

Review Article

Cite this article: Ongko E, Philip J, Zomerdijsk N (2024) Perspectives in preparedness of family caregivers of patients with cancer providing end-of-life care in the home: A narrative review of qualitative studies. *Palliative and Supportive Care* 22(6), 2125–2135. <https://doi.org/10.1017/S1478951523001013>

Received: 15 June 2022

Revised: 10 April 2023

Accepted: 20 June 2023

Keywords:

Family carers; Home palliative care; End of life; Cancer; Preparedness

Corresponding author: Emily Ongko;

Email: emily.ongko@hotmail.com

Perspectives in preparedness of family caregivers of patients with cancer providing end-of-life care in the home: A narrative review of qualitative studies

Emily Ongko, M.D., B.B.MED.¹ , Jennifer Philip, PH.D., M.MED., M.B.B.S., F.A.CH.P.M.^{2,3,4}  and Nienke Zomerdijsk, PH.D., G.DIP.PSYCH., B.BUS.^{5,6} 

¹Melbourne Medical School, University of Melbourne, Melbourne, VIC, Australia; ²Parkville Integrated Palliative Care Service, Peter MacCallum Cancer Centre and The Royal Melbourne Hospital, Melbourne, VIC, Australia; ³Department of Medicine, University of Melbourne, Parkville, VIC, Australia; ⁴Department of Medicine, St Vincent's Hospital, Melbourne, VIC, Australia; ⁵Melbourne School of Psychological Sciences, University of Melbourne, Melbourne, VIC, Australia and ⁶Victorian Comprehensive Cancer Centre Alliance, Melbourne, VIC, Australia

Abstract

Background. Many patients with advanced cancer identify home as being their preferred place of death. A critical component in achieving a home death is the support of family members, who often take on responsibilities for which they feel insufficiently prepared with subsequent impacts upon their health and well-being.

Objectives. This study sought to review existing qualitative literature on family carers' experiences in providing end-of-life care at home for patients with advanced cancer, with an emphasis on exploring factors that influence how prepared they feel for their role.

Methods. A narrative review was chosen to provide an overview and analysis of qualitative findings. MEDLINE, PubMed, PsychINFO, and EMBASE databases were searched with the following search terms: "Cancer," "Caregiver," "End of Life Care," "Home," and "Qualitative." Inclusion criteria were as follows: English language, empirical studies, adult carers, and articles published between 2011 and 2021. Data were abstracted, and study quality was assessed using the Critical Appraisal Skills Programme checklist for qualitative research.

Results. Fourteen relevant articles were included. Three overarching themes reflecting the factors influencing family preparedness for their role were identified: "motivations for providing care," "interactions with health-care professionals," and "changes during the caring process."

Significance of results. Inadequate preparation of family carers is apparent with regard to their role in providing end-of-life care at home for patients with advanced cancer. There is a need for health-care workers to more effectively identify the information and support needs of families, and utilize evidence-based strategies that have emerged to address these needs.

Introduction

Despite therapeutic advances, advanced cancer continues to carry a poor prognosis (Sung et al. 2021). For these patients, palliative care holds an important role, as it seeks to improve quality of life for patients and families through early identification and management of pain and other symptoms, as well as attending to psychosocial and spiritual issues (Radbruch et al. 2020; Rome et al. 2011). An important goal of palliative care is to initiate discussions about where patients wish to receive end-of-life care and eventually die. In an international population survey of 9344 patients living with a serious illness, including advanced cancer, up to 84% reported home as their preferred place of death (Gomes et al. 2012). Despite these strong preferences for a home death, a smaller proportion of up to 46% of cancer deaths have been recorded to occur within the home (Cohen et al. 2015). This disparity between preferred and actual place of death deserves consideration, given achievement of patient end-of-life wishes is an essential indicator for quality of death (Meier et al. 2016).

Family carers are a key player in enabling home end-of-life care and death, with responsibilities such as complex medical management, identifying and reporting side effects of treatment, administering medications, and co-ordination of care (Aranda and Hayman-White 2001; Gomes and Higginson 2006). Carers manage these responsibilities while also navigating the challenging emotional terrain of their loved one who has cancer. Indeed, the burden experienced by family carers is well documented, and this is compounded because of family carers' relative inexperience in providing complex clinical care at home (Kristjanson and Aoun 2004). This can lead to high levels of stress and reduced quality of life among family carers as well as

© The Author(s), 2023. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.

poorer outcomes for patients, highlighting an important area requiring greater attention (Oechsle *et al.* 2020).

While dying at home is considered a key indicator of quality end-of-life care, the emotional stress and burden of caring for someone with advanced cancer at home are significant and may affect the possibility of achieving a home death. Therefore, it is important to question if and how carers may be supported in providing this care. Frameworks in psychology may guide our understanding of the emotional stress experienced by family carers and offer solutions for reducing this stress. One such framework is Lazarus and Folkman's stress and coping framework, which proposes that psychological distress results from an imbalance between the demands placed on a person and the resources available to them for coping, including skills, abilities, and emotional and informational resources (Folkman *et al.* 1986). The framework further suggests that effective coping requires the provision of adequate resources for dealing with stressful situations. Therefore, ensuring family carers have access to the resources required to facilitate greater preparedness for the caregiving role may well influence their ability to manage the responsibilities associated with this role (Holm *et al.* 2015). This may help reduce distress and sense of burden of care among family members, while also enabling a higher quality of care for patients with advanced cancer at home, and potentially reduce costs of care to the community.

Understanding and addressing the needs of family carers is important to minimize family burnout and allow them to better support their loved ones' preference to die within the home. The aim of this narrative review was to gain insight into family carers' experiences in providing end-of-life care at home for patients with advanced cancer, with an emphasis on identifying various factors that influence their perceived preparedness for their role. A review of qualitative studies was chosen to provide rich and in-depth data on family carers' experiences and allow for the identification of descriptive themes to be derived for interpretation.

Methods

A narrative review of the existing literature relating to family carers' experiences of providing end-of-life care at home for patients with advanced cancer was undertaken, with emphasis on exploring factors that influence how prepared carers feel for their role.

