Psychosocial vulnerability among carers of persons living with a chronic illness: A scoping review

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Abstract

**Aims:** To outline and examine evidence related to the meaning of ‘psychosocial vulnerability’ among caregivers of persons with chronic illnesses.

**Background:** The number of informal caregivers continues to rise globally. Their risk of psychosocial vulnerability is frequently overlooked, but understanding their psychosocial vulnerability may offer insights into meeting their needs.

**Design:** Scoping review following the PRISMA 2020 extension guidelines.

**Data sources:** The databases CINAHL, Embase, Medline/Pubmed, Cochrane Library, PsycINFO, Web of Science, Google Scholar, Lenu and ProQuest were systematically searched to identify original research. No date limit was set, and 23 studies were included.

**Review methods:** A five-step approach using the Arksey and O’Malley framework. Thematic analysis guided data analysis.

**Results:** Carers’ psychosocial vulnerability occurs when they experience barriers to resources while access and use of supports reduce risk. Antecedents of psychosocial vulnerability include a carer’s age and sex, socioeconomic status and their health and wellbeing. Psychosocial vulnerability affects carers’ relationships and causes personal losses.

**Conclusions:** The concept of carers’ psychosocial vulnerability is complex. Recognition of carers at risk for psychosocial vulnerability would help nurses direct relevant support and information to carers who need it most.

**KEYWORDS**
chronic illness, informal carers, psychosocial, scoping review, vulnerability

**Summary statement**

What is already known about this topic?

- Carers play an increasingly important role in the delivery of holistic care in the community.
Barriers and access to relevant support and homecare remain an issue for carers and patients worldwide.

Caregivers frequently succumb to vulnerability as a result of their new identification with the role as well as the duty tied to the role.

What this paper adds?

- Findings offer an understanding of factors which may contribute to carers’ psychosocial vulnerability.
- An overview of the impact of caring for individuals with a chronic illness on carers’ lives.

The implications of this paper

- Recognition of those at risk for psychosocial vulnerability could enable health care professionals to provide the relevant support and information to carers who need it most.
- Further qualitative research is needed to increase understanding of carers’ experience of caring for someone with a chronic illness.
- Carers must be seen as essential components of healthcare in order to ensure connection between policy and service delivery.

1 | INTRODUCTION

Worldwide, the burden of chronic illness is rapidly increasing. In the year 2020 alone, 57% of diseases were considered to be chronic illnesses (WHO, 2020). The number of carers continues to rise, with recent statistics in 2016 showing an increase to 4.4% from the previous 4.1% in 2011 in Ireland (Central Statistics Office, 2016), increasing from 15% in 2011 to 17% in the United Kingdom (Carers, 2020) and consisting of 11% of the population in Australia (Carers Australia, 2021). Similarly, a rise in caregiver numbers is reported in the United States, 19.2% of the population versus a previous 16.6% in 2015 (National Alliance for Caregiving, 2020).

Providing informal care for people with chronic disease and multimorbidity is burdensome, owing to an increased use of health care services, increased risk of adverse events and outcomes and a decreased ability to adhere to complex treatment regimens (Price et al., 2020). Carers develop a unique relationship with patients (Vermorgen et al., 2021) and are often the experts with tacit knowledge of the patient’s condition, symptoms and disease exacerbations (Whitehead et al., 2018).

Often forgotten is the vital role of carers to the economy. It is financially impossible for formal health and social care systems to provide the level of unpaid care given by informal carers (Vermorgen et al., 2021). For instance, in the United Kingdom, carers save up to £132 billion per year, almost the equivalent of the cost of a second NHS (Carers, 2015).

Primary care is at the forefront of chronic disease management, and the future of nursing will inevitably include supporting those with long-term conditions and their families in the community (Rothman & Wagner, 2003). There is now an opportunity to maximize family-centred care through holistic models of care empowering patients and families (Salmond & Echevarria, 2017). However, nursing practice in the field of families, chronic illness and self-management remains relatively unexplored and there is a need to find ways of engaging caregivers as part of nursing care (Rosa et al., 2016; Whitehead et al., 2018). Evolving nursing roles such as the nurse practitioner, care coordinator and case manager in the community offers opportunity to shift the focus from a patient-centred model to a patient and family-centred model (Salmond & Echevarria, 2017).

For carers, inadequate access to services leaves them prone to vulnerability. Vulnerability as a concept in healthcare has received increasing attention in the last decade despite conflicting discussions over its heterogeneity. It is widely accepted that the population’s health and access to medical care strongly relate to vulnerability (de Groot et al., 2019). Vulnerability is described as a human condition and constant experience. More specifically, vulnerability is susceptibility to any kind of harm, whether physical, moral or spiritual, at the hands of an agent or agency and is often affected by the individual’s perception and the situation that they currently experience. It is also related to disempowerment and loss of autonomy (Gjengedal et al., 2013). Psychosocial care refers to concern with the psychological and emotional wellbeing of the patient and carers, including issues of self-esteem, adaption to illness and its consequences, communication, social functioning and relationships (Dix & Glickman, 1997).

Caregivers’ susceptibility to psychosocial vulnerabilities is frequently overlooked as the patient is considered the core of the healthcare system. However, caregivers frequently succumb to vulnerability as a result of their new identification with the caregiver role.
as well as the duty tied to the role (Kittay, 2011). The majority of studies on vulnerability in healthcare have focused on biomedical outcomes relating to mortality and morbidity; however, this approach fails to provide insight into how it feels or what it feels like to experience psychosocial vulnerability (Flaskerud & Winslow, 1998; Rogers, 1997; Shi et al., 2008). Understanding how and why people experience vulnerability is crucial to ensuring that services meet a community’s need (Heaslip et al., 2018).

This scoping review is timely as it offers examination of psychosocial vulnerability in this population, and insight into how services may meet carers’ needs.

2 | REVIEW METHODS

2.1 | Aim

The scope of our review is broad, focusing on psychosocial vulnerability in relation to informal carers of patients with a chronic illness.

2.2 | Design

A scoping review seeks to provide an overview of the coverage of the available literature on a topic. We conducted our scoping review using Arksey and O’Malley’s (2005) framework. The framework has advanced since 2005 through the work of others (Levac et al., 2010; Peters et al., 2015), and we followed the steps outlined in the advanced framework (Peters et al., 2017). We registered our protocol in February 2020 on the open science forum (https://osf.io/us3jc/?view_only=05f3ac3b7c7c472a98e4c804ad92b678) to ensure transparency.

2.3 | Search Methods

2.3.1 | Step 1: Identifying the research question

Our research question aimed to explicate the meaning of ‘psychosocial vulnerability’ in informal caregivers of patients with chronic diseases.

2.3.2 | Stage 2: Identifying relevant studies

The search strategy was developed iteratively by the research team with the help of a specialist information librarian. Firstly, we searched EBSCO CINAHL using a combination of relevant Subject Headings and keywords in the title and abstract using wildcards and truncation to test out our chosen search terms (See Supporting Information S2). We also piloted different searches using proximity operators. The initial search query used the key concepts; however, differing concepts in the literature related to the key concepts were also used in the searches (See Table 1).

This strategy was adapted for the remaining databases: Embase, Medline/Pubmed, Cochrane Library, PsycINFO, Web of Science and Google Scholar. We also searched for grey literature in Lerus and ProQuest. The search began in November 2019 and was completed on 14 February 2020. No year limit was set in the search.

2.3.3 | Reference lists

We checked the bibliographies of full text studies selected for inclusion to ensure they had been included in the scoping exercise. This process identified seven further references, of which one full text was included.

2.3.4 | Eligibility criteria

(See Appendix 1)

2.3.5 | Stage 3 selecting studies

A total of 17 750 articles were retrieved. The software tool Rayyan © was used for data management and screening (Ouzzani et al., 2016).

Two authors (first and last authors) independently conducted blind title and abstract screening; 41 studies were selected for full text review with 23 included in the review. (See supporting information S1).

