meaningful opportunities for the PwD to be happy and comfortable, appeared to empower carers to continue in their caregiving role. Using such adaptive strategies enabled carers to go beyond just coping with the situation, to growing and taking something positive from it.

The use of qualitative methodologies to explore in detail the experiences of participants has highlighted the multiple dimensions of PAC. Furthermore, by providing a platform for the voices of the caregivers, the qualitative studies reviewed here have demonstrated the importance of these experiences. These caregivers spoke with passion and emotion, describing how they had not just adapted to their circumstances but how they had been able to take something good from them and in some cases, be changed for the better by them. It is noteworthy that for some of the papers reviewed, the initial purpose of collecting the data was not to look for positive experiences, yet these were so prominent within the data that they prompted re-analysis and further articles to be written (Butcher & Buckwalter, 2001; Peacock et al., 2010).

A striking finding of the present review was the remarkable degree of consistency in the positive aspects reported by carers across the studies. Despite studies being conducted in a number of locations around the world, at different times and using different theoretical frameworks and methodologies, similar findings were reported throughout. Of particular note were the studies conducted by Farran et al. (1991) and Duggbleby et al. (2009). The former adopted a deductive, theory-driven approach to explore how carers found meaning in their role, whereas the latter took an inductive grounded theory approach to investigating carers' experiences of hope. Despite these very different approaches they reached similar conclusions in terms of caregivers making personal choices to care and to take a positive attitude to caring, valuing these positive aspects and drawing on the support of those around them and their faith to maintain their caregiving role.

There were subtle differences in how PAC were experienced by different groups of carers. Adult child carers seemed to find personal growth a particularly salient outcome. Caregiving

was identified as an opportunity to learn more about themselves and appeared to give them confidence in their ability to handle difficult situations in the future. In contrast, spousal carers, particularly wives, tended to place a higher value on gains based in the dynamic of their relationship and on spiritual growth. These differences support previous research (Ott, Sanders & Kelber, 2007) and may reflect the different times of life that these carers embark on their caregiving journey. Adult child carers tend to be younger and therefore may have had less opportunity for personal development than older spousal carers.

For husbands, both of these domains appeared to be salient. They were reported as gaining particularly from the opportunity to reciprocate the care they had received through the marriage and from the new sense of purpose gained from taking on the caregiving role. Wives, by contrast, viewed their caring role as an extension of their marital relationship. Furthermore, husbands reported benefitting from a perceived social honour of being a male carer. In terms of the gender perspective, this supports previous research which has suggested that the social recognition associated with being a male carer is intrinsic to the positive caring experiences of husbands (Rose & Bruce, 1995). However, the findings of the present review suggest that this is not the only means by which male carers experience caregiving as positive and that other factors, such as gaining a new sense of purpose, are important and worthy of further investigation.

Notably, prior relationship quality appeared to be a significant factor in understanding the experience of PAC. Carers who described their prior relationship with the PwD in positive terms were more likely to report a deeper level of satisfaction in their role and appeared more able to draw satisfaction, pride and strength from the reciprocity of the relationship. This finding is in line with previous research which highlights that prior relationship quality



may be an important factor that influences a number of aspects of the caregiving journey. For example, relationship quality has been shown to influence motivation to undertake a caregiving role, with carers who describe a positive prior relationship being more likely to be motivated by an intrinsic desire to maintain quality of life for the PwD rather than an extrinsic motivation based on obligation (Quinn, Clare & Woods, 2010). Furthermore, a recent review demonstrated that a positive prior relationship results in better outcomes for both the caregiver and PwD (Ablitt, Jones & Muers, 2009).

### ***Summary of the critical appraisal of studies in the review***

Overall, the studies in the present review scored relatively well on a quality framework checklist. However, those studies with lower scores tended to fall down on aspects relating to data collection, reporting of methodology and analysis. In particular, the data in several studies was collected as part of larger mixed method studies and therefore not collected or reported with the necessary rigour. Whilst the process of analysis of the data was generally described well, studies often lacked an appropriate justification and theoretical underpinning for the methods chosen. Some studies drew techniques from particular methodologies and used them in isolation without rooting them in their theoretical framework. The theoretical frameworks of different qualitative methods are key to helping the reader understand the epistemological position of the researcher and how they view the data. Without this, those studies lack some transparency and the usefulness of their conclusions can be limited.

### ***Research implications***

The quantitative research base underlying PAC in dementia currently lacks clear definitions of key concepts which could hinder further progress in developing understanding in the area (Kramer, 1997a). The qualitative research reviewed here provides a rich and detailed insight into caregivers' experiences. Not only do the findings highlight the breadth and depth of the positive experiences of the carers, they also give insight into how these are achieved and the subtle differences between groups of carers. As such, the present review evidences the presence of a consistent and solid base of understanding from which concepts can be further defined and operationalised through quantitative studies.