Search strategy

An electronic literature search of articles published in English between January 2011 and August 2021 was conducted in PubMed, Medline, Embase, and PsychINFO and included MeSH (PubMed) or Emtree (EMBASE) terms, and free-text words. The following search terms were used: ("cancer" OR "malignancy" OR "oncology" OR "neoplasm") AND ("caregiver" OR "carer" OR "informal carer" OR "informal caregiver" OR "family" OR "spouse") AND ("terminal care" OR "supportive care" OR "end of life care" OR "palliative care") AND ("home" OR "community" OR "out of hospital") AND ("qualitative" OR "mixed methods"). Additionally, the following sources were searched: (a) Grey literature through Google Scholar; (b) reference lists of identified eligible articles for relevant studies; and (c) hand search of identified eligible articles for further research carried out by the authors.

Inclusion and exclusion criteria

Articles were included if they reported on empirical qualitative research, were published in a peer-reviewed journal in the English language, and reported experiences of adult family caregivers, *i.e.*, ≥ 18 years, of adult patients with advanced cancer. Further, only articles reporting aspects regarding experiences of preparedness for care provision at home and/or family perspectives of the information and support provided were included. Studies were excluded if they only reported outcomes for carers of pediatric patients, evaluated the impact of an intervention or transitions between inpatient and community care, or if they primarily focused on pain management difficulties in the home setting, or solely on the dying experience.

Screening

One author (E.O.) identified potentially relevant articles by reviewing the titles and abstracts retrieved from the databases. Articles identified as potentially relevant were exported to EndNote, where duplicates were manually checked and removed. After this, 3 assessors (E.O., J.P., and N.Z.) screened the records based on the title, abstract, and full text for inclusion. Based on the inclusion criteria, several articles were excluded at different phases of this review. Consensus was achieved through discussion.

Quality appraisal

The included studies were individually assessed against the Critical Appraisal Skills Programme (CASP) for qualitative research studies, a 10-item checklist that evaluates study quality. The checklist includes items ranging from a clear statement of study aims to a logical flow of ideas from stated aims to conclusions drawn (Treloar *et al.* 2000). Additional items assessed included an appropriate description of sampling strategies, data analysis methods, and consideration of, and efforts to minimize, the factors which impact on data validity and reliability.

Data extraction and synthesis

Data were extracted independently by 1 author (E.O.) using a customized Excel database and included the following:

- Aim(s)
- Sampling
- Analysis
- Sample
- Results
- Study limitations

Analysis

Results of included studies were subjected to thematic analysis. This involved the initial reading and re-reading of the primary data presented in the studies. Findings from individual studies relevant to the experience of family carer preparedness were then identified and grouped according to emerging ideas by EO. These emerging ideas were subsequently reviewed and discussed by the broader study team (J.P. and N.Z.) and a consensus was reached on the key themes arising from the analysis of the collective data, which have been refined for presentation here. Ethics approval was not required.

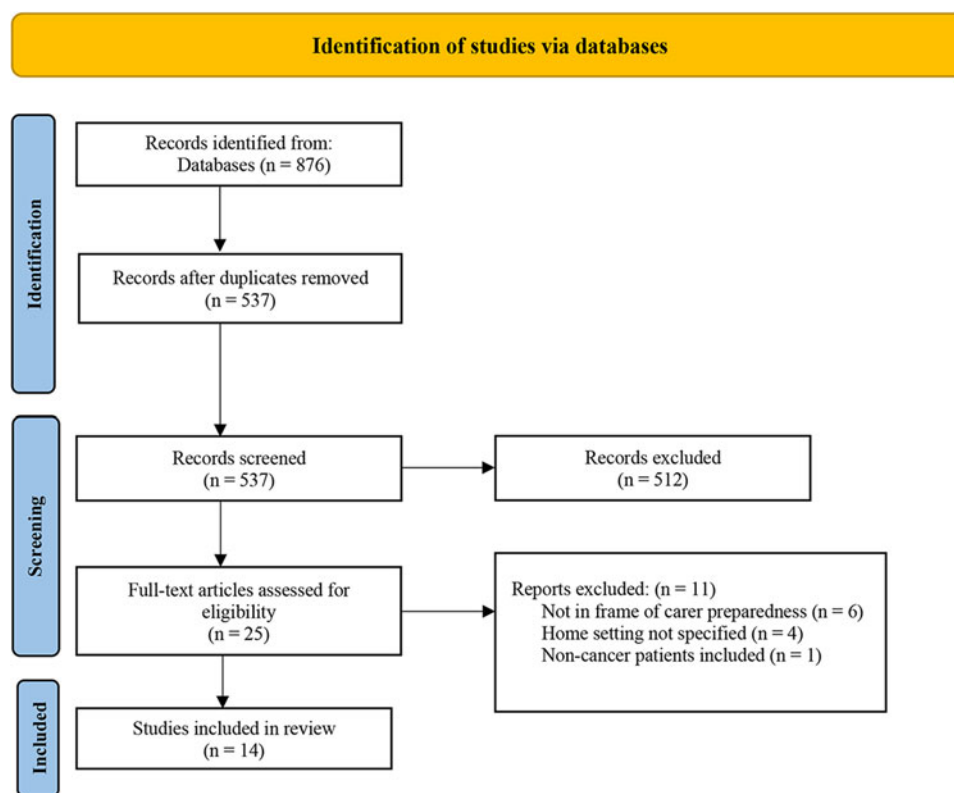


Figure 1. The preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram.

Results

Search results

The database search yielded a total of 876 potentially relevant studies. After the removal of duplicates, 537 studies were screened for eligibility based on their abstract. Of these, a further 512 studies were excluded for the following reasons: conference abstracts only, caregivers of pediatric patients only, and pain management focus only. Full-text copies were obtained of the 25 studies. After inspection, a further 11 studies were excluded as they did not adequately specify home as the location of care and included caregivers of non-cancer patients. In total, 14 studies fulfilled the eligibility criteria and were included in the review (Fig. 1).

