



Published in final edited form as:

Psychol Health. ; : 1–23. doi:10.1080/08870446.2020.1867136.

Informal caregiver burden for solid tumour cancer patients: a review and future directions

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Abstract

Objective: Recent shifts in healthcare delivery and treatment for solid tumour cancer patients have modified the responsibilities of informal caregivers. The objective of this study was to: review informal caregiver burden factors and determine areas where future research is needed.

Methods: The Arksey and O'Malley's framework and a modified Preferred Reporting Items for Systematic Reviews and Meta-Analyses were used in conducting this review. Research literature was systematically searched using five-electronic databases, including PubMed, PsycINFO, Cochrane, CINAHL, and SCOPUS, and reference lists from included studies to identify publications since 2010. Inclusion criterion was caregivers providing home-based care to a cancer patient.

Results: The search yielded 43 eligible papers of 2119 reviewed, including articles from over 17 countries. Caregiver physical and psychological health, financial strain, and social isolation, as well as limited family and social support continued to be important factors contributing to high levels of caregiver burden. Less recognised factors affecting higher burden included caregivers' self-esteem, male gender, and the dynamic nature of cancer treatment.

Conclusions: This review updates the state of the science on informal caregiver burden when caring for patients with solid tumour cancers and informs future interventions on how to reduce this burden.

Keywords

Cancer; caregiving; burden; review

Introduction

A cancer diagnosis is a devastating event for patients and their informal caregivers, who are typically friends or family members. Informal caregivers play an important role in the

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Disclosure statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

home-based management of newer therapeutics and the accompanying symptoms. Informal caregivers experience a high level of caregiver burden, which can adversely affect their health and well-being, and in turn the outcomes of their cancer patient. Further, cancer patients may perceive themselves as a burden on their caregivers since cancer limits an individuals' ability to care for themselves independently (Badr et al., 2019; Hu et al., 2019; Lambert & Girgis, 2017). In recent years, there has been an increasing number of studies about cancer-caregiver relationships with their patients and dyadic interventions aimed at improving patient well-being and reducing caregiver distress (Badr et al., 2019; Hu et al., 2019; Lambert & Girgis, 2017). Studies such as the one by Holmstrom et al. (2016) focused specifically on the cancer dyadic relationship and found no change in the quality of relationship due to caregiving for either the patient or caregiver. Yet, greater examination of this essential relationship warrants further investigation.

When pursuing nursing research in oncology, it is most practical to select a phase in the continuum of care to investigate since each is unique. Informal caregivers are involved in very different ways during the diagnostic phase, treatment phase, survivorship and/or end-of-life phases. Each phase has distinct needs and in turn pose different caregiver demands. Therefore, when reviewing the literature it is often best to focus on a specific phase as this review has done the treatment phase. The treatment phase is frequently perceived as the most demanding in terms of physical care, time requirements and uncertainty about long-term outcomes (Frambes et al., 2018; Northouse et al., 2010)

With the advance in cancer treatment, cancer patients are often prescribed oral antineoplastic medications, targeted therapy, and immunotherapies that are taken and managed at home (Marshall et al., 2018; Milne et al., 2020). Such home-based care also means that family caregivers are on the front lines of coping with the symptoms presented by the new therapeutics. Informal caregivers may experience a substantial burden associated with cancer and treatment-related symptoms that need to be managed in a home setting (Given et al., 2017; Wyatt et al., 2017). Care in the home setting, as opposed to a professional healthcare setting, is becoming the norm (National Alliance for Caregiving, 2018). Informal caregivers often take on the responsibility of assisting cancer patients with tasks of daily living, organising visits and appointments with healthcare providers, complex symptom management, hygiene care, and promoting healthy life style for cancer patients (Badger et al., 2019; Frambes et al., 2018).

Caregiver burden is defined as the extent to which caregivers perceive that their physical health, psychological health, schedule, social life, and financial status have suffered due to providing care for a cancer patient (Given et al., 2012). Perceived burden may lead to increased anxiety and depressive symptoms, as well as changes in social relationships, which may impact the capacity of caregivers to provide optimal care (Badger et al., 2019; Girgis et al., 2013; Litzelman & Yabroff, 2015; Wyatt et al., 2019).

Although several factors associated with caregiver burden are recognised, recent changes in the healthcare system and progress in curative cancer treatments must be considered, such as oral anticancer medication, targeted therapy, and immunotherapies. These newer therapeutics often require additional care components to support patients. Given these

changes, there is a need to update the current state of the science on caregiver burden. Therefore, this review aimed to: (1) confirm consistently reported burden factors among cancer caregivers of patients in treatment with solid tumours in the home setting; (2) explore previously less reported burden factors in the current era of healthcare delivery; and (3) identify areas where future research is needed. Such updated findings carry the potential for a better understanding of cancer caregiver burden in this era of new therapeutics and provide direction for supportive care research to assist healthcare professionals in recommending targeted services.

Methods

This review was guided by the Arksey and O'Malley (2005) literature review method. The selected methodology included five steps: (1) identification of the research aims;(2) identification of relevant studies; (3) study selection; (4) data charting; and (5) summarising and reporting the results (Arksey & O'Malley, 2005).

Search strategies and study selection

For the purposes of this review, the following electronic databases were searched: PubMed, PsycINFO, Cochrane, CINAHL, and SCOPUS. Keywords and MeSH terms were used to search for titles and abstracts. Keywords included: informal, family, unpaid caregiver, cancer, neoplasm, solid tumour, spouse, partner, couple, caregiver burden, strain, stress, distress, coping, well-being, health issue, self-neglect. Hand searches were conducted based on references from the initial articles. Any publications between 2010 and the present were considered for evaluation. This timeframe was intended to capture current issues associated with informal caregiving due to evolving trends in healthcare. New anticancer drug therapy has become available, plus there has been a marked shift to administration of such therapy in ambulatory and home settings (Page et al., 2015). These changes over the past 10 years in types of therapy and delivery have added to caregiver responsibilities as never before in cancer care.

