

Review Article

Influence of Positive Aspects of Dementia Caregiving on Caregivers' Well-Being: A Systematic Review

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Abstract

Background and Objectives: There is a growing evidence base that informal caregivers can identify positive aspects of providing care and that this may have a beneficial influence on their well-being. The aim of this systematic review was to explore how positive aspects of caregiving (PAC) affects the well-being of caregivers of people with dementia.

Research Design and Methods: We searched electronic databases for quantitative studies exploring the association between PAC and caregiver well-being. Studies were included if they involved informal (unpaid) caregivers of people with dementia, at least 75% of whom had to be residing in the community. A narrative synthesis was used to explore patterns within the data.

Results: Fifty-three studies were included in the narrative synthesis. Most studies utilized a cross-sectional design. The majority of samples consisted primarily of spouses and female caregivers. Twenty different PAC measures were employed and studies referred to a variety of constructs, such as satisfactions, gains, meaning, and rewards. PAC was associated with lower depressive symptoms and burden. Conversely, PAC was associated with better mental health, quality of life, satisfaction with life, and competence/self-efficacy. PAC was not associated with self-rated health or personal strain/stress.

Discussion and Implications: The findings suggest that identifying PAC is associated with better caregiver well-being, although further longitudinal studies are required to explore how this relationship changes over time. Interventions that enable caregivers to gain a more positive experience of caregiving could be beneficial for their well-being.

Keywords: Burden, Gains, Meaning, Satisfaction, Quality of life

Informal caregiving has been conceptualized as a career, beginning as an individual is introduced to the caregiving role and marked by transitional events (Pearlin, 1992). Many factors influence how caregivers respond to and adapt to caregiving. One way caregivers may adapt is to identify positive aspects of providing care, perceiving the potential benefits of caregiving for either themselves and/or the person cared for. A review by Kramer (1997b) described how a plethora of studies had explored the “negative” and “detrimental” aspects of caregiving, with little attention

paid to the role of positive psychological functioning in caregiving. Kramer identified that a “lack of attention to the positive dimension of caregiving seriously skews perceptions of the caregiving experience and limits our ability to enhance theory of caregiving adaption” (p. 218). Although Kramer’s (1997b) review included all caregivers without differentiation between them based on care recipients’ health conditions, it is feasible that caregivers’ experiences may differ depending on the health condition of the care recipient. Dementia is a progressive degenerative condition

and there may be fewer opportunities for dementia caregivers to have positive experiences than caregivers of people with other health conditions (Pinquart & Sörensen, 2004). However, there is a growing evidence base concerning how identifying positive aspects of caregiving (PAC) can be beneficial for dementia caregivers' well-being. The aim of this paper is to review the literature on positive aspects of dementia caregiving, specifically exploring the impact of PAC on caregiver well-being.

Conceptually there is no clear definition of PAC, and research indicates that it may have different dimensions. For instance, caregivers have described experiencing personal growth, identifying that caregiving had made them a better person or made them more resilient (e.g., Netto, Goh, and Yap (2009) and Quinn, Clare, and Woods (2015)). Caregivers have also described feelings of gratitude and a sense of mastery (Cheng, Mak, Lau, Ng, and Lam (2016)). Within the quantitative literature, it is also clear that different terms and measures are used to describe PAC. The review by Kramer (1997b) identified the following terms used to describe PAC: satisfactions, uplifts, rewards, gratifications, growth, meaning, and enjoyment. Many of these terms lack a theoretical basis, so it is difficult to determine whether they constitute separate or overlapping concepts. A range of measures of PAC have been developed using a variety of approaches. Some of these measures are based on existing tools; for instance, the Positive Aspects of Caregiving Scale (PACS; Tarlow et al., 2004) is based on the Caregiving Satisfaction Scale (CSS; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989), which in turn was based on other existing measures. Other measures have been developed through identifying domains and questions from the existing literature (e.g., Faba, Villar, and Giuliani (2017)). A few have involved caregivers in the measure-development process (e.g., Abdollahpour, Nedjat, Noroozian, Salimi, and Majdzadeh (2017) or generated questions from interviews with caregivers (e.g., Farran, Miller, Kaufman, Donner, and Fogg (1999) and Yu et al. (2016)).

Theoretical models and constructs underpin understandings about PAC. Models of stress and coping have incorporated positive psychological functioning. For instance, the adapted stress and coping model (Folkman, 1997) proposed that both positive and negative emotions can co-occur in response to challenging circumstances. In this model, positive psychological states were associated with searching for and finding positive meaning, a form of coping. Finding meaning relates to the ability to identify something positive in adversity, helping the person to make sense of the situation, and accept what has happened. This could result in the person being able to identify positive life changes (Park, 2010). However, in the "broaden-and-build" theory, Fredrickson, Tugade, Waugh, and Larkin (2003) proposed that positive emotions have a more adaptive role in dealing with stressful circumstances, as they can provide an emotional break, replenishing depleted resources. Positive emotions can also be involved in cognitive broadening, widening people's

attention, thinking, and behavior. Longitudinally this broadening effect fosters the building of a range of adaptive and durable personal resources (Fredrickson, 2004). Similarly, theories of benefit-finding imply that this emerges over time as a way of adapting to stressful circumstances. In the early stages, benefit-finding may be considered to be a form of coping, but over time may reflect positive change or growth (Tennen & Affleck, 2002).