Characteristics and quality of included studies

Of the 14 studies included in the review, 10 were conducted in Europe (United Kingdom, Norway, Sweden, and the Netherlands), while the remaining 4 were conducted in Canada, Ghana, and Singapore. The studies were conducted between 2011 and 2021 and involved a total of 314 participants with ages ranging from 21 to 94. Carers were predominantly women. Seven studies reported the experiences of current caregivers to living patients with advanced cancer, while the remainder related the experiences of bereaved cancer caregivers. Twelve studies utilized purposive sampling techniques, with a minority using mixed sampling and consecutive patient series sampling. Data analysis approaches employed by the studies included thematic analysis (13 studies) and grounded theory analysis (1 study).

The included studies addressed most of the criteria presented in the CASP checklist. At a minimum, study aims were specified, with

appropriate reasoning provided for the qualitative approach. Data collection and analysis methods were also described in sufficient detail (Treloar et al. 2000). The items that distinguished some studies from others were whether an underlying conceptual framework for the study was described. Half of the studies clearly described a theoretical framework as the basis of their research question, while others did not specify this. Another distinguishing feature was the level of consideration given to threats to study validity and reliability. All included studies addressed this by using multiple researchers to analyze the data and acknowledging the potential biases in participant recruitment conducted by health-care professionals (HCPs). Three studies specifically detailed additional steps to strengthen data validity, including utilizing testimonial validity checks, an audit trail, and conducting the analysis process in line with a series of credibility checks. Further details, including the summarized findings of the studies, are provided in Table 1.

Results from qualitative analysis

Analysis of the qualitative data revealed a consistent report of family carers feeling ill-prepared for their role (Barlund et al. 2021; Devik et al. 2017; Leow and Chan 2017; Mohammed et al. 2018; Salifu et al. 2021; Tarberg et al. 2019; Totman et al. 2015). Family carers described their caregiving responsibilities as complex and challenging but persevered despite feeling ill-prepared. Managing these concerns while also managing their worry about their loved one's advanced cancer led to feelings of distress (Epiphaniou et al. 2012; Salifu et al. 2021; Totman et al. 2015). Three main themes reflecting the key factors influencing family preparedness for their role emerged from the thematic analysis of the qualitative studies;

Table 1. Summary of included studies and their characteristics

Author/Year	Aim	Sampling, analysis	Sample (age range)	Results ^a (corresponding category)		Study limitations	Items addressed in CASP checklist	
				Commitment to fulfill patient's wishes	(motivations) (HCPs)		Theoretical framework described	Validity and reliability addressed
Barlund et al. (2021), Norway	Explore factors influencing security and facilitating home death	Purposive sampling, qualitative content analysis	10 bereaved caregivers (41–76), hospital community palliative care team 100% females, 50% spouse	<ul style="list-style-type: none"> Commitment to fulfill patient's wishes HCPs to address carer's needs and give affirmation Clear instructions on what to expect in the terminal phase Well-organized health-care services 	(motivations) (HCPs, changes) (HCPs)	<ul style="list-style-type: none"> Questions focused on positive aspects of care All participants were female No exclusion criteria in participant recruitment Recruitment based on health-care staff No participant feedback on findings 	N	✓
Devik et al (2017), Norway	Explore bereaved family members' perceptions of suffering relatives during the last phase of life	Purposive sampling, directed qualitative content analysis	10 bereaved caregivers (45–61), palliative home nursing care 100% female, 50% child	<ul style="list-style-type: none"> Witnessing suffering & deterioration evoked feelings of helplessness Need to advocate when pain underestimated by HCPs Failure to alleviate patient's suffering evoked guilt Reassurance from personable, approachable HCPs 	(changes) (HCPs) (changes) (HCPs)	<ul style="list-style-type: none"> HCPs involved in participant recruitment All participants were female Recall bias Inclusion and exclusion criteria not clearly specified 	Y – perceptions of suffering	✓
Epiphaniou et al. (2012), UK	Identify existing coping and support mechanisms	Purposive sampling, thematic analysis	20 current informal carer caregivers (25 – 79), community palliative care team 55% female, 60% spouse	<ul style="list-style-type: none"> Support from HCPs, family and friends was important 	(HCPs, changes)	<ul style="list-style-type: none"> English speakers only HCPs involved in recruitment of participants 	N	✓
Fjose et al. (2018), Norway	Explore what patients and family members experience as important and difficult when facing health services	Purposive sampling, inductive content analysis	26 families/60 current carers (27–84), palliative cancer patients NR, 73% child	<ul style="list-style-type: none"> Family involvement in care decisions was desired Benefit of taking initiative and requesting information Consistency of HCPs essential for building trust HCPs help to navigate health system & enhanced sense of preparedness 	(HCPs) (HCPs) (HCPs)	<ul style="list-style-type: none"> No participant feedback on findings Joint interviews – information withheld Single interview; 1 point in time Recruitment process guided by HCPs 	N	✓

(Continued)

Table 1. (Continued.)