Inclusion/exclusion criteria—Publications were included if they met the following criteria: (1) published in English (regardless of country of origin); (2) focused on informal caregivers over 18 years old caring for adult patients with solid tumour cancer undergoing out-patient curative treatment; (3) were research-based, including quantitative, qualitative, and mixed method approaches; and (4) investigated factors associated with caregiver burden. Publications were excluded if: (1) patients were terminally ill, at the end-of-life phase, hospice care or no longer undergoing any curative cancer treatment; (2) caregivers of paediatric patients; (3) paid or professional caregivers; (4) burden was not the primary outcome of the studies, or review literature; or (5) abstracts or conference proceedings.

The initial search yielded 2119 publications. After screening titles and abstracts, 49 publications remained. The full-text of the publications were reviewed to determine whether the inclusion criteria were met. The authors reviewed the publications and conducted independent assessments. After close review, six publications were rejected. The final review included 43 publications. A modified PRISMA flow diagram depicted this review and elimination process (Moher et al., 2009) (Figure 1).

Data charting and summarising the results

Information from the selected studies was collected and sorted using an investigator-developed data extraction form. The charting information is presented in Table 1 including study characteristics, the profile of family caregiver characteristics, and patients' diagnosis. Table 2 shows factors associated with caregiver burden. Two authors reviewed these tables and developed descriptive reports from the evidence sources. The summative findings as they pertained to each research question are reported in the results section.

Results

The 43 publications selected for the review were conducted in 17 countries worldwide (see Table 1). Despite this international representation, most caregiver studies lacked broad diversity. The publications included a combined total of 11,431 eligible informal caregivers. Caregivers were predominantly female ($n = 8002$, 70%). More than half of caregivers were spouses (average, $n = 6287$, 55%). The mean age of caregivers was 51.34 years. Six studies focused on patients with breast cancer, five on lung cancer, four on colorectal cancer, three on brain tumour, three on lung and colorectal cancers, and one each on ovarian cancer, melanoma, and gastrointestinal cancer. The remaining 19 publications included patients in treatment with mixed solid tumour cancers. Three secondary analyses from the CanCORS project were included since each study contributed unique data (Mollica et al., 2017; van Ryn et al., 2011; Van Houtven et al., 2010).

The areas to be covered in this literature review include: an update on frequently reported burden factors, less reported burden factors, and future research needs.

Frequently reported burden factors

Newer trends in cancer therapeutics are primarily administered out-patient, with the responsibility for treatment-related side effects, monitoring, reporting, and symptom management falling to patients and their home-based caregivers (Marshall et al., 2018). Given this movement toward additional home-based caregiving, factors associated with burden have evolved, which have also compounded issues for informal caregivers.

All 43 studies (Table 2) reported that cancer caregivers experience significant caregiver burdens stemming from their roles. The five factors that continued to stand out in this updated review on caregiver burden were caregiver physical health, psychological factors, financial status, social isolation, and family or social support.

Caregiver physical health—Cancer caregiving can contribute to adverse effects on the caregiver's physical health. In particular, caregivers with comorbid conditions report exacerbated health issues and higher burden than those without chronic diseases (Esra et al., 2017). Findings indicate that the most prevalent physical problems reported included sleep disturbance, fatigue, pain, and weight gain (Hanly et al., 2015; Lee et al., 2018; Nemati et al., 2018). In a European study, over one third of caregivers in a large sample ($n = 825$) reported that caregiving directly affected caregiver's comorbid conditions such as gastrointestinal problems, irritable bowel syndrome and dyspepsia, hypertension, and other cardiovascular diseases (Goren et al., 2014). A Japanese study indicated that cancer

caregivers had a higher prevalence of gastrointestinal problems and stress-related comorbid conditions compared with non-cancer caregivers (Ohno et al., 2020). Moreover, caregivers with more than one comorbid condition tended to report higher levels of depression and anxiety compared to caregivers with fewer or no chronic health issues (Goren et al., 2014).

Caregivers with childcare responsibilities reported an increased negative impact on their physical health (Kavanaugh et al., 2015; Kemp et al., 2018). Further, caregivers may neglect activities that benefit physical health. A study by Beesley et al. (2011) found that caregivers of ovarian cancer patients in Australia reported skipping self-care activities, such as exercise, because they did not have time. Approximately 35% of these caregivers ($n = 36$) experienced weight gain that exceeded the healthy body mass index range and 12% of the sample ($n = 12$) increased alcohol intake (Beesley et al., 2011).

Psychological factors—Cancer caregiving has been found to affect caregivers' mental health resulting in anxiety, depression, fatigue, exhaustion, and hopelessness (Goren et al., 2014; Milbury et al., 2013; Shaw et al., 2013). Caregivers with poor psychological health, high depressive symptoms, poor self-sufficiency for symptom management, and high anxiety experienced a greater burden (Johansen et al., 2018; Lee et al., 2018; Petruzzi et al., 2013; Rha et al., 2015). Informal caregivers reported high levels of anxiety and worry regarding observation and reporting of patient's symptoms or treatment-related side effects (Milne et al., 2020; Reblin et al., 2018).

Financial status—Informal caregivers of cancer patients reported significant financial concerns secondary to direct treatment costs, nontreatment associated expenses, and loss of income incurred by the impact of the disease (Jeong et al., 2016; Ohno et al., 2020; Van Houtven et al., 2010; van Ryn et al., 2011). Managing costs for cancer treatment, along with other medical care costs, was often dependent on the presence of adequate health insurance coverage (Milne et al., 2020; van Ryn et al., 2011).

