

Challenges and Facilitators for Psychosocial Support when Aging and Dying in Place: A Rapid Review of the Literature

Helena M. Daudt  and Emily L. Spargo 

Department of Education and Research, Victoria Hospice Society, Victoria, British Columbia, Canada.

Article

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Corresponding author:

La correspondance et les demandes de tirés-à-part doivent être adressées à : /
Correspondence and requests for offprints should be sent to: Helena M. Daudt, Ph.D., Department of Education and Research, Victoria Hospice Society, 4th floor, Richmond Pavilion, 1952 Bay St., Victoria BC, V8R 1J8, Canada (helena.daudt@painbc.ca)

Résumé:

Au Canada, la plupart des personnes âgées vivent à domicile et déclarent généralement qu'elles préfèrent y demeurer le plus longtemps possible. Ce souhait exerce une pression croissante sur les soutiens mis en place, dont ceux offerts par les proches aidants et les services communautaires. La recension rapide effectuée dans cette étude a pour but d'examiner les aspects psychosociaux du vieillissement et de la fin de vie sur place qui révèlent des lacunes dans les programmes et les services visant cette préférence. Nous avons effectué des recherches sur PubMed, PSYCINFO et Google Scholar pour recenser des articles évalués par des pairs. Quarante-deux articles ont été sélectionnés pour cette analyse, et ceux-ci ont été représentés sur un formulaire que nous avons créé et testé. Le manque d'attention portée à la personne dans son ensemble, le manque de préparation pour le parcours à venir et les difficultés à établir des relations de collaboration et de confiance sont les principaux défis recensés. Un ensemble d'initiatives dans la communauté pourraient être associées à une approche intégrée en soins palliatifs pour répondre à certains défis qui limitent les options en matière de vieillissement et de fin de vie sur place.

Abstract

Most seniors in Canada live at home and consistently indicate that they prefer to stay there for as long as possible. Consequently, this desire places increasing pressure on supports such as informal caregivers and community services. The current rapid review set out to examine the psychosocial aspects of aging and dying in place that point to gaps in programs and services to support this preference. We searched PubMed, PsycInfo, and Google Scholar for peer-reviewed entries, and identified 42 articles for analysis, which we charted on a form we created and tested. Lack of attention to the whole person, lack of preparation for the journey ahead, and difficulties establishing collaborative and trusting relationships were, broadly, the challenges identified. A blend of initiatives in the community combined with an integrated palliative approach to care may mitigate some of the challenges that limit options for aging and dying in place.

Background

The Canadian Institute for Health Information (2017) projected that the older seniors' population in Canada (those 75 years of age and older) will almost double in size within the next 20 years, from 2,600,000 to 5,700,000 people (6.2–10.4% of the overall Canadian population). In British Columbia, the older seniors' population is expected to reach almost 850,000 by 2037 (Statistics Canada, 2020). Stonebridge and Hermus (2017) indicate that as the Canadian seniors' population grows, health care services and supports will be strained. The incidence of frailty increases as people age, and frailty is associated with impaired functionality, which frequently requires ample resources to adequately address people's complex health needs (see also Compton et al., 2019).

Most seniors in Canada live at home and consistently indicate that they prefer to stay there for as long as possible (Compton et al., 2019; Health Council of Canada, 2012; Mustel Group Market Research & Sotheby's International Realty Canada, 2020). Aging in place generally requires a high level of in-home health services and the support of informal caregivers, usually family caregivers, to manage seniors' daily activities and attend to their health care needs (Health Council of Canada, 2012). Previous research suggests that there is a significant gap in adequate and effective support for family caregivers who wish to help their loved ones die at home (Reinhard, Given, Petlick, & Bemis, 2008; Robinson, Bottorff, McFee, Bissell, & Fyles, 2017). In the Canadian context, maintaining care supports is a critical step in efforts to meet the needs of seniors who choose to remain at home instead of living in long-term care (Hermus, Stonebridge, & Edenhoffer, 2015). The BC Care Providers Association forecasts a high demand for new

long-term care beds as a result of expected demographic shifts in our province. A portion of this demand could potentially be mitigated by ensuring that appropriate supports are in place in other areas of the continuing care sector, and by introducing and promoting new models of or approaches to care (Kary, 2019).