				Items addressed in CASP checklist			
Author/Year	Aim	Sampling, analysis	Sample (age range)	Results* (corresponding category)	Study limitations	Theoretical framework described	Validity and reliability addressed
Harding et al (2012), UK	Understand caregivers' perceived information and support needs	Purposive sampling, thematic analysis	20 current caregivers (25–79), community palliative care 55% female, 68% spouse	<ul style="list-style-type: none"> Preparation for the caregiving role Need to be visible to professionals Clear information needed Emotional support was key 	<ul style="list-style-type: none"> English speakers only Staff-guided recruitment Exclusion criteria not specified No participant feedback on findings Recruitment strategy not fully described 	Y – MRC framework for development and evaluation of complex interventions	✓
Klarare et al (2018), Sweden	Describe patient and family experiences of palliative home care team actions, as helping or hindering interventions	Purposive sampling, thematic analysis	7 current family carers' (50 – 89) specialist palliative home care services 62% female, NR	<ul style="list-style-type: none"> HCPs to aid with organizing care, listen to needs & provide resources accordingly Access & availability of help from HCPs, responsiveness in following through on concerns Collaborative partnerships and family involvement in decisions Unmet information needs, not listened to, boundaries not respected Experienced as hindering 	<ul style="list-style-type: none"> Participants recruited by care providers Detailed inclusion and exclusion criteria not provided 	Y – enhanced critical incident technique	✓✓ – use of credibility checks
Leow and Chan (2017), Singapore	Describe the experiences of family caregivers	Purposive sampling, thematic analysis	19 current caregivers (21–64), home hospice services 74% female, 80% child	<ul style="list-style-type: none"> Difficult to manage patient condition & family conflicts while balancing other commitments Rollercoaster of emotions experienced Support of family, friends, HCPs & spiritual support identified as important Coped via distraction and balancing stress Fulfilled by carer role, saw greater meaning in life 	<ul style="list-style-type: none"> Majority of participants Chinese Single interviews; 1 point in time Recruitment by home hospice staff No details on interviewer/facilitator No participant feedback on findings Recruitment strategy not described 	N	✓✓ – use of audit trail
Mohammed et al (2018), Canada	Explore caregivers' experiences and supports received	Purposive sampling, grounded theory analysis	61 bereaved caregivers (29–85), community palliative care 72% female, 54% spouse	<ul style="list-style-type: none"> Inadequate support led to physical exhaustion Need to be assertive to access resources and support HCPs provide reassurance Required more detailed explanation on dying process 	<ul style="list-style-type: none"> English speakers only Highly educated, moderate income, enrolled in past trial Done in comprehensive cancer center – less generalizable Recall bias 	Y – constructivist grounded theory	✓

(Continued)

Table 1. (Continued.)

Author/Year	Aim	Sampling, analysis	Sample (age range)	Results ^a (corresponding category)	Study limitations	Items addressed in CASP checklist	
						Theoretical framework described	Validity and reliability addressed
Oosterveld-Vlug et al. (2019), Netherlands	Determine elements considered important for good quality care	Purposive sampling, thematic analysis	14 current caregivers (40–79), primary care 79% female, 64% spouse	<ul style="list-style-type: none"> Medical proficiency, clear communication of diagnosis/prognosis fostered trust in HCPs HCPs to be available and responsive to demands HCPs demonstrating empathy, interest in patients & carers Wish for HCPs to be proactive in initiating end-of-life discussions Integrated health system 	<ul style="list-style-type: none"> Recruitment guided by GPs Participants highly educated Participants from past quantitative research study Inclusion, exclusion criteria not specified 	N	✓
Pottle et al. (2020), Wales	Explore perceptions of quality of death and experience of caring at home	Purposive sampling, thematic analysis (Framework approach)	15 bereaved cancer carers (NR), specialist palliative care teams 80% female, 73% spouse	<ul style="list-style-type: none"> Home allowed carers to prioritize patient care Loss of normality in home as care progressed Conflicting patient and carer views on information desired and need for practical support; with patient views taking precedence Families' needs should be recognized as separate to patients' Solutions required to safeguard carers when carer & patient needs mismatched 	<ul style="list-style-type: none"> Participants from single health service Recruitment led by HCPs Carers with complaints omitted 	N	✓
Robinson et al (2017), Canada	Describe the experiences of families who achieved home death and understand enabling factors	Mixed sampling, grounded theory analysis (constant comparative method)	29 bereaved caregivers (35–94), local community 66% female, 55% spouse	<ul style="list-style-type: none"> Determination was key Initiation of formal palliative care services gave recognition & access Support of HCPs, family, friends & patient Proactivity in making demands 	<ul style="list-style-type: none"> English speakers only Incentive for participation Inconsistency in recruitment – informal and formal approaches 	N	✓

(Continued)

Table 1. (Continued.)

Author/Year	Aim	Sampling, analysis	Sample (age range)	Results ^a (corresponding category)	Study limitations	Items addressed in CASP checklist	
						Theoretical framework described	Validity and reliability addressed
Salifu et al. (2021), Ghana	Explore experiences of prostate cancer patients and families in home care in resource-poor context	Purposive sampling, thematic analysis	23 current caregivers (NR), care at home NR, 44% spouse	<ul style="list-style-type: none"> Struggle experienced with end-of-life care Families described insufficient knowledge, absent HCP input Conflicts arose when the patient refused food Persevered without support due to moral obligation, through trial and error Pain difficult to manage, herbal medicines often used 	<ul style="list-style-type: none"> Coding by primary author, Ghanaian native, cultural bias Palliative care center in northern Ghana HCPs involved in recruitment 	Y – social constructivist theory and interpretivism	✓
Tarberg et al. (2019), Norway	Explore family caregivers' experiences of information and involvement in different phases of palliative care	Purposive sampling, inductive analysis	11 bereaved caregivers (31–80), community palliative care services 82% female, 82% spouse	<ul style="list-style-type: none"> Specific information on expected disease trajectory Difficult when patients did not want to know Opportunities to clarify expectations & needs Need for support Need to be prepared for the patient's death Established follow-up networks after death may also assist 	<ul style="list-style-type: none"> Emotional undertones and grieving Recall bias Recruitment by HCPs responsible for care No participant feedback on findings Exclusion criteria not specified 	Y – Thompson's theory of involvement	✓
Totman et al. (2015), UK	Explore emotional challenges in caregiving and role of HCPs	Consecutive patient series sampling, thematic analysis	15 bereaved relatives (27–66), community palliative care 73% female, 53% child	<ul style="list-style-type: none"> Families faced high levels of responsibility and difficult decisions HCPs helped to reduce isolation, desperation Death was confronting Desire to give back to patient provided motivation 	<ul style="list-style-type: none"> English speakers only Recall bias Sampling from single service Majority older, female carers Recruitment inadequately described 	Y – existential psychology	✓✓ – testimonial validity checks

HCPs = health-care professionals, NR = not reported, N = no theoretical framework described, and listed accordingly. "Motivations" is abbreviated for providing care. "HCPs" is abbreviated for interactions with health-care professionals – enablers and barriers. "changes" abbreviated for changes in the caregiving trajectory. ^aResults listed as factors identified which facilitated or impacted on the experience of preparedness and family carer coping. The theme that each factor can be grouped under is listed in the column to the right, with some factors grouped under more than 1 theme. ✓ = addressed study validity and reliability. ✓✓ = addressed study validity and reliability to a higher level, additional methods used listed accordingly.

