Review article

The oldest carers: A narrative review and synthesis of the experiences of carers aged over 75 years

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A R T I C L E   I N F O

A B S T R A C T

As populations age, numbers of older carers are increasing. These carers play a vital role in supporting others, often partners or spouses with dementia.

This narrative review synthesised peer-reviewed evidence published over the last two decades concerning the experiences of carers aged over 75 years, specifically exploring whether their experiences differ from those of younger carers. Four electronic databases were searched and 4102 publications were identified. Eighteen studies involving over one thousand carer participants were included (11 quantitative, 6 qualitative, and 1 mixed-methods study). Most studies came from Europe or North America and almost all were cross-sectional, but few directly compared younger and older carers, making it difficult to determine whether carers' experiences vary with age. Quantitative studies generally emphasised the challenges of caring and frequently highlighted, for example, relationships between carer characteristics and negative outcomes such as burden. Qualitative studies were often more positive, emphasising carers' active responses and the rewards of caring. The normality of caring was highlighted, with some suggesting that caring may be less challenging for older than for younger carers.

As with younger carers, being an older carer can be both rewarding and difficult. Our understanding of the experiences of these older carers would be enhanced with more research specifically comparing older and younger carers or comparing older carers and those not in a caring role. Carers are diverse and future research should explore the experiences of carers from different demographic groups. More longitudinal research perhaps focusing on caring dyads and mutual caring is needed.

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1. Introduction

Worldwide populations are aging and as medical care improves, people are living longer with long-term disabling conditions. In the United Kingdom (UK) the number of people aged 75+ is expected to almost double in the next 25 years, rising from 5.2 million in 2014 to 9.9 million in 2039 [1]. Much of their support comes from unpaid, often family carers or caregivers as they are also known.

One in eight (13%) people in the UK aged 75 years or older are carers [2] with nearly one in five (18.8%) aged 85 years or over [3]. Numbers of these oldest carers are increasing more rapidly than younger age groups. For example, comparison of the 2001 and 2011 UK census figures shows the number of carers aged over 85 has increased by 128% compared to 25% for those aged 60–64 years [4].

Carers aged 70+ most frequently care for spouses or partners, [2] and nearly half aged 75 or older care for someone with dementia [4] – a condition where caring is often more challenging and where depression is more common than in carers of people with other conditions [5]. With increasing age, they also spend longer caring with proportions spending 50 hours or more a week caring rising from about 45% for those aged 75–79 to over 55% for those 85+ years [2].

Overall, carers are more likely to be female (52%) than male (48%) but as they age, the proportion of male to female carers rises. Between 75–84 years, there are equal proportions of male and female carers but after 85, nearly three in five (59%) carers are male [4].

Older carers are not an homogenous group and diversity in, for example, ethnicity and sexuality should not be ignored. Older people from black minority groups are more likely to be carers [6] and carers from black and minority ethnic (BME) groups may also have different experiences of receiving [7] and accessing support [8]. Older lesbian, gay, bisexual and transgender (LGBT) carers are both less likely to be identified and to find available services suitable [2].

Being a carer is not without rewards [9] and is usually freely given, but it is also often associated with negative consequences on carers' physical (e.g. [10]) and mental health (e.g. [11]). Irrespective of age, all carers have a very important role and may need support, but with older carers the challenges of being a carer may be exacerbated by their age and own health. Older carers may also be less likely to access services, as they may be unaware of services and less likely to request support [3]. Any support provided needs to help them and the person they care for to remain independent and in control of their lives for as long as possible.

1.1. Aims

Evidence shows that being an older carer is both not uncommon and is potentially a demanding role. The aims of this review are therefore to synthesise the available peer reviewed literature from the last two decades to explore the following questions:

- What is known about the experiences of carers aged over 75 and are their experiences different to younger carers?
- What more do we need to know about these carers and how best to support them?

1.2. Definitions and rationale for age category selection

The term carer or caregiver here refers to those in an unpaid capacity supporting others with long-term conditions living at home. Literature searches suggest that many different ages are described as 'older' with many different terms used to describe older carers. These include 'elderly', 'old', 'older', 'oldest', 'old old' and 'oldest old'. However, the precise ages included in these categories are both variable and not always explicitly defined. Initially it was intended that this synthesis would only include research with carers aged 75 or older (henceforth referred to as 75+). However, preliminary literature searches revealed very few studies specifically with this age group. In an attempt to maintain the focus on older carers but not to be too exclusive, it was decided to include research where the mean age of carers was 75+. However, this too proved problematic as many qualitative studies only provided age ranges for participants. In order to maximise the evidence, a pragmatic decision was taken to scrutinise carefully all studies fitting the inclusion criteria and to decide on an individual basis what to include in the final analysis. In the interests of transparency, studies coming very close but excluded at this final stage are also described.

2. Methods

The review followed the Centre of Reviews and Dissemination (CRD) guidelines [12] and was reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [13].