The present review also demonstrates the flexibility of qualitative methods. For example, the papers by Donovan and Corcoran (2010) and Shim et al. (2012) took qualitative data from specific groups of carers to examine their different experiences thus furthering understanding of how and why different carers experience PAC. This type of secondary analysis is not without critics (Hinds, Vogel & Clarke-Steffen, 1997); however these studies had quality ratings similar to or higher than those of original studies reviewed and therefore represent alternative and novel means of examining the experiences of participants which should be encouraged.

In terms of further research, the present review highlights the importance of separating out groups of carers in studies. Whilst there was some overlap in the positive experiences of husbands, wives and adult child caregivers, there were important subtle differences meaning that carers should not be considered a homogenous group. The majority of studies reviewed looked at spousal or mixed groups of carers and thus future work focusing specifically on adult child and other sub-groups of carers could be valuable.

In addition, further research is needed to explore whether or not the positive experiences identified by carers of people with dementia in the present review extend to carers of people with other physical or mental health difficulties. For example, a recent paper exploring the experiences of adult children caring for parents with either Alzheimer's disease or Parkinson's disease reported similar findings of enjoying time together, becoming closer and giving back care (Haberman, Hines & Davis, 2013). This suggests that the findings from the present review may be generalizable to other caregivers and this is worthy of further investigation.

### ***Practical implications***

The present review supports previous findings that PAC are important to caregivers (Kramer, 1997a). It is therefore important to recognise this fact in order to facilitate the provision of a holistic approach to supporting family carers. Expanding the assessment of carers by health or social workers to include the positive aspects could be a useful first step, enabling support and validation to be provided to those who experience caregiving as rewarding. Furthermore, the absence of positive aspects could be seen as a risk factor when identifying carers who are struggling. However, it is also important that the presence of PAC is not exploited as a reason for not encouraging caregivers to access services from which they and the PwD could benefit.

The present review has also demonstrated that PAC do not simply occur for carers, but are dependent on their choices and strategies which suggests a potential opportunity for intervention. Notably, acceptance of the situation appears to be a key first step in being able to view caregiving as a positive experience. Interventions based on this such as Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 2004) could be helpful to carers

struggling at this point. ACT promotes a mindful acceptance of the present. Specifically, it acknowledges the struggles that people might experience but suggests that engaging with the difficult thoughts and feelings that arise from them may not be helpful. Instead, it encourages people to adopt a values-based approach to life through identifying what is truly important to oneself and setting goals accordingly. This seems consistent with the experiences of positive carers described in the studies reviewed. Initial pilot studies have demonstrated positive outcomes and support this as a viable avenue for further investigation (Losada & Márquez-González, 2011).

Another key finding of the present review was the importance of relationship variables in how carers experience their caregiving role. Prior relationship quality appeared to be central in predicting positive experiences and many gains reported were relationship based. Therefore, including the PwD in work to support the carer may be beneficial. This could include supporting the carer and PwD to engage in meaningful activities together or encouraging them to share memories if appropriate (Donovan & Corcoran, 2010).

### ***Limitations***

Only studies published in English were included in the present review, potentially limiting the findings which could be discussed. In addition, the inclusion criteria limited studies to those which had a primary aim to explore PAC through a qualitative methodology. This meant that studies which discovered positive aspects serendipitously through other research questions were excluded, again limiting the findings which could be discussed.

The present review raises methodological questions regarding the critical review of qualitative studies. There is debate regarding quality ratings of qualitative studies and

particularly whether to include all studies that meet inclusion criteria or to exclude studies based on quality. The present review decided on the former approach due to difficulties in deciding what constitutes good design and to minimise bias by excluding 'poor' studies. Furthermore, it could be argued that another way to approach the present review with a focus on different groups of carers would be to use a meta-synthesis to synthesise and compare the results for different groups (spouses, adult child etc.). However, this would have been difficult with carers falling into more than one group (husbands vs wives, spouses vs adult child, sons vs daughters). The decision to conduct a critical review allowed these relationships to be explored more freely.

## **Conclusion**

In light of the conflicting quantitative evidence base regarding the PAC in dementia, the present review aimed to critically evaluate the qualitative literature in this area. The findings highlight a consistent and thorough base of qualitative evidence describing the multiple dimensions of PAC experienced by carers as well the factors that caregivers identify as important in developing and maintaining a positive caregiving experience. In particular, the present review demonstrates that PAC do not just occur for carers but are at least partly the result of their choices and strategies. The use of qualitative methodologies allowed the subtleties within the experiences to be examined, especially in relation to the different groups of carers. The present review reinforces previous findings that carers should not be considered a homogeneous group and advocates for further research with specific sub-groups of carers such as adult children. Clinically, the findings presented support the inclusion of PAC in holistic carer assessments and also identify opportunities for intervention with carers, for example through the techniques used within ACT. Further research is

needed to investigate whether the findings relating to PAC in the present review can be generalised to carers of people with difficulties other than dementia, however, they do provide a solid base from which concepts and theories in this area can be developed.

### **Declaration of Conflicting Interests**

The authors declare that there is no conflict of interest.

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