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article

The positive effects of caring for family carers of older adults: a scoping review

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The negative effects of caring are well documented; however, positive effects have received less attention. A scoping review of 22 studies published between 2000 and 2018 was conducted regarding the positive effects of family caring for older adults. Our analysis revealed that positive effects are embedded in relationships, summarised in three themes: in relationship with one's self (the carer), for example, personal growth; in relationship with the care recipient, for example, a deepened dyadic relationship; and in relationship with others, for example, new care-related relationships. Seeing the positive effects of caring relationally may shape environmental factors, such as assistive device, social policy or health services development.

Key words positive effects • family caring • scoping review • older adult

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Introduction

As the baby-boomer generation ages, an increasing number of people will become family carers, that is, family or friends who provide, usually unpaid, physical or emotional care for an ill or disabled person with whom the carer is in a relationship (Keating et al, 2019). Care provided by family and friends is rooted in linked lives and relationships that bring people together; care can be provided out of respect, love, duty or a sense of obligation to family or friends (Kleinman, 2009; Keating et al, 2019). In some communities, almost one in four people report providing care to a family member or friend with a long-term health condition, disability or age-related need (Sinha, 2012). For society, the economic cost of caring for an ageing population is significantly offset by the labour of family carers, often without financial recompense. In some jurisdictions, more than 40 million hours of care per week are provided to older adults by family carers, amounting to a replacement value of US\$23–45 billion annually (AGE-WELL, no date). The economic contribution and savings to healthcare systems that carers produce is thus invaluable.

The social good produced by carers does not come without a cost to them. The potential negative social, psychological, physical health and employment-related effects of caring on carers are well documented. For instance, caring for older adults can have a negative impact on social relationships between the carer and care recipient, with other family members, and across larger social networks (Keating and Eales, 2017). Also, caring can create a sense of burden for carers (Adelman et al, 2014) and cause higher rates of illness (Vitaliano et al 2003) and depression (Pinquart and Sörensen, 2003); carers can also be injured while performing care tasks such as heavy lifting (Hinojosa and Rittman, 2009). Furthermore, carers are often unable to be in the paid labour force because of their caring responsibilities (Bauer and Sousa-Poza, 2015). For those who do work, employment-related negative effects are common, stemming from the difficulties of juggling dual responsibilities, which may lead to reducing work hours or exiting the labour force altogether (Bauer and Sousa-Poza, 2015).

Yet, not all effects of family caring are negative. Several researchers have sought to elucidate the potential positive aspects of caring. One of the earliest works that, in part, reviewed the literature on the positive effects of caring was Kramer (1997). The author asserted that a dearth of a sound theoretical framework and clear definitions of carer ‘gains’ created a lack of generalisable conclusions, limiting cumulative knowledge advancement. More recently, Carbonneau et al (2010) attempted to address this theoretical deficit by putting forward a conceptual framework for the positive effects of caring for people with dementia based on an integrative literature review. Their conceptual model centred around three interdependent domains of positive aspects of caring that emerge through what they termed ‘enrichment events’: the quality of the carer–care receiver relationship; the carer’s feeling of accomplishment; and the meaning of the carer’s role. Recent diagnosis-specific literature reviews have

found several positive outcomes for carers of people living with cancer (Li and Loke, 2013) and dementia (Lloyd et al, 2016; Yu et al, 2018). Among the positive outcomes identified were an improved relationship between the carer and care recipient, a feeling of accomplishment (Li and Loke, 2013; Lloyd et al, 2016; Yu et al, 2018), a sense of purpose (Li and Loke, 2013; Yu et al, 2018), the mastery of caring tasks (Lloyd et al, 2016), and improved relationships with family or others (Lloyd et al, 2016; Yu et al, 2018).

There are some limitations of the aforementioned reviews, and some areas of discussion yet to be explored. One limitation of these reviews is their focus on a specific care-recipient diagnosis, prompting the need for a broader look at the positive effects of caring across diseases and/or disabilities. Another aspect not entirely accounted for in this body of literature is a description of the nature of the positive effects of caring within a larger social context, extending beyond the family. Finally, there is a lack of discussion of how the knowledge of positive effects could shape the design and implementation of assistive devices (for example, communication aids and mobility aids), social policy and health services, three items that the World Health Organization (WHO, 2017) has identified as environmental factors that influence the lives of people living with disabilities and, we posit, the lives of carers. Thus, examining and understanding the positive effects of caring may assist with the development of assistive devices, policy interventions or health service delivery.

Accordingly, a scoping review was conducted to understand the nature of the most contemporary literature regarding the positive effects of caring for carers of adults aged 65 or older, with an eye to thinking about their implications for environmental factors, such as the development of assistive devices, related social policy and health service delivery. The specific objectives of this review were: (1) to synthesise the positive effects of family caring for older adults; and (2) to consider how the reported results of the positive effects of family caring affect the development of assistive devices, social policies and health services.