### Table 1

Terms used for search strategies across databases, framed in the PICo mnemonic

| Concept 1 | Concept 2 | Concept 3 |
|-----------|-----------|-----------|
| Key concepts | Informal caregivers | Vulnerability | Chronic disease |
| Free text terms/ natural language terms | Informal caregivers OR caregivers OR caregivers OR carer OR care giving OR care* | Vulnerability OR Vulnerab* OR burden OR helplessness OR openness OR Susceptib* | Chronic disease OR chronic illness OR chronic condition OR incurable disease OR chronic disorder OR long-term illness |
| Controlled vocabulary terms/ subject terms | Exp caregiver/Exp care | AND | Exp vulnerability/ | AND | Exp chronic disease/ |
2.3.6 | Stage 4: Charting the data

The 23 studies included in this review were read and summarized by the first and last authors, and a template for data extraction was generated. The first author analysed each paper and undertook data extraction (Table 2). Given the heterogeneity of studies, we used a narrative synthesis approach to collate, summarize and map the literature. The first author examined which concepts related to ‘psychosocial vulnerability’ in each study as presented in the results and how they were organized. For each paper, the logic of the structure of the description was extracted based on the terms used.

2.3.7 | Quality appraisal

In line with scoping review methodology, an assessment of the quality of the included studies was not performed (Table 3).

3 | RESULTS

The results section represents Stage 5 of the scoping review approach, presented in the PRISMA-screening flowchart and a narrative description based on themes that emerged from the extracted data (Table 4).

3.1 | Study characteristics

3.1.1 | Setting

Twenty three studies, including 116 112 informal carers of patients with a chronic illness were included in the results. The chronic illnesses addressed included dementia/Alzheimer, diabetes, multiple sclerosis (MS) cancer and Parkinson’s disease. Most (n = 12) studies included carers in the United States. Studies from other countries included the following: Argentina, Australia, Canada, Iran, Italy, Kuwait, Netherlands, Singapore and Turkey (Table 3).

3.1.2 | Methodologies

The most common methodology was cross-sectional (12 studies). Sociodemographic data were collected across all studies, and a variety of measures were used to measure carers’ burden, quality of life and depression. Two randomized clinical trials were included. One focused on a family-centred empowerment intervention model (Bagheri et al., 2019); the other used an assistive technology technology intervention (Ben Mortenson et al., 2018). Two experimental studies focusing on a bio (lymphocytes) psychosocial perspective were included (Mills et al., 1999, 2004), and one pilot study explored the impact of caregivers providing gentle massage to their loved ones (Kempson & Conley, 2009) Two qualitative studies were included (Blank, 2018; Simpson et al., 2010) and one mixed method study (Aloweni et al., 2019) (Table 3).

3.2 | Factors relating to carers’ psychosocial vulnerability

3.2.1 | Barriers to resources

Carers experiencing a lack of information about the disease trajectory, inadequate financial support and respite, were more vulnerable to coping (Kenny et al., 2014; Simpson et al., 2010). Furthermore, difficulty providing care, higher levels of care and unmet needs were attributed to vulnerability to cope (Navaie-Waliser et al., 2002).

3.2.2 | Facilitators of support

Lower levels of vulnerability had a higher correlation with social support, and higher vulnerability scores are associated with unwillingness to use the support (Crossen-Powell, 1993). In one study, carers were aware of support groups (69.4%, n = 242), but only 27% attended, mainly due to lack of time, challenges in access and concerns over anonymity (Hussain et al., 2018). A further 30% were unaware of support groups, leading to marginalization particularly for those living in rural areas (Hussain et al., 2018). Sharing with peers was viewed as vital to caregiver wellbeing, enabling them to ‘bounce back’ (Blank, 2018; p.74), and community and organizational agencies offered a forum for communicating and validating feelings. Strengths emerged with supportive resources enabling carers to negotiate the life changes brought on by caring (Blank, 2018). Further coping facilitators identified include the following: family, a caring medical team, financial aid and formal medical system support (Simpson et al., 2010).

Training sessions or participation in resources offered were believed to strengthen the family to endure the burden of care, increasing knowledge, awareness and problem solving (Bagheri et al., 2019). Training also benefited individual carers, increasing their self-efficacy which is important considering that as caregiver burden increases self-efficacy decreases (Kempson & Conley, 2009; Yildiz et al., 2017). However, caregiver training was rarely available despite some caregivers performing specialized nursing tasks (Aloweni et al., 2019; Di Stasio et al., 2020).