2.1. Electronic search strategy

Four electronic databases were searched: Medline (1996 – August 2016), PsychINFO (1996 – August 2016), Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus, 1996 – August 2016) and the Social Sciences Citation Index (SSCI, 1996 – August 2016).

The search strategy for PsychINFO is provided in Table 1 as an example. Similar search strategies were developed according to specific database requirements and consisted of both keywords and Medical Subject Heading (MeSH) terms. Keywords and combinations applied were the same throughout the database searching.

Table 1
Example electronic search strategy conducted in PsychINFO.

	Search concept	Search terms
1	Carers	*Caregivers* OR caregiver$ OR care giver$ OR care-giver$ OR carer$ OR informal caregiver$ OR informal care giver$ OR informal care-giver$ OR informal carer$ OR family caregiver$ OR family care giver$ OR family care-giver$ OR family carer$ AND
2	Age	Oldest old OR middle old OR aged 75 and over OR aged 75 or over OR aged 75 or above OR aged 75 and above OR oldest OR elderly AND
3	Experiences	Experienc$ OR burden$ OR strain$ OR wellbeing OR well-being OR quality of life OR coping OR mental health OR depression OR anxiety OR caregiving confidence OR caring confidence.

The MeSH (Medical Subject Heading) terms used are reported in italics and key words with truncation where appropriate.

To concentrate on the most recent evidence, searches were limited to publications from the last two decades.

2.2. Inclusion criteria and study selection

Inclusion criteria:

1. Mean age of 75+ for carer participants
2. English language
3. Qualitative, quantitative or mixed methods
4. Published in peer reviewed journals (1996–2016)

Exclusion criteria:

1. Grey literature
2. Not peer reviewed (e.g. posters or conference abstracts)
3. Reviews and opinion publications
4. Case studies

Following duplicate removal, both authors screened the titles and abstracts to identify those potentially fitting the inclusion criteria. Full texts were sourced for all potential articles which were then scrutinised for the final selection. Where there was uncertainty, consensus was achieved by discussion (Fig. 1).

2.3. Other sources

Experts in carer research and policy were contacted to help identify any additional literature. Reference lists of the included studies identified from the electronic database searches were also searched.

2.4. Data extraction and management

Data were entered into tables which included study aims, methods, results and overall conclusions. Different tables were developed for quantitative and qualitative articles for ease of reporting.

2.5. Data synthesis

Data were synthesised using a narrative approach. Given the broad research questions and diverse study types, narrative synthesis was an appropriate choice. This method is inclusive, allows integration of qualitative and quantitative data from a wide variety of sources and can be more descriptive and interpretive than other review types [14].
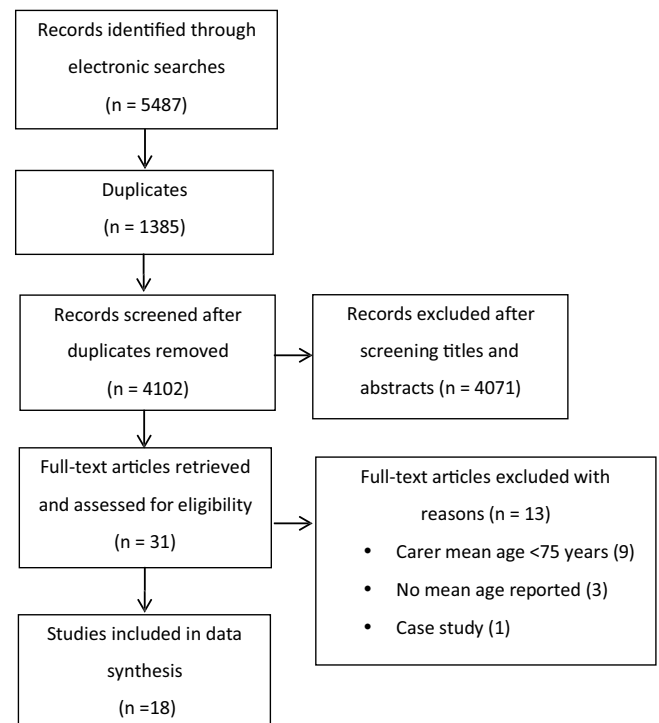
Fig. 1. PRISMA [13] flow diagram showing the process of article identification and selection.

3. Findings

Electronic searches identified a total of 5487 articles: Medline – 1847; PsychINFO – 2085; SSCI – 408; CINAHL Plus – 1147. After duplicate removal, the titles and abstracts of the remaining 4102 articles were scrutinised and 31 full texts were retrieved. Eighteen studies fitted the inclusion criteria. Eleven were quantitative, six qualitative and one used mixed methods.

3.1. Studies coming close to inclusion but excluded

Two articles came close to inclusion but were excluded because the participants' mean age was less than 75 years [15,16].