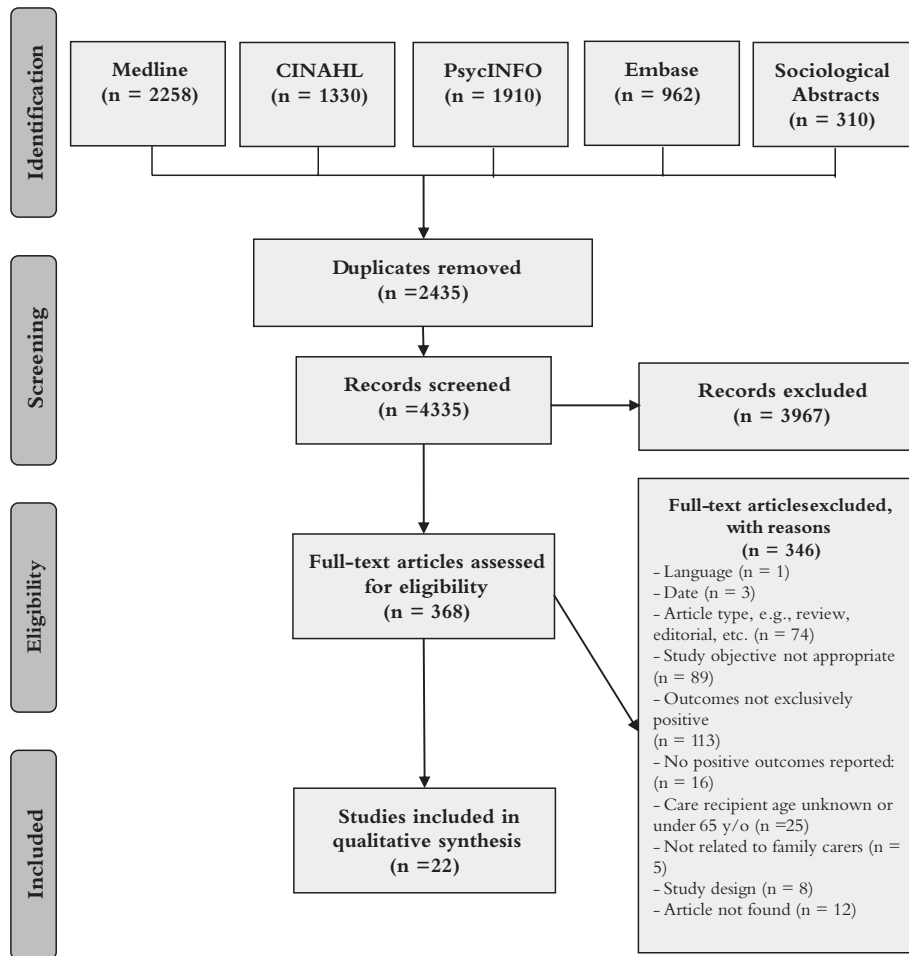
Methods

A scoping review was selected as the best method to achieve the aforementioned objectives given the methodological purpose of a scoping review: to ‘map’ a phenomenon and, where relevant, its key domains (Arksey and O’Malley, 2005; Levac et al, 2010; Tricco et al, 2016). Scoping reviews differ from other kinds of reviews (for example, a systematic review) in that the questions posed are broader, a larger set of credible studies with a range of study designs are included and studies are not included or excluded based on a strict set of quality criteria (Arksey and O’Malley, 2005; Tricco et al, 2016). Breadth rather than depth is the goal of scoping reviews (Tricco et al, 2016).

Search strategy

The selection of keywords and a search strategy were carried out with the assistance of a biomedical librarian. The search terms included: caregiver, Caregiv*, Gain*, Effect*, Senior* (for a complete list of keywords, see Appendix 1). Four databases were searched using these terms: Ovid (Medline and Embase), EBSCOHost (CINHAL), APA PsycNet (PsycInfo) and ProQuest (sociological abstracts). Recent studies

Figure 1: PRISMA diagram



published between January 2000 to December 2018, written in English, French or Spanish, using qualitative, cross-sectional or longitudinal quantitative methods, or mixed-methods studies, were included. The first author and two research assistants screened the articles.

Literature selection

The literature selection process followed the guidelines set out in the 'Preferred Reporting Items for Systematic reviews and Meta-Analyses' (PRISMA) (Moher et al, 2009). After duplicates were removed, the first author and a research assistant independently rapid-screened all 4,335 articles based on their title and abstract. Of the remaining 368 articles, the first author and a second research assistant independently screened and selected 22 for data extraction and analysis. The results of the independent screening process were tracked using a web-based systematic review data management system (covidence.org). Where there was disagreement, the first author and the research assistant discussed their perspective and came to a consensus. To meet our objective,

only studies that exclusively investigated the positive effects of family caring were included (that is, examining positive effects was the stated objective of the study). In keeping with our desire to examine studies that were looking to identify and/or understand the positive effects of caring, if a study examining negative effects also reported positive effects, or if a study associated the lack of a negative effect as a proxy for a positive effect, it was excluded. In order to maintain a broad and inclusive scoping review approach, studies were selected if they had at least one care recipient over the age of 65 (or were studies of people with dementia). [Figure 1](#) shows the PRISMA diagram that provides an overview of the scoping review process.

Synthesis of the evidence

The studies were summarised in a data-extraction table by the first author and verified by the second author. Information recorded for each article included: author(s), year of publication, country, purpose/research question, study design, reported participant population characteristics, and relevant results. The second author verified the table contents. [Table 1](#) presents the data-extraction table of the main findings from each study.

The first and second authors conducted a thematic analysis ([Braun and Clarke, 2006](#)) of the qualitative and quantitative extracted results through an iterative process, which was verified by all authors. The code definitions were created through an inductive process after the first and second author independently coded a selection of studies. The two authors then met to discuss their independent codes and established a total of 12 codes to describe the positive effects of caring and a further 13 codes to describe factors that influenced these effects. The two authors then continued the coding process with the use of the established codes, meeting regularly to ensure consensus regarding the code definitions and the coding of the extracted data. The last author then verified the coding by reviewing the coding guide, extraction table and codes assigned to the data. Finally, the codes were grouped into themes by the first and second authors. The themes were finalised through discussion between all the authors.

Once data analysis was completed, the first author reviewed coded material for representative quotes from participants in qualitative studies. This novel approach to enriching our findings has been conducted in another recent review ([Carver et al, 2018](#)). By sharing the words of the respondents in the original studies, as represented by the original researchers, it may be possible to gain a deeper appreciation of the lived experience of a phenomenon ([Carver et al, 2018](#)) – in our case, the positive effects of caring for carers of older adults.

Results

The 22 articles reviewed were rich in diversity. Of the included studies, 41 per cent ($n = 9$) used a quantitative research design, 41 per cent ($n = 9$) were qualitative studies and 18 per cent ($n = 4$) used a mixed design. In total, there were 4,326 study participants. Of the studies reviewed, 32 per cent ($n = 7$) were studies carried out in North America, 27 per cent ($n = 6$) were conducted in Asia, 23 per cent ($n = 5$) were from Europe, an additional 9 per cent ($n = 2$) were from Oceania, 5 per cent ($n = 1$) was from South America, and 5 per cent ($n = 1$) was a study conducted in multiple counties. Of the studies that reported mean ages, the carer mean age was 55