Hospice palliative care (HPC) aims to relieve suffering and improve the quality of living and dying (Canadian Institute for Health Information, 2018). HPC services generally encompass medical (e.g., pain and symptom management), personal care (e.g., bathing, grooming, and dressing), and psychosocial services (e.g., psychological support, spiritual care) (Canadian Hospice Palliative Care Association, 2013). Psychosocial services in the palliative care context attend to one's emotions, thoughts, attitudes, and behaviors, as well as the way in which a person relates to and interacts with their environment (palliAGED, 2021; World Health Organization, 2016). In HCP organizations, counsellors, social workers, and spiritual health professionals typically provide specialized psychosocial care to people experiencing life-limiting illnesses and to their families, including bereavement services. This structure is not universal, however, as different hospices provide various types of psychosocial services to their respective populations (Hospice Toronto, 2020; Hospice Yukon, 2021; Prince George Hospice Palliative Care Society, 2021).

A group of HPC professionals from British Columbia set out to assess the current state of HPC provided by hospices in British Columbia and to identify, with key stakeholders, how hospices can better support the challenges that the province will face considering the ongoing demographic shifts. The Provincial Hospice Working Group (PHWG) was established in 2019 with membership from the BC Centre for Palliative Care, BC Hospice and Palliative Care Association, the Sovereign Order of St. John, the Vancouver Island Federation of Hospices, and Victoria Hospice Society. The group's strategy included a literature review, a survey of hospice organizations in British Columbia, a roundtable discussion with provincial HPC experts and stakeholders, and the development of a report with key findings and recommendations. This article reports findings of the literature review portion of said work.

This literature review was undertaken in preparation for the PHWG roundtable discussion. The PHWG guided the development of our research question; the conclusions are, however, entirely those of the authors of this review. The authors had no access to the PHWG survey or its results prior to completing the review. The authors conducted this rapid review (RR) during their employment with Victoria Hospice Society, and no additional funding was sought or received for this study. The RR method is appealing in its ability to produce systematic results in a short amount of time (Tricco et al., 2015). RR is a type of systematic literature review in which some components of the systematic review method are simplified or omitted to produce a synthesis of available evidence, usually to support decision making in a short period of time without compromising the quality of findings (Haby et al., 2016). Although HPC services encompass medical, personal care, and psychosocial care services (Canadian Hospice Palliative Care Association, 2013), the PHWG was primarily interested in exploring the gaps in psychosocial care services and programs. Our review was guided by the question: *Which psychosocial aspects of aging and dying in place identified in the literature point to gaps in programs and services?*

This report follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco et al., 2018) slightly modified for this rapid review (Appendix 1 – online only).

Methods

Protocol and Study Selection

Our approach followed the working definition of RR and recommendations outlined by Tricco et al. (2015). The streamlined methods used in the current review included: limiting the literature search to peer-reviewed articles on three databases (PubMed, PsycInfo, and Google Scholar; no hand search, no contact with authors), limiting inclusion criteria by date and language, having one person screen articles and another verify screening, and presenting results in a narrative summary. We have focused on articles in English, German, and Portuguese according to the language proficiencies of the research team. Only studies that addressed psychosocial programming, psychosocial challenges, or psychosocial means of facilitating aging and dying in place were included. Studies not addressing seniors were excluded. We created a protocol to guide the RR, which is summarized in Table 1.

The initial protocol outlined was adjusted after work had begun. We decided to include “bereavement” and “grief” as terms in the search criteria, to exclude “screened studies for which we were unable to obtain full text” as well as “literature reviews without a thorough description of their review methods”. We also expanded the time frame of the search to “October 1, 2009 until May 1, 2020” to present updated information in this manuscript. Each category in the data collection framework for experiences/impact was further divided into “challenges” and “opportunities”.