Qualitative studies by Marshall et al. (2018) and Milne et al. (2020) reported that the high cost of oral anticancer medication and immunotherapy was the greatest financial challenge to informal caregivers. Health insurance benefits often did not cover all costs of immunotherapy agents. Further, there was frequent travel and accommodations related to treatment, causing a high level of financial strain (Milne et al., 2020). In general, the financial burden has been compounded by costs associated with the newer therapies.

In Japan, financial strains were exacerbated by decreased household income due to work absences, transportation for cancer treatment, and changes in work hours during the patient's treatment (Hanly et al., 2015; Céilleachair et al., 2012; Shieh et al., 2012). Loss of occupational productivity contributed to immediate financial strain and had a long-term negative impact on the capacity to accrue retirement savings (Goren et al., 2014). Caregivers with only a high school education reported significantly higher levels of financial burden due to providing home care and loss of paid hours (Esra et al., 2017; Rha et al., 2015). Finally, several studies showed that a younger caregiver age, combined with greater patient symptom severity, resulted in more financial burdens (Kavanaugh et al., 2015; Li et al., 2013; Van Houtven et al., 2010).

Social isolation—A study by Nemati et al. (2018) reported that informal caregivers experienced life changes that caused interference with their routine while being caregivers. Several studies showed that involvement in caregiving tasks required adjustments in the caregiver's daily routine and disrupted social activities (Bayen et al., 2017; Esra et al., 2017; Li et al., 2013). Informal caregivers reported spending more than 21 h per week caring for their cancer patients and providing a range of daily domestic care tasks such as dressing, symptom management, and medicine administration, over an average of 2.5 years from cancer diagnosis to remission (Grant et al., 2013; Maguire et al., 2018; Marshall et al., 2018). Other caregiving activities requiring significant time and commitment included a wide range of tasks, such as stoma care and health appointment commutes (Mollica et al., 2017; Mosher et al., 2016). Concerns over the number of hours per week spent in caregiving increased the levels of burden due to the impact of scheduling demands (Bayen et al., 2017; Esra et al., 2017; Mosher et al., 2016), which limited time for outside social activities. This type of social isolation has also been shown to lead to a decrease in the quality of the relationship between caregiver and cancer patient (Soriano et al., 2018).

Heightened burden was also associated with the reduced time for personal privacy, recreation, stress management, vacations and trips, personal chores, and socialising with friends or relatives (Grant et al., 2013; Hanly et al., 2015; Rha et al., 2015). Informal caregivers reported they often made efforts to participate in social and entertainment activities, but decline as a result of concerns about the patient during their absence (Jeong et al., 2016; Kavanaugh et al., 2015). Studies by Jeong et al. (2016) and Kavanaugh et al. (2015) revealed that younger age caregivers perceived that the caring role impinged on their personal life and challenged their capacity to express their needs. Social isolation issues emphasise the importance of providing more caregiver support and assistance (Li et al., 2013; Vahidi et al., 2016).

Family or social support—Informal caregivers with inadequate availability of supportive resources felt this contributed to higher burden (Petruzzi et al., 2013; van Ryn et al., 2011). Several studies showed that some informal caregivers were not using existing resources due to lack of family support, inability to obtain resources, and burden associated with caregiving (Bayen et al., 2017; Oven Ustaalioglu et al., 2018; Shieh et al., 2012). Conversely, caregivers with high levels of perceived social support reported a lower level of burden (Badger et al., 2020; DuBenske et al., 2014; Reblin et al., 2018; Shieh et al., 2012).

Family size was one factor contributing to burden level. Extended families reported lower levels of burden compared to nuclear families, given the increased numbers of members available to provide care (Akpan-Idiok & Anarado, 2014). A study by Nemati et al. (2018) showed that caregivers with a relatively demanding patient care schedule and poor family functioning experienced a greater burden. The type of relationship, such as spouse, sibling, or child-in-law was correlated with greater emotional attachment and higher burden (Li et al., 2013; Milbury et al., 2013). Informal caregivers who performed care for a spouse or in-law with cancer reported a higher level of burden compared to those who provide care for their children or friends (Cassidy, 2013).

The five key areas of known caregiver burden continue to be an issue with an added focus due to changes in therapies and care delivery. All areas (physical, psychological, financial, social, and support) are impacted by additional time constraints and uncertainty as to how to manage their own health and well-being, along with patient caregiving.

Previously less reported burden factors

Throughout the cancer treatment trajectory, informal caregivers face many challenges as they adapt to new demands brought on by caregiving responsibilities. Of 43 studies, there were three previously less reported factors associated with cancer caregiver burden: caregiver self-esteem, male gender, and the changing dynamics of cancer treatment.

Caregiver self-esteem—Caregiver self-esteem has been reported as both benefiting from caregiving and in other studies adding to burden. Caring for a friend or family member with cancer has been reported as having a positive effect on caregiver self-esteem (Hendrix et al., 2016; Cassidy, 2013; Johansen et al., 2018). For example, caring for an intimate partner or relative was perceived as rewarding, enhancing confidence and self-esteem among informal caregivers (Ávila et al., 2016; Bayen et al., 2017). Further, caregivers with clinical skills had a higher level of self-esteem than those who were less well-prepared for cancer caregiving (Bahrami & Farzi, 2014; Heckel et al., 2018; Mahendran et al., 2017; Mollica et al., 2017). On the other hand, Mosher et al. (2016) reported on caregivers who felt helpless and did not know what to do when cancer patients faced physical symptoms, such as pain, fatigue, diarrhea, weight loss, and functional decline. Other caregivers reported being fearful of doing harm or the wrong thing for their patients (Nemati et al., 2018). Caregiver self-esteem can benefit from further study due to the range of responses in this area.