(A) motivations for providing care, (B) interactions with health-care professionals, and (C) changes during the caring process.

(A). Motivations for providing care

There were a variety of factors motivating family members to provide end-of-life care at home for patients with advanced cancer. Of these, family values emerged as a strong motivator that underpinned the willingness of family members to adopt and continue in the carer role (Barlund *et al.* 2021; Robinson *et al.* 2017). That is, family carers wished to maintain patient well-being by facilitating end-of-life care in a place that the patient would find comfortable and familiar (Barlund *et al.* 2021; Robinson *et al.* 2017). For adult children who provided care to an ill parent, a duty to “give back” the love they had received from their parents was also a contributing factor (Leow and Chan 2017; Robinson *et al.* 2017; Salifu *et al.* 2021). Even in situations where palliative home care was driven by necessity due to an under-resourced medical system, the desire to protect and support the patient underpinned families’ decision to provide end-of-life care at home (Salifu *et al.* 2021). These values altogether helped family members to remain committed to their caregiving role and provided the motivation needed to navigate the complex challenges associated with caregiving (Robinson *et al.* 2017; Totman *et al.* 2015).

Some family members reported feeling pressure to accept the role of caregiving and a lack of choice due to social expectations for them to care for an ill family member (Salifu *et al.* 2021). Family members who had a strong desire to protect the patient described a better sense of perceived preparedness for their role, while those who were influenced by social expectations frequently described apprehension. Flow on effects also emerged after the patient’s death, where carers driven by family values described an emotionally rewarding experience which strengthened family ties, encouraged personal growth, and a greater appreciation for life (Leow and Chan 2017; Pottle *et al.* 2020).

(B). Interactions with health-care professionals and systems – enablers and barriers

Many family carers reported receiving support from palliative care services and general practitioners. The introduction of palliative care during the early stages of the patient’s disease trajectory enabled family carers to feel more prepared (Barlund *et al.* 2021; Robinson *et al.* 2017). In a practical sense, having HCPs involved enabled access to resources and education to assist families in the management of the patient’s condition (Klarare *et al.* 2018). From a psychological perspective, family carers viewed HCPs as an important support system, who helped to alleviate the burden of responsibility and reduced their sense of isolation (Leow and Chan 2017). Those who provided care within the home without formal support from health-care services often described feeling overwhelmed and reported challenges such as misinterpreting patient symptoms (Salifu *et al.* 2021).

Interactions between HCPs and family carers were broadly categorized into enablers of, or barriers to families feeling prepared for their role. HCPs who displayed empathy and conveyed a person-centered approach and interest in the patient and their family carers’ well-being were appreciated by family carers. Families described these qualities as important to build their trust in HCPs and reassured them that they were part of a team that worked together to optimize the patient’s well-being (Klarare *et al.* 2018; Robinson *et al.* 2017).

Family carers wished to see HCPs demonstrate medical competency and placed great importance on having continuity in HCPs

involved, alongside their availability and responsiveness to concerns (Barlund *et al.* 2021; Fjose *et al.* 2018; Klarare *et al.* 2018; Oosterveld-Vlug *et al.* 2019). For example, family carers expressed appreciation when HCPs were able to make additional home visits when the need arose (Oosterveld-Vlug *et al.* 2019). Another enabler to perceived preparedness was family recognition, with carers reporting that they valued HCPs who sought their opinion and asked how they were coping (Klarare *et al.* 2018). A specific area wherein family carers wished to speak up more was in assessment of the patient’s pain, which was based on carers seeing themselves as best placed to detect changes in the patient’s behavior, while HCPs were frequently perceived to underestimate the patient’s pain (Oosterveld-Vlug *et al.* 2019). Family carers reported that their views were often dismissed in these instances, and expressed a wish for their input to be heard by HCPs and incorporated into decisions surrounding care (Klarare *et al.* 2018).

Barriers to caregivers’ perceived preparedness were also identified. Family carers reported a need for clear care descriptions of their own role and responsibilities versus those of HCPs (Barlund *et al.* 2021; Oosterveld-Vlug *et al.* 2019). Some family carers expressed having inadequate understanding of the exact requirements of their role, which frequently led to increasing stress over time (Mohammed *et al.* 2018). Additionally, family carers felt frustrated when care was fragmented. For example, some carers were unsure who to contact when care needed to be escalated as a central contact person had not been identified (Barlund *et al.* 2021; Tarberg *et al.* 2019). There also appeared to be a lack of clear communication between HCPs and different services involved, which became evident when carers had repetitive conversations with the different parties involved (Oosterveld-Vlug *et al.* 2019). Family carers described these as barriers to their sense of preparedness and expressed a need for an improved system wherein HCPs provide assistance with their new responsibilities (Klarare *et al.* 2018).

Another commonly reported barrier was information inadequacy (Tarberg *et al.* 2019). That is, families described a mismatch between their actual information needs and their needs as perceived by HCPs (Pottle *et al.* 2020). Family carers expressed a strong desire to have more information about the patients’ prognosis and expected disease trajectory (Totman *et al.* 2015). While carers recognized that this may not always be possible given uncertainties in the disease trajectory, they wanted HCPs to initiate these challenging conversations as they valued open and honest communication about prognostic information, despite its inherent uncertainties and the risks of forming expectations based on an unreliable estimate (Barlund *et al.* 2021; Oosterveld-Vlug *et al.* 2019; Pottle *et al.* 2020). Overlooking these conversations had consequences, as families had inadequate information regarding their loved one’s prognosis, which contributed to them feeling unprepared for what lay ahead (Harding *et al.* 2012). Family carers also wanted information about what to expect during the terminal phase and described experiences of being unprepared for the patients’ death which led to considerable distress (Totman *et al.* 2015). Carers expressed a need for comprehensive HCP-directed education on death, including explanations on possible end-of-life symptoms and how they can differentiate these from baseline deterioration (Barlund *et al.* 2021; Harding *et al.* 2012; Salifu *et al.* 2021).