3.2.3 | Carer’s age and sex

Across studies, there were consistent patterns reported in terms of caregivers’ age and sex and susceptibility to vulnerability. Older carers were reported to have greater susceptibility to vulnerability. In the majority of studies, carers were classified as ‘middle age’ or over
| Author                  | Important results                                                                                                                                                                                                 | Key findings related to the research question                                                                                                                                                                                                                                                                                                                                 | Themes                                                                                                                                                                                                                                                                                                                                 | Relevance to nursing practice                                                                                           |
|-------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|
| Aloweni et al. (2019)   | Most caregivers were female, mean age 69, mean years of marriage 43 and total duration of caregiving ranged from 6 months to 29 years. Only 12% had caregiver training and 13% had a helper to assist with caregiving duties. 39% performed specialized nursing tasks such as changing of UC (urinary catheter) bags, operating a peritoneal dialysis machine, changing stoma bags and wound dressings. None used respite services and only one used day care services. Caregivers with HPLN (high positive, low negative) had lower perceived stress than LPHN (low positive high negative) caregivers. Caregivers with HPLN had a better relationship with their spouse and a higher life satisfaction which demonstrates the importance of relationship quality in reducing the negative effects of caregiving and increasing satisfaction in the caregiving role. Caregivers with HPLN had lower anxiety. Conditional happiness is related to negative perceptions of caregiving. | By paying attention to caregivers’ description of their experience HCP (health care professional) can identify those at risk to negative reactions to caregiving.                                                                                                                                                                                                 | Individual perception of vulnerability. Relationship dynamic impacts on vulnerability. Socioeconomic status. Carer health. Length of time caring.                                                                                                                                  | Carers are performing specialized nursing tasks highlighting the need for training by specialist nurses. |
| Awadalla et al. (2006)  | Caregivers were typically more likely to be women, married, of lower educational status and unemployed. Satisfied with strengths of their society, support from friends, personal relationships and personal strengths and moderately satisfied on life of lower educational status and unemployed. Caregivers who were married and in medium-high skill employment had better QOL (quality of life). Patient's age and duration of illness is positively associated with caregiver QOL. Caregivers who were siblings and spouses had lower QOL. The most important predictor of caregiver QOL was the caregiver’s appraisal of the patient’s QOL. | Caregivers who are younger, unemployed, have little education and with the illness in the early stages with the caregivers having medical problems were more vulnerable to poor QOL. Social determinants influence vulnerability. Employment positively affects caregiver wellbeing. Relationship dynamics impact vulnerability.                                                                 | Nurses need to complete a holistic family centric assessment to identify those carers at risk.                                                                                                                                                                                                                                         |
| Author | Important results | Key findings related to the research question | Themes | Relevance to nursing practice |
|--------|-------------------|-----------------------------------------------|--------|------------------------------|
| Badr et al. (2017) | Most caregivers who participated were female of ethnic minority and spouse or son or daughter of the patient. Length of time caregiving 1–7 years. Many (47%) described their health as excellent, but current smokers were likely to be more depressed. Higher levels of depression associated with high caregiver burden in the context of COPD (chronic obstructive pulmonary disease) and women caregivers are at increased risk for depression when their partners are depressed. | The influence of the dyadic relationship on caregiver outcome. | Women caregivers more susceptible to vulnerability. The mental wellbeing of the care recipient influences the mental health of the caregiver. Social determinants influence vulnerability. Increased level of burden and poorer general health associated with depression in both. | Collaboration with the carer is vital to ensure better outcomes for the patient and carer. As part of nursing care, assessment of the informal carers’ coping may be vital to ensure the best outcomes. |
| Bagheri et al. (2019) | The family-centred empowerment tool can strengthen the family to endure the burden of care by focusing on increased knowledge and awareness and managing problem solving in confronting with the problems of chronic patients. | The empowerment model can help change the attitudes of caregivers regarding disease symptoms as well behavioural signs and physical strain while promoting QOL and self-efficacy. The family-centred empowerment model training can reduce the burden of care among caregivers. | Resources can influence empowerment | Nurses are in a position to empower families through training. |
| Baanders and Heijmans (2007) | Many (40%) felt a strain on personal life but intrinsically rewarded. Personal strain increases when the patient’s disease is accompanied by physical, social and mental impairments and fatigue. Also increased for partners of patients with cancer and for unemployed women. Most carers are without professional help. For women and those working, social impact increased. Financial burden increases for partners of patients with physical and social impairments. Where one partner unemployed or both, financial burden increased. | The consequences of a chronic disease on a partner’s life. What affects the partner’s physical and psychological wellbeing? | Social determinants influence vulnerability. Life changes. Carer wellbeing. Resource availability | Nurses should assess carers for their risk of burden regularly. |
| Blank (2018) | Many (43%) had cared for >5 years. The majority were caregiving for a spouse. Most (67%) reported their health as good. All care recipients were >60 years of age with conditions such as Alzheimer’s/dementia and Parkinson’s. | The health empowerment theory perspective provided a relevant basis for theory based intervention focused on promoting strengths, abilities, and potential among older adults, limiting vulnerability was determined on an individual level through the use of their own personal resources. Empowerment influences levels of vulnerability, sought and added through social support and engagement with caregivers and promotion of wellness and psychosocial support within this population is needed. | | |
| Author | Important results | Key findings related to the research question | Themes | Relevance to nursing practice |
|--------|------------------|---------------------------------------------|--------|-----------------------------|
| Carter (2010) | Caregivers more likely to be female. No significant correlation between caregiving and self-reported health and happiness. Unemployment associated with depression. Caregiving alone is not related to family member wellbeing. Being employed is related to more positive reports of health. Caring for more than one family member is related to lower reports of health. The household structure (single headed or not) was directly related to depression and self-reported health. | Vulnerability, to diminished health and wellbeing. | Inner self. Life changes. Relational dynamics. | Vulnerability associated with social determinants. Resource availability has a significant effect on levels of vulnerability. Community based nurse practitioners and primary care nurses are ideally placed to improve carer outcomes. |
| Author                  | Important results                                                                 | Key findings related to the research question                                                                 | Themes                                                                                                           | Relevance to nursing practice                                                                                     |
|------------------------|-----------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|
| Crossen-Powell (1993)  | Significant relationships appear to exist between burden and certain variables, i.e. appraised severity of stressors, certainly personality traits and the availability of social supports and the willingness to use these supports. | Personal vulnerability has an association with burden.                                                      | Vulnerability is determined by the individual’s perception. Influenced by resource availability.                  | Nurses should ask carers about their personal perceptions of vulnerability and views on accessing available supports. |
| Di Stasio et al. (2020)| A direct association between the SVS (stress-related vulnerability scale) scale and the perception of the usefulness of interventions was detected and significant differences were observed for caregivers’ tele support group, peer led support interventions suggesting an important role for caregivers’ support interventions suggesting an important role for caregivers. | Caregivers are split between low vulnerability, with minimal perception of training need and high burden state with the acute necessity of support to manage patients. The more stressed and involved in care the higher the need for help. | The higher the level of care the more vulnerable a carer is. Resources have an impact on caregiver wellbeing.       | Nurse led interventions should be targeted at those in need of most support.                                      |
| Ficker (2010)          | Vast majority of caregivers were daughters. Most caregivers were caring for their parents and grandparents. All of the caregivers lived with the carers. Minority caregivers were less educated, participate in caregiving for a longer amount of time and had more people in the household. Employment was associated with being younger and more educated. Many (41%) reported that they had reduced hours or quit working due to caring. Caregiving housewives tended to have more physical health problems than those working full time. Unemployed caregivers tended to have more health problems than those working or retired. Higher income was associated with being employed. Those caregivers who identified as unemployed or home makers were more at risk for depression. The caregiver’s ability to engage in pleasant events was associated with ADL impairment of care recipient and the caregivers’ number of physical health conditions. Higher employment plays a role preventing role engulfment. Unemployed and homemaker caregivers were more vulnerable to mental and physical health problems. | Employment plays a role preventing role engulfment. Unemployed and homemaker caregivers were more vulnerable to mental and physical health problems. | Women caregivers more susceptible to vulnerability. Social determinants influence vulnerability. Resource or social activities determine level of vulnerability. Carer wellbeing. Loss of self. | As part of their assessment, nurses should ask carers about their feelings of wellbeing generally and what contributes to their wellbeing. |
| Author                                | Important results                                                                                                                                                                                                                                                                                                                                                      | Key findings related to the research question                                                                                                           | Themes                                                                                           | Relevance to nursing practice                                                                                                                                                                                                                                                                                                                                 |
|---------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Hussain et al. (2018)                 | Carers were aware of social supports available to them but did not access them leaving them vulnerable to marginalization. Access to support services were also rarely accessed due to inaccessibility, poor timing and a lack of anonymity. Barriers to the provision of care in rural areas: Significant impact associated with travel requirements to assist with care and the impact of care provision on the carers own personal health. Employment consequences were associated with inflexibility and limited job options. Problems associated with employment resulted in financial pressures and associated personal stress and anxiety for caregivers. | Rural caregivers are more vulnerable to marginalization                                                                                                                                                                  | Vulnerability is determined by resource availability and social determinants. Loss of empowerment. | A comprehensive holistic approach to support those providing long-term care at home is vital. Carers’ education needs should focus on nonclinical knowledge and skills; such as communication with the family, patient and wider healthcare team.                                                                 |
| Author           | Important results                                                                                                                                                                                                                                                                                                                                 | Key findings related to the research question                                                                                                                                                                                                 | Themes                       | Relevance to nursing practice                                                                                                                                 |
|------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Mills et al. (1999) | Vulnerable caregivers had 60% fewer公益活动selectin negative cell variants than nonvulnerable caregivers. The resting plasma epinephrine levels were 44% higher in vulnerable caregivers compared to nonvulnerable caregivers. | There is functional immune deficits in elderly caregivers of patients with AD and suggests the identity of specific lymphocyte subsets related to this phenomenon.                                                                                                                   | Physical vulnerability of caring | Provides evidence of the adverse physical effects on carers and the importance of a family centric model of care in nursing. |
| Author                        | Important results                                                                                                                                                                                                 | Key findings related to the research question                                                                                                                                                                                                 | Themes                                                                                           | Relevance to nursing practice                                                                 |
|-------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|
| Ben Mortenson et al. (2018)   | The functional autonomy of AT (assistive technology) users in the experimental and comparison group did not differ significantly. AT users showed significant decline over time in daily activity and mobile related functional autonomy. Family caregivers in the experimental group did not show significant reductions in their frequency of perceived physical and psychological burden associated with problematic activities compared to the comparison group. Overall caregiver burden was not significantly different between the two. | There may be beneficial effects to AT provision involving care givers in the process.                                                                                                                                                                                                             | Resources such as assistive technology do not influence autonomy or empowerment.                | Nurses are in a position to source suitable resources and strategies for caregivers to influence their autonomy and empowerment. |
| Navaie-Waliser et al. (2002)  | Many (36%) were in fair or poor health or had a serious health condition. Vulnerable caregivers were more likely to be greater than 65 years old, female, married have less than secondary education and be primary caregivers. Vulnerable caregivers were more likely be providing bathing, dressing, and transferring than nonvulnerable. Vulnerable caregivers were more likely to make phone calls on behalf of the care recipient, manage the care recipients' finance, and help the care recipient obtain assistance from government programs. Vulnerable caregivers were also more likely to be providing > 20 hours per week of care giving, to experience difficulty in providing care, to have unmet needs in providing care, suffered physical health since becoming a caregiver and less likely to be employed. | Reliance on caregivers to provide care without considering the caregivers ability to provide care can create a stressful and potentially unsafe environment for the caregiver and the care recipient. These findings signal a need to provide a broader range of accessible, affordable, innovative services and programs that lend support to family caregivers in their roles. | Level of care influences vulnerability. Physical vulnerability of caring.                           | Nurses should assess the level of care delivery by carers regularly to identify vulnerable caregivers. |
| Rivers (2016)                 | Dyadic adjustment was negatively associated with caregiver burden such that as dyadic adjustment increases, caregiver burden decreases. Male carers may benefit the most from interventions to improve dyadic adjustments. Lower caregiver burden was associated with MS spouse/partner caregivers experience significant caregiver Burden, a host of negative mental and physical health impairments and they find benefit and protection through a range of several psychosocial factors. | MS spouse/partner caregivers experience significant caregiver Burden, a host of negative mental and physical health impairments and they find benefit and protection through a range of several psychosocial factors.                                                                 | Level of care influences vulnerability. Individual perception of vulnerability. Psychological. Isolation. Empowerment | Identifies importance of nurses promoting a quality relationship between the carer and care recipient. |
| Author                  | Important results                                                                                                                                                                                                 | Key findings related to the research question                                                                                                                                                                                                 | Themes                                                                                                                                                                                                 | Relevance to nursing practice                                                                                     |
|------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------|
| Simpson et al. (2010)  | Loss of intimate relationships/identity: “duty to care” no longer the person they once loved disease-related demands: Worsening illness worsened distress and relational dynamics caregiving vulnerability risk increases with previous hx of relational stress, conflict, instability and co-existence of social determinant: Poverty, low education and co-existing health conditions. One day at a time approach: Finding a balance between caregiver burden and coping. | Substantial caregiver vulnerability in terms of an imbalance between burden and coping capacity. Interventions should address coping facilitators and barriers as disease advances it is a downward spiral for carers.                                                                 | Loss of empowerment as the disease progresses. Psychosocial vulnerability influenced by level of burden and the disease-related demands. As well as the relationship between the caregiver and recipient. Vulnerability associated with social determinants. | As part of holistic assessment, nurses can identify carers’ need for psychosocial support.                                                                                                               |
| Author | Important results | Key findings related to the research question | Themes | Relevance to nursing practice |
|--------|-------------------|---------------------------------------------|--------|-------------------------------|
| Tartaglini et al. (2014) | 48% of the sample experienced unfavourable changes in their health and condition of being a caregiver somehow predicted the changes. 85% of the caregivers went through physical disturbances, however there was no differences between self-perception of caregivers versus non care givers health wise | The caregiver suffers unfavourable health effects despite not sometimes being aware of the negative consequences. Family caregivers are often “hidden patients” health services should promote psycho educational services and diagnose for proper pharmacological treatment of depression and anxiety. | Caregivers are vulnerable to physical and psychological problems. Isolation. Social determinants influence vulnerability. | As part of holistic assessment, nurses can identify adverse effects on carers' health. |
| Trivedi et al. (2014) | Caregivers frequently reported chronic health problems. A greater proportion of caregivers than noncaregivers were women, out of work for a year more carers were white or Hispanic race. Most caregivers report <15 days of poor mental health per month and their overall health was good. Most caregivers reported that they received the necessary social and emotional support and more than half of carers received the recommend amount of sleep. Caregivers are more likely than noncaregivers to have poor mental health, low social support and inadequate sleep which can lead to poor QOL. | Being a caregiver may increase vulnerability to poor QOL. | Vulnerability is determined by social determinants. Caregivers more susceptible to health issues. Women caregivers more susceptible to vulnerability. | Nurses should assess the level of care delivery by carers regularly to identify vulnerable caregivers. |
| Von Känel et al. (2019) | Most caregivers reported good health. Higher levels of physical health problems, lower caregiver physical function and more negative affect differentiated caregivers with poor/fair SRH (self-rated health) from those with good SRH. Less physical activity and less alcohol consumption differentiated caregivers with poor/fair SRH to those with good and excellent SRH. Moreover higher BMI (body mass index) and lower positive affect differentiated caregivers with poor/fair SRH from those with excellent SRH. Higher total caregiving stress was associated with younger age, better physical function and more negative effect. Greater care recipient | Poor/fair SRH v at least good SRH reflects an inclusive measure of low physical and mental health as well as caregiving specific stress in dementia caregivers. Screening for poor/fair SRH may be valuable in identifying care givers at risk of adverse outcomes. A better poor/fair SRH may prompt target interventions aimed at understanding of improving SRH in the most vulnerable caregivers. | Caregivers with poor SRH levels were more vulnerable to less physical activity, higher BMI and younger age. Level of care influences vulnerability. Carer wellbeing. | Provides evidence of the physical toll of caring on the carer and the importance of a family centric model of care in nursing. |
55 years (Aloweni et al., 2019; Baanders & Heijmans, 2007; Blank, 2018; Carter, 2010; Crossen-Powell, 1993; Di Stasio et al., 2020; Mills et al., 1999, 2004; Ben Mortenson et al., 2018; Navaie-Waliser et al., 2002; Simpson et al., 2010; Tartaglini et al., 2014; Trivedi et al., 2014; Von Känel et al., 2019). Ageing carers struggled with physical and emotional issues with implications for their health and mental wellbeing (Hussain et al., 2018; Simpson et al., 2010). Furthermore, females were more likely to be carers, and only two of the studies reported a higher number of male carers than female carers (Baanders & Heijmans, 2007; Rivers, 2016).