Table 1: Data extracted

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
Alpert and Womble (2015)	Multiple countries	<ul style="list-style-type: none"> Determine coping techniques utilised by carers of elderly CR Understand how coping methods broaden carer perspectives of their role 	Qualitative study using thematic analysis	<ul style="list-style-type: none"> N = 154 participants Carer: children (87%), mean age 54 y/o 	<ul style="list-style-type: none"> Coping through: (1) humour; (2) positive framing; (3) acceptance Carers reconnecting w/ family through redefinition of relationships and role
Andren and Elmstahl (2005)	Sweden	<ul style="list-style-type: none"> Examine characteristics of carers of dementia CRs living at home Determine factors associated with carer satisfaction 	Quantitative design using factorial analysis	<ul style="list-style-type: none"> CR: mean age 81 y/o, Alzheimer's disease (25%), stroke (6%), cancer (5%), other ailments (64%) N = 153 participants Carer: women (61%), mean age 62 	<ul style="list-style-type: none"> Shared benefit items: (1) CR would do the same for me; caring is an expression of love CR Greatest satisfaction item: (1) seeing CR clean and comfortable; (2) giving CR pleasurable experience; (3) carer pleasure from CR happiness; and (4) maintaining CR dignity Carer items: (1) make carer feel needed and wanted; and (2) CR is appreciative of what carer does
Berg-Weger, Rubio and Tebb (2001)	USA	<ul style="list-style-type: none"> Use a strengths-based perspective to understand carer experience 	Qualitative design using content analysis	<ul style="list-style-type: none"> N = 75 participants 	<ul style="list-style-type: none"> Four positive theme groups: (1) carer adjustment – seeing caring as opportunity, not burden; (2) carer competence – learning about illnesses and becoming resourceful; (3) carer needs – reaching out to carer support groups; and (4) spiritual connection – fulfilment through reliance on God, family and friends

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
				<ul style="list-style-type: none"> • Carer: women (84%), mean age 62 y/o 	
				<ul style="list-style-type: none"> • CR: chronically ill with various diagnoses, including dementia 	
Cameron et al (2014)	Canada	<ul style="list-style-type: none"> • Identify aspects of caring situation that contribute to carer psychological well-being • Examine changes in carer psychological well-being for first year post-stroke 	Mixed-methods longitudinal cohort study using chart reviews and statistical models	<ul style="list-style-type: none"> • Y1 N = 399 participants • Y1 carers: women (70%), mean age 58 y/o • Y2: N = 80 participants • Y2 carers: women (63%), mean age 57 y/o • Y1 & 2 CR: women (41%), mean age 68 y/o, stroke survivor • N = 52 participants 	<ul style="list-style-type: none"> • Carers have ↑ sense of mastery and ↑ personal gain
Cheng et al (2016)	Hong Kong	<ul style="list-style-type: none"> • Identify positive gains for carers of CRs with Alzheimer's disease 	Qualitative design using text analysis		<ul style="list-style-type: none"> • Carers reported positive effects: (1) learning new things; (2) becoming closer to God; (3) growing as a person; (4) ↑ self-confidence; (5) ↑ sensitivity to persons w/ disabilities; (6) ↑ sense of what is important in life; (7) ↑ awareness of inner strengths; (8) ↑ patience; (9) ↑ leadership and advocacy; (10) ↑ intimacy with others; (11) ↑ sense of fulfilling duty; and (12) becoming closer to family and making new friends

(Continued)

Table 1: (Continued)

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
				<ul style="list-style-type: none"> • Carer: mean age 54 y/o • CR: mild to moderate Alzheimer's disease • N = 88 participants 	<ul style="list-style-type: none"> • Environmental and spiritual aspects of comfort scored highest
De Araujo Lamino, Turrini and Kolcaba (2014)	Brazil	<ul style="list-style-type: none"> • Assess comfort of carers of CRs w/ cancer 	Cross-sectional analytic survey using central trend measures and correlational statistics	<ul style="list-style-type: none"> • Carer: women (85%), 18–81 yrs of age • CR: women (81%), 25–90 yrs of age, cancer diagnosis 	<ul style="list-style-type: none"> • Duration of care positively affects carer comfort • Older carers = ↑ comfort • Having paid work = ↑ carer comfort • Negative influences on carer comfort = family/financial concern, communication difficulties and CR discomfort • Taking time for one's self through sports, humour and faith
Duggleby et al (2012)	Canada	<ul style="list-style-type: none"> • Explore experience of hope in male spouse carers 	Qualitative design using interpretive description and constant comparative method	<ul style="list-style-type: none"> • N = 11 participants • Carer: male spouses (100%), mean age 55 y/o 	<ul style="list-style-type: none"> • Discovering what works and learning to work with what you have: gaining hope through mastery

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
				<ul style="list-style-type: none"> • CR: mean age 53 y/o, breast cancer diagnosis 	<ul style="list-style-type: none"> • Learning to very consciously balance the positive and negative aspects of the situation • Learning to support CR through being present, open, listening and becoming informed • Focusing on the positive provided hope and courage • Learning about one's self
Grover, Nehra, Malhotra and Kate (2017)	India	<ul style="list-style-type: none"> • Evaluate the experience of positive aspects of caring for carers of CR w/ dementia • Evaluate the association of positive aspects of caring with carer burden, coping and social support 	Quantitative, cross-sectional study using multivariate analysis	<ul style="list-style-type: none"> • N = 55 dyads • Carer: women (51%), mean age 49 y/o 	<ul style="list-style-type: none"> • Married carers scored higher in the domain of motivation for caring role • Subjective carer burden correlated negatively with domain of self-esteem
Habermann, Hines and Davis (2013)	USA	<ul style="list-style-type: none"> • Explore the positive aspects experienced by adult children carers of CRs w/ Parkinson's or Alzheimer's disease 	Qualitative descriptive design, semi-structured interviews and conventional content analysis	<ul style="list-style-type: none"> • CR: women (44%), mean age 69 (52-87), dementia • N = 34 participants 	<ul style="list-style-type: none"> • ↑ social support correlated positively with motivation for caring • Three relationship-centred themes: (1) appreciating each other and becoming closer, carer appreciating living w/ and caring for CR, appreciation for deepening relationship with parent or family; (2) spending and enjoying time together – carers enjoying spending time with CR and seeing CR enjoying that time as well; and (3) returning and giving back care – willingness and joy in caring for CR, importance of being with and caring for CR for as long as needed

(Continued)

Table 1: (Continued)

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
				<ul style="list-style-type: none"> • Carer: women (82%), mean age 52 y/o • CR: mean age 81 y/o, Parkinson's and/or Alzheimer's disease diagnosis • N = 125 participants 	<ul style="list-style-type: none"> • Smallest sources of reward: personal growth, self-satisfaction and personal meaning from caring • Largest sources of reward: (1) feeling of being helpful to CR; (2) giving something to CR brought happiness; (3) just being there for CR; and (4) making life easier for CR
Henriksson, Carlander and Arestedt (2015)	Sweden	<ul style="list-style-type: none"> • Describe feelings of reward for carers during ongoing palliative care • Compare experiences of rewards in relation to sex and age 	Descriptive design using comparative statistics	<ul style="list-style-type: none"> • Carer: women (61%), mean age 58 y/o • CR: mean age 65 y/o, cancer (89%) or other diagnosis (11%) • N = 501 participants 	<ul style="list-style-type: none"> • Four perceived reward domains: (1) sense of mastery; (2) appreciation for others; (3) meaning in life; and (4) reprioritisation in life
Kang et al (2013)	South Korea	<ul style="list-style-type: none"> • Examine factors for positive consequences of caring for terminal cancer CRs 	Cross-sectional analytic survey using multivariate logistic regression analyses	<ul style="list-style-type: none"> • Carer: women (59%), mean age 53 y/o • CR: women (47%), mean age 64 y/o, cancer (81%), other (19%) 	