In some circumstances, the desire for more information on the patient’s prognosis appeared to be in conflict with the patient’s own needs for information (Pottle *et al.* 2020). Family carers described instances when patients expressed their wish not to know their deteriorating health status, while families themselves desired frank and early discussions about the illness progression (Barlund *et al.*

2021; Totman et al. 2015). Ultimately, patient preferences were prioritized and family members' need for information was unmet in these instances (Epiphanou et al. 2012). These issues were perceived as belonging more broadly to the lack of family carer recognition in many important decisions surrounding care (Tarberg et al. 2019).

(C). Evolving changes in the caregiving trajectory

Family carers identified changes throughout the process of providing care to their loved one in the home environment. Witnessing the decline in the patient's physical and mental health was distressing for family carers (Leow and Chan 2017). This was particularly overwhelming when the patient's disease progressed and there was greater reliance on family carers to provide care in the home setting. Family carers commonly reported feeling helpless and guilty as they witnessed their loved one's suffering first-hand (Devik et al. 2017). These descriptions appeared to reflect a perceived inadequacy of the support that they provided at home (Totman et al. 2015). Family carers had to adapt as they became the patient's advocate, learnt new practical and clinical skills, and sacrificed aspects of their own life to fulfill the caregiving role (Devik et al. 2017; Fjose et al. 2018; Leow and Chan 2017; Oosterveld-Vlug et al. 2019; Robinson et al. 2017; Totman et al. 2015).

Family carers also described that the dynamics of their relationship with the patient changed (Totman et al. 2015). The dual role of being both family member and carer required a professional perspective which interfered with their ability to relate to their loved one on an intimate level (Totman et al. 2015). Similarly, the home was seen as being changed from a place of comfort and privacy to a site for health-care provision (Barlund et al. 2021; Pottle et al. 2020). Changes within the home, such as medical equipment and presence of HCPs, became part of daily routine and led to a perceived loss of normality and privacy (Pottle et al. 2020).

While some of these changes were understood to be inevitable, family carers described a need to be better informed of the disease trajectory in order to avoid unexpected distress associated with the patients' physical deterioration (Leow and Chan 2017). Families also wished for a clear understanding of caregiving goals and clarification that the objective of end-of-life care was not to delay illness progression, but rather to prioritize the patient's comfort (Fjose et al. 2018; Robinson et al. 2017). Support from family and friends was described as crucial and decreased the burden of care (Epiphanou et al. 2012). Family carers also expressed the desire to hear stories from caregivers with similar lived experiences. Support groups where they could share and learn from other family carers were sought after and perceived as important (Harding et al. 2012).

Discussion

Family carers have been recognized as essential stakeholders in end-of-life care within the home for people with advanced cancer (Gomes and Higginson 2006). This review of qualitative literature revealed that in order to better facilitate caregivers' perceived preparedness and reduce their burden of caregiving, a greater emphasis on education, information, and establishing a good working relationship between families and HCPs should be prioritized (Bee et al. 2009).

Lazarus and Folkman's stress and coping framework proposes that psychological distress results from an imbalance between the demands placed on a person and the resources available to them

for coping (Folkman et al. 1986). In the case of family carers providing end-of-life care at home, the unfamiliarity and complexity of the role can lead to a perceived threat. Family carers had no prior experience in caregiving yet were required to navigate complex issues which arise in end-of-life care. This sense of threat may promote stress and maladaptive coping responses, and may contribute to high levels of carer depression previously reported (Oechsle et al. 2020). Although many of the challenges of providing home end-of-life care appear to be intrinsic to the role itself, attention to areas of concern raised in this review may serve to enhance family carer preparedness for the role and thereby reduce the perceived level of threat posed to families and facilitate healthy coping mechanisms.

Indeed, previous research has shown family carer preparedness is associated with improved outcomes in family well-being and the fulfillment of the patient's preference to die at home (Jack and O'Brien 2010). From this review, it is clear that the factors identified by family carers as important in shaping their preparedness are interconnected and manifest throughout the caregiving trajectory, from first considering their motivations for providing care to the time of the patient's death. This suggests that family carers consider being prepared to involve an ongoing sense of readiness as they move through the various stages of providing care.

Based on this, we could infer that there are multiple opportunities to enhance family carers' preparedness. Existing research evaluating the efficacy of psychosocial and educational interventions for families addresses this opportunity through the delivery of consecutive education and support sessions over time (Badr et al. 2015; Dionne-Odom et al. 2015; Holm et al. 2016). However, to maximize the opportunities available for enhancing family carers' preparedness, future studies should implement longer-term interventions that deliver sustained support for families throughout the duration of care. This is likely to be challenging given the high attrition rates evidenced in previous studies (Dionne-Odom et al. 2015; DuBenske et al. 2014).

A key finding of this review was the value family carers placed on forming relationships with HCPs based on trust and mutual respect. As a foundation of this collaborative relationship, carers held the expectation that they would be adequately informed of key aspects in the provision of care, including the patient's prognosis, anticipated course of illness, and common end-of-life symptoms. This supports conclusions from previous reviews, where unmet information needs were a limiting factor in carer preparedness (Bee et al. 2009). Accordingly, interventions to meet families' information needs based on education and training in the skills of providing care have been evaluated in a number of research studies, as summarized by a recent review (Ahn et al. 2020). These interventions encompassed a wide range of formats, from phone counseling sessions to tailored education manuals and programs, specialized caregiver nurses, and electronic resources. The shared outcome of these studies was that educational interventions have had positive effects on family carers' perceived ability to cope with their role and have helped to reduce carer burden (Badr et al. 2015; DuBenske et al. 2014; Sun et al. 2015).

Family carers commonly described gaps in their access to information, which could be attributed to an underestimation of their information needs by HCPs. In response, Ewing and Grande have developed the Carer Support Needs Assessment Tool (CSNAT) to identify domains in which carers require increased support, such as their understanding of the patient's illness and access to assistance to carry out caregiving responsibilities (Ewing and Grande 2013). The CSNAT has proven to be a valid and reliable tool from

both family carers' and HCPs' perspectives, and its use in clinical practice has demonstrated a significant reduction in caregiver burden (Alvariza *et al.* 2018; Aoun *et al.* 2015).