3.2. Study and participant characteristics

3.2.1. Qualitative studies

Six qualitative [17–22] and one mixed methods study [23] fitted the inclusion criteria. They included a total of 160 carers (mean 22.9, median 17) but sample size varied considerably (range 4–53). Five studies were European [18,19,21–23] and two American [17,20]. Publication dates ranged from 2001 to 2016. There were more female than male carer participants and in most cases spouses were supporting partners, often with dementia. Carers' average age was 75+ years with some carers in their nineties. Participant ethnicity was only reported in one study where the majority were white Americans [20]. All were cross-sectional and most employed in-depth or semi-structured interviews. Analysis varied but included content and thematic analysis. Table 2 shows the main study and participant characteristics for the included qualitative studies.

3.2.2. Quantitative studies

Eleven quantitative and the mixed methods study [23] with nearly four thousand participants fitted the inclusion criteria. Four studies [24–27] appeared to come from one data set and therefore the review findings, for example in terms of, participant numbers, reflect this. Studies were published between 2004 and 2015 and included 9487 participants (mean 410.1, range 57–1214). Five publications (including [23]) were Scandinavian [23–27], four came from the USA [28–31] with one each from Taiwan [32], Hong Kong [33] and Australia [34]. Again there were more female than male carer participants and where relationships were reported, carers were mostly spouses. Three studies reported carer ethnicity. In two, most carers were described as white or white American [30,31] and in the third, all were Mexican American [29]. Health conditions of the person being cared for were infrequently reported but included dementia, Parkinson's disease and 'impaired health'. Data were collected by a mixture of surveys and face-to-face interviews. All were cross-sectional except one which was longitudinal [31]. Most studies used validated outcome scales, often investigating carer well-being, depression, burden and strain. Analysis included a mixture of non-parametric tests and regression (Table 3).

3.3. Overall findings

Given the number of studies included, it is not possible to describe the findings in detail and therefore the following are brief summaries.

3.3.1. Qualitative studies

All included qualitative studies explored older carers' experiences. However, importantly none directly compared older and younger carers making it unwise to be confident about similarities and differences in experiences. In some, the focus was on overall experiences [17,19,21] but others concentrated on specific points in the caring trajectory. For example, carers' experiences of a dementia diagnosis [23], decisions surrounding institutional care [18] and caring for a dying partner [22]. Two studies investigated the experiences of male carers and masculinity [17,21] and emphasised how men sought to retain masculinity in a traditionally female role. The demands (e.g. the constancy of caring) and negative impacts (e.g. anxiety) of being a carer were highlighted in several studies [17,20,23] but the active nature of older carers' responses [17,23,22] and positive aspects of caring [22,23] were also highlighted. Ribeiro [21], for example, drew attention to the rewards and praise from others for taking on the role. Caring as something accepted by carers because they had 'signed up for it' in marriage was mentioned in two studies [21,23] (Table 4).

3.3.2. Quantitative studies

The overwhelming aim in the quantitative studies was to investigate the negative consequences of caring on older people including depression, strain, burden and loneliness. Many investigated the relationships between carer demographic characteristics or the characteristics of those being cared for on these negative outcomes [25–29,33].

Investigations took diverse approaches. Two explicitly compared younger with older carers [28,33] and two compared carers with non-carers [25,29]. Four articles also made comparisons between male and female carers [24–27]. One reported gender differences with women more frequently reporting loneliness [25] whilst another publication from the same authors found that males reported more satisfaction from caring [29]. However, another study found no gender differences in carer depression [29]. Caring tasks undertaken by older carers and their frequency were also investigated [24,26]. Findings demonstrate the diversity of these tasks which range from helping with activities of daily living to liaising with hospitals, but also highlight less specific activities such as proactively keeping in touch to avoid problems. Some gender differences in tasks undertaken were identified but not, for example, in quality of life scores [24,26].

Findings from studies comparing older carers and older non-carers appear slightly contradictory. For example, although carers may have wider social networks and report loneliness less frequently than non-carers [25], they may also be more depressed whilst approximately half of older carers report little or no burden [29]. An investigation looking at caring transitions [31] showed that non-carers described lower levels of stress than carers and that stress was greater for carers providing high intensity caring or those moving from low to high intensity caring. However, reports of sleep problems did not differ between carers and non-carers but sleep problems were associated with depression, irrespective of caring status [30]. Comparisons between older and younger carers also suggest that as they age, carers may experience lower distress, depression and higher well-being [28,33] and may find more rewards in caring [28].

The largest proportion of these studies explored relationships between carer, cared-for characteristics, caring circumstances and carer outcomes. Several studies investigated and reported associations between negative caring outcomes, for example, between strain, burden and depression [29,32,33]. Others focused on relationships between caring tasks or activities and carer outcomes. For example, carers' higher sense of coherence and maintaining outside interests predicted higher quality of life, whilst poor economic situations predicted lower quality of life [24]. Both lower health scores and burden predicted depression [29].