Male caregivers—While females are most often identified as caregivers in the literature, males are increasingly found to be the primary home-based caregivers, especially in studies of women with breast and ovarian cancer (Ávila et al., 2016; Beesley et al., 2011; Oven Ustaalioglu et al., 2018). Male caregivers reported a lower level of confidence compared to female caregivers (Esra et al., 2017; Shieh et al., 2012). Two Asian studies found that male caregivers were reluctant to provide home-based care, as they did not feel adequately prepared for the role by the health team (Jeong et al., 2016; Leow & Chan, 2017; Turkoglu & Kilic, 2012). Male caregivers with less education reported higher burden due to challenges in obtaining important information and/or other support from nurses and healthcare personnel (Beesley et al., 2011; Esra et al., 2017).

Dynamic nature of cancer treatment—The reoccurrence of cancer in treated patients, and the often inevitable drift to disease metastases, highlight the dynamic nature of cancer care. Solid tumour cancers are complex diseases, which often require new therapeutic strategies including immunotherapies, targeted therapy, and oral oncologic agents. For example, patients who were prescribed oral anticancer agents often received variable treatment schedules and had to be monitored closely for symptoms and to ensure treatment adherence (Marshall et al., 2018). Further, many cancer patients have advanced disease and have exhausted more traditional treatment options (Marshall et al., 2018; Mahendran et al., 2017; Milne et al., 2020).

Another dynamic trend was the change from short-term in-hospital stays to ambulatory settings and now increasingly home-based care as a key strategy to reduce the costs of healthcare worldwide (DuBenske et al., 2014; Lee et al., 2018; McLean et al., 2013; Milne et al., 2020; Mollica et al., 2017; Nemati et al., 2018). The length of hospital stays was the key performance indicator for reimbursement of cancer care cost; therefore, with the move to greater home-based care the intensity and increased responsibility of care provision placed on informal caregivers has significantly increased (Shaw et al., 2013; Turkoglu & Kilic, 2012; Vahidi et al., 2016).

Cancer caregiving during active treatment strongly contributes to greater challenges and thus increases caregiver burden (Leow & Chan, 2017; Milbury et al., 2013; Mosher et al., 2016). Assisting patients to manage their cancer treatment and its' effects requires complex skilled-care activities. Informal caregivers often lack training, skills, and supportive resources (Bayen et al., 2017; Halpern et al., 2017; Lee et al., 2018; van Ryn et al., 2011). Caregivers may consider the new home-based care expectation extremely difficult, and require training before transition to home-based care (Hendrix et al., 2016; Mollica et al., 2017; Mosher et al., 2016; Shaw et al., 2013). For example, caregivers must be trained in tasks such as administering medications, changing dressings, managing delivery of oxygen, dietary restrictions, and food preparation at home (Mosher et al., 2016; Shaw et al., 2013; van Ryn et al., 2011).

Longer cancer treatment trajectories also increase burden for caregivers who have to regularly escort and/or transport patients to appointments over the course of therapy (Mollica et al., 2017; Shieh et al., 2012). The duration of treatment time was found to increase caregiver burden in cross-sectional studies (Ávila et al., 2016; Johansen et al., 2018; Petruzzi et al., 2013; Rha et al., 2015), and caregiver burden was found to fluctuate over the course of cancer treatment (Beesley et al., 2011; Milbury et al., 2013; Shaw et al., 2013). Due to these multiple issues related to the dynamic nature of cancer treatment, more research that evaluates the impact on caregiver burden based on such factors is needed (Marshall et al., 2018; Reblin et al., 2018; Vahidi et al., 2016).

Discussion

This review evaluated various factors associated with caregiver burden of cancer patients. The findings demonstrate that previously identified problems affecting caregivers continue to persist and are often exacerbated with newer therapeutics. Also, the dyadic intervention research is limited. There is a need for future research to design interventions that relieve caregiver burden and directly address the dyadic relationship.

The known factors contributing to caregiver burden are physical health, psychological factors, financial status, social isolation, and family or social support. For caregivers with comorbid conditions, resources need to emphasise a healthy lifestyle for self-care and proper time management to efficiently accomplish tasks for themselves as well as their patient. Caregivers' psychological concerns can be compounded by financial stressors so that there is less opportunity for respite (Balfe et al., 2018; Mosher et al., 2016; Vahidi et al., 2016). This fact draws attention to the need for health professionals to provide information on

available resources, especially in relation to newer therapeutics. Social support has been associated with significantly less caregiver burden (Kemp et al., 2018; Oven Ustaalioglu et al., 2018; Reblin et al., 2018). Caregiver support groups, on-line chat rooms, and/or web-based conference may be useful to some caregivers who feel isolated (DuBenske et al., 2014; Given, 2019). In this review, major differences were acknowledged across various countries. Further, changes such as those seen in the United States regarding cancer treatment and delivery may be indicative of trends in other countries. Each country will need to address its health resources for caregivers and implement a culturally appropriate plan.

The top issues for the less reported factors associated with caregiver burden were caregiver self-esteem, male gender, and dynamics of cancer treatment. Informal caregivers felt low self-esteem during moments when they saw the patient suffer from adverse symptoms or treatment related side-effects, and they perceived themselves as having not provided adequate care for the patient. This suggested the importance of educating caregivers on each patient's illness trajectory so that they know how to support and manage the symptoms as part of the disease and treatment process. While not measuring caregiver burden, Mazanec et al. (2019) tested a simulation-based intervention with caregivers for specific skills needed in home-based care. Less than half of the enrolled caregivers completed the study; therefore, the investigators recommended more feasibility testing. Caregivers who did complete showed trends toward improved psychological health and self-efficacy (Mazanec et al., 2019).