Our study selection is summarized in Figure 1. The PsycInfo database search yielded a large number of items (59,795). After screening the first pages, we realized that there was an abundance of non-relevant entries. We then proceeded to filter results using each search terms as the first step in screening the results. This measure yielded a more manageable number of entries (2,111), which were then screened using established inclusion criteria. Screening and exclusion of abstracts was conducted by one reviewer and then verified by a second, who checked a random selection of excluded items. All full texts were read by two reviewers independently. Disagreements about exclusion of full texts were discussed until consensus was reached, and reasons for exclusion were recorded.

Data Abstraction

Data abstraction began using three articles (Grande et al., 2009; Jack, Mitchell, Cope, & O'Brien, 2016; Phongtankuel et al., 2016) from our initial sample, and these guided the organization of data into a chart format. Each team member independently conducted a thematic analysis of the articles using a combined inductive (data-driven) and semantic (following explicit meaning of the data) approach (Braun & Clarke, 2006). Each member generated major themes guided by our research question. The content of one of the articles (Grande et al., 2009) helped guide the development of the data collection chart, but was subsequently excluded from the review because the article's review method was not thoroughly described.

Once independent work was complete, we reconvened as a group to share our findings and discuss the identified themes in search of consensus. The final chart used for data abstraction included one page of demographic data: full citation, geographic location, expertise of the researchers, data collection method, study design, aim of the project, sample description, and setting of care. A second page of the chart focused on the psychosocial aspects of care and related services to support aging and dying in place, including the experiences of patients and caregivers, the experiences of health

Table 1. Rapid review protocol summary

Element	Our Approach
1. Research question	What gaps in programs and services have been identified in the literature related to psychosocial aspects of care that support aging and dying in place?
2. Time frame for the review	Two months (Fall 2019)
3. Eligibility criteria	Articles were included if: they provided information from the perspective of health care providers, patients, and/or families/informal caregivers; they discussed gaps in psychosocial programming or existing programs/services; they addressed the psychosocial challenges of layperson caregivers, family members, or unpaid caregivers; they addressed psychosocial related barriers to aging and dying in place or any psychosocial means of facilitating dying at home.
3.1 Type of studies	We considered qualitative, quantitative, and mixed-methods studies as well as literature reviews.
3.2 Type of publication	Peer-reviewed articles (no grey literature)
3.3 Publication date	October 1, 2009 – October 1, 2019
3.4 Language	English, German, and Portuguese
3.5 Search strategy	Three electronic databases were accessed: PubMed, PsycInfo, and Google Scholar. No hand search of cited literature in full articles was undertaken. Search terms included: <u>hospice</u> , <u>palliative care</u> , <u>health care</u> , <u>aging in place</u> , <u>dying in place</u> , <u>end of life</u> , <u>seniors</u> , <u>long-term care</u> , <u>nursing home</u> , <u>residential care</u> , <u>services</u> , <u>programs</u> , <u>support</u> , <u>opportunities</u> , <u>home care</u> , <u>carers</u> , <u>caregiving</u> , <u>caregivers</u> , <u>gaps</u> , <u>barriers</u> , <u>challenges</u> , <u>psychosocial needs</u> , <u>psychological service gaps for dying in place</u> , <u>psychological service needs for end of life in place</u> , <u>hospice psychological services for dying in place</u> , and <u>senior sociocultural gaps to hospice care at home</u> .
4. Exclusion criteria	Studies were excluded that did not mention psychosocial aspects of care, or focused only on pediatric hospice and palliative care, as well as commentaries, briefings, editorials, and perspective/opinion articles.
5. Data collection framework	In an Excel file (chart), we built one spreadsheet to collect general demographic characteristics of studies and a second to collect the experience of patients/caregivers and health care providers as well as impacts on the health care system related to the psychosocial aspects of care and associated services to support aging and dying in place (to be developed further after reading three articles).
6. Analysis and synthesis method	Thematic analysis and narrative synthesis were used.