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
Kim, Schulz and Carver (2007)	USA	<ul style="list-style-type: none"> Characterise benefit finding domains of caring for cancer survivors 	Quantitative study design using factorial analyses	<ul style="list-style-type: none"> N = 896 participants 	<ul style="list-style-type: none"> Domains of benefit finding: (1) acceptance – changes in effort to accept things; (2) empathy – increases in empathy for all human beings; (3) appreciation – changes in appreciation in life; (4) family – getting closer to family members; (5) positive self-view – changes in self-perception; and (6) reprioritisation – changes in evaluating importance of certain values
		<ul style="list-style-type: none"> Relate domains to other psychosocial variables 		<ul style="list-style-type: none"> Carer: women (66%), mean age 54 y/o CR: women (41.8%), mean age, 60y/o, (SD, 11.5), cancer diagnosis N = 290 participants 	
Kuuppelomäki et al (2004)	Finland	<ul style="list-style-type: none"> Explore sources of satisfaction of carers looking after CRs living in their own home with any ailment Establish certain factors associated with sources of satisfaction (gender of carer, age, carer role, carer burden, life satisfaction, caring duration, caring hours/day, age and gender of CR) 	Cross-sectional analytic study using survey and descriptive associations	<ul style="list-style-type: none"> Carer: women (68%), 50+ y/o (78%) 	<ul style="list-style-type: none"> Carer satisfaction: sense of being needed/wanted (98%), caring as a way of showing love to CR (91%), helping another person (80%), from doing their best to help and/or the sense of being appreciated by family and friends Sources of carer satisfaction: most common related to the cared-for person (67%) (example, clean, comfortable and well-turned-out cared-for person)

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Table 1: (Continued)

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
				<ul style="list-style-type: none"> • CR: women (52%), 70+ y/o (90%), one illness or ailment (41%) 	<ul style="list-style-type: none"> • Carer motivation – fulfilment of their duty, personal growth and development, the sense of being able to overcome difficulties, the challenge of caring, and the chance to repay past acts of kindness (63–78%) • Other benefits: closer relationship w/ CR; strengthened family ties; and belief that the CR would do the same for them
Lopez, Lopez-Arrieta and Crespo (2005)	Spain	<ul style="list-style-type: none"> • Determine predictors of the positive aspects reported by carers of elderly CRs 	Cross-sectional analytical study using multiple regression analyses	<ul style="list-style-type: none"> • N = 111 participants 	<ul style="list-style-type: none"> • Carers feel closer to CR, carers enjoy being with CR and gives a sense of purpose to carers' life
				<ul style="list-style-type: none"> • Carer: women (82%), mean age 58 y/o • CR: women (68%), mean age 82 y/o, no specified diagnosis • N = 191 dyads 	<ul style="list-style-type: none"> • ↑ carer satisfaction noted with ↑ time spent with CR
Malhotra et al (2018)	Singapore	<ul style="list-style-type: none"> • Delineate short-term (6–8 mo) trajectories of positive aspects of caring among carers of stroke survivors 	Mixed-method prospective longitudinal design using multivariate analysis and semi-structured interviews		<ul style="list-style-type: none"> • CR disability associated w/ a significant ↓ of positive aspects of caring for carers w/ low trajectory (consistently low scores on PAC scale across all time points), and a significant ↑ of positive aspects of caring for carers w/ high trajectory (consistently high scores on PAC scale across all time points) • Older age correlated with high trajectory
		<ul style="list-style-type: none"> • Assess influence of stroke-survivor disability change over time on delineated trajectories of positive aspects of caring 		<ul style="list-style-type: none"> • Carer: women (62%), mean age 50 y/o 	

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
McCausland and Pakenham (2003)	Australia	<ul style="list-style-type: none"> Explore benefit finding in HIV/AIDS caring 	Mixed-method, cross-sectional design using descriptive statistics, regression analyses and thematic analysis of qualitative data	<ul style="list-style-type: none"> CR: women (51%), mean age 72 y/o N = 64 participants 	<ul style="list-style-type: none"> Personal growth in 11 areas: (1) understanding one's emotions; (2) personal strength; (3) patience; (4) self-awareness; (5) self-acceptance; (6) compassion; (7) support for self; (8) courage; (9) self-confidence; (10) personal growth; and (11) learning from CR mistakes Also reported: ↑ understanding, tolerance/acceptance and respect of other, change in values, sense of satisfaction/purpose/achievement, new relationships, strengthened relationship w/ CR, ↑ knowledge of HIV/AIDS, health services and health in general
Mehrotra and Sukumar (2007)	India	<ul style="list-style-type: none"> Explore sources of strength for carers of CRs w/ cancer in India 	Qualitative design using interviews	<ul style="list-style-type: none"> CR: women (0%), mean age 36 y/o (13–73), HIV/AIDS diagnosis N = 20 participants 	<ul style="list-style-type: none"> Sources of strength: (1) religious beliefs and practices; (2) previous caring experience gave sense of preparedness; (3) positive appraisal of carer role; and (4) discovering hidden potential for patience, strength, deal w/ multiple demands, ↑ awareness and appreciation of support received, ↑ tolerance, ↑ acceptance Interpersonal sources of strength themes: (1) family and friends as sources of emotional, instrumental, informational and spiritual support; and (2) medical fraternity and hospital staff

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Table 1: (Continued)

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
Netto, Jenny and Philip (2009)	Singapore	<ul style="list-style-type: none"> Investigate gains experienced by carers of CRs w/ dementia 	Qualitative design using semi-structured interviews	<ul style="list-style-type: none"> CR: 3–86 y/o, heterogeneous cancer diagnoses, receiving active treatment N = 12 participants 	<ul style="list-style-type: none"> Positive changes: philosophy (↓ emphasis on material wealth, ↑ emphasis on relationships with others), spiritual growth (awareness of God, feelings of peace/joy, ↑ meaning), altruism Personal growth: becoming ↑ patient/ understanding, stronger/↑ resilient, ↑ self-awareness, ↑ medical knowledge
Pakenham (2005)	Australia	<ul style="list-style-type: none"> Investigate relations between carer and CR benefit finding, and between benefit finding and the adjustment domains of both partners 	Mixed-method short-term prospective study using factor analyses, hierarchical regression and qualitative content analysis	<ul style="list-style-type: none"> Carer: 83.3% women, 32–72 y/o CR: dementia N = 222 participants 	<ul style="list-style-type: none"> Gains in relationships: improvement in relationships w/ CR, family members and other older persons Personal growth: ↑ patience, ↑ acceptance, ↑ tolerance, ↑ compassion, ↑ appreciation for carer health and physical ability, including healthier lifestyle, re-evaluation of diet and exercise