Theoretical models of caregiving have also explored the influence of PAC on caregiver well-being. In the Stress Process Model (SPM; Pearlin, Mullan, Semple, & Skaff, 1990), gain is encompassed under "secondary intrapsychic strains," which relates to the caregiver's self-concept. In this context, the diminishment of, or barriers to the development of feelings of, gain is considered to constitute strain. Based on two-factor models of psychological well-being, which distinguish between positive and negative aspects of psychological well-being, two-factor models of caregiving (Kramer, 1997b; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991) acknowledge that caregiving can have both positive and negative outcomes. In these models, PAC is associated with positive dimensions of well-being, whereas negative aspects are associated with negative dimensions of well-being. However, Lawton and co-worker (1991) reported support for the two-factor model only for spousal caregivers and not for adult-child caregivers. These results highlight the inconsistent findings regarding the association between PAC and positive and negative dimensions of caregiver well-being.

A comprehensive understanding of the influence of PAC on caregiver well-being requires a systematic synthesis of the existing literature. Previous reviews have included mixed samples (Carbonneau, Caron, & Desrosiers, 2010; Kramer, 1997b) or focused on caregivers of older people (Pinquart & Sörensen, 2004). Of the reviews that have focused only on dementia caregivers, the review by Lloyd, Patterson, and Muers (2016) referred to the qualitative literature and the review by Quinn, Clare, and Woods (2010) identified the literature on finding meaning. The integrative review by Yu, Cheng, and Wang (2018) included both qualitative and quantitative studies, with a focus on the nature of PAC and factors predicting PAC. To date, no review has specifically explored the association between PAC and caregiver well-being. The aim of this systematic review was to explore how PAC affects the well-being of caregivers of people with dementia. As part of the review process, we also explored the theoretical underpinnings of the included studies and, related to this, the measures of PAC employed in the studies.

Methods

The review protocol was registered with PROSPERO: CRD42017059919. The following electronic databases were searched for studies from inception to March 2017: MEDLINE (via OvidSp), PsycINFO (via OvidSp), ASSIA (via ProQuest), SSCI (via Web of Science), and CPCI (via Web of Science). Sources of gray literature were also

searched, including the British Nursing Index (BNI; via ProQuest) and CINAHL (via EBSCO). An example of the search terms can be found in [Supplementary Document 1](#). Forward and backward citation searching was used to identify additional studies from relevant retrieved papers. Endnote X7 was used for reference management.

Inclusion and Exclusion Criteria

No date restrictions were applied, but studies had to be published in English. The inclusion criterion for caregivers was that they had to be informal (unpaid) caregivers of people with dementia, and we excluded studies where more than 25% of the people with dementia had died. The person with dementia could have any dementia diagnosis, though studies of people with mild cognitive impairment were excluded. Studies with mixed samples were included if the data for the person with dementia were provided separately: if the data were not presented separately, at least 75% of the sample had to have a diagnosis of dementia. At least 75% of the people with dementia had to be community dwelling (calculated at baseline in longitudinal studies). In many papers, the place of residence of the person with dementia was not stated or was unclear, and in these circumstances it was inferred that they were community dwelling if this was implied by the other data reported. For instance, some papers noted that caregivers were providing over 4 hr of care a day, which suggests that they were residing with the person with dementia.

Studies reporting cross-sectional or longitudinal associations between PAC and caregiver well-being were included. PAC was defined as the caregiver deriving something positive out of providing care; thus, positive aspects had to be directly related to caregiving. Caregiver well-being is a multidimensional concept ([Manthorpe & Bowling, 2016](#)) and global measures, such as quality of life (QoL) and satisfaction with life, as well as caregiver-specific well-being measures, such as stress, burden, role strain, and competence, were included.

Review Process

[Figure 1](#) illustrates the literature search process. Title, abstract, and full-text screening were conducted by two reviewers. Although there was uncertainty on a study, it was included in the next stage of screening. There was 86% agreement on title screening, 84% agreement on abstract screening, and 82% agreement on full-text screening. Any disagreements were resolved through discussion. Study information was extracted from the included papers by the principal reviewer using a structured pro forma and checked by the second reviewer. Details of the information extracted from the papers are provided in [Supplementary Document 2](#).

Study Quality

Study quality was assessed using the QATSDD ([Sirriyeh, Lawton, Gardner, & Armitage, 2012](#)) and we used the 14

indicators in the tool that applied to quantitative studies (two items are applicable only to qualitative studies). Indicators were rated on a 4-point Likert scale, with possible total scores ranging from 0 to 42; higher scores indicated higher quality reporting. Study quality was rated by two reviewers and discussed until consensus was reached. In six instances, data from a study were reported in two papers. If data were reported in a thesis/dissertation and a published paper, only the published paper was included in the review. When data were reported in two published papers, the higher scoring (or most detailed) paper was included in the analysis. One paper obtained a particularly low score ([Uwakwe, 2006](#)), but was not excluded as it was published as a short research letter and the word limit may have constrained the amount of information provided.