Female caregivers had a higher incidence of depression, and the impact of caring on vulnerability was found to be higher in female carers (Baanders & Heijmans, 2007; Badr et al., 2017; Carter, 2010; Navaie-Waliser et al., 2002; Trivedi et al., 2014). Furthermore, higher levels of personal strain were more prevalent in female carers compared to male carers (Baanders & Heijmans, 2007; Rivers, 2016; Yıldız et al., 2017). In addition, a study of protective psychosocial factors in (MS) caregivers found that female caregivers had higher rates of probable posttraumatic stress disorder (PTSD) and symptoms versus males (22.7% female vs. 13.3% male) (Rivers, 2016). Furthermore, a longitudinal study on the impact of care giving on the physical and mental health function of the caregiver concluded that physical and mental health functioning worsened 2-year post care giving in females while physical functioning improved in males (Kenny et al., 2014). In addition, female caregivers were found to be more vulnerable (61% female vs. 39% male) and vulnerability led to unmet needs, difficulty providing care and a deterioration in health (Navaie-Waliser et al., 2002). Finally, female caregivers of patients with cancer were also found to have higher burden scores than males in relation to the impact on their personal life and lifestyle, with researchers’ concluding that this was because male partners felt less consequences of their spouse’s chronic disease than females (Baanders & Heijmans, 2007).