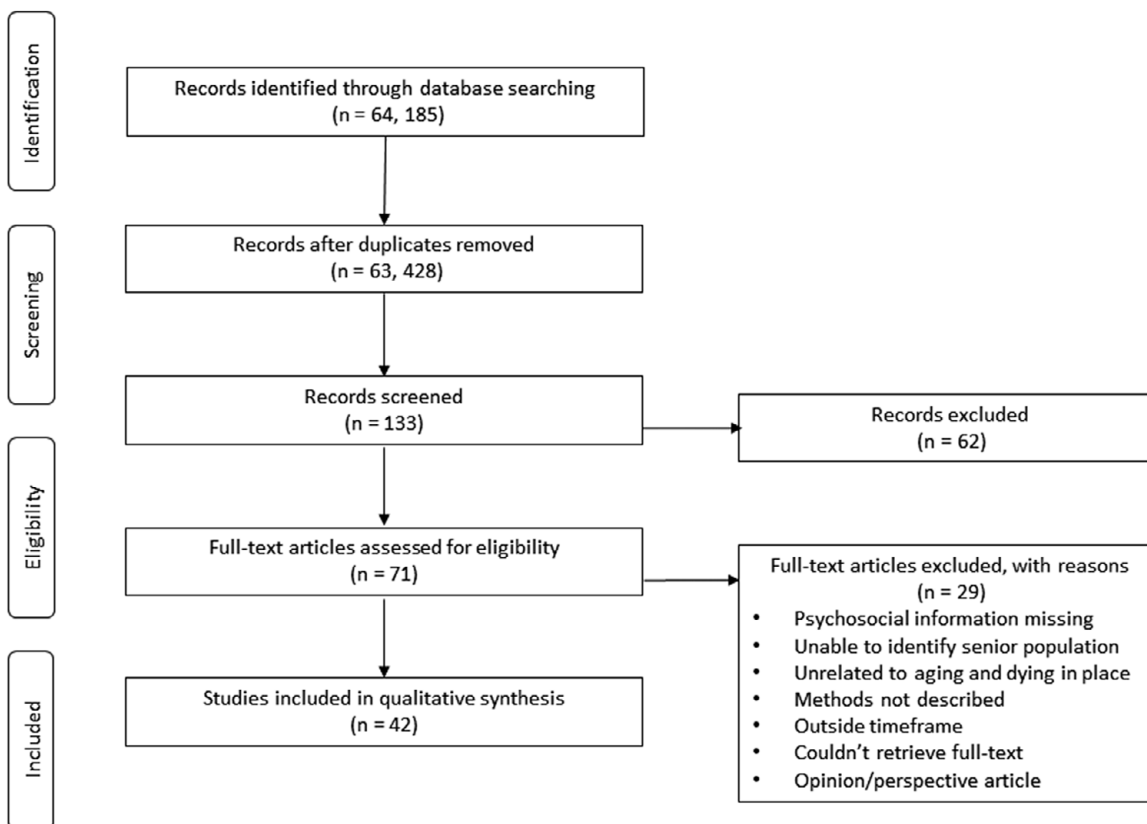


Figure 1. Flow chart of the literature search and selection process for inclusion in the review.

care providers, and impacts on health care systems. The term “caregiver” encompassed any unpaid caregiver, family-related or not. Within each category, we collected “challenges” and/or “opportunities”. Two team members read each article written in English and conducted data abstraction independently. Data abstracted was discussed when disagreements existed, until consensus was reached. The German-language articles were read by one reviewer, and data abstraction was conducted by the same person. Regrettably, no manuscripts written in Portuguese matched our inclusion criteria.

Quality Appraisal

All included literature was subject to quality assessment by two team members independently using validated tools, depending on the type of article: Mixed Method Appraisal Tool (MMAT) (Hong et al., 2018), Assessing the Methodological Quality of Systematic Reviews (AMSTAR 2) (Shea et al., 2017), or Health Evidence Quality Assessment Tool – Review Articles (Health Evidence, 2018). Quality assessments were discussed when disagreements existed, until a consensus was reached. No articles were eliminated during the quality appraisal phase.