Narrative Synthesis

Due to the heterogeneity of study designs and outcome measures, a narrative synthesis was used. A narrative synthesis approach involves the synthesizing of findings using a textual approach to discuss the findings of the review. In this study, it was used to review the nature and direction of effects and explore patterns within the data. A similar approach to that reported in [Farina and colleagues \(2017\)](#) was followed. In the narrative synthesis, findings in the included studies were explored to see whether they reported a significant association with the outcome measures and if so in what direction. Non-significant associations were also recorded. The findings explored were the results from correlation, regression, or other analytical techniques that explored associations between variables. When studies reported regression analyses, it was noted whether PAC was a predictor of the outcome measure.

Results

Fifty-nine papers reporting 53 studies were included in the narrative synthesis (reported in [Supplementary Document 3](#)). Papers were published between 1989 and 2017 and the majority employed cross-sectional designs: only five papers used longitudinal designs. Most studies were conducted within America and Canada (reported in [Table 1](#)).

Paper Quality

No paper achieved the maximum score on the QATSDD (reported in [Table 2](#)). The overall range of ratings was 11–38, and 49% of papers ($N = 26$) achieved ratings of between 31 and 35. All papers achieved maximum scores for selecting an appropriate data collection method and 98% ($N = 52$) achieved maximum scores for selecting an appropriate data analysis method. The majority of studies (83% [$N = 44$]) provided clear evidence that they recruited representative samples (i.e., they achieved a maximum score of 3 for this criterion). There was significant variation across

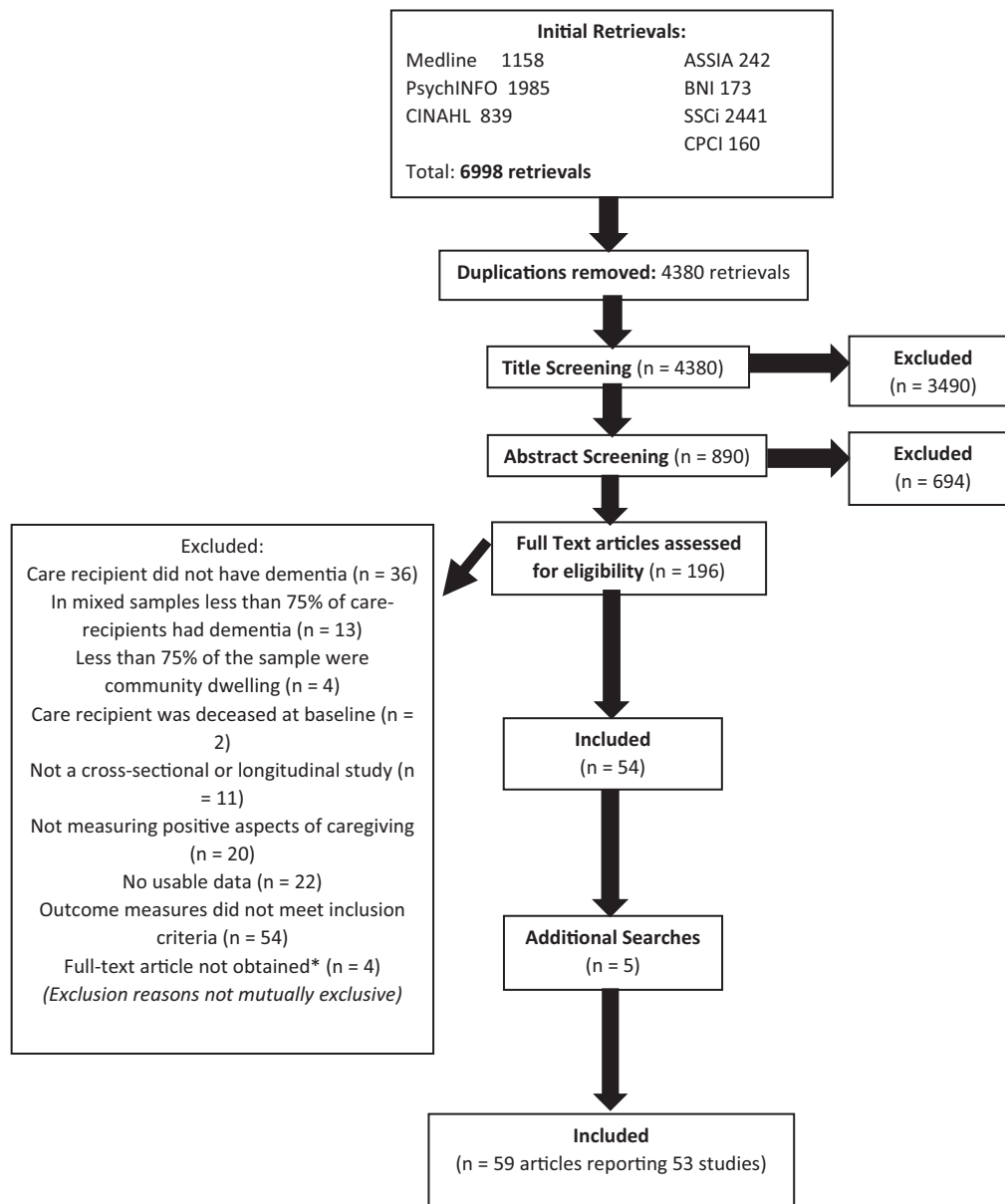


Figure 1. Flowchart of the search strategy.