Male caregivers may experience additional barriers compared with female caregivers, since often the perception is that caregiving is predominantly a female role. While not assessing the level of burden among male caregivers, a clinical trial study by Wyatt et al. (2017) reported that male caregivers in the US were highly likely to deliver home-based symptom management for spouses with advanced breast cancer. As reported above, the number of male caregivers is growing and the support and education directed toward male caregivers needs to reflect such changes. Internationally, research can explore culturally sensitive caregiving issues such as helping male caregivers adapt to the caregiver role within a given culture.

Regarding dynamic factors of treatment, immunotherapy has extended survival in metastatic cancer patients and taking in-home medication like palbociclib or enzalutamide (Antonarakis, 2018; Milne et al., 2020). Such dynamic factors in the evolving responsibilities of home-based caregiving must be addressed. Health professionals must be prepared to alleviate the burden posed by these newer therapies as they continue to present new challenges over time. Additional creative interventions for caregivers and new or different support structures must be considered for dyadic relationships during caregiving.

There are clearly unexplored areas for caregiver burden research including those found in this review: duration of cancer treatment, preparation for caregiving, available resources, and interventions designed to relieve caregiver burden. For example, the review of literature on other phases of the cancer continuum of care could enhance understanding of the full spectrum of caregiving.

Also, the dyadic relationship warrants further investigation due to shifting trend of cancer treatment that are provided by patients and their caregivers at home. The intervention for caregiver–patient dyad as a unit should be focused to improve the caregiving experience and health outcomes for both patients and their caregivers (Frambes et al., 2017; Li & Loke, 2014). Knowing more about caregiver characteristics will help health providers determine which caregivers will need more support over time. Caregivers may require specialised training to cope with oral anticancer drugs, targeted therapy or immunotherapy agents. Previous studies showed that psycho-educational, skill training, and therapeutic counseling have been the predominant methods used in the caregiver burden interventions. Those interventions were found to have small to medium effects on reducing burden (DuBenske et al., 2014; Frambes et al., 2018; Hendrix et al., 2016; Northouse et al., 2010).

Future trend on caregiver burden research

Further, investigators need to evaluate if the right questions are being asked of caregivers. This could include focus groups with caregivers to assess what training they might need, such as skills, coping strategies, general health behaviours to revitalise themselves. Also, the dyadic relationship could benefit from further investigation. Other research methods that may prove helpful are tailored interventions with standardised measurement scales to enhance the translation of findings to healthcare professionals who can implement preventive strategies in order to alleviate caregiver burden.

Currently, valuable symptom management intervention testing is moving forward that will impact caregivers, and more specifically, add to their responsibilities. Organisations such as the Oncology Nursing Society are developing guidelines on topics such as safe handling of oral anticancer agents at home (Neuss et al., 2016; Oncology Nursing Society, 2016). Specific home-based interventions are being tested to facilitate symptom reporting and management (Beck et al., 2017; Berry, 2019; Mooney et al., 2019; Mooney et al., 2017). These home-based interventions can be considered in the future for their impact on caregiver burden. In summary, there remains limited evidence of support available to help caregivers in undertaking cancer-caring tasks, particularly in the face of newer therapies. Despite growing research on informal caregiving, there is a crucial need to develop effective interventions to reduce or alleviate caregiver burden. Such interventions may need to be tailored based on each caregiver's individual characteristics and current skill set.

Limitations of review

While this review focused on the treatment phase of care, other phases still need in-depth investigation. Articles were limited to those published in English, which might overlook relevant work published in other languages. While search strategies were developed by agreement of the authors, there remain challenges in searching through all studies on caregiver burden. Therefore, it is plausible that potential eligible studies may have been missed for inclusion. Finally, while the publications represented 17 countries, they still lacked diversity in demographics; however, the international focus is a strength. Nevertheless, there are some questions that cannot be answered with such homogenous characteristics. Such questions include: Would there be other types or level of burden

mentioned by various racial or ethnic groups? Would categories of burden be similar for low socioeconomic groups or rural populations? Diversity should be a goal of future studies.

Conclusions

The delivery of cancer care by informal caregivers is a global public health issue. Policies and programs that strengthen community capacity to promote caregivers' health are imperative. Public policies currently addressing cancer patients' need to include access to high-quality care, and the availability of resources, and attending to the needs of and providing adequate resources for informal caregivers. Informal caregivers need information and their own support services to preserve their critical role as caregivers.

In an era of changing cancer treatment and therapies, nurse scientists must continue to develop and test new supportive interventions targeting informal caregivers and patient-caregiver dyads. Based on this review, there remains a need to design and test multipronged caregiving interventions capable of addressing a combination of complex factors such as caregiver characteristics, including ethnic, racial, comorbid conditions, social, and geographic diversity for reducing caregiver burden. As informal caregivers represent a critical extension to formal care, innovative solutions are required that account for these new challenges and address caregiving needs across the cancer continuum.

Acknowledgment

Authors would like to thank Dr. Charles Given and Dr. Sueng-Hee Choi, for their thoughtful comments and efforts toward improving this manuscript.