4. Discussion

This review identified 18 relevant studies from both Western countries and the Far East and included nearly four thousand carer participants. However, the investigations were diverse in nature making it difficult to summarise the sometimes apparently conflicting results. Some suggested that older carers may find caring more challenging than younger carers whilst others suggested that in some ways, older carers may be better equipped for the role. There is no obvious explanation for these discrepant findings but, once again, qualitative research tends to identify more positive aspects of carers' experiences. A major barrier to reaching meaningful conclusions here is the dearth of research explicitly making comparisons between older and younger carers and between carers and non-carers. As a result, it is impossible to confidently say, for example, whether older carers find caring more or less challenging than younger carers or whether their quality of life is usually poorer

Table 2
Included qualitative papers: background details and study details.

Authors (Date) [Country]	Carer participant numbers & demographics Age (years) % female % spouses	Cared-for numbers & demographics Age (years) % female Health condition	Methods	Theoretical background & data analysis
[17] Black et al. [USA]	4 Age >80 0% female (100% male) 100% spouses	4 Age NR 100% female 100% dementia	Ethnographic interviews & informal conversations	Constructivism, phenomenology, sociology of knowledge, ethnography, thematic analysis
[18] Kraijo et al. [Netherlands]	14 Mean age 76.07, range 72–87 42.9% female 100% spouses	14 Mean age 79.92, range 70–89 57.1% female 100% dementia	Semi-structured interviews	Grounded theory/constant comparative method
[23] Laakkonen et al. [Finland]	38 Mean age 78.2 63% female 100% spouses	63 Age NR % female NR 100% AD	Survey with open-ended questions	NR
[19] McGarry and Arthur [UK]	14 Mean age NR, range 76–92 71% female 92.86 spouses	14 Age NR % female NR Health condition NR	Non-directive interviews	Thematic analysis
[20] Perry [USA]	20 Mean age 76.3, range 57–82 100% female 100% spouses	20 Mean age 78, range 59–84 100% male 100% AD	In-depth interviews	Grounded theory Open & axial coding with identification of the core concepts
[21] Ribeiro et al. [Portugal]	53 Mean age 78, range 65–89 100% male 100% spouses	53 Mean age 78, range 65–92 100% female All impaired, 50.94% dementia	In-depth interviews	Social constructionism Content analysis
[22] Turner et al. [UK]	17 Mean age 83.7, range 80–90 53% female 100% spouses	17 53% cancer & 47% non-malignant disease at time of death	Interviews	Secondary analysis of larger subset Framework analysis

Key: AD – Alzheimer's disease; NR – not reported; UK – United Kingdom; USA – United States of America.

than that of non-carers. Importantly, despite being more likely to have their own health conditions, some research identified here suggests older carers may have more positive perspectives and coping strategies and may identify rewards in caring more often than younger carers (Table 5).

No formal quality evaluation of the included studies was undertaken, but understanding of older carers' experiences could be enhanced with, for example, the inclusion of more longitudinal studies to learn how caring roles evolve and how any challenges and rewards change with time. Research with carers of people with stroke suggests that over time carers are more able to identify rewards from caring [35,36]. This may be particularly relevant for older carers who may have been caring for a long time perhaps supporting a disabled child through adulthood [37]. Future research should also provide more participant details with direct comparisons between different carer demographic groups from the same sample (e.g. by gender, age and ethnicity). As with carer research in general [35], there were more female than male participants in the included studies. This imbalance is particularly important here given that men are over-represented amongst the oldest carers [4], making understanding their experiences particularly important. Two qualitative studies here focused on masculinity and older male carers. Both suggested that although caring might be expected to threaten masculinity, older men adopt strategies to protect this and

can find caring personally rewarding and accompanied by kudos. More research is also needed that focuses on the older carer and cared-for dyad. Caring is often mutual [37,38] and this may be particularly true with older spousal carers. Focus on such dyads would offer insights into dyad members' experiences and how they may best be supported as a pair.

Ethnicity was seldom reported here – a disappointing omission given the importance of understanding the perspectives of carers from all ethnic groups. More studies are needed that directly compare different ethnic and cultural groups. Without these it will be very difficult to understand what experiences, if any, are unique to any ethnic group. In addition, notably none of these studies investigated friends' or neighbours' experiences of caring. Although less common than family carers, understanding their experiences would be a valuable addition here.

The research focus here was largely negative, but as with other research [36], qualitative studies tended to report more positive aspects of caring than quantitative ones. If these studies' aims are to improve carers' negative experiences, this is perhaps understandable but equally they fail to provide a balanced picture of caring and may hinder development of appropriate interventions based on the rewards of caring [39]. A further concern is that many studies continue to investigate interrelations between negative carer outcomes such as burden and stress often reporting relationships.

Table 3
Included quantitative papers: background information and study details.