Table 1. Geographical Regions Represented in Publications

Geographical region	No. of publications
America and Canada	32
New Zealand	1
Europe (including the United Kingdom)	8
East Asia	10
Middle East	1
Africa	1

studies in the extent to which the reliability and validity of the measures had been considered (only 30% [N = 16] of studies achieved maximum scores, whereas 23% [N = 12] scored between 0 and 1 on this criterion). Similarly, there was variation in the reporting of data collection procedures (32% [N = 17] of studies achieved maximum scores,

whereas 9% [N = 5] scored between 0 and 1 on this criterion). However, no paper provided evidence of patient/public involvement and 55% (N = 29) did not provide any justification for the sample size.

Participants

The majority of samples (n = 51) comprised over 50% female caregivers. Most caregivers were aged 65 and older. The majority of caregivers were spouses of the person with dementia (represented in 83% [n = 119] of associations), followed by adult child or daughters/sons-in-law (represented in 76% [n = 109] of associations). The duration of caregiving was difficult to extrapolate: several papers did not contain this information. Where stated, the average duration of caregiving ranged from 2.6 to 5.6 years.

Details about the person with dementia were often not reported. The most commonly specified diagnosis was Alzheimer's disease (represented in 57% [$n = 81$] of associations). Only 20 papers contained information about the severity of the person's dementia: the majority fell in the moderate (41% [$n = 11$]) and moderately severe (30% [$n = 8$]) stages with fewer being in the early/mild stage (15% [$n = 4$]) or severe stage (15% [$n = 4$]). Most studies recruited through support services including health services or charities such as the Alzheimer's Association. Only a minority of studies recruited participants directly from the community, such as through churches or community centers.

Theoretical Basis

The majority of papers (83% [$n = 44$]) made reference to theory, models, frameworks, and constructs. Some papers referenced multiple models, constructs, and theories; thus, the total number referenced was 76. However, only 60% of papers ($n = 32$) provided a specific theoretical basis for the study reported or applied a theoretical framework, model, or construct to the research findings. Furthermore, nine studies made no reference to any theories, models, or constructs.

The majority of models referenced (36% [$n = 27$]) related to the positive and negative aspects of caregiving with the dominant model being the stress and coping model (Lazarus & Folkman, 1984) and its revision (Folkman, 1997), referenced on 12 occasions. The SPM and its revision (Pearlin et al., 1990) was referenced on eight occasions and the two-factor model of caregiving (Lawton et al., 1991) was referenced on four occasions. Generic models and theories of stress and adaptation were frequently referenced ($n = 13$) but only the socio-cultural stress and coping model (Knight, Silverstein, McCallum, & Fox, 2000) was referenced by more than one paper ($n = 2$). Some models ($n = 8$) concerned the relationship dynamics and interactions between caregivers and the care recipient or environment. For instance, the ABCX family crisis model (McCubbin & Patterson, 1983), which explores family's adjustment and adaptation to stressful events, was referenced on three occasions. However, only one paper referenced the broaden-and-build theory of positive emotions (Fredrickson, 2004).

Measures of PAC

The titles of the measures employed in the studies infer that various constructs were captured, including finding meaning, satisfaction, gains, uplifts, rewards, esteem, gratification, and coping. A total of 20 different of PAC measures were used in the studies, and these ranged in length from four items to 110 items, the majority having 10 items or fewer. The Positive Aspects of Caregiving Scale (PACS; Boerner, Schulz, & Horowitz, 2004; Tarlow

et al., 2004) was most commonly used, being included in 18 studies (and in 29% [$n = 40$] of associations). The Caregiving Satisfaction Scale (CSS; Lawton et al., 1989) and its revised version were used in eight studies (and in 15% [$n = 21$] of associations). The Finding Meaning Through Caregiving Scale (FMTCS; Farran et al., 1999) was used in four studies (and in 11% [$n = 15$] of associations), and Strawbridge's caregiving satisfaction scale (Strawbridge, 1991) and its adapted version were used in four studies (and in 6% [$n = 8$] of associations). Even when the same measure was used by studies, variation in the items used was apparent. For instance, the original PACS has 11-items, the revised scale has nine items, and there is a further Chinese version. Sixteen other measures were also used, and four of these were study-developed. Sometimes two measures of PAC were used and this occurred in five studies. In three instances, the purpose of this was to validate a newly developed PAC measure. However, two other cross-sectional studies included measures of both satisfaction and gain. Finally, three linked studies employed a qualitative approach, which asked caregivers to report the most enjoyable aspects of their role and then quantified these responses for the purposes of analysis.

Associations Between Positive Aspects of Caregiving and Caregiver Well-Being

A total of 143 relevant associations were extracted from the 53 studies. Most papers used standardized measures (i.e., measures with specified guidance to enable consistent and comparable administration and scoring); the only anomaly was that in 75% ($n = 12$) of the associations concerning health, a self-report item was used. Half of the outcome measures used ($n = 19$) were caregiver-specific. The most frequent association explored was with burden (28% [$n = 40$]). Other commonly explored associations were with depression (18% [$n = 26$]) and mental health/psychological health 18% [$n = 25$]). Findings for each well-being category are presented below and summarized in [Supplementary Table 1](#).