Data Synthesis

Data were analyzed through thematic analysis. We followed the framework proposed by Braun and Clarke (2006), using a data-driven approach to analysis because of the descriptive nature of this study. We also chose to provide a thematic description of our entire data set, rather than a detailed account of one aspect of the data. After reading and re-reading the abstracted data, each team member generated codes independently. Based on the number of times and ways in which themes were raised in the literature, associated codes were determined and ranked by their importance to our research question. We then gathered as a team to share findings, discuss the identified codes, and refine themes for consensus.

Results

Included articles reported findings from a range of research study designs: qualitative (17 articles), quantitative (11 articles), mixed methods (5 articles), and literature reviews (9 articles). Roughly half of the articles were authored by researchers from the United Kingdom, only four were authored by researchers from Canada. The majority of articles (22 out of 42) included data obtained through interviews and/or focus groups. Five studies included patient primary data; 21 included caregiver primary data; and 3 included both. Table 2 summarizes the characteristics of the included articles.

Thematic Analysis

Guided by our research question, we were able to identify specific challenges related to psychosocial aspects of care that pointed to gaps in services/programs. In addition, we were able to tease out potential opportunities from the widespread challenges that patients, caregivers, and health care providers faced. As we embarked on our analysis of the literature, we realized that many of the included articles not only focused on services directly related to psychosocial aspects of care, but also included medical and or practical factors important to support aging and dying in place with

an impact on psychosocial health (Aoun, Ewing, Grande, Toye, & Bear, 2018; Danielsen, Sand, Rosland, & Førland, 2018; Ewing, Brundle, Payne, & Grande, 2013; Ewing & Grande, 2012; Fukui, Fujita, Tsujimura, Sumikawa, & Hayashi, 2011; Gomes, Calanzani, Koffman, & Higginson, 2015; Hashem, Brigden, Wilson, & Butler, 2020; Hutchinson & Van Wissen, 2017; Knighting et al., 2015; Lee et al., 2013; Mills, Rosenberg, & McInerney, 2015; Mogan, Lloyd-Williams, Harrison Denning, & Dowrick, 2018; Morris, King, Turner, & Payne, 2015; Oliver, 2010; Phongtankuel et al., 2016; Robinson et al., 2017; Sims-Gould & Martin-Matthews, 2010; Turner & Flemming, 2019; Waling et al., 2019; Wilson & Birch, 2017). We then expanded our original concept of “services/programs” to include practical and medical aspects of care. We identified four main themes: (1) lack of preparation for the journey ahead, (2) lack of attention to the whole person, (3) lack of collaborative and trusting relationships, and (4) facilitating caregiving at home. The first three themes are directly linked to our research question; the fourth one goes beyond the original goal and summarizes ways to address the challenges identified in the literature.

Lack of preparation for the journey ahead

Emotional turmoil. Both caregivers and patients experienced positive and negative feelings that changed as the end-of-life trajectory unfolded (Ewing et al., 2013; Ewing & Grande, 2012; Hutchinson & Van Wissen, 2017; Lee et al., 2013; Wilson & Birch, 2017; Woodman, Baillie, & Sivell, 2015). Positive feelings included peacefulness, a sense of giving back, and a sense of accomplishment in supporting the wishes of loved ones to die at home (Hammond & Baxter, 2019; Heath, Carey, & Chong, 2018; Hutchinson & Van Wissen, 2017; Lee et al., 2013; Robinson et al., 2017; Totman, Pistrang, Smith, Hennessey, & Martin, 2015; Woodman et al., 2015). These positive responses contrasted with feelings of guilt and despair, particularly for caregivers who could not keep their aging person within a familial environment, or when patients’ end-of-life preferences were not fulfilled (Heath et al., 2018; Woodman et al., 2015).