### 3.2.4 Social economic status

Our review found that vulnerability was correlated with low education and unemployment, suggesting that full time caregivers were more vulnerable to a change in socio economic status, which negatively affected coping (Navaie-Waliser et al., 2002). Carers with financial concerns had significant anxiety around finance. Low income resulted in financial dissatisfaction and was associated with ethnic minorities and lower education levels across many studies (Awadalla et al., 2006; Badr et al., 2017; Carter, 2010; Crossen-Powell, 1993; Ficker, 2010; Hussain et al., 2018; Tartaglini et al., 2014). Furthermore, employed caregivers had better health, were higher educated and reported less financial strain (Carter, 2010; Ficker, 2010; Yıldız et al., 2017). As caregiving hours increased over time, carers reduced their workforce participation with a longitudinal study concluding that only 5 out of 424 carers remained working 5 years after taking up care giving (Kenny et al., 2014). Ficker (2010) concluded that work disruption led to financial strain which decreased leisure activity and produced a lack of positive effects for caregivers.
| Author          | Year of publication | Country       | Study design                  | Participants and sampling | Aim                                                                 | Measures of burden, quality of life and depression | Outcomes                              | Limitations                                                                 |
|-----------------|---------------------|---------------|-------------------|-------------------------|----------------------------------------------------------------------|------------------------------------------------|----------------------------------------|--------------------------------------------------------------------------------|
| Aloweni et al.  | 2019                | Singapore     | Mixed method survey design | 75 caregiver dyads convenience sampling | To examine the factors associated with the four types of caregivers reactions according to the modified caregiver reaction assessment and assess the differences in the narrative assessment from spouse caregivers between the high positive and high negative caregiver reactions | Life satisfaction scale EQ-5D-5L | Total perceived stress was found to be negatively associated with high-positive, low-negative caregiver reaction. Caregivers with positive experience viewed caregiving as a responsibility; the opposite viewed it as having ‘no choice’. Perceived stress is an important indicator of caregiver reactions. Words used when describing caregiving experiences can potentially depict the spouse caregivers’ current state of being as a caregiver. | Convenience sampling: Lacks Generalisability. Most of participants were poorly educated and had a low income therefore may only be generalisable to low income families. Survey unable to account for adaptation process throughout disease trajectory/changing caregiver needs. Conducted in 1 area, may not be generalisable to other areas due to access to different resources or facilities. Predominately female caregivers; males may have a different experience. |
| Awadalla et al. | 2006                | Kuwait        | Cross-sectional     | 105 caregivers of patients with T1DM 135 caregivers of patients with T2DM. Convenience sampling | Assess the subjective QOL of family caregivers of Sudanese type 1 and 2 diabetic outpatients using the WHO 26 item QOL instrument compared to a general population sample and examine the factors associated with caregiver QOL | The WHOQOL-BREF scale | Caregivers who were sick, younger, single, less educated and caring for patients with more recent illness appear relatively vulnerable. | Cross-sectional (not representative of general population of diabetic patients family caregivers). |
| Badr et al.     | 2017                | USA           | The Zarit burden tool |                                        |                                                                      |                                          |                                        |                                                                                 |
| Author         | Year of publication | Country  | Study design        | Participants and sampling                                      | Aim                                                                 | Measures of burden, quality of life and depression | Outcomes                                                                 | Limitations                                                                 |
|----------------|---------------------|----------|---------------------|----------------------------------------------------------------|----------------------------------------------------------------------|------------------------------------------------|--------------------------------------------------------------------------|---------------------------------------------------------------------------|
| Bagheri et al. | 2019                | Iran     | RCT                 | 60 caregivers and elderly people with PD. convenience sampling. | This study investigated the effect of a family-centred empowerment model on the burden of care among the caregivers of the elderly with PD. | The Zarit burden tool                                                  | The use of a family-centred empowerment model for the main caregiver can reduce the burden of care among caregivers of the elderly with PD. | Differing learning levels of families and ways of transferring education to elderly patients. Convenience sampling. |
| Banders       | 2007                | Netherlands | Longitudinal study | Random sample: 1093 partner dyad                               | To investigate in what areas and to what extent partners of persons with a chronic somatic disease are confronted with specific consequences in daily life. The second aim was to investigate what factors are related to | N/A                                                            | Living with a chronically ill person has an impact on the partner's life that goes beyond the consequences of caregiving. | Cross-sectional: The partners data was collected at one point in time. |
| Author | Year of publication | Country | Study design | Participants and sampling | Aim | Measures of burden, quality of life and depression | Outcomes | Limitations |
|--------|---------------------|---------|--------------|---------------------------|-----|-----------------------------------------------|----------|-------------|
| Blank  | 2018                | USA     | Qualitative descriptive study | 21 informal caregivers of older people. Purposive sampling. | Explore caregiver recognition and engagement of personal and social contextual resources to purposefully participate in self-care activities building on the health empowerment theory. | N/A | Empowerment reflected recognition of strengths and resources as well as growth consistent with valued goals facilitating new health patterns and wellbeing. Vulnerability was limited to diminished health and well being. | Purposive sampling. 80% of participants were Caucasian, ongoing research needed with ethically diverse. Majority female. There may be gender differences in caring role. Urban area, does not reflect the experiences of those living in rural area with limited resources. Most carers were mid length of time caregiving, no early experiences. |
| Carter | 2010                | USA     | Longitudinal-cross-sectional-Quan | African American caregivers-multi state. Probability sampling | Conduct an exploratory inquiry into how chronic illness is experienced by the African American caregiver through dissecting the contextual variables that inform care giving guided by the model of family stress, adaption and resiliency the study looked at the role that family stress and coping factors have on caregiver wellbeing. | CES-D scale | Caregivers more likely to be females. Caregiving as an independent family member stressor was not related to depression or other well being indicators. Caregiver vulnerabilities such as employment and caring for more than one family member were significantly related to health reports. Caregivers family life is directly related to their wellbeing perhaps. | Secondary data > 20 years of onset of caregiving. Absence of data prior to onset of caregiving. |
| Author          | Year of publication | Country | Study design | Participants and sampling | Aim                                                                 | Measures of burden, quality of life and depression | Outcomes                                                                 | Limitations                                                                 |
|-----------------|---------------------|---------|--------------|---------------------------|----------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------|-----------------------------------------------------------------------------|
| Crossen Powell  | 1993                | USA     | Correlational study-Quan | 120 spouses of chronically ill husbands or wives. Non random sample convenience | Investigate burden in 120 spousal caregivers of cardiac patients using the 5 constructs of Vitaliano’s theory that burden is a function of stressors and personal vulnerability moderated by psychological resources and social supports. | Montgomery measures of objective and subjective burden | Significant relationships appear to exist between burden and certain variables: The appraised severity of stressors; certain personality traits, the availability of social supports and the willingness to use these supports. | Restricted to cardio patients therefore lacks generalisability. Since only restricted to spousal caregivers cannot be assumed for non spousal caregivers. Low socioeconomic status underrepresented. 75% female, male underrepresented: Gender bias |
| Di Stasio et al.| 2020                | Italy   | Cross-sectional study | 69 family caregivers PD, convenience sample | Evaluate whether the stress-related level of caregivers is related to their perception of the need for healthcare education | N/A                                                                 | A direct association between the SVS scale and the perception of the usefulness of interventions was detected, and significant differences were observed for “caregivers tele-support group” and “peer-led support group” interventions, thus suggesting an important role for caregivers’ emotional status in considering of training courses. | Small sample. Not possible to correlate results with severity of illness as no data available. The tool was not created based on caregivers and parkinsons disease patients. No information collected on previous training or caregiver illness, co morbidity, level of burden to detect a incidence of higher stress. |
| Ficker          | 2010                | USA     | Cross-sectional study. Secondary data | Adult caregiver at least 21 years of age providing more than 4 hours per day of | Examine how employment, work disruption and subsequent financial strain affect | CES-D scale | Employment is associated with younger, healthier caregivers who have been caring for less | Non random sampling: Data not necessarily representative of general population |
| Author            | Year of publication | Country | Study design       | Participants and sampling | Aim                                                                 | Measures of burden, quality of life and depression | Outcomes                                                                 | Limitations                                                                 |
|-------------------|---------------------|---------|--------------------|---------------------------|----------------------------------------------------------------------|------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------|----------------------------------------------------------------------------|
| Hussain et al.    | 2018                | Australia | Cross-sectional survey | 225 rurally based carers. Convenience sampling | Explore how the provision of care in rural settings may influence employment and social support opportunities. | The majority of caregivers were aware of the social support available in their local rural community but did not access them leaving the carers vulnerable to marginalization. Unpredictability associated with providing care exacerbated demands on carers time with many reporting significant employment consequences. | Other factors may play a role in a decision to decrease or stop working such as social support, religion or financial support. |