Global Measures of Well-Being

Depressive symptoms

Twenty-six associations explored the relationship between PAC and depression symptoms and 81% of these were significant. The weight of evidence suggests that higher PAC is associated with reporting fewer symptoms of depression. This association was explored in a wide range of caregiving relationships. In most cases, where this information was reported, the person with dementia was diagnosed with Alzheimer's disease. All these associations employed cross-sectional data and the most frequently used measure was the PACS ($n = 11$), but a total of seven different measures were employed.

Table 2. Summary of Studies Included in the Review

Reference	Design	Sample size	Positive aspects of caregiving measures	Well-being measures*	Quality rating
Abdollahpour et al., 2017	Measure validation	132	Positive aspects of caregiving questionnaire—10 items	SR health	31
Alvira et al., 2015	Cross-sectional	2014	Caregiver esteem subscale—7 items	Iranian caregiving burden questionnaire ZBI EQ-5D GHQ	28
Andren & Elmstahl, 2005	Cross-sectional	153	CASI	Nottingham health profile scale CBS	29
Baker et al., 2010	Cross-sectional	70	Strawbridge caregiving satisfaction scale-5 items	SR health ZBI	25
Cheng et al., 2013	Cross-sectional	99	PACS	ZBI	35
Cohen et al., 1994	Longitudinal measure validation	196 baseline	Asked caregivers about most enjoyable aspects of role, which were then quantified	Role overload measure Hamilton depression rating scale	24
de Labra et al., 2015	Cross-sectional	101	Revised CSS	GHQ ZBI ZBI	25
DeGregory, 2014	Cross-sectional	55	PACS	Caregiving competence scale SwLS	36
Faba et al., 2017	Measure validation	260 (study 2)	GAC	WHOQOL-BREF SwLS GDS-SF	30
Farran et al., 1999	Measure validation	215 (study 2)	Provisional meaning subscale—19 items, FMTCS	ZBI CES-D Global role strain scale Personal gain measure	24
Gold et al., 1995	Longitudinal	196 baseline	Asked caregivers about most enjoyable aspects of role, which were then quantified	Caregiver satisfaction measure GHQ ZBI	28
Goncalves-Pereira et al., 2010	Cross-sectional	116	PACS	ZBI	31
Harris et al., 2011	Cross-sectional	621	PACS	GHQ CES-D ZBI	33
Harwood et al., 2000	Cross-sectional	64	CSS—5 items	SF-36 CES-D CBS	24
Heo, 2014	Cross-sectional	648	PACS—9 items	CES-D ZBI	35
Hilgeman et al., 2007	Cross-sectional	243	PACS—9 items	CES-D	34
Kajiwara et al., 2015	Cross-sectional	354	Caregiving gratification scale—8 items	ZBI—Japanese version	30
Kinney & Stephens, 1989	Cross-sectional	60	Caregiving hassles and uplifts scale—110 items appraised as hassle or uplift	SCL-R-90-R	21

Table 2. Continued

Reference	Design	Sample size	Positive aspects of caregiving measures	Well-being measures*	Quality rating
Kramer, 1993	Cross-sectional	72	Strawbridge caregiving satisfaction scale—15 items	SR health	33
Kramer, 1997	Cross-sectional	74	Strawbridge caregiving satisfaction scale—15 items	SR health	32
Lawton et al., 1991	Cross-sectional	632	CSS—5 items	Screen for caregiver burden SR health Subjective caregiving burden Affect balance scale CES-D	30
Lawton et al., 1992	Cross-sectional	629	CSS—5 items	SR health Subjective caregiving burden Affect balance scale	32
Lethin et al., 2017	Longitudinal cohort	1223 in total	Caregiver esteem subscale—7 items	GHQ	25
Lévesque et al., 1995	Cross-sectional	265	Satisfaction with caregiving role—5 items	Brief symptom inventory Negative feelings about caregiving role scale	32
Lévesque et al., 1998	Longitudinal	265 baseline	Satisfaction with caregiving role—5 items	Affect balance scale Brief symptom inventory Negative feelings about caregiving role scale	32
Liew et al., 2010	Cross-sectional	334	GAIN—10 items	Affect balance scale GHQ ZBI	30
Liu, 2009	Cross-sectional	257	PACS—9 items	SSCQ	31
Liu et al., 2012	Cross-sectional	96	PACS-9 items	CES-D ZBI	35
Lloyd, 2008	Cross-sectional	64	Provisional meaning subscale—19 items, FMTCS	SF-36 CES-D	34
Lou et al., 2015	Measure validation	374	PACS—11 items, Chinese version	CES-D SR health ZBI	32
Mbiza, 2016	Cross-sectional	643	PACS—11 items	CES-D SR health	38
McLennon et al., 2011	Cross-sectional	84	FMTCS—43 items	SF-36 ZBI	38
Monin et al., 2015	Cross-sectional	58	PACS—11 items	ZBI CES-D	32
Morano, 2003	Cross-sectional	204	CSS—5 items Personal gain—4 items	CES-D Life satisfaction	31
Morano, 2003b	Cross-sectional	103	CSS—5 items, Personal gain—4 items	CES-D Life satisfaction	34