Another important finding is the influence of family carers' own expectations on their perceived sense of preparedness. Family carers bring different expectations into their role, from the responsibilities they envision to be a part of the role to the level of support they wish and expect to receive from HCPs. When experiences differ from families' expectations, their sense of preparedness is likely diminished. An alternative approach to ensuring family preparedness would therefore be to align experiences more closely with expectations. This could be achieved through active efforts by HCPs to inquire specifically about families' expectations and, where practical, tailor the supports provided to meet these expectations. These efforts would also emphasize the recognition of family carers by HCPs, thereby strengthening the working relationship between families and HCPs. This approach also identifies an opportunity for HCPs to use the CSNAT to identify carers' expectations on support provided based on their reported areas of need and subsequently deliver targeted support to meet these expectations.

Alternatively, in situations where families' expectations cannot be reasonably met due to constraints of the clinical setting or limitations in resource and HCP availability, HCPs may need to discuss with family carers the scope of support that is possible, and in the process, help adjust carers' expectations. This approach is receiving attention in this research field, with a recent study assessing an intervention designed to specifically address areas of reported need as informed by the CSNAT, which demonstrated a small improvement in carers' psychological outcomes (Grande *et al.* 2017). The study described limitations in maintaining consistency of interventions across different participating services, which also highlights one of the practical barriers to integrating streamlined support for family carers in clinical practice (Grande *et al.* 2017). Despite these limitations, the impact of this study cannot be understated as it represents a move towards family carer led and targeted interventions. The integration of the CSNAT tool, and CSNAT-based intervention into routine clinical practice is the focus of work currently underway, with the impact of widespread implementation yet to be realized (Diffin *et al.* 2018).

Limitations

This review has several limitations that need to be noted. First, only English articles were included, with a geographical concentration in European countries. The experiences of caregivers in other countries may differ according to different health-care systems and cultural responses. Second, a narrow focus was adopted to identify articles relevant to family preparedness. There may be elements within the broader perspective of family experiences, such as previous health-care encounters or differing family dynamics, which are indirectly related to preparedness and not represented here. Third, as acknowledged by most of the studies, selection bias is likely to be present, given their recruitment strategy relied on HCPs to identify suitable candidates. Last, as half of the studies described bereaved caregivers, it is important to consider recall bias as influencing the data gathered.

Conclusion

Ensuring preparedness of family carers providing end-of-life care at home for patients with advanced cancer may reduce their caregiving burden, facilitate a more sustainable caregiving role, and, in

turn, benefit patients who are more likely to achieve their preferences for a home death. The key areas by which HCPs may increase family carer preparedness include the promotion of family integration into care, the recognition of families' specific information needs and implementation strategies to ensure these are met. The evidence base underpinning interventions to support family carers is expanding rapidly, and future research is increasingly focusing attention upon further refining strategies for their widespread implementation into clinical practice.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951523001013>

Author contributions. All authors contributed to the literature review and analysis process. The first draft of the manuscript was written by E.O. and all authors (E.O., J.P., and N.Z.) commented on previous versions of the manuscript. All authors read, edited, and approved the final manuscript.

Funding. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Competing interests. None to declare.

References

- Ahn S, Romo RD and Campbell CL (2020) A systematic review of interventions for family caregivers who care for patients with advanced cancer at home. *Patient Education and Counseling* **103**, 1518–1530. doi:10.1016/j.pec.2020.03.012
- Alvariza A, Holm M, Benkel I, *et al.* (2018) A person-centred approach in nursing: Validity and reliability of the Carer Support Needs Assessment Tool. *European Journal of Oncology Nursing* **35**, 1–8. doi:10.1016/j.ejon.2018.04.005
- Aoun SM, Grande G, Howting D, *et al.* (2015) The impact of the carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial. *PLoS ONE* **10**, e0123012. doi:10.1371/journal.pone.0123012
- Aranda SK and Hayman-White K (2001) Home caregivers of the person with advanced cancer: An Australian perspective. *Cancer Nursing* **24**, 300–307. doi:10.1097/00002820-200108000-00011
- Badr H, Smith CB, Goldstein NE, *et al.* (2015) Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: Results of a randomized pilot trial. *Cancer* **121**, 150–158. doi:10.1002/cncr.29009
- Barlund AS, André B, Sand K, *et al.* (2021) A qualitative study of bereaved family caregivers: Feeling of security, facilitators and barriers for rural home care and death for persons with advanced cancer. *BMC Palliative Care* **20**, 7. doi:10.1186/s12904-020-00705-y
- Bee PE, Barnes P and Luker KA (2009) A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of Clinical Nursing* **18**, 1379–1393. doi:10.1111/j.1365-2702.2008.02405.x
- Cohen J, Pivodic L, Miccinesi G, *et al.* (2015) International study of the place of death of people with cancer: A population-level comparison of 14 countries across 4 continents using death certificate data. *British Journal of Cancer* **113**, 1397–1404. doi:10.1038/bjc.2015.312
- Devik SA, Hellzen O and Enmarker I (2017) Bereaved family members' perspectives on suffering among older rural cancer patients in palliative home nursing care: A qualitative study. *European Journal of Cancer Care* **26**, e12609. doi:10.1111/ecc.12609
- Diffin J, Ewing G and Grande G (2018) Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: A qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention. *BMC Palliative Care* **17**, 129. doi:10.1186/s12904-018-0382-5
- Dionne-Odom JN, Azuero A, Lyons KD, *et al.* (2015) Benefits of early versus delayed palliative care to informal family caregivers of patients with advanced cancer: Outcomes from the ENABLE III randomized controlled