Caregivers’ physical and psychological health were impacted by the demands of the caregiving role, and depression and anxiety were often reported (DiGiacomo, Davidson, Byles, & Nolan, 2013; Dionne-Odom et al., 2017; Jack, O’Brien, Scrutton, Baldry, & Groves, 2014; Totman et al., 2015). Feeling homebound and sleep deprived contributed to the emotional distress of caregivers (Morris et al., 2015; Robinson et al., 2017; Totman et al., 2015). In addition, a sense of responsibility for patients’ well-being seemed to exacerbate the burden of caregiving (Totman et al., 2015).

Depression and anxiety affected patients at end of their lives (Fukui et al., 2011; Vassal, Le Coz, Hervé, Matillon, & Chapuis, 2011). Fukui et al. (2011) reported that palliative cancer patients experiencing depression and anxiety prior to discharge from hospital to home-care settings were less likely to have a home death than those who did not report depression and anxiety. Home death, however, was reported to positively influence bereaved caregivers’ mental health (Hatano et al., 2017).

Grief, including anticipatory grief, was a major challenge for caregivers. They valued bereavement support, although they did not always receive it (Aoun, Breen, White, Rumbold, & Kellehear, 2018; Bainbridge & Seow, 2018; Ewing & Grande, 2012; Hughes, Noyes, Eckley, & Pritchard, 2019; Knighting et al., 2015; Totman et al., 2015; Woodman et al., 2015). The reactive, rather than proactive, nature of bereavement supports, or the lack of services

Table 2. Characteristics of included articles

Author(s)/Year	Title	Setting of Care/ Location	Method	Aim of Project	Sample Description (N)	Funding	Quality Assessment
Aoun, Breen, et al. (2018)	The impact of supporting family caregivers before bereavement on outcomes after bereavement: Adequacy of end-of-life support and achievement of preferred place of death	Palliative care and homes in Australia	Quantitative; telephone survey	To investigate the extent to which using the Carer Support Needs Assessment Tool (CSNAT) intervention during the caregiving period has affected bereaved family caregivers' perceptions of adequacy of support, their grief and well-being, and achievement of their preferred place of death	n=212 bereaved family caregivers	Australian Research Council linkage grant and Silver Chain (grant no. LP110100622)	High
Bainbridge and Seow (2018)	Palliative Care experience in the last 3 months of life: A quantitative comparison of care provided in residential hospices, hospitals, and the home from the perspectives of bereaved caregivers	Residential hospice in Ontario, Canada	Quantitative; questionnaire	To capture the end-of-life care experiences across various settings from bereaved caregivers of individuals who died in residential hospice	n=1,153 caregivers	Cancer Care Ontario, Ministry of Health and Long-Term Care (Ontario), and Canadian Institutes of Health Research	High
Danielsen et al. (2018)	Experiences and challenges of home care nurses and general practitioners in home-based palliative care: A qualitative study	Homes and hospital in Norway	Qualitative; focus groups with semi-structured question guide	To achieve more insight, through home care nurses and general practitioners, of conditions that facilitate or hamper more time at home and more home deaths for patients with terminal disease and short life expectancy	n=19 home care nurses or GPs	Not declared	High
DiGiacomo et al. (2013)	An integrative and socio-cultural perspective of health, wealth, and adjustment in widowhood	Bereaved caregivers at home in Australia and the USA	Literature review; database search	To synthesize recent research and interventions and identify current trends and gaps in knowledge and services for widowhood	n=62 articles included in the review	Not declared	High
Dionne-Odom et al. (2017)	Participation and interest in support services among family caregivers of older adults with cancer	Home in the USA	Quantitative; cross-sectional mail survey across 8 cancer centers	To describe distressed and underprepared family caregiver's use of and interest in formal support services (e.g., professional counseling, education, organizational assistance)	n=294 caregivers	UAB Center for Palliative and Supportive Care PREP Grant; NIH/NINR, Grant/Award Numbers: R01NR013665 and 1K99NR015903; NIH/NCI UAB Cancer Center Core, Grant/Award Number: 5P30CA13148; American Cancer Society, Grant/Award Number: RSG PCSM-124668; National Palliative Care Research Center; National	High