| Kempson and Conley| 2009                | USA     | Pilot study        | 11 female caregivers. Convenience sampling | Explore whether rural caregivers would learn and provide gentle massage to their chronically ill loved ones, would | Gentle massage techniques used by carers for their loved ones may enhance rural caregivers perceptions of self- | Small sample, caution when generalizing the findings across the diverse population of rural caregivers. Strong bias towards female of middle age which would need to be considered when comparing the cohorts of carers elsewhere. | Self-selecting participants; likely to perceive themselves as possessing self-efficacy otherwise. |
| Author | Year of publication | Country | Study design | Participants and sampling | Aim | Measures of burden, quality of life and depression | Outcomes | Limitations |
|--------|---------------------|---------|--------------|---------------------------|-----|-----------------------------------------------|---------|-------------|
| Kenny et al. | 2014 | Australia | Longitudinal study, Secondary data | 424 carers versus 424 non carers. Convenience. Household income and labour dynamics data set. | Investigate the impact of caregiving on the mental and physical health of informal caregivers taking into account contextual factors including family and work | SF 36 mental health scale | The study found that not all carers suffer adverse health impacts; however, the combination of high levels of caregiving with workforce participation can increase the risk of negative physical and mental health effects (particularly in female carers). Working carers providing high levels of care represent a vulnerable subgroup where supportive and preventive services might be focused. | Large number of carers excluded due to missing or insufficient data. No caregiver of less than 1 year duration which may have excluded some demanding and stressful caregiving episodes (such as end-of-life cancer care) of relatively short duration. Self-reported time spent caregiving. |
| Mills et al. | 1999 | USA | Experimental | 20 caregivers of people with AD. Convenience | Determine the effect of chronic stress. On L selectin expression on peripheral lymphocytes in elderly spousal caregivers of patients with AD. | N/A | Vulnerable caregivers had 60% fewer L-selectin negative CD81 T cells (CD81CD62L2) (p 5.01) but no difference in CD81CD62L1 cells. Vulnerable caregivers also showed significantly fewer CD41CD62L2 T lymphocytes (p 5.04). Sample at one point in time after an acute stress period. It is possible that the kinetics of the stress response is different in chronically stressed caregivers, and consequently may have missed detecting such a difference. | |
| Author          | Year of publication | Country | Study design | Participants and sampling | Aim                                                                                                                                                                                                 | Measures of burden, quality of life and depression | Outcomes | Limitations                                                                                                                                 |
|-----------------|---------------------|---------|--------------|---------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------|----------|------------------------------------------------------------------------------------------------------------------------------------------|
| Mills et al.    | 2004                | USA     | Experimental | 106 spousal and non caregivers. Convenience | Determine the effects of being a spousal caregiver of a patient with Alzheimer disease on the lymphocyte b2 adrenergic receptor                                                                 | N/A                                                                                                  | Vulnerable caregivers have reduced b2 adrenergic receptor sensitivity and density when compared with their non vulnerable counterparts or with noncaregivers. | Data does not determine whether loss of b2 adrenergic receptors in the vulnerable caregivers might be as a result of excessive sympathetic drive or other mechanisms. |
| Ben Mortenson et al. | 2018            | Canada  | RCT          | Care recipient and family care provider. Convenience sampling. 94 participants | Investigate whether a caregiver-inclusive assistive technology intervention improved older care recipients' functional autonomy and decreased the perceived burden of their family caregivers compared to customary care. | N/A                                                                                                  | The overall findings lend support for the provision of assistive technology to reduce caregiver burden. | The study had an inability to control for the intervention provided through customary care. The adherence questionnaire evaluated general usage of AT and environment modification completed at each follow up time point did not explore adherence at each intervention specifically. |
| Navaie-Waliser et al. | 2002          | USA     | Cross-sectional random sampling | Informal caregivers. 1,002 carers | Examine the characteristics, activities and the challenges of high risk informal caregivers. | N/A                                                                                                  | Thirty-six percent of caregivers were vulnerable. Compared with non vulnerable caregivers, vulnerable caregivers | Survey limitations specific to non sampling error such as: Risk of non response bias/coverage bias/item (Continues) |
| Author | Year of publication | Country | Study design | Participants and sampling | Aim | Measures of burden, quality of life and depression | Outcomes | Limitations |
|--------|---------------------|---------|--------------|---------------------------|-----|-------------------------------------------------|----------|-------------|
| Rivers 2016 | USA | Cross-sectional survey | Spouses/partners providing care for MS patients. | Examine dyadic adjustment as a possible protective factor against MS spousal/partner caregiver. Examine both giving and receiving social support as possible protective factors. To understand MS spousal/partner caregivers’ experience of MS and their caregiving duties as especially stressful by examining PTSD, subclinical posttraumatic stress symptoms and anticipatory grief. | Caregiving burden inventory scale PTSD checklist | Reducing caregiver burden, increasing social support and giving social support by engaging in MS related volunteer work were associated with improved caregiver outcomes. MS spousal/partner caregivers are at higher risk for PTSD and subclinical posttraumatic stress symptoms than other caregivers and the general population. MS spousal partners/caregivers should be screened for PTSD and prevention and intervention efforts should target reducing caregiver | Self-report (recall bias). Self selecting bias. Online completion; query higher socioeconomic status than non completers. Demographics: High number of Caucasian participants. | response bias, question order and context effects. |
| Author             | Year of publication | Country | Study design          | Participants and sampling | Aim                                                                 | Measures of burden, quality of life and depression | Outcomes                                                                 | Limitations                                                                 |
|--------------------|---------------------|---------|-----------------------|---------------------------|----------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------|
| Simpson et al.     | 2010                | Canada  | Interpretive descriptive-Qual | 14 informal caregivers COPD-purposeful | To better understand the extent and nature of “burden” experienced by informal caregivers in advanced COPD | N/A                                                                                          | This study suggests that informal caregivers of patients with advanced COPD are experiencing significant burden related to their role and that increasing disease related demands contributed to the negative relational impact that decreased the caring motivation and intimacy feelings of many caregivers who then experiences more stress and vulnerability in their effort to cope. | Not statistically representative. Risk of bias                                  |
| Tartaglini et al.  | 2014                | Argentina | Cross-sectional study | 124 older adults: 62 carers v non carers. Non probabilistic of intentional type | Analyse whether older caregivers’ health suffers affections if compared to the health of those who do not take care of family members | The caregiver suffers unfavourable health effects despite the fact that sometimes he is not aware of those negative consequences experienced. Therefore, family caregivers are referred to as “hidden patients.” | Non probabilistic sample strategy. Small sample size. |                                                                                                                                 |
| Trivedi et al.     | 2014                | USA     | Cross-sectional survey | Individuals who provided informal | Caregivers remain vulnerable for worse | Lacks complete information on | | |
| Author                  | Year of publication | Country | Study design          | Participants and sampling | Aim                                                                                           | Measures of burden, quality of life and depression | Outcomes | Limitations                                                                 |
|------------------------|---------------------|---------|-----------------------|---------------------------|-----------------------------------------------------------------------------------------------|---------------------------------------------------|----------|-----------------------------------------------------------------------------|
| Von Kanel et al.        | 2019                | USA     | Cross-sectional study | Community sampling strategy. 134 elderly providing in home care for a spouse with dementia. | Sought to identify determinants of poor/fair SRH versus categories of at least good SRH in informal caregivers | Zarit caregiver burden scale                       | Caregivers with poor/fair SRH were characterized by higher levels of medical comorbidity, low physical function, high negative, but low positive affect and longer duration of caregiving, as well as more severe dementia and greater functional impairment of the care recipient. These findings suggest that caregivers need to be more closely evaluated and targeted for preventive care. | outcomes than non caregivers. Men caregivers reported worse overall health than non caregivers whereas women reported better overall health. | characteristics of care due to source use. Based on cross-sectional data; one point in time. The caregiver module does not include a measure of burden making it difficult to compare population level caregiver burden with published studies. Gender differences between caregivers may differ in the US and in other countries. |
| Author       | Year of publication | Country | Study design               | Participants and sampling | Aim                                                                 | Measures of burden, quality of life and depression | Outcomes                                                                                     | Limitations                                                                                      |
|--------------|---------------------|---------|---------------------------|---------------------------|----------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|
| Yildiz et al. | 2017                | Turkey  | Descriptive cross-sectional study | 101 caregivers of patients with cancer. Convenience sampling | To determine the burden of care and the self-efficacy levels of caregivers of patients with cancer | Zarit caregiver burden scale                                                                    | Caregivers of patients with cancer have moderate levels of care burden and self-efficacy. In addition, a significant, negative relationship is determined between self-efficacy and burden of care. The provision of psychosocial support and the organization of activities and programs to increase the self-efficacy levels of caregiving family members should be incorporated into nursing interventions. | Cross-sectional in nature cannot examine cause and effect                                          |
3.2.5 | Health and wellbeing