Funding

This research was supported through funding from National Cancer Institute 1R01 CA 193706, ChiangMai University, Faculty of Nursing, The Michigan State University, College of Nursing scholarship, and Glenn R. Dean and Anita C. Dean Endowed Fellowship

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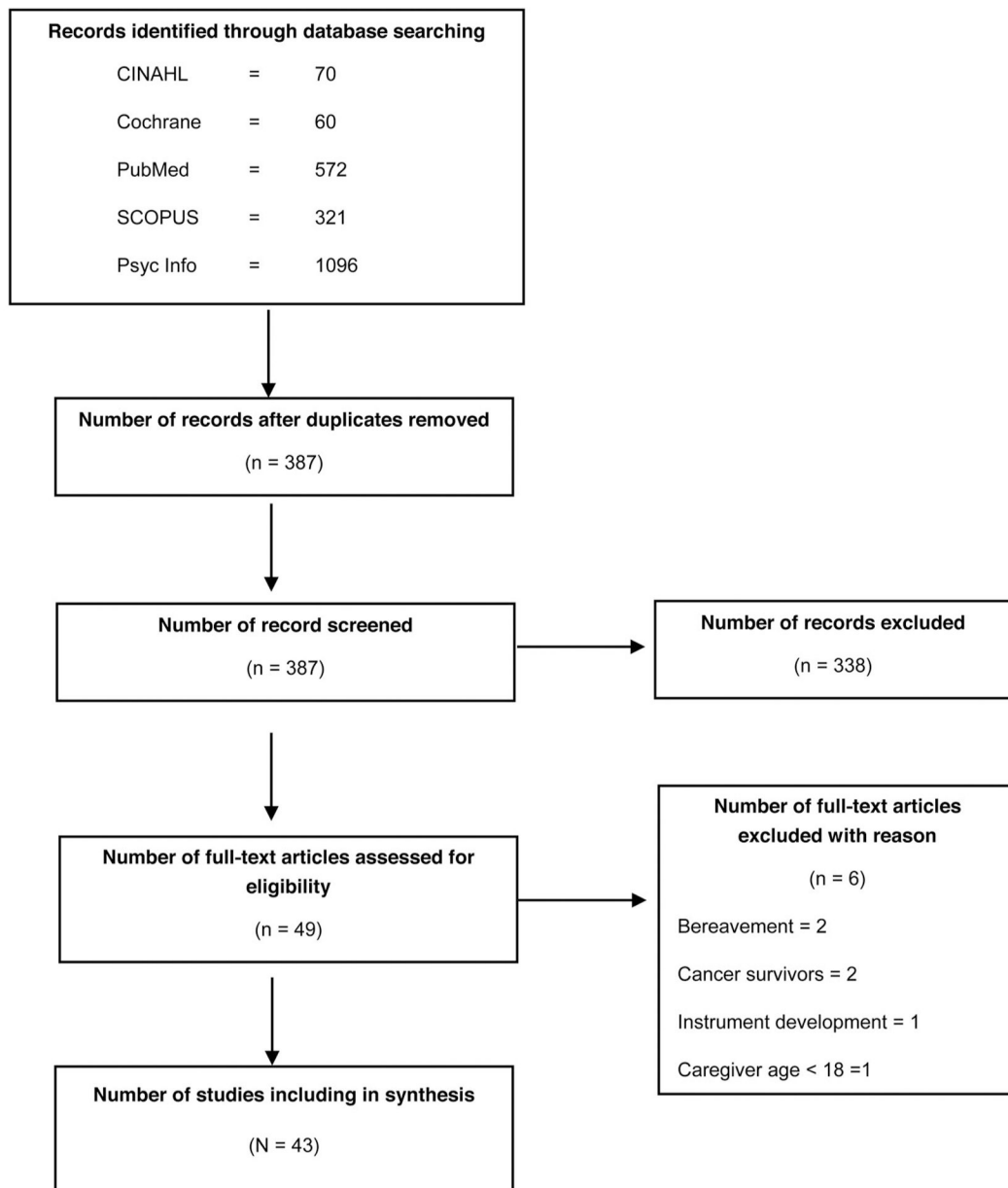


Figure 1.
A PRISMA flow chart of article selection.

Table 1.

Study and caregiver characteristics.

Author	Country	Study design	Cancer type	Numbers of caregiver	Mean age	Female (%)	Relationship to patient
Akpan-Ikio and Anarado (2014)	Nigeria	C	Solid tumor cancer	210	42.6	62.9	62.9% Parent
Ávila et al. (2016)	Portugal	C	Breast cancer	124	50	0	100% Spouse/partner
Badger et al. (2020)	USA	RCT	Breast cancer	230	44.7	21.5	30% Spouse 30% Son/daughter
Bahrami and Farzi (2014)	Iran	RCT	Breast cancer	64	36.9	48	53.1% Son/daughter
Bayen et al. (2017)	France	C	Solid tumor cancer	84	55	56.2	64% Spouse
Beesley et al. (2011)	Australia	L	Ovarian cancer	101	58	87	71% Spouse/children
Cassidy (2013)	England	C	Solid tumour cancer	842	51.3	25	39.42% Adult-children 30.87% Spouse
DuBenske et al. (2014)	USA	RCT	Lung cancer	285	65.7	87.6	78% Spouse
Ezra et al. (2017)	Turkey	C	Solid tumour cancer	101	37.6	70.3	51.5% Adult-children
Goren et al. (2014)	European country	C	Solid tumour cancer	1713	46.4	58.7	68.5% Partner
Grant et al. (2013)	USA	L	Lung cancer	163	57.23	64.4	68.1% Spouse/Cohabiting
Halpern et al. (2017)	USA	S	Solid tumour cancer	373	60	64.4	29% Spouse/partner
Hanly et al. (2015)	Ireland	S	Colorectal cancer	228	50.3	62	73% Spouse/Cohabiting
Heckel et al. (2018)	Australia	RCT	Brain tumour	216	57.2	81.2	79.6% Spouse/partner
Hendrix et al. (2016)	USA	RCT	Solid tumour cancer	138	56.2	53.7	67.4% Spouse
Jeong et al. (2016)	Korea	S	Solid tumour cancer	990	50	82.4	54.9% Spouse
Johansen et al. (2018)	Norway	C	Solid tumour cancer	281	50	62.1	80.78% Spouse/partner
Kavanagh et al. (2015)	USA	C	Lung cancer	138	65	53.2	100% Spouse
Kemp et al. (2018)	Australia	C	Breast cancer	44	55.9	81	86.4% Spouse
Lee et al. (2018)	Taiwan	L	Lung cancer	150	48	67	50% Spouse
Leow and Chan, (2017)	Singapore	Q	Solid tumour cancer	19	54.3	70	78.95% Son/daughter
Li et al. (2013)	USA	R	Solid tumour cancer	88	68.2	73.7	100% Spouse
Mahendran et al. (2017)	Singapore	Quasi	Solid tumour cancer	120	43.4	100	83.2% Spouse/ other
Marshall et al. (2018)	USA	Q	Solid tumour cancer	7	61.4	64.9	85.71% Spouse
McLean et al. (2013)	Canada	RCT	Solid tumour cancer	42	48.8	100	100% Spouse
Milbury et al. (2013)	USA	L	Lung cancer	158	60.5	54.6	84% Spouse
Milne et al. (2020)	Australia	Q	Melanoma	9	49	67.1	77.8% Spouse