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
		<ul style="list-style-type: none"> Explore relations between carer benefit-finding and demographics, CR characteristics, Multiple Sclerosis caring parameters (for example, severity CR illness, psychological adjustment), problem context and stress appraisal 		<ul style="list-style-type: none"> Carer: women (37%), mean age 51 y/o (20–82) 	<ul style="list-style-type: none"> Appreciation of life: ↑ determination for caring, ↑ personal time and ↓ guilt for taking personal time, ↓ workload to spend time with CR
		<ul style="list-style-type: none"> Examine relations between benefit-finding and both positive and negative carer adjustment domains 		<ul style="list-style-type: none"> CR: women (71%), mean age 49 y/o (16–78), Multiple Sclerosis 	<ul style="list-style-type: none"> Additional benefits: meeting new people, ↑ medical knowledge
Peacock et al (2010)	Canada	<ul style="list-style-type: none"> Describe positive aspects of caring identified by carers of CRs w/ dementia 	Qualitative interviews	<ul style="list-style-type: none"> N = 39 participants 	<ul style="list-style-type: none"> Positive aspects of caring: developing coping strategies and reaching out to others for help/support; developing a sense of competence; relieved to keep CR safe and in a loving environment; adapting and managing to a variety of situations; opportunity to give back; closer relationship w/ CR and family
				<ul style="list-style-type: none"> Carer: women (82%), age 60+ y/o (56%) 	<ul style="list-style-type: none"> Spouses affirmed that caring was part of the marital relationship
				<ul style="list-style-type: none"> CR: women (32%), age 70+ y/o (84%), dementia 	<ul style="list-style-type: none"> Personal growth: sense of peacefulness; discovering more about oneself and one's inner strengths
					<ul style="list-style-type: none"> Finding strength and comfort from support groups

(Continued)

Table 1: (Continued)

Citation	Study location	Study purpose/research question	Design	Reported participant characteristics	Relevant results
Ribeiro and Paul (2008)	Portugal	<ul style="list-style-type: none"> Analyse positive aspects of care for older men caring for spouses w/ dementia or physical impairments 	Qualitative interviews and content analysis	<ul style="list-style-type: none"> N = 57 participants 	<ul style="list-style-type: none"> Positive aspects of caring; 'just being there' w/ CR; positive feelings (self-protectiveness); problem-focused coping strategies; better self-rated health; satisfaction from social recognition; new meaning to life; special meaning for spousal relationship w/ CR; learning new tasks Caring an opportunity to express love and affection
				<ul style="list-style-type: none"> Carer: women (0%), mean age 78 y/o CR: women (100%), dementia (51%), physical impairment (49%) (example: stroke, Parkinson's, orthopaedic, arthritis) 	
Roth et al (2015)	USA	<ul style="list-style-type: none"> Evaluate potential differential item functioning on the PAC scale by race, gender and relationship factors Evaluate psychometric properties of the PAC items to determine instrument suitability across race/ethnic, gender, relationship groups 	Cross-sectional analytic design using multiple regression analysis and multiple indicators, models and analyses	<ul style="list-style-type: none"> N = 642 participants 	<ul style="list-style-type: none"> African-American carers report more positive attitude towards life and 'appreciate life more' compared to white people or Hispanics. No differences noted for gender and marital status for white people and Hispanics
				<ul style="list-style-type: none"> CR: dementia or related disorder 	

Notes: Studies were selected if they were published after 2000, had at least one care recipient over the age of 65 (or were studies of people with dementia), and focused exclusively on the positive effects of family caring (that is, examining positive effects was the stated objective of the study). Abbreviations: ↑ = increase; ↓ = decrease; CR = care recipient; hrs = hours; min = minimum; mo = month; PAC = Positive Aspects of Caregiving scale SD = standard deviation; w/ = with; wk = week; y/o = years old; and yrs = years.

and the mean age of care recipients 66. Women were reported to be the majority of carers in 15 studies. Family carers were caring for people who had a wide range of health problems, with some having several diagnoses. Cancer and dementia diagnoses were the predominant health problems reported. Table 1 describes included study characteristics and reported participant demographics.

The central finding of this review was that the positive effects of caring are relational. That is, through the thematic analysis of the studies reviewed, the reported positive effects were seen as relational and linked to the carer through distinct relationships. These relationships form the themes discussed in the following. The positive effects of caring were in relationships with one's self (for example, personal or spiritual growth as a carer), the care recipient (for example, positive effects stemming from a deepened relationship) and other people (for example, support and recognition from new friends). Table 2 provides a summary of the themes and the associated codes describing the positive effects of caring.

While not explored any further here, it is worth noting that several studies identified factors that influence the positive effects of caring. Some of these factors are carer disposition, age, gender, race, occupation (that is, employment and leisure activities), income, care-recipient diagnosis and duration of illness or disability (Kuuppelomäki et al, 2004; Andren and Elmstahl, 2005; Lopez et al, 2005; Kim et al, 2007; Mehrotra and Sukumar, 2007; Ribeiro and Paul, 2008; Duggleby et al, 2012; Kang et al, 2013; Cameron et al, 2014; De Araujo Lamino et al, 2014; Henriksson et al, 2015; Roth et al, 2015; Grover et al, 2017; Malhotra et al, 2018).

In relationship with oneself

From the studies reviewed, the primary area of positive effects reported by carers was the relationship with oneself, identified in 21 studies (Berg-Weger et al, 2001; McCausland and Pakenham, 2003; Kuuppelomäki et al, 2004; Andren and Elmstahl, 2005; Lopez et al, 2005; Pakenham, 2005; Kim et al, 2007; Mehrotra and Sukumar, 2007; Ribeiro and Paul, 2008; Netto et al, 2009; Peacock et al, 2010; Duggleby et al, 2012; Habermann et al, 2013; Kang et al, 2013; Cameron et al, 2014; De Araujo Lamino et al, 2014; Alpert and Womble, 2015; Henriksson et al, 2015; Cheng et al, 2016). The relationship with oneself was characterised as the process of a deepening sense of identity through the discovery of inner strengths, the development of character and the enhancement of a positive view of oneself. There were three main positive effects gained through the relationship with oneself: personal growth; adaptation through becoming knowledgeable and gaining competency; and life purpose.