Table 2. Continued

Reference	Design	Sample size	Positive aspects of caregiving measures	Well-being measures*	Quality rating
Narayan et al., 2001	Cross-sectional	50	PACS—11 items	Caregiving competence scale Role captivity scale	32
Picot, 1991	Cross-sectional	83	Caregiver rewards scale—24 items	Cost of care index	37
Plata, 2007	Cross-sectional	60	FMTCS—43 items	SR health ZBI CES-D GHQ	36
Quinn et al., 2012	Cross-sectional	447	Meaning in caregiving scale—12 items	Quality of life Role captivity scale Caregiving competence scale	33
Rapp & Chao, 2000	Cross-sectional	63 (in data analysis)	Appraisals of gain—11 items	SR health SR health ZBI	26
Rapp et al., 1998	Cross-sectional	65	BENEFIT—11 items	Positive and negative affect SR health Quality of life CES-D	28
Reis et al., 1994	Longitudinal	213 baseline	Asked caregivers about most enjoyable aspects of role, which were then quantified PACS—9 items	ZBI GHQ CES-D	27
Roff et al., 2004	Cross-sectional	618		Spiegelberger state trait personality inventory GHQ	33
Roud et al., 2006	Measure validation	45	Personal gain scale—6 items Positive value, 5 items, COPE index	Burden interview Caregiving competence scale CES-D	22
Semiatin & O'Connor, 2012	Cross-sectional	57	PACS—9 items	RIS Eldercare self-efficacy scale FCI role strain scale SF-36	29
Shyu et al., 2010	Cross-sectional	176	Rewards of caregiving scale—14 items	CES-D Chinese version SR health Korean burden inventory	35
Son et al., 2003	Cross-sectional	117	Strawbridge caregiving satisfaction scale—16 items CSS—5 items	Subjective caregiver burden scale Schwab, Holzer & Warheit (1973) depression scale RSS ZBI	34
Talkington-Boyer & Snyder, 1994	Cross-sectional	110			20
Uwakwe, 2006	Cross-sectional	30	CSS—5 items		11
Williams, 2005	Cross-sectional	720	PACS—11 items	CES-D	32

Table 2. Continued

Reference	Design	Sample size	Positive aspects of caregiving measures	Well-being measures*	Quality rating
Yap et al., 2010	Measure validation	238	GAIN—10 items PACS—9 items	ZBI	30
Yu et al., 2016	Cross-sectional	401	PACS—9 items, Chinese version	ZBI	33
Yu et al., 2015	Cross-sectional	168	PACS—9 items	Caregiving burden interview—Chinese version	31

Notes. References in the table are the papers included in the review. See [Supplementary Document 3](#) for the full reference list.

BENEFIT = Perceived Role Benefit Score; CASI = Carers Assessment of Satisfaction Index; CBS = Caregiving Burden Scale; CES-D = Centre for Epidemiologic Studies-Depression scale; CSS = Caregiving Satisfaction Scale; EQ-5D = EuroQol-5D; FMTC = Finding Meaning Through Caregiving Scale; GAC = Gains Associated with Caregiving; GAIN = Gains in Alzheimer's Care Instrument; GDS-SF = Geriatric Depression Scale-Short Form; GHQ = General Health Questionnaire; PACS = Positive Aspects of Caregiving Scale; SF-36 = Short Form-36; SR = Self Reported; SSCQ = Short Sense of Competence Questionnaire; SwLS = Satisfaction with Life Scale; WHOQOL-BREF = World Health Organization Quality of Life assessment-Bref; ZBI = Zarit Burden Inventory.

*Only the well-being measures that were used in the analyses with the PAC measures are extracted.

Mental health

Twenty-five associations explored the relationship between PAC and mental health and 80% of these were significant. A connection between PAC and better mental health is suggested. Positive associations were reported for psychological well-being, psychological health, mental health, and positive affect. In comparison, negative associations were found for mental health problems, anxiety, psychological distress, depression, negative emotional reactions, and negative affect. These associations were explored in a range of caregiving relationships and dementia diagnoses. Sixteen studies used a cross-sectional design and nine used longitudinal data. The most common means of capturing PAC was to quantify caregiver qualitative reports. However, eight other standardized measures were also used.

QoL/health-related QoL

Nine associations explored the relationship between PAC and QoL/health-related QoL and 89% of these achieved significance. The majority of the evidence suggests that reporting higher PAC is associated with higher QoL. The one significant association with poorer QoL came from a European multisite study by [Alvira and coworkers \(2015\)](#), which reported associations between PAC and QoL from each study site. The significant negative association was found in Estonian data but this represents only 6% of the QoL associations reported in this study. Associations with QoL were explored in a range of caregiving relationships. However, all these associations came from cross-sectional studies and, when stated, most people with dementia were diagnosed with Alzheimer's disease. Five different measures of PAC were used, with the PACS ($n = 4$) employed most frequently.

Satisfaction with life

Four associations explored the relationship between PAC and satisfaction with life and 75% of these achieved significance. Reporting higher PAC is predominately associated with greater satisfaction. This association was explored in a range of caregiving relationships using cross-sectional designs. When the information was provided, all people with dementia were diagnosed with Alzheimer's disease and four different PAC measures were employed.

Health

Sixteen associations explored the relationship with PAC and health and 38% of these were significant. The balance of evidence suggests that there is no significant association between PAC and self-reported health. This association was explored using cross-sectional designs in a range of caregiving relationships and types of dementia. Eight different measures of PAC were used, with the Strawbridge caregiver satisfaction scale ($n = 4$) employed most.

Caregiver-Specific Well-Being Measures

Burden

Forty associations explored the relationship between PAC and burden and 85% of these were significant.