Author	Country	Study design	Cancer type	Numbers of caregiver	Mean age	Female (%)	Relationship to patient
Mollica et al. (2017)	USA	S	Lung and colorectal cancer	641	58	89	62.56% Spouse
Mosher et al. (2016)	USA	Q	Colorectal cancer	23	56	80.5	78% Spouse/partner
Nemati et al. (2018)	Iran	Q	Solid tumour cancer	21	46.3	87	47.6% Son/daughter
Ohno et al. (2020)	Japan	C	Solid tumour cancer	251	47.9	57.3	65.3% Spouse
Oven Ustaalioglu et al. (2018)	Turkey	Cohort	Solid tumour cancer	302	56.7	54.6	44.9% Adult-children
Céilleachair et al. (2012)	Ireland	Q	Colorectal cancer	6	48	48.7	66.67% Spouse
Petruzzi et al. (2013)	Italy	C	Brain tumour	72	51	66.67	65.3% Spouse
Reblin et al. (2018)	USA	S	Brain tumour	147	51.8	73.6	74.8% Spouse
Rha et al. (2015)	Korea	S	Solid tumour cancer	227	46.2	70.7	48.6% Spouse
Shaw et al. (2013)	Australia	L	Gastrointestinal cancer	15	50.6	79.2	53% Spouse
Shieh et al. (2012)	Taiwan	C	Colorectal cancer	100	52.2	80	46% Spouse
Sortiano et al. (2018)	USA	C	Breast cancer	72	54.6	76	81.5% Spouse
Turkoglu and Kilic (2012)	Turkey	C	Solid tumour cancer	190	56.7	76	38.4% Son/daughter
Vahidi et al. (2016)	Iran	C	Breast cancer	150	39.6	58.7	34.7% Spouse
van Ryn et al. (2011)	USA	S	Lung and colorectal cancer	667	43	48.7	63% Spouse
Van Houtven et al. (2010)	USA	R	Lung and colorectal cancer	1629	68.2	79	63.8% Spouse

Abbreviations: C, Cross-sectional; L, Longitudinal; Q, Qualitative; Quasi, Quasi-experimental; R, Retrospective; RCT, Randomised Control Trial; S, Secondary analysis.

Table 2.

Notes and specifics of the caregiver burden literature used for this review.

Study by author name	Caregiver burden			
	Frequently reported burden factors	Previously less reported burden factors		
Akpan-Idiok and Anarado (2014)	1	Caregiving responsibility	Supportive strategies/interventions for caregivers	
	2	Impact on social and personal relationships		
Ávila et al. (2016)	1	Impact on caregiver health	Caregiver self-esteem	
	2	Couple attachment-based interventions		
Badger et al. (2020)	1	Impact on caregiver health	Dynamic nature of cancer treatment	
	2	Supportive health education intervention		
	3	Telephone interpersonal counseling intervention		
Bahrami and Farzi (2014)	1	Psycho- Education intervention	1	Caregiver education
Bayen et al. (2017)	1	Lack of familial and/or social support and inadequate availability of supportive resources	1	Caregiver self-esteem
	2	Impact on social and personal relationships	2	Dynamic nature of cancer treatment
	3	Caregiving responsibility		
	4	Impact on financial status		
Beesley et al. (2011)	1	Impact on social and personal relationships	1	Male caregivers
	2	Impact on caregiver's health	2	Dynamic nature of cancer treatment
Cassidy (2013)	1	Lack of familial and/or social support and inadequate availability of supportive resources	1	Dynamic nature of cancer treatment
	2	Impact on caregiver's health		
	3	Impact on caregiver's health		
DuBenske et al. (2014)	1	Lack of familial and/or social support and inadequate availability of supportive resources	Dynamic nature of cancer treatment	
	2	Impact on caregiver's health		
Esra et al. (2017)	1	Impact on social and personal relationships	1	Caregiver self-esteem
	2	Lack of familial and/or social support and inadequate availability of supportive resources	2	Male caregivers
Goren et al., 2014	1	Impact on caregiver's health	1	Caregiver self-esteem
	2	Impact on social and personal relationships	2	Dynamic nature of cancer treatment
	3	Lack of familial and/or social support and inadequate availability of supportive resources		
Grant et al. (2013)	1	Impact on social and personal relationships	1	Dynamic nature of cancer treatment
	2	Lack of familial and/or social support and inadequate availability of supportive resources	2	Caregiver self-esteem
Halpern et al. (2017)	1	Lack of familial and/or social support and inadequate availability of supportive resources	1	Dynamic nature of cancer treatment