More than half of the studies cited personal growth as a positive effect of caring (McCausland and Pakenham, 2003; Lopez et al, 2005; Pakenham, 2005; Kim et al, 2007; Mehrotra and Sukumar, 2007; Netto et al, 2009; Peacock et al, 2010; Duggleby et al, 2012; Habermann et al, 2013; Kang et al, 2013; Cameron et al, 2014; Cheng et al, 2016). Personal growth was defined as the process of overcoming difficulties by growing more mentally and emotionally resilient, leading to positive outcomes, such as becoming a self-advocate and a leader for others. Speaking about their experience of personal growth, one carer of a person living with dementia described it as becoming

Table 2 : Themes and related codes

Themes	Codes
In relation to one's self: discovering inner strengths, new areas of fulfilment, personal growth, life purpose and/or a new or deeper sense of spirituality	• Adapting to a 'new normal'
	• Becoming/enhancing spirituality
	• Developing new skills and knowledge
	• Gaining confidence and competence
In relation to the care recipient: becoming closer to the care recipient and deriving pleasure from feeling needed and seeing the care recipient happy and comfortable	• Receiving recognition
	• Strengthening bonds
	• Paying back/reciprocating
	• Feeling satisfied
In relation to others: developing new or deeper relationships with other people. Two types of relationships dominate: family and friends; and other care-related relationships (health professionals and carers)	• Strengthening kinship ties
	• Finding or strengthening friendships
	• Creating relationships with health professionals
	• Connecting with other carers

'stronger mentally [and] emotionally... you learn a lot of things to be a better person' (Netto et al, 2009: 252).

Several nuances related to personal growth were identified within the studies. For example, the study conducted by Lopez et al (2005) found that carers noted improved self-esteem as the most common area of personal growth. In addition to this, increased patience and/or tolerance were found in two studies (McCausland and Pakenham, 2003; Cheng et al, 2016). This new-found tolerance and patience are illustrated by one carer of a parent with Alzheimer's disease, who shared that her 'Mom has repetitive behaviors [sic] a lot. They have inadvertently made me a more patient person. I used to be short-tempered but now I learn to savor [sic] every moment' (Cheng et al, 2016: 455). Kim et al (2007) found that some carers felt a greater sense of empathy for others as a result of caring.

Another positive effect associated with the relationship with oneself was adaptation (Berg-Weger et al, 2001; Pakenham, 2005; Kim et al, 2007; Ribeiro and Paul, 2008; Peacock et al, 2010; Duggleby et al, 2012; Kang et al, 2013; De Araujo Lamino et al, 2014; Alpert and Womble, 2015). Adaptation was defined as creating or adjusting to a new rhythm of life, or creating alternative ways for everyday life that was in tandem with the needs of the care recipient. In the words of one spouse-carer of a woman with breast cancer: 'You learn to accept ... and work with what you have. The worst thing you can possibly do to not give you hope is to ignore it [the realities of caring]' (Duggleby et al, 2012: 403). Adapting also meant the development of a strong knowledge base giving carers confidence in being well informed about the disease, disability or ageing process (Berg-Weger et al, 2001; McCausland and Pakenham, 2003; Pakenham, 2005; Duggleby et al, 2012; Cheng et al, 2016). Another component of adaptation was a sense of competency that carers gained through developing the ability to safely perform caring tasks successfully and efficiently (Berg-Weger et al, 2001; Mehrotra and Sukumar, 2007; Ribeiro and Paul, 2008; Peacock et al, 2010; Duggleby et al, 2012; Kang et al, 2013; Cameron et al, 2014; Cheng et al, 2016). This is illustrated by one carer of a chronically ill person, who explained that 'I am quite competent in learning what I need to do' (Berg-Weger et al, 2001: 268), while

another carer of a chronically ill person stated: 'I realized that I was doing so much more than I ever thought I could do' (Berg-Weger et al, 2001: 268).

Finally, studies also noted positive effects related to life purpose or a deeper sense of spirituality. Six studies found that participants gained a new sense of purpose in their lives as a result of being a carer, including an enjoyment of the challenges and doing one's best when caring, the fulfilment of a sense of duty, a sense of feeling needed and wanted, and giving back to the care recipient (McCausland and Pakenham, 2003; Kuuppelomäki et al, 2004; Andren and Elmstahl, 2005; Mehrotra and Sukumar, 2007; Ribeiro and Paul, 2008; Henriksson et al, 2015; Cheng et al, 2016). One man who cared for his wife explained: 'I feel honoured ... washing her clothes, putting them to dry, I feel honoured.... I feel an enormous pleasure in changing her, turning her, providing her with everything she needs, giving her a bath whenever needed.... I feel pleased, with [a sense of] satisfaction' (Ribeiro and Paul, 2008: 172, insertion in original). Furthermore, some carers believed that they were becoming spiritual or enhancing their spirituality as a result of caring (Berg-Weger et al, 2001; Mehrotra and Sukumar, 2007; Netto et al, 2009; De Araujo Lamino et al, 2014). Through the caring journey, carers in one study felt that caring was an act by God that tested one's faith, as illustrated by one carer of a relative with cancer, who stated that they felt 'cared for and supported by Him [God]' while also being 'tested by Him [God]' (Mehrotra and Sukumar, 2007: 1363). Others reported that caring enhanced a sense of closeness to God or strengthened their spiritual practice (Berg-Weger et al, 2001; Mehrotra and Sukumar, 2007; Netto et al, 2009).

In relationship with the care recipient

The second theme focused on the relationship with the care recipient. Ten studies spoke about the quality of the relationship and interactions between the carer and care recipient (McCausland and Pakenham, 2003; Kuuppelomäki et al, 2004; Andren and Elmstahl, 2005; Lopez et al, 2005; Mehrotra and Sukumar, 2007; Ribeiro and Paul, 2008; Netto et al, 2009; Peacock et al, 2010; Habermann et al, 2013; Cheng et al, 2016). Several studies (McCausland and Pakenham, 2003; Kuuppelomäki et al, 2004; Lopez et al, 2005; Netto et al, 2009; Peacock et al, 2010; Cheng et al, 2016) mentioned that growing closer to the care recipient was important and meaningful, and a direct result of the caring experience. One person caring for their spouse with dementia described this feeling of closeness: 'I'm drawn closer to him. There's that closeness 'cause I pay so much attention to him, drawn closer to him, and understand him more, you know, his needs, all his needs' (Netto et al, 2009: 254). Another study (Habermann et al, 2013) highlighted that just spending and enjoying time together, often doing quotidian activities, became meaningful moments for carers. Another carer expressed that the motivation for caring was a kind of reciprocity: 'I think for me it's the love I have for my father and I want to make the rest of his life comfortable for him' (Peacock et al, 2010: 647). Similarly, a few other studies (Kuuppelomäki et al, 2004; Andren and Elmstahl, 2005; Mehrotra and Sukumar, 2007) also noted that for the carers who had a long-term, pre-existing relationship with the care recipient, being able to care for that person was an opportunity for reciprocity or to repay previous acts of kindness.