- trial. *Journal of Clinical Oncology* **33**, 1446–1452. doi:10.1200/JCO.2014.58.7824
- DuBenske LL, Gustafson DH, Namkoong K, et al.** (2014) CHES improves cancer caregivers' burden and mood: Results of an eHealth RCT. *Health Psychology* **33**, 1261–1272. doi:10.1037/a0034216
- Epiphaniou E, Hamilton D, Bridger S, et al.** (2012) Adjusting to the caregiving role: The importance of coping and support. *International Journal of Palliative Nursing* **18**, 541–545. doi:10.12968/ijpn.2012.18.11.541
- Ewing G and Grande G** (2013) Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. *Palliative Medicine* **27**, 244–256. doi:10.1177/0269216312440607
- Fjose M, Eilertsen G, Kirkevold M, et al.** (2018) "Non-palliative care" - a qualitative study of older cancer patients' and their family members' experiences with the health care system. *BMC Health Services Research* **18**, 745. doi:10.1186/s12913-018-3548-1
- Folkman S, Lazarus RS, Dunkel-Schetter C, et al.** (1986) Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology* **50**, 992–1003. doi:10.1037/0022-3514.50.5.992
- Gomes B and Higginson IJ** (2006) Factors influencing death at home in terminally ill patients with cancer: Systematic review. *BMJ* **332**, 515–521. doi:10.1136/bmj.38740.614954.55
- Gomes B, Higginson IJ, Calanzani N, et al.** (2012) Preferences for place of death if faced with advanced cancer: A population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology* **23**, 2006–2015. doi:10.1093/annonc/mdr602
- Grande GE, Austin L, Ewing G, et al.** (2017) Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: A stepped wedge cluster trial. *BMJ Supportive & Palliative Care* **7**, 326–334. doi:10.1136/bmjspcare-2014-000829
- Harding R, Epiphaniou E, Hamilton D, et al.** (2012) What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. *Supportive Care in Cancer* **20**, 1975–1982. doi:10.1007/s00520-011-1300-z
- Holm M, Årestedt K, Carlander I, et al.** (2016) Short-term and long-term effects of a psycho-educational group intervention for family caregivers in palliative home care - results from a randomized control trial. *Psycho-Oncology* **25**, 795–802. doi:10.1002/pon.4004
- Holm M, Henriksson A, Carlander I, et al.** (2015) Preparing for family caregiving in specialized palliative home care: An ongoing process. *Palliative & Supportive Care* **13**, 767–775. doi:10.1017/S1478951514000558
- Jack B and O'Brien M** (2010) Dying at home: Community nurses' views on the impact of informal carers on cancer patients' place of death. *European Journal of Cancer Care* **19**, 636–642. doi:10.1111/j.1365-2354.2009.01103.x
- Klarare A, Rasmussen BH, Fossum B, et al.** (2018) Actions helping expressed or anticipated needs: Patients with advanced cancer and their family caregivers' experiences of specialist palliative home care teams. *European Journal of Cancer Care* **27**, e12948. doi:10.1111/ecc.12948
- Kristjanson LJ and Aoun S** (2004) Palliative care for families: Remembering the hidden patients. *The Canadian Journal of Psychiatry* **49**, 359–365. doi:10.1177/070674370404900604
- Leow MQH and Chan SWC** (2017) The challenges, emotions, coping, and gains of family caregivers caring for patients with advanced cancer in Singapore: A qualitative study. *Cancer Nursing* **40**, 22–30. doi:10.1097/NCC.0000000000000354
- Meier EA, Gallegos JV, Thomas LP, et al.** (2016) Defining a Good Death (Successful Dying): Literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry* **24**, 261–271. doi:10.1016/j.jagp.2016.01.135
- Mohammed S, Swami N, Pope A, et al.** (2018) "I didn't want to be in charge and yet I was": Bereaved caregivers' accounts of providing home care for family members with advanced cancer. *Psycho-Oncology* **27**, 1229–1236. doi:10.1002/pon.4657
- Oechsle K, Ullrich A, Marx G, et al.** (2020) Prevalence and predictors of distress, anxiety, depression, and quality of life in bereaved family caregivers of patients with advanced cancer. *American Journal of Hospice & Palliative Medicine* **37**, 201–213. doi:10.1177/1049909119872755
- Oosterveld-Vlug MG, Custers B, Hofstede J, et al.** (2019) What are essential elements of high-quality palliative care at home? An interview study among patients and relatives faced with advanced cancer. *BMC Palliative Care* **18**, 96. doi:10.1186/s12904-019-0485-7
- Pottle J, Hiscock J, Neal RD, et al.** (2020) Dying at home of cancer: Whose needs are being met? The experience of family carers and healthcare professionals (a multiperspective qualitative study). *BMJ Supportive & Palliative Care* **10**, e6. doi:10.1136/bmjspcare-2016-001145
- Radbruch L, De Lima L, Knaul F, et al.** (2020) Redefining palliative care-A new consensus-based definition. *Journal of Pain & Symptom Management* **60**, 754–764. doi:10.1016/j.jpainsymman.2020.04.027
- Robinson CA, Bottorff JL, McFee E, et al.** (2017) Caring at home until death: Enabled determination. *Supportive Care in Cancer* **25**, 1229–1236. doi:10.1007/s00520-016-3515-5
- Rome RB, Luminais HH, Bourgeois DA, et al.** (2011) The role of palliative care at the end of life. *Ochsner Journal* **11**, 348–352.
- Salifu Y, Almack K and Caswell G** (2021) 'My wife is my doctor at home': A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliative Medicine* **35**, 97–108. doi:10.1177/0269216320951107
- Sung H, Ferlay J, Siegel RL, et al.** (2021) Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians* **71**, 209–249. doi:10.3322/caac.21660
- Sun V, Grant M, Freeman B, et al.** (2015) Effectiveness of an interdisciplinary palliative care intervention for family caregivers in lung cancer. *Cancer* **121**, 3737–3745. doi:10.1002/cncr.29567
- Tarberg AS, Kvangarsnes M, Hole T, et al.** (2019) Silent voices: Family caregivers' narratives of involvement in palliative care. *Nursing Open* **6**, 1446–1454. doi:10.1002/nop2.344
- Totman J, Pistrang N, Smith S, et al.** (2015) 'You only have one chance to get it right': A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer. *Palliative Medicine* **29**, 496–507. doi:10.1177/0269216314566840
- Treloar C, Champness S, Simpson PL, et al.** (2000) Critical appraisal checklist for qualitative research studies. *The Indian Journal of Pediatrics* **67**, 347–351. doi:10.1007/BF02820685