Authors (Date) [Country]	Carer numbers & demographics Age (years) Gender (% female) % spouses	Cared-for numbers & demographics Age (years) Gender Health condition	Rating scales/outcome measures	Methods	Data analysis
[28] Carter et al. (2010) [USA]	64 (37 younger & 27 older) Younger mean age 51.11 (SD 4.91) 78% female Older mean age 75.71 (SD 3.03) 61% female 100% spouses	Numbers NR Age NR Gender NR 100% PD	Negative ratings – 3 dimensions of role strain – worry; lack of personal resources; global strain. Positive ratings – mutuality; preparedness; rewards	Mail survey using rating scales (positive & negative)	Hierarchical multiple regression to examine the contribution of age to positive & negative aspects of caring
[32] Chen et al. (2014) [Taiwan]	108 Mean age 74.03 (SD 6.20) 65.74% female 81.48% spouses	Numbers NR Age 80.53 (SD 7.17) Gender NR100% Disabled older adults	CBS, SF-36; Rosenbaum's self-control schedule	Face-to-face interviews using structured questionnaire	Pearson correlations between carer burden, health status LR
[33] Chow and Ho (2014) [Hong Kong]	112 Mean age 74.80 (SD 6.88) Range 56–90 59.80% female 100% spouses	Numbers NR Age 76.87 (SD 6.14) Gender NR Health condition NR	CSI; RSS; GHG; GDS; PWI;LSS; PIL	Face-to-face survey using structured questionnaire	t-tests to identify differences between groups
[24] Ekwall et al. (2004) [Sweden]	783 42% female Female mean age 81.8 (SD 4.96) Male mean age 81.7 (SD 4.32) Relationship NR	Numbers NR Mean age NR Gender NR 100% Impaired health	SF-12; Nolan's typology of caring tasks; PCS12; MCS12	Postal survey	Compared males & females in relation to circumstances & caregiving tasks using Chi- squared & logistic regression
[25] Ekwall et al. (2005) [Sweden]	783 41.6% female Mean age 81.7 (SD 4.6) Relationship NR	Numbers NR Age NR Gender NR Health condition NR	SF-12; PCS12; MCS12	Postal survey	Compared carers with non-carers using Chi-squared
[27] Ekwall and Hallberg (2007)[Sweden]	171 40.40% female Mean age 81.5 (SD 4.70) Relationship NR	Numbers NR Age NR Gender NR Health condition NR	SF-12; Sense of Coherence	Postal survey	Chi-squared & Mann-Whitney U test
[26] Ekwall et al. (2007) [Sweden]	171 Mean age 81.5 (SD 4.30) 40.40% female 79.0% spouses	Numbers NR Age NR Gender NR Health condition NR	CASI; CAMI; SF-12; PCS12; MCS12	Postal survey	Chi-squared & t-test
[29] Hernandez and Bigatti (2010) [USA]	57 Carer mean age 78.46 (SD 4.39) 68.4% female 72.2% spouses	Numbers NR Age NR Gender NR 100% 100% AD/physical disability	Self-reported health; objective carer burden; ZBI; CES-D	Interviews using questionnaire survey	Regression
[30] Kochar et al. (2007) [USA]	375 Mean age 81.0 (SD 3.6) 100% female 47% spouses	Numbers NR Age NR Gender NR 28.2% dementia	CES-D; Compared those who 'often' had sleep problems with those who sometimes/never did.	Face- to-face interviews using the CES-D	Logistic regression

[23] Laakkonen et al.[Finland](2008)	1214 Mean age overall 78.2 Range 45–95 100% spouses	Numbers NR Mean age 80.5 37.2% female 100% dementia	Questions relating to the carers' opinions on the disclosure of dementia & follow up care	Postal survey	Chi-squared & Mann-Whitney *U* test
[31] Lyons et al. [USA]	702 (400 high & 302 low intensity caring) High intensity mean age 83.77 (SD 3.64) Low intensity mean age 83.5 (SD3.90) 100% female 54.3% spouses	Numbers NR Age NR Gender NR 28.1% AD	PSS; CES-D	Interviews at annual intervals	Mixed effects regression models
[34] Tooth et al. [Australia]	276 Mean age 78.8, range 78–83 100% female 92.4% spouses	Mean age 79.10 Gender NR 74.6% CVD; 23.2% AD; 9.4% PD	SF-36; DSSI; CBI; CSI;	Survey using a mixture of open & closed questions	Regression

Key: CAMI – Assessment of Managing Index; CADI-Carers' Assessment of Difficulties Index; CASI-Carers' Assessment of Satisfaction Index; CBS – Carer Burden Scale; PD – Parkinson's disease; CBI – Caregiver Burden Inventory; CSI – Carer Strain Index; DSSI – Duke Social Support Index; RSS – Relative Stress Scale; GHQ – General Health Questionnaire; GDS- Geriatric Depression Scale; PWI- Personal Well-being Index; LR – learned resourcefulness; LSS – Life Satisfaction Scale; MCS12–Mental Component Summary; PD – Parkinson's disease; PIL- Purpose in Life Test; PCS12- Physical Component Summary; PSS- Perceived Stress Scale; SF-12–Short Form Health survey 12; SF-36 – Short Form Health survey 36; USA – United States of America; ZBI – Zarit Burden Scale.