Study by author name	Caregiver burden			
	Frequently reported burden factors		Previously less reported burden factors	
	2	Impact on financial status	2	Caregiver self-esteem
Hanly et al. (2015)	1	Impact on caregiver's health	1	Caregiver self-esteem
	2	Impact on social and personal relationships	2	Dynamic nature of cancer treatment
	3	Impact on financial status		
	4	Lack of familial and/or social support and inadequate availability of supportive resources		
Heckel et al. (2018)	1	Lack of familial and/or social support and inadequate availability of supportive resources	Caregiver self-esteem	
Hendrix et al. (2016)	1	Impact on social and personal relationships	1	Male caregivers
			2	Social support or availability of supportive resources
			3	Male caregivers
Jeong et al. (2016)	1	Lack of familial and/or social support and inadequate availability of supportive resources	1	Male caregivers
	2	Impact on social and personal relationships	2	Caregiver self-esteem
	3	Lack of familial and/or social support and inadequate availability of supportive resources		
Johansen et al. (2018)	1	Impact on caregiver's health	1	Dynamic nature of cancer treatment
	2	Lack of familial and/or social support and inadequate availability of supportive resources	2	Caregiver self-esteem.
	3	Impact on social and personal relationships		
Kavanaugh et al. (2015)	1	Impact on financial status	1	Caregiver self-esteem
	2	Lack of familial and/or social support and inadequate availability of supportive resources	2	Male caregivers
			3	Dynamic nature of cancer treatment
Kemp et al. (2018)	1	Impact on social and personal relationships	Caregiver self-esteem	
	2	Impact on caregiver's health		
Lee et al. (2018)	1	Impact on social and personal relationships	Male caregivers	
	2	Impact on financial status		
	3	Impact on caregiver's health		
Leow and Chan, (2017)	1	Lack of familial and/or social support and inadequate availability of supportive resources	1	Male caregivers
	2	Impact on social and personal relationships	2	Caregiver self-esteem
Li et al. (2013)	1	Impact on financial status	1	Caregiver self-esteem
	2	Impact on caregiver's health	2	Male caregivers
Mahendran et al. (2017)	1	Impact on social and personal relationships	Caregiver self-esteem	

Study by author name	Caregiver burden	
	Frequently reported burden factors	Previously less reported burden factors
	2	Lack of familial and/or social support and inadequate availability of supportive resources
Marshall et al. (2018)	Impact on financial status	
McLean et al. (2013)	Impact on social and personal relationships	1 Caregiver self-esteem 2 Dynamic nature of cancer treatment
Milbury et al. (2013)	1 Lack of family and/or social support and inadequate availability of supportive resources 2 Impact on social and personal relationships 3 Impact on financial status 4 Impact on caregiver's health	1 Caregiver self-esteem 2 Dynamic nature of cancer treatment
Milne et al. (2020)	1 Impact on financial status 2 Lack of family/social support	Dynamic nature of cancer treatment
Mollica et al. (2017)	1 Lack of familial and/or social support and inadequate availability of supportive resources 2 Impact on social and personal relationships	Dynamic nature of cancer treatment
Mosher et al. (2016)	1 Lack of familial and/or social support and inadequate availability of supportive resources 2 Impact on social and personal relationships	1 Dynamic nature of cancer treatment 2 Caregiver self-esteem
Nemati et al. (2018)	1 Lack of familial and/or social support and inadequate availability of supportive resources 2 Impact on caregiver's health 3 Impact on social and personal relationships	Dynamic nature of cancer treatment
Ohno et al. (2020)	1 Impact on financial status 2 Impact on caregiver's health 3 Impact on social and personal relationships	1 Caregiver self-esteem 2 Dynamic nature of cancer treatment
Oven Ustaalioglu et al. (2018)	1 Lack of familial and/or social support and inadequate availability of supportive resources 2 Impact on caregiver's health	Caregiver self-esteem
Céilleachair et al. (2012)	1 Impact on financial status 2 Impact on social and personal relationships 3 Lack of familial and/or social support and inadequate availability of supportive resources	Dynamic nature of cancer treatment
Petruzzi et al. (2013)	1 Lack of familial and/or social support and inadequate availability of supportive resources 2 Impact on social and personal relationships 3 Impact on caregiver's health	1 Caregiver self-esteem 2 Dynamic nature of cancer treatment
Reblin et al. (2018)	1 Lack of familial and/or social support and inadequate availability of supportive resources	Dynamic nature of cancer treatment

Study by author name	Caregiver burden	
	Frequently reported burden factors	Previously less reported burden factors
	2	Impact on caregiver's health
Rha et al. (2015)	Lack of familial and/or social support and inadequate availability of supportive resources	
Shaw et al. (2013)	1	Lack of familial and/or social support and inadequate availability of supportive resources
	2	Impact on caregiver's health
Shieh et al. (2012)	1	Lack of familial and/or social support and inadequate availability of supportive resources
	2	Impact on social and personal relationships
	3	Impact on financial status
Soriano et al. (2018)	1	Impact on social and personal relationships
	2	Impact on caregiver's health
	3	Lack of familial and/or social support
	4	Couples coping intervention
Turkoglu and Kilic (2012)	1	Lack of familial and/or social support and inadequate availability of supportive resources
	2	Impact on financial status
Vahidi et al. (2016)	1	Lack of familial and/or social support and inadequate availability of supportive resources
	2	Impact on financial status
	3	Impact on social and personal relationships
van Ryn et al. (2011)	1	Impact on financial status
	2	Impact on social and personal relationships
Van Houtven et al. (2010)	1	Impact on financial status
	2	Impact on social and personal relationships