The majority of studies suggest that higher PAC is associated with less burden. This association was explored in a wide range of caregiving relationships. People with dementia had a range of diagnoses, including some of the rarer forms of dementia. Longitudinal as well as cross-sectional data were interrogated. Fifteen different measures of PAC were used to explore this association, with the PACS being the most commonly used ($n = 12$).

Role strain

This category includes constructs related to role overload, role captivity, and negative feelings about the caregiving role. Eleven associations explored the relationship between PAC and role strain and 46% of these were significant. The balance of evidence suggests that no conclusions can be drawn on the association between PAC and role strain. This association was explored in a range of caregiving relationships and different dementia diagnoses. Only one study employed a longitudinal design, with the rest being cross-sectional. Of the seven different PAC measures used, the most common was the PACS ($n = 3$).

Personal strain/stress

Five associations explored the relationship between PAC and stress and 40% of these were significant. The balance of evidence suggests no significant association between PAC and stress or personal strain. This association was explored in a range of caregiving relationships and dementia diagnoses. Five different measures of PAC were used but associations have been based on cross-sectional data only.

Competence/self-efficacy

Seven associations explored the relationship between PAC and competence and 71% of these were significant. There is some evidence that reporting higher PAC is associated with higher competence or self-efficacy. This association was explored in a range of caregiving relationships using cross-sectional data. Out of the five measures of PAC, the most commonly used were the PACS ($n = 2$) and the Meaning in caregiving scale ($n = 2$).

Discussion

This is the first review to explore the impact of PAC on dementia caregiver well-being comprehensively. Overall the findings indicate that being able to identify PAC is associated with higher caregiver well-being. The available evidence indicates that PAC was associated with lower depressive symptoms and burden. It was also associated with better mental health, QoL, satisfaction with life, and competence/self-efficacy. The balance of evidence indicates that PAC is not associated with caregiver self-rated health. However, self-rated health is likely to be affected by many factors and caregivers' appraisal of PAC may have less influence than other determinants such as caregiver health condition or daily functioning. Despite PAC being

associated with burden, PAC was not significantly associated with personal strain/stress and there was inconclusive evidence about the association with role strain. This finding may be a reflection that more studies have explored the association with burden or it could suggest that personal strain/stress and role strain are conceptually different from caregiving burden. There were some inconsistencies in the findings; for example, not all studies reported a significant association between PAC and depression. One explanation for these inconsistencies is that the studies varied in the measures of PAC employed and also in the outcome measures used. Thus, the measures employed may have had an influence on the results. In addition, studies varied in the sample sizes; studies with smaller samples may not have had enough power to detect a statistically significant result.

The majority of studies referred to theories, frameworks, models, or constructs. However, only 60% of papers used these concepts as a basis for the research study. Various models were referenced, with most authors referencing stress-coping frameworks. The SPM (Pearlin et al., 1990) was the most commonly cited caregiving model. However, the SPM does not provide a clear role for PAC. The two-factor model, referenced in four papers, conceptualizes PAC as a form of appraisal linked to positive dimensions of well-being. Yet, the findings of this review indicate that PAC was associated with both positive and negative dimensions of well-being. Other papers referenced more generic theories of stress and coping (Folkman, 1997; Lazarus & Folkman, 1984), in which PAC is also viewed as a form of appraisal or a method to mitigate the effects of caregiving stress. Thus, in these models, PAC is viewed more as a moderator of the caregiving experience. Furthermore, some studies referenced models, in which PAC is perceived as an outcome of caregiving, such as the ABCX family crisis model which concerns families' adaptability to stressful circumstances. In the ABCX model, PAC can be a positive outcome, or "bonadaptation" (Kramer, 1993). These findings suggest that there is a need for further caregiving models to be developed that fully encompass the role of PAC. This may involve building on positive psychological approaches: only one included paper (DeGregory, 2014) drew on the broaden-and-build theory of positive emotions.

The findings of this review are consistent with Kramer's (1997b) conclusion that there is a lack of conceptual clarity around the definition of PAC. Examination of the measures employed in the studies indicates the main domains being investigated were satisfactions, gains, meaning, and rewards. It is difficult to determine whether these measures are tapping into different dimensions of PAC or similar constructs, particularly as not all measures are published. Furthermore, the names of measures may not necessarily reflect their content. For instance, it is possible that the GAIN and BENEFIT measures (Lawton et al., 1991; Lawton, Rajagopal, Brody, & Kleban, 1992) were the same measure, as they both contained the same number of items. Interestingly, in two papers (Morano, 2003a, 2003b),

measures of both gain and caregiving satisfaction were included, implying that these were considered to be separate constructs. The most commonly used measure was the PACS. However, the popularity of this measure may be due to it being included in the large-scale multisite REACH and REACH II intervention studies; many of the included studies used these datasets for analyses. The review identified that, in recent years, new measures of PAC have been developed (Faba et al., 2017; Yu et al., 2016), including more culturally specific measures (Abdollahpour et al., 2017).