Table 4
Included qualitative studies: aims, findings and conclusions.

Authors	Date	Study aims	Main findings relevant to review	Conclusions
[17] Black et al. (2008)		To explore suffering in later life.	Narratives showed the inter-relation between masculinities, a sense of personal control & suffering within caregiving. 3 strategies were used to mediate their suffering. 1) power of the little 2) preserving dignity & marriage identity 3) finding purpose in the carers' role.	These findings give insight into the world of the oldest male carers through their accounts of suffering, their daily tasks, thoughts about themselves & the way in which they embody their masculinity in caring.
[18] Kraijo et al. (2014)		To investigate the decision by spouses to have their partner with dementia admitted to a nursing home & to determine whether the admission took place at the right time from their perspective.	Placement decisions had to be made in phases over time. The first decision is to place their spouse on a waiting list, the second decision is accepting a place once available. The latter felt under time pressure to avoid losing the place & most said they would have continued caring if they had more time to consider. Placements were either at the right time, too early, too late or out of control.	Spouses would have kept caring for longer if they had been given more time & space to make their final decision. It may help informal & formal carers to focus on perseverance time in considering placement or prolonged home support. Placement at an appropriate time may lead to higher well-being in informal carers.
[23] Laakkonen et al. (2007)		To examine the experiences of spousal carers of AD patients of the disclosure of AD diagnosis & subsequent care.	Many felt grief, anxiety, loneliness & uncertainty about how to deal with caring for the person with AD. Many were disappointed because of lack of support & follow-up care. Some demanded improved healthcare.	Carers want continuity & expert support with cooperation between health & social care. Education is needed for primary care with perhaps a case manager to manage follow-up care.
[19] McGarry and Arthur (2001)		To examine the experiences of informal carers aged >75.	4 key themes emerged: the organizational demands & structure of caring relationships; informal support networks; formal services; the constancy of caring & the need for recognition of the carers' role.	The >75 health check may provide a valuable tool to identify older carers. Nurses can take a lead role in working with this group in 3 ways: 1) identifying older carers 2) developing strategies to assist older carers in their caring role 3) responding swiftly to crises.
[20] Perry (2002)		To examine the process of becoming & being a carer from the perspectives of wives caring for husbands with dementia.	Caring is an interpretive process which begins with seeing spouses changing. Gradually wives took over the roles & responsibilities of their partners. This prompted them to rewrite their husbands' identities (incorporating dementia) & their own identity to reflect their new roles, abilities & strengths. Finally, they began to reconstruct a daily life to sustain them both. This process is neutral & allows the positive aspects of caring to be considered along with grief & frustration.	There is a cognitive aspect of caring in addition to the emotional & task-orientated dimensions. How wives interpreted the situation was integral to their daily lives & brought their intimate, in-depth knowledge of their partners to the fore. This not only facilitated planning & designing approaches to supporting their husbands but also helped them maintain relationships with them.
[21] Ribeiro et al. (2007)		To explore the experiences of older husbands caring for dependent wives to understand how they see themselves in the caring role & to explore issues of identity & masculinity.	3 major themes with subthemes were identified: 1) (wo)man in charge (subthemes man/husband caregiver 2) power & the caring relationship) 3) social visibility of care (subthemes: perceived social honour; roles' social legitimation); contemporary notions of masculinity.	When describing their gendered understanding of themselves, men negotiated with the dominant masculine ideology in order to maintain their sense of masculinity & legitimise being in a feminine role. They did this by reframing their definition of men & reinforcing that of husbands by retaining power over the caring relationship. The role's social visibility was important in shaping their masculinities.
[22] Turner et al. (2016)		To explore the experiences of the oldest carers in caring for a dying spouse at home.	These carers demonstrated the highest resilience & ability to adapt to caring. It was difficult & stressful but caring was talked about with positivity & humour. Caring until death was accepted as part of the 'wedding contract'. Carers benefited from informal & formal support but their own needs were not always recognised by health & social care services.	These carers' experiences are complex & challenging. Healthcare professionals need to understand the many ways caring is enacted in this group. Interventions specifically for older carers are needed.

Key: AD – Alzheimer's disease.