Carers with an illness or condition struggled both physically and emotionally (Hussain et al., 2018; Simpson et al., 2010), with a report that 63.9% (n = 369) of caregivers experienced depression (Carter, 2010). Higher levels of caregiver burden and poorer general health were associated with increased levels of depression in both the carer and care recipient (Badr et al., 2017).

Those caring for older adults were more likely to have a chronic condition, with 76% in total (21 informal caregivers) in one study and 85% of caregivers in another study experiencing physical disturbances (62 caregivers) (Blank, 2018; Tartaglini et al., 2014). Badr et al. (2017) concluded that on average caregivers had 2.7 chronic health problems and over half of them had less than optimal health in a survey on caregiver dyads (n = 92) with COPD. In addition, caregivers’ physical health problems were significantly related to decreased engagement in leisure activities and those with low leisure activities reported more symptoms of depression (Ficker, 2010).

Length of time spent providing care led to deterioration in caregivers’ self-rated health. In a longitudinal study on carers’ health functioning, physical functioning worsened at 4 years (Kenny et al., 2014). This was most likely because the level of care provided increased over time (Kenny et al., 2014; Navaie-Waliser et al., 2002). The length of time providing care, especially in the context of severe dementia and care recipient functionality, resulted in the increased likelihood of caregivers reporting poor/fair self-rated health (von Känel et al., 2019).

From a biopsychosocial perspective, Mills et al. (1999) concluded that vulnerable caregivers had a threefold greater duration of health and medical problems over 6 months and longer recovery times when

| Studies | Factors relating to psychosocial vulnerability | Consequences of psychosocial vulnerability |
|---------|---------------------------------------------|------------------------------------------|
| Aloweni et al. (2019) | x | x |
| Awadalla et al. (2006) | X | x |
| Badr et al. (2017) | X | |
| Bagheri et al. (2019) | x | x |
| Baanders and Heijmans (2007) | x | x |
| Blank (2018) | X | x |
| Carter (2010) | X | x |
| Crossen-Powell (1993) | X | x |
| Di Stasio et al. (2020) | x | x |
| Ficker (2010) | x | x |
| Hussain et al. (2018) | X | x |
| Kempson and Conley (2009) | x | x |
| Kenny et al. (2014) | x | x |
| Mills et al. (1999) | x | |
| Mills et al. (2004) | x | |
| Ben Mortenson et al. (2018) | x | x |
| Navaie-Waliser et al. (2002) | x | x |
| Rivers (2016) | X | x |
| Simpson et al. (2010) | X | x |
| Tartaglini et al. (2014) | x | x |
| Trivedi et al. (2014) | X | x |
| Von Känel et al. (2019) | X | |
| Yildiz et al. (2017) | x | |
unwell. The chronic stress of caregiving led to sympathetic and immune deficits thus implicating their wellbeing (Mills et al., 1999, 2004).

3.3 | Consequences of psychosocial vulnerability

3.3.1 | Relationship changes

Over time, a person’s chronic illnesses has a significant negative impact on their relationship with the informal carer, especially when the disease burden worsens, and impacts the carer’s coping capacity (Badr et al., 2017; Blank, 2018; Carter, 2010; Simpson et al., 2010). Carers recognized the impact of caring on many aspects of their lives, and with disease progression, loss of the family, relationship intimacy and identity became significant (Simpson et al., 2010).

As disease progresses, it can lead to carers questioning their feelings and intimacy for their partner, resulting in a gradual loss of connection to the care recipient (Blank, 2018). Furthermore, over time, relationship changes can lead to a change in caregiver perspective, grieving for the loss of the relationship especially where the care recipient has become increasingly more demanding. The level of appreciation shown by the care recipient for the carer impacts the carer (Awadalla et al., 2006). The carer can struggle not only with caring for the patient but often the loss of their companionship and parts of themselves unique to the relationship with the care recipient (Blank, 2018). However, reducing caregiver burden and increasing dyadic adjustment through prevention and intervention can improve caregivers’ mental health thus emphasizing the impact the quality of the relationship has on the carer (Rivers, 2016).

In a pilot study involving carers administering a massage to care recipients, carers felt deeply connected to their loved one and further empowered to express their love. It enabled carers to feel like they had an additional tool in their ‘toolkit’ and felt more able to ‘hang in there’ (p120); it also calmed the care recipient and led to ‘connection’ again, thereby facilitating the grieving process (Kempson & Conley, 2009). In addition, a mixed method design examining factors associated with caregivers’ reactions found that spouses who felt care giving was a positive experience were more likely to view care giving as a ‘responsibility’ rather than ‘no choice’ (Aloweni et al., 2019).

3.3.2 | Personal losses

As length of time caring and level of caring increases, carers’ loss of autonomy can be overwhelming. Carers are more likely to be unemployed, thus impacting financial autonomy and independence. With disease progression, carers questioned who they were and their loss, often resulting in powerlessness (Simpson et al., 2010). Powerlessness is a lack of control over their situation and the isolation that comes with care giving. At times, carers had little or no family support, especially when family lived far away. Caregivers’ losses included their social life, freedom, security and sense of stability (Simpson et al., 2010).

3.3.3 | Positive effects and empowerment

Acceptance was a crucial component of carer wellbeing (Blank, 2018) and finding new meaning in life contributed to caregivers’ wellbeing, as well as learning to value every day (Awadalla et al., 2006; Blank, 2018).

Carers’ empowerment was influenced by their recognition of inner strength and personal resources. Family and friends offer a source of connection, a sense of reinforcement as well as empathy and assistance. Engaging socially helped carers to stay connected and negotiate life changes, which was important especially when their own self-identity was lost (Blank, 2018; Simpson et al., 2010).

Involving caregivers in altruism such as volunteer work also led to empowerment especially as carers felt they were contributing something to the disease knowledge. Altruism and engagement with charity and advocacy organizations enabled carers to feel like they were receiving the social support they needed and increased satisfaction with life (Rivers, 2016).

Feeling intrinsically rewarded was positive for the caregiver and enabled them to persevere with a sense of accomplishment thus empowering them (Baanders & Heijmans, 2007; Kempson & Conley, 2009). Furthermore, the search for a new sense of who they were was vital to wellbeing especially when connection was lost as the disease progresses (Blank, 2018).

3.3.4 | Finding a new sense of self-awareness

Acknowledging the ‘ups and downs’ and taking ‘one day at a time’ (p.143) were coping mechanisms employed by carers (Hussain et al., 2018; Simpson et al., 2010). Hopefulness and finding new meaning of life was also a way of coping. Carers found a new purpose to their life and sought solace in faith, religion, reaching out to others and self-care (Awadalla et al., 2006; Blank, 2018; Simpson et al., 2010). Those who coped well found a new sense of who they were, enabling growth and acceptance, learning to be grateful and enabling love to give them strength to continue on (Simpson et al., 2010).

4 | DISCUSSION

Using a thematic approach, this review has revealed the complexity of carer psychosocial vulnerability comprising of factors such as barriers to resources, facilitators of support, age and sex, socioeconomic status and health and wellbeing. Consequences of psychosocial vulnerability include relationship changes, personal losses, positive effects and empowerment and finding a new sense of self-awareness.
4.1 | Factors relating to psychosocial vulnerability

Studies described carers’ demographic characteristics as being generally female, middle aged, with a low to middle income and often unemployed or ceased employment due to the nature of caring. Older caregivers and those with pre-existing conditions were shown to find caregiving physically challenging. Caregivers were more likely to be older, in the middle age to older age category (Lai, 2012). This is a cause for concern, with the reality of older adults caring for older adults, with often a reduced ability to provide adequate care due to their own declining health, presence of an illness, mobility and strength in carrying out tasks (Schulz & E. J., 2016).

In terms of socioeconomic status, financial burden was a major concern reported in this review. Chronic illness adds expense to households (Essue et al., 2011). Financial burden is considered more prevalent among the older population of caregivers, particularly females and higher levels of caregiver burden are associated with financial pressure (Lai, 2012).

In our review, reported depression was commonplace among carers, specifically females and carers with an illness themselves tended to struggle more physically and emotionally. Worry is a feature of carers’ lived experience (Jowsey et al., 2016). As well as this, depression in caregivers is associated with potentially harmful behaviours (e.g. screaming and yelling) and poor levels of tolerance (Smith et al., 2011). Leisure engagement plays an important role in mediating the relationship between caregiver stress and subjective wellbeing (Chiu et al., 2020). Furthermore, access to services for those who are considered to be more at risk alleviates stress and maintains resilience and wellbeing thus emphasizing the vital role of appropriate support (Palacio et al., 2019).