From the dynamic relationship between the carer and care recipient came other forms of positive effects for the carer: feelings of pleasure and appreciation. The feeling

of pleasure was identified in two of the studies reviewed (Kuuppelomäki et al, 2004; Andren and Elmstahl, 2005), being described as a sense of happiness, satisfaction or enjoyment derived from seeing the care recipient being comfortable, experiencing moments of joy or overcoming difficulties in their life. As one carer in the study conducted by Cheng et al (2016: 454, insertion in original) noted: ‘Seeing mom getting better and better [being more responsive and less demanding], all the work I do, no matter how hard it seems, is worth it.’ These same studies reported that appreciation was derived from either one or both of two sources. The first source was the care recipient’s recognition of the carer’s efforts or their demonstration of gratitude for the care received (Kuuppelomäki et al, 2004; Ribeiro and Paul, 2008; Cheng et al, 2016). The second source was expressions of love and appreciation between carers and care recipients. For example, one carer shared that after helping his father with a task, ‘he stood there for a minute, and he started to say something and ... he just kept standing there and he tried to say something again and ... finally he just said, “Thank you”. And I told him he was welcome. And we went on about what we were doing’ (Habermann et al, 2013: 6).

In relationship with others

Overall, similar to carers’ feelings of a deepened relationship with care recipients, ten studies identified that positive effects of caring emerged out of relationships with other people (McCausland and Pakenham, 2003; Kuuppelomäki et al, 2004; Pakenham, 2005; Kim et al, 2007; Mehrotra and Sukumar, 2007; Ribeiro and Paul, 2008; Netto et al, 2009; Peacock et al, 2010; Alpert and Womble, 2015; Cheng et al, 2016). Three types of relationships dominated in these studies: family, friends/neighbours and other care-related relationships (healthcare professionals and other carers). In general, the prevailing positive effects were described as new or deepened connections within these relationships (including, in some cases, these ‘other’ relationships as a source of support).

Deepening the bond with other family members was the most often cited ‘other’ relationship in this theme (McCausland and Pakenham, 2003; Kuuppelomäki et al, 2004; Pakenham, 2005; Kim et al, 2007; Mehrotra and Sukumar, 2007; Netto et al, 2009; Peacock et al, 2010; Alpert and Womble, 2015; Cheng et al, 2016). One carer of a person living with dementia believed that ‘because of this caregiving experience, we [family] have become closer. We realize that we treasure our loved ones more and we understand that unity is very important in the family when things happen like that’ (Netto et al, 2009: 253). One study added that caring for a loved one meant that carers spent more time with other family members, something that was valued (Peacock et al, 2010). Two studies noted that carers believed that families were also a source of support (Mehrotra and Sukumar, 2007; Peacock et al, 2010).

Positive effects of caring also stemmed from relationships outside the family, both in terms of being recognised as a carer by friends and neighbours, and/or in terms of building new relationships (McCausland and Pakenham, 2003; Mehrotra, and Sukumar, 2007; Ribeiro and Paul, 2008). McCausland and Pakenham (2003) noted that a couple of carers felt that they were making new friends, while Mehrotra and Sukumar (2007) observed that carers believed that existing friends formed a similar support role as family. Another kind of support was elucidated in Ribeiro and Paul’s (2008) study, which documented that friends and neighbours also became the source

of external acknowledgement for, in some cases, fulfilling a social honour by providing care to a loved one. Carers seemed to appreciate this public recognition and saw this as a positive effect by some carers. One carer noted that his neighbours: 'praise me and say that I'm an example, that's what they say ... they go on and tell me that, they tell me they are astonished' (Ribeiro and Paul, 2008: 173). In this study, several carers expressed that they sensed that one was fulfilling a social honour by providing care for a loved one (Ribeiro and Paul, 2008).

The third type of care-related relationships concern those with healthcare professionals or other carers (Pakenham, 2005; Mehrotra and Sukumar, 2007). New relationships were established with healthcare professionals (Mehrotra and Sukumar, 2007; Peacock et al, 2010). In one study, relationships with medical staff provided carers with a sense of being cared for (Mehrotra and Sukumar, 2007). Finally, one of the studies reviewed found that connecting with other carers through support groups was seen as a positive effect, with carers seeing it as a way to help discover one's inner strength (Peacock et al, 2010).

Discussion

Our analysis of 22 studies illustrates the relational nature of the positive benefits of caring for carers of older adults. Indeed, this seems sensible given that people become carers precisely because of their ongoing relationships with loved ones (Keating et al, 2019). Positive benefits were found to be in relationships with oneself, with the care recipient and with other people within and beyond the family (that is, other family members, friends, neighbours, other carers and healthcare professionals). Given the generally broad inclusion criteria for this study, which were not limited to one specific disease or disability, and included studies with heterogeneous populations in terms of age, location and so on, the insights garnered here may be transferable across a wide range of carers and caring circumstances.

The findings of this scoping review are supported by, and extend, the findings of existing literature reviews (Lopez-Hartmann et al, 2012; Li and Loke, 2013; Lloyd et al, 2016; Yu et al, 2018; Keating et al, 2019). Our review broadens these findings by identifying benefits beyond specific diagnostic groups, as well as by describing the nature of those benefits within a larger social context. Thinking of the positive effects of caring as relational and in relationship is a helpful reminder that humans and caring events do not exist or occur in isolation. This relationality can be understood through an ecological framework in which humans are embedded in a web of interconnected actors, influences and environments (Hoare, 2008).

Other insights into the nature of the positive effects of caring can be gleaned from a relational or relationship-based approach. For example, a relational perspective positions positive effects as dynamic and changing. As with many relationships, the positive effects will likely change over time and over the course of the caring journey. Some of the positive effects may be perceived at certain times and then not at other times, or their prominence may wax and wane. Cultural specificities (for example, the cultural expectation to care for older family members that is commonplace in some contexts versus a more state-centred approach to older adult care) may also influence the caring experience (Pharr et al, 2014) and the positive effects derived from it.