The majority of studies employed cross-sectional designs; thus, there is little longitudinal information about the association between PAC and well-being. Studies tended to use samples of convenience; caregivers were often recruited through support services, health services, or charities with only a few studies directly recruiting from the community. Approaching caregivers directly in the community may have enabled researchers to access people who were not accessing any formal support. It is possible that these caregivers do not feel the need to access support services because they feel more positive about their role, or conversely they may be more negative about their role because they are not in contact with any external formal support. In terms of caregiver characteristics, many were in the early stages of their caregiving career. Unfortunately, the samples were often heterogeneous, which might hide meaningful differences. For instance, although most participants were spousal caregivers, it was not unusual for studies to include up to seven different forms of caregiving relationship within the sample. Probably the experience of PAC differs depending on the type of caregiving relationship (e.g., Broese van Groenou, de Boer, and Iedema (2013)). Furthermore, most participants were women: only Baker, Robertson, and Connelly (2010) and Kramer (1997a) focused solely on male caregivers. The lack of male caregivers hinders the exploration of meaningful gender comparisons.

In considering the findings, it is important to recognize the review's strengths and limitations. At the abstract screening stage, we identified four dissertations of which full-text versions could not be located. However, published papers from two of these dissertations were included in the review. The focus of this review was on the association between PAC and caregiver well-being; thus, factors predicting PAC were not explored. As two recent systematic reviews have explored the qualitative literature (Lloyd et al., 2016; Yu et al., 2018), this review focused on the quantitative literature. As in other reviews (e.g., Farina et al. (2017)), a narrative synthesis approach was taken, given the heterogeneity in the included studies. Although this review included both published papers and unpublished dissertations/theses, there is a risk of publication bias, as it is possible that studies reporting significant associations between PAC and other measures are more likely to be published. Furthermore, studies often included multiple measures, but some did not report the associations

between all of these measures. Eight of the included studies used data from the REACH and REACH II studies, so the same dataset may have been used in multiple studies.

In comparison to the number of tools available for rating the quality of randomized controlled trials and qualitative studies, there seems to be a dearth of tools for rating cross-sectional quantitative studies. The QATSDD (Sirriyeh et al., 2012) was selected because the items seemed appropriate for the types of papers included; however, there have been criticisms that the QATSDD is too subjective (Fenton, Lauckner, & Gilbert, 2015). Although there were clearly benefits in using the QATSDD, there were also challenges to implementing the tool. For instance, we found that studies with smaller word counts (because of journal requirements) risked having a lower score because there is less scope to explain the study in-depth. This suggests that quality-rating tools would benefit from more flexibility: for instance, the ability to take into account the length of the paper.

The findings of the review identify areas which require further investigation. First, we used a broad definition of well-being, which included both caregiver-specific measures and more global measures. The majority of the well-being measures used focused on the "negative" aspects of well-being, such as burden and depression. This reflects the wider dementia caregiving literature where the majority of research has focused on specific domains of well-being (Manthorpe & Bowling, 2016). Few studies explored the association between PAC and more "positive" global measures of QoL, satisfaction with life, or well-being. Thus, there needs to be more research exploring these associations, particularly as QoL is a commonly used outcome in intervention research (Pendergrass, Becker, Hautzinger, & Pfeiffer, 2015). Additionally, few studies have explored PAC longitudinally, and research is needed to explore whether experiences of PAC change throughout the caregiving career and, if so, how this influences well-being. The broaden-and-build theory states that over time positive emotions broaden a person's way of thinking. This implies that the adaptive effects of positive emotion occur longitudinally and may play a greater role later on in the caregiving career.

The findings of this review suggest that being able to identify PAC seems to be beneficial for caregiver well-being. Healthcare professionals providing support for caregivers need to consider and recognize that caregivers can have both positive and negative experiences. The findings also raise the possibility that PAC can be targeted through interventions. Although interventions may not be able to directly enable caregivers to experience PAC, caregivers might be helped appraise their situations more positively, resulting in a better experience of caregiving. Cheng and co-workers (2012) developed the "Benefit-finding intervention" program, which promoted the use of positive appraisal to engender benefit-finding. Building on a psychoeducational program, caregivers in the intervention completed exercises on positive reappraisal, identifying stressful situations

and then reevaluating them to provide more positive appraisals. Compared with the control groups (receiving psychoeducational programs), caregivers in the intervention reported lower depression symptoms postintervention (Cheng et al., 2017). Similarly, a multimedia support intervention, which also targeted appraisals of caregiving, was effective in increasing reports of PAC and caregiving competence (Beauchamp, Irvine, Seeley, & Johnson, 2005). Interventions may also be able to indirectly improve experience of PAC through targeting the caregiving situation. For example, Savundranayagam (2014) found that increases in the amount of help received from others, as well as satisfaction with this help, were both associated with an increase in PAC in the form of positive attitudes towards the dementia caregiving role.

Conclusion

The review findings suggest that identifying PAC is associated with better caregiver well-being. There is an increasing evidence base for the role of PAC in the dementia caregiving experience, although gaps in the literature should be addressed. A more consistent terminology and approach to the conceptualization and measurement of PAC is needed. The majority of papers relied on stress-coping frameworks and there is a need for caregiving models to be developed that fully encompass the role of PAC. This may involve building on concepts from positive psychology. There was heterogeneity in the samples and most studies relied on cross-sectional designs; furthermore, longitudinal studies are required to explore how experiences of PAC change over time. The findings have important implications for the development of interventions and supportive services for caregivers. Interventions that help caregivers gain a more positive experience of caregiving could be beneficial for their well-being.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

Conflict of Interest

None reported.

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