4.2 | Consequences of psychosocial vulnerability

Studies described major life changes on the carer, including life losses, intimacy losses and attempts to seek a new meaning for their relationship to the care recipient. A positive relationship with the care recipient prior to illness or disease onset has been shown to have an impact on caregivers’ wellbeing and their responses to caregiving (Quinn et al., 2009). Moreover, caregivers’ gender and relationship to the recipient has implications for the quality of the relationship (Ringer et al., 2017).

Over time and disease progression, caregiving becomes more demanding. The concept of ‘anticipatory grief’ appears to be common in the carer experience especially among those caring for individuals with a dementia diagnosis. The defining characteristics include fear, uncertainty and loss and can be associated with long-term caregiving and yearning for the past (Wells & Kartoz, 2019). In addition, carers often feel ‘trapped’ and in an inescapable situation where there is a lack of freedom, attributable to grieving for the change in their lives suggesting that there is a need to address caregiver grief (Duignean, 2014).

4.3 | Support for carers

Our review has shown the importance of support for carers. Many carers are disadvantaged by caregiving and few are offered support from services (Larkin & Milne, 2014). Overcoming barriers to accessing services or resources is crucial and can be helped by having early and constant contact with a HCP (Stephan et al., 2018). However, a recent qualitative study with multiple stakeholders involved in dementia care found that barriers in accessing services or resources could often be attributed to the individual themselves which may be as a result of a lack of knowledge and information or because of their own beliefs about formal care (Stephan et al., 2018).

Those who do not recognize themselves as carers can be less likely to access support (Larkin & Milne, 2014). Perceived social support may be a good predictor of subjective burden (Del-Pino-Casado et al., 2018). Uptake of services was generally found to be better among carers who were open minded and sought support proactively whereas emotions such as fear and anxiety contributed to non utilization (Stephan et al., 2018).

4.4 | Carer empowerment

Helping unpaid carers and family members to develop knowledge, skills and actions to care for themselves and others is essential for empowerment. Carers should be in the driving seat of change, defining what empowerment means and seeking ways to empower those who are disadvantaged or unable to negotiate life changes brought on by caring (Blank, 2018; Larkin & Milne, 2014).

Carers’ growth and acceptance of their caring role can lead to a more positive experience (Blank, 2018; Solomi & Casiday, 2017). Those who experience positive effects of caregiving generally sought meaning or a new purpose through intrapersonal satisfaction such as growth, self-acceptance and the development of new skills (Campos et al., 2019). Understanding the interplay of rewards, challenges and personal development is a necessary step in creating adaptive solutions that better support the caregiving family (Anderson & White, 2017).

4.5 | Implications for nursing practice

Consideration of evolving nursing roles needs to take place in line with changing aspects of disease and diagnosis (Coates, 2017). Worldwide, the role of the nurse needs to re-evaluate chronic disease management to address the challenges faced. It is expected that there will continue to be an ongoing shortage of nurses worldwide (McGill, 2019), and this will impact on the support for informal carers unless addressed.

The challenge of managing chronic disease is best addressed through collaboration between the healthcare provider, patient and their family or informal carer (Canadian Nurses Association, n.d.). There is now a significant move towards the primary care setting for
managing long-term illness, and this is often the best place for a relationship to be established and interventions introduced (CordisBright, 2018).

Nurses can ensure that families are well supported through educating carers on diagnosis and disease management and include patients and carers as members of their own healthcare team, working with other healthcare professionals and services to ensure that the best supports are available (Reinhard et al., 2008). Furthermore, nurses’ skillset places them in an optimum position to provide appropriate health education and self-management strategies for both patients and caregivers and provide information that makes the best use of community resources (Watts et al., 2015). An essential part of this process would be an assessment of carers’ psychosocial vulnerability, and the factors identified in this review could guide this.

Nurse practitioners are ideally placed to support carers, with their interventions reported to reduce levels of caregiver burden with particular benefits for people rendered vulnerable for example due to ethnicity, socioeconomic status and ageing (Grant et al., 2017). With chronic illness management centred within the primary care system, there is a need for nursing and other health care professionals to modernize and move towards treating patients and their families as a complete unit (O’Connor et al., 2018). The focus of education for future nurses must be prioritized and differentiated from other disciplines addressing the person in a holistic manner and what it means to include family (Ambrosio et al., 2021). This focus will ensure that nurses work towards a model which empowers patient and families to assume responsibility for the disease and self-management (Salmond & Echevarria, 2017).

Carers have expressed their need for collaboration with healthcare professionals, as well as a contact for their care journey, especially for the transition between services and psychosocial support (Campling et al., 2017). This offers opportunity for the development of nursing roles such as nurse navigators and care coordinators to support families (Vermorgen et al., 2021), roles shown to decrease costs and improve outcomes (Toles et al., 2017).

4.6 | Limitations

Only studies in the English language were included; most had small sample sizes with purposeful or convenience samples, thus limiting generalizability. Furthermore, there were few longitudinal studies and a high number of cross-sectional studies. Male carers were underrepresented, with only two studies including more male than female caregivers. However, the majority of caregivers worldwide are females accounting for approximately 66–70% of the caregiving population (Carers Australia, 2021; Sullivan & Miller, 2015). Studies were also limited in representing ethnic minorities. Moreover, most of the studies were undertaken in the high-income countries. The applicability of these studies internationally with varied healthcare systems and contexts is therefore limited.

Mapping the results was challenging due to the heterogeneous nature of the included studies. No study specifically focused on psychosocial vulnerability among carers, confirming its conceptual immaturity. However, rich insights were provided by one qualitative study describing a caregiver vulnerability concept map, suggesting a downward spiral effect, where disease-related issues appear to initiate or escalate negative affects which in turn impacts coping thus leading to vulnerability (Simpson et al., 2010). In addition, the findings reported in the two RCT’s highlight that resource availability has positive effects on carers and influences levels of psychosocial vulnerability (Bagheri et al., 2019; Ben Mortenson et al., 2018).

5 | CONCLUSION

The results of our scoping review will frame further exploration to help refine an understanding of carer psychosocial vulnerability. Our findings will also be useful in policy implementation and service design, ensuring a carer-based approach to planning.

As the prevalence of chronic illnesses continues to rise, carers’ psychosocial vulnerability deserves more attention and carers must be seen as essential components of healthcare in order to ensure connection between policy and service delivery.

ACKNOWLEDGEMENTS

We would like to thank Rosie Dunne for her support with the specialist search of the literature.

FUNDING STATEMENT

Open access funding provided by IReL. WOA Institution: National University of Ireland Galway. Blended DEAL: IReL. This work was conducted as part of the SPHeRE Programme under Grant no: [SPHeRE/2017/1].

CONFLICT OF INTEREST

No conflict of interest to declare.

AUTHORSHIP STATEMENT

Confirming that all listed authors meet the authorship criteria and that all authors are in agreement with the content of the manuscript. OC and MD: Conception or design of the work. OC: Data collection. OC and MD: Data analysis and interpretation. OC: Drafting the article. OC, MD and PM: Critical revision of the article. OC, MD and PM: Final approval of the version to be published.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher’s website.

How to cite this article: Cormican, O., Meskell, P., & Dowling, M. (2021). Psychosocial vulnerability among carers of persons living with a chronic illness: A scoping review. International Journal of Nursing Practice, e13024. https://doi.org/10.1111/ijn.13024

APPENDIX A: ELIGIBILITY CRITERIA

A.1 | Inclusion criteria
1. Studies in the English language only due to time and resource availability.
2. Qualitative and/or mixed method studies
3. Quantitative studies
4. Studies involving carers >18 years.
5. Studies to include informal carers who have been caring for those with a chronic illness/malignancy.
6. Informal caregivers- defined as people who provide care to others in need of assistance or support on an unpaid basis. Generally, informal care is provided by family members or friends of the person receiving care.
7. Studies that mention a lack of empowerment and autonomy which are terms used to describe the definition of vulnerability. These terms were chosen after the initial search.
8. Studies’ describing what vulnerability is in informal caregivers.

A.2 | Exclusion criteria
1. Studies with languages other than English.
2. Opinion/discussion papers, conference papers presentations.
3. Systematic reviews.