Authors	Date	Study aims	Main findings relevant to review	Conclusions
[28] Carter et al. (2010)		To compare differences in negative aspects of strain & modulators of strain in young & older carers of people with PD.	In the early stages of PD, younger spouses (who often had multiple roles) were at greater risk of negative consequences of caring & reported significantly more strain from lack of personal resources & lower levels of mutuality & rewards of meaning than older spouses aged >70. Controlling for spouse gender & physical health, age group explains 13% of the variance in strain from lack of personal resources & 15% in rewards meaning suggesting being younger is a risk factor for morbidity in long-term caring.	It is important to examine both positive & negative aspects of caring. The findings also suggest the importance of age specific interventions. Clinicians are well placed to identify young spouses' unique needs & to intervene. These findings give ideas for targeted interventions.
[32] Chen et al. (2014)		To examine relationships between carer burden, health status, & LR in older carers. To predict the factors affecting carer burden.	Carer burden was negatively correlated with physical & mental health & LR. Physical & mental health were positively correlated with LR. Predictors of carer burden included health & economic status, LR & ADL, accounting for 58.6% variance in carer burden.	The health status of older carers is important in caring. Carers should be encouraged to have healthy life-styles. Health professionals should pay attention to carer burden & the abilities of older carers to cope with stress.
[33] Chow and Ho (2014)		To examine differences in psychological well-being in spouses of people with dementia with high & low strain. To also investigate differences in dimensions of psychological well-being between young-old (56–74) & old–old (75–90) spousal carers.	22.9% reported high levels of strain & 9.9% reported high levels of depression. T-tests showed that carers with lower levels of strain were more likely to report lower caregiving distress, higher mental health, lower depressive symptoms, higher well-being, higher life satisfaction & higher purpose in life. Old-old carers were more likely to report lower caregiving distress, lower depressive symptoms & higher subjective well-being than young-old carers.	Low levels of distress & depression suggest adjustment to caring. According to Confucian philosophy, relationships e.g. being spouses come with internalised responsibilities & obligations & can affect the appraisal of the situation allowing it to be gratifying & rewarding despite the caring demands. Caring can lead to positive feelings e.g. personal growth & accomplishment. Old-old carers may have developed positive qualities which help buffer against the negatives of caring. Compared to younger carers, they may have skills that make caregiving tasks easier.
[24] Ekwall et al. (2004)		To investigate the dimensions of caring amongst elderl carers caring for someone with impaired health based on Nolan's model of informal caregiving. To study the dimensions of caregiving in relation to gender & health-related QoL.	Activities included: e.g. being prepared if something happens (52%); helping with IADLs (49%) or personal ADLs (14%); having regular contact to prevent problems (35%); helping improve functions (14%). Female carers more often kept in touch to prevent problems & helped with personal care. Male carers more often helped with IADLs. Adapting their own activities; regular contact; weak economy & needing instrumental help with daily living oneself predicted low MCS12. Weak economic situations & needing help predicted low scores on physical QoL. Helping with IADL correlated positively with physical QoL	Considering informal caring as a dimension in a process was supported here. Other caring activities than those related to PADL were the most common suggesting that care starts before help with PADL is needed. Dimensions present in the early stages of caring such as anticipatory & preventive care had a negative impact on carers' QoL.
[25] Ekwall et al. (2005)		To investigate QoL in relation to loneliness, caregiving, social networks, gender, age & economic status among carers in a population-based sample aged >75.	Carers had a larger social network & reported loneliness less often than non-carers. 40% helped very day. Female carers were more likely to have felt lonely over the last year than men. Having a small or non- existent network & loneliness were both significantly associated low QoL among carers & non-carers.	Loneliness together with small (1 or 2 people) or a non-existent network was the most important predictor of low mental QoL amongst carers & older people in general indicating they are crucial in the care of older people.
[27] Ekwall andHallberg (2007)		To study the association between gender, extent & content of care, satisfaction, coping & caring difficulties in carers aged >75.	Compared to females, male carers were more satisfied reporting that caring had widened their horizons & helped them grow as a person. Satisfied carers were more likely to be male & to care for longer hours. They also used more problem-solving strategies.	Those who found satisfaction with caring use more problem focussed coping strategies & were more often male. Elderly female carers need more help as they do not find caring as rewarding as males.

Table 5 (*Continued*)