The relational nature of the positive effects described earlier could be expanded to describe relationships within and between human and non-human actors

(Latour, 2005) that influence and are a part of the caring experience (for example, between humans, between humans and animals, and between humans and objects or organisational structures). The nature of the positive effects of caring described here could possibly form the basis for a conceptual model that builds off the work of others, such as the conceptual framework of the positive aspects of caring advanced by Carbonneau et al (2010), which already incorporates the positive effects associated with the dyadic relationship and the relationship with oneself. The insights gleaned here contribute to such a framework by incorporating relationships beyond the carer's self and the care recipient. These external relationships may be an important determining factor that affects the positive experience of caring.

Seeing the positive effects of caring as based in relationships has several implications beyond theoretical understanding. It may shape certain aspects of environmental factors, such as assistive device design, social policy creation and medical professional engagement in health service delivery (WHO, 2017). Just as they can modify stressors in the caring scenario (Demers et al, 2009), assistive devices may also modify or create positive effects. Given the interconnected nature of the positive effects of caring, addressing a stressor targeting a positive effect through assistive devices could enhance that positive effect (for example, ensuring that a carer has adequate training so that a sense of competency of care is attained). This same logic could also be applied to policy interventions. The effects of interventions targeted at creating or enhancing the positive effects of caring would likely have a ripple effect throughout the entirety of the caring trajectory and the care network.

Future assistive devices and related policy development processes should consider the complete spectrum of the caring experience. More specifically, interventions and the development of assistive devices for carers are almost always designed to alleviate a problem that the carer may face. To our knowledge, there are virtually no assistive devices and no policies or interventions specifically designed to target or accentuate the positive effects of caring. Leslie et al (2019) assert that a goal-oriented intervention or technology design (that is, focusing on and drawing out the aspirations of the carer), as opposed to a needs-based approach, may centre the relational aspects of the caring experience by capitalising on the carer's strengths. This may improve social ties by creating more meaningful choices for carers that are linked to their desires (Leslie et al, 2019) and enable a possible perceived sense of control over the caring process. An example of a goal-oriented assistive device could be an online carer storytelling forum, like the website analysed in Alpert and Womble's (2015) study, with a specific component dedicated to stories of positive effects. Such a site may allow carers to reflect or unwind, and possibly assist in discovering the positive effects of their caring. Assistive devices that aid in strengthening interpersonal relationships through online chat groups – a common strategy used in Internet-based interventions for carers (Guay et al, 2017) – and beyond the virtual world could be instrumental in making the caring experience more positive.

Decision-makers may also want to consider policy and programme initiatives that target the positive effects of caring. Policy that sets aside funding for social programmes may help carers discover/enhance the positive gains, such as educational programming for carers that emphasises the positive effects of caring while recognising carer burden. Another approach would be to work towards diminishing possible stressors in the carer's life. For example, financial compensation for family carers, a flexible work environment for employed carers and enshrining the rights of carers into law may clear

the path for the positive effects to germinate by reducing financial or employment-related challenges (Fast, 2015).

Healthcare professionals are in a unique position of potentially building a meaningful and positive relationship with carers. Carers look to healthcare professionals for emotional and technical support (Lopez-Hartmann et al, 2012; Sheets et al, 2014). Ethically, healthcare professionals can work with carers, as clients in their own right, to support and empower them, including them in care discussions, while maintaining the care recipient's privacy (Reid et al, 2005). Devising intervention strategies or engaging carers in discussions that highlight the positive effects of caring could begin with questions about their values, their motivations for caring and the aspects of caring that they find enjoyable. Thoughtfully engaging carers in a manner that foregrounds an exploration of the possible positive effects of caring may encourage improved outcomes. However, it is important to recognise that not all carers can or want to focus on the positives.

Future research could address the role of assistive devices in enhancing the positive effects of caring. Such studies may want to examine if positive effects can be sustained or prolonged with assistive devices. A similar set of questions could be brought to bear on the role and efficacy that social policy and health services may have in relation to the positive effects of caring for the carers of older adults.

Limitations

By not limiting to a specific geographic location, disease or disability type, we were able to identify generalisable trends among a wide range of caring scenarios. However, there are limitations to this study. In keeping with the methods for a scoping review, the quality of the research methods and the strength of included study findings were not evaluated. In addition, the references cited in the included studies were not considered for inclusion.

Conclusion

Carers play a central role in supporting the ageing process. Despite the mental, emotional, physical and financial costs that can impact carers, there are positive effects associated with caring, and they are relational in nature. The first theme identified the positive effects of caring in relation to the carer's self through a discovery of inner strengths, new areas of personal fulfilment and growth, life purpose, and/or a new or deeper sense of spirituality. Second, the positive effects of caring are in relation to the care recipient by growing closer to the care recipient throughout the caring journey, and deriving pleasure from feeling needed and seeing the care recipient happy and comfortable. Third, the positive effects of caring are in relation to others by developing deeper and more meaningful relationships with family, friends, other carers and healthcare professionals.

Future enquiry could further flesh out the relational nature of the positive effects of caring. For example, longitudinal qualitative or mixed-methods research could explore changes in the positive effects of caring over the course of a caring journey. Another approach could be a social network analysis, which may yield a deeper understanding of existing carer relations that could help to identify the strengths and gaps in a support network. This type of information could also lend itself to developing a

relationship-based conceptual framework of caring. In terms of environmental factors, research exploring if and how assistive devices or social policy create or enhance the positive effects of caring would be instructive for future design and policy thinkers. With an awareness of the positive effects of caring, technology, policy and practices can be developed to enhance the positive effects of caring for the carers of older adults.

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Conflict of interest

The authors declare that there is no conflict of interest.

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Appendix A: Search terms

Ovid (Medline and Embase)	EBSCOHost (CINHAL)	APApsycNet (PsycInfo)	ProQuest (Sociological abstracts)
Caregiver			
Caregiver/ (Medline)	MH Caregivers	Caregiv*	Caregiv*
Caregivers/ (Embase)	MH Caregiver support	Carer*	Carer*
Caregiv*	Caregiv*		
Carer*	Carer*		
Positive effects			
Positiv*		Aspect*	
Benefi*		Light*	
Gain*		Feeling*	
Satisfaction*		Consequence*	
Gratification*		Experience*	
Health*		Positive gain*	
Outcome*		Personal gratification	
Effect*		Personal satisfaction	
Impact*			
Older adults			
Elder*		Alzheimer*	
Senior*		Dementia*	
Older people		Parkinson*	
Old people		Adult*	