Authors	Date	Study aims	Main findings relevant to review	Conclusions
[26] Ekwall et al. (2007)		To investigate coping strategies & sense of coherence in relation to gender, the extent of caring, caregiving activities & health- related QoL of a population- based sample of carers aged >75.	Almost 70% of carers provided help every day with a mean of 46 h per week. There were differences in the caring activities undertaken by males & females (e.g. females cooked more often). Using self-sustaining coping strategies (e.g. keeping interests outside caring) & high sense of coherence predicted higher health-related QoL. Lower scores were predicted by poor economic situations.	These findings could help identify carers at risk of low QoL due to dysfunctional coping or lack of information about care. Early intervention including education about alternative coping strategies & practical information might offer carers improved possibilities to continue caring with a less negative impact on their lives.
[29] Hernandez and Bigatti (2010)		To compare depression in matched carers & non-carers & to determine which variables explain depression in carers.	Carers reported higher depression (CES-D) & were more likely to be in the depressed range than non-carers. A regression model with all participants showed that being a carer & health scores significantly predicted CES-D scores. Carer burden significantly predicted depression in carers.	The findings suggest that older American Mexican carers are more depressed than non-carers as has been reported with younger populations but nearly half reported little or no burden.
[30] Kochar et al. (2007)		To determine whether depressive symptoms modify the association between caregiving & sleep problems in elderly women.	Carers did not report more sleep problems than non-carers, although participants with high depressive symptoms were 2 X more likely to report sleep problems. Carers in high stress situations (e.g. caring for someone with dementia) had more trouble staying asleep or waking up early but not falling asleep (6 X more likely).	Depressive symptoms appear to modify the relationship between caring & sleep problems. These may all be inter-related. These results underscore the importance of screening older female carers for depressive symptoms & sleep problems.
[23] Laakkonen et al. (2008)		To examine spousal carers' experiences of disclosure of dementia diagnosis & subsequent care.	71% of carers received sufficient information about dementia, but 50% said follow-up care was well organised. 97% of carers would prefer the diagnosis to be shared with the cared for person, even though 55% of carers felt their spouse had become depressed after diagnosis. 68% of carers felt the dementia diagnosis had led to grief or symptoms of depression.	Elderly spousal carers were satisfied with the information given them about dementia. However, the support with regard to the follow-up care of care-giving families failed to meet their needs.
[31] Lyons et al. (2015)		To evaluate the interplay between transitions in caregiving status & caregiving intensity based on the number of basic & instrumental ADL tasks performed by carers.	High intensity carers reported the highest stress. Non-carers reported the lowest stress. Low intensity carers whose intensity increased had higher stress than continuing high intensity carers. Carers stopping caring reported the same amount of stress as non-carers irrespective of their caring intensity levels. Those stopping caring reported less stress than those who remained as carers but these associations were not statistically significant.	Transitions in caring status & the intensity level influence carers' perceived stress. The highest stress is reported by those in high intensity caring & those moving from low to high intensity caring.
[34] Tooth et al. (2008)		To investigate the effect of type of impairment of care recipients on the level of burden & QoL of elderly Australian carers.	60% of elderly female carers were looking after someone with cognitive & physical impairment. Carers of people with both impairments had higher objective burden than those caring for people with only one type of impairment (p < 0.01). Scores for limitations on their own lives were higher for women caring for people with cognitive impairments (with or without physical impairments) (p < 0.001).	The majority of elderly women caring for someone else are likely to suffer multifaceted burdens of caring. There is greater burden for those caring for someone with both physical & cognitive impairment. Support for these carers needs to be informed by the type of impairment of the person cared for.

Key: ADL – activities of daily living; CVD – cardiovascular disease; GDS; IADLs instrumental activities of daily living; LR – learned resourcefulness; PADL – physical activities of daily living; PD – Parkinson's disease; QoL – quality of life; SOC – carer competence.

However, the conceptual overlap and lack of clarity between these outcomes [40] clearly increase the chances of identifying such relationships.

Thought also needs to be given to what is meant by 'older' carers. The database searches uncovered a considerable range of ages described as older and included carers in their 50′s and those in their nineties. What is meant by 'old' is changing rapidly. People are living longer and remaining healthy longer and are also more likely to remain in paid employment. This has implications, for example, in terms of potential role conflict. Furthermore, older carers' situations are diverse. A fit, healthy older carer, with a wide social network and receiving a lot of support, is likely to experience caring very differently to an isolated older carer with their own health problems. Any support needs to be tailored to the individual circumstances of the caring dyad.

Although one study here suggested that older carers would benefit from interventions tailored specifically for them [28], overall there is insufficient evidence to be confident that this would be beneficial or cost effective. Our understanding of older carers' experiences and the development of quantitative outcome measures may well benefit from more involvement of older carers themselves in research projects. Their inclusion would allow identification of what is important to them and what, if anything, they find challenging or rewarding.

4.1. Strengths and limitations

Narrative synthesis is often limited by lack of transparency and absence of guidance undertaking it [14]. However, a strength of this approach is that it allows integration of qualitative and quantitative findings. The literature searches were focused but inclusive and the included studies came from the four most relevant databases. The review was also reported using the PRISMA [13] guidelines providing transparency in the methods employed.

5. Conclusion

It should not be assumed that caring always has a negative impact on older carers or that they always want or need support. Caring can be mutual and satisfying and support provided should be focused on what these older carers and those they care for want. Further research is needed, but including older carers in research design should ensure the relevance of research and the interventions offered.

Contributors and their role

With the support of Raymond Smith, Nan Greenwood conceived the review focus and together they developed the search strategy. Raymond Smith undertook the literature searches and both authors selected the relevant articles. Nan Greenwood led on writing the paper but both authors developed the final manuscript.

Contributors

NG conceived the review focus with the support of RS and together they developed the search strategy.

RS undertook the literature searches.

Both authors selected the relevant articles.

NG led on writing the paper but both authors developed the final manuscript.

Conflict of interest

The authors declare that they have no conflict of interest.

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