(Continued)

Table 2. Continued

Author(s)/Year	Title	Setting of Care/ Location	Method	Aim of Project	Sample Description (N)	Funding	Quality Assessment
						Cancer Institute, Grant/Award Number: 2R25CA047888-24	
Ewing et al. (2013)	The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: A validation study	Bereaved caregiver homes in the UK	Qualitative; focus groups and telephone interviews	To obtain carers' perspectives on key aspects of support needed during provision of end-of-life care at home and to develop a carer support needs assessment tool suitable for use in everyday practice	n=75 adult bereaved carers who were family members/friends of patients referred to five Hospice at Home services	Dimbleby Cancer Care Research Fund	High
Ewing and Grande (2012)	Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study	Caregiver homes in Manchester, UK	Mixed methods; questionnaires, interviews, and advisory group	To assess face, content, and criterion validity of the CSNAT and measure sensitivity to change over time	n=225 adult carers of patients from six UK hospice home care services	Burdett Trust for Nursing (Grant reference number 392/451)	High
Fukui et al. (2011)	Predictors of home death of home palliative cancer care patients: A cross-sectional nationwide survey	Hospitals and homes in Japan	Quantitative; cross-sectional nationwide survey	To identify factors influencing the place of death among home palliative cancer care patients, focusing on the role of nurses in terms of pre- and post-discharge from hospital to home care settings	n=568 primary community nurses of home palliative patients just after their hospital discharge	Grant-in-Aid for Encouragement of Young Scientists (A) from the Japan Society for the Promotion of Science (JSPS) (No.19689041)	High
Gauthier and Gagliese (2012)	Bereavement interventions, end-of-life cancer care, and spousal well-being: A systematic review	Bereavement, but patients in specialized end-of-life care in China, USA, Sweden, and England	Systematic review; database search	To determine outcomes of bereavement interventions and adjustment to bereavement following specialized end-of-life patient care for spouses of patients with cancer	n=10 articles were included in the review	Canadian Breast Cancer Research Alliance, Canada Foundation for Innovation, Ontario Ministry of Health and Long Term Care	Moderate
Gomes et al. (2015)	Is dying in hospital better than home in incurable cancer and what factors influence this?	Homes and hospitals in London, UK	Quantitative; questionnaires	To determine the association among place of death, health services used, and pain, feeling at peace, and grief intensity	n=352 bereaved relatives of 352 cancer patients (≥18 years-old) who died in hospital (n = 177) or at home (n = 175)	Cicely Saunders International, Department of Health	High
Hashem et al. (2020)	Understanding what works, why, and in what circumstances in Hospice at Home Services for End of Life Care: Applying a realist logic of analysis to a systematically searched literature review	Hospice and patient homes in England	Systematic review	To find out in the existing literature what features of hospice at home models work best, for whom, and under what circumstances	n=34 articles accepted for final synthesis	No financial support	High

(Continued)

Table 2. Continued

Author(s)/Year	Title	Setting of Care/ Location	Method	Aim of Project	Sample Description (N)	Funding	Quality Assessment
Hatano et al. (2017)	The relationship between cancer patients' place of death and bereaved caregivers' mental health status	Hospice at home, palliative care units, and acute hospitals in Japan	Quantitative; nationwide, cross-sectional questionnaire	To examine the relationship between cancer patients' place of death and bereaved caregivers' mental health	n=8,968 bereaved caregiver responses were analyzed	Japan Hospice Palliative Care Foundation	High
Heath et al. (2018)	Helping carers care: An exploratory study of factors impacting informal family carers and their use of aged care services	Homes in Australia	Mixed methods; survey with open- and closed- ended questions	To consider the role of informal carers and their decision making regarding various aged care services that supposedly support their ageing relatives	n=44 carers of aging relatives	Not declared	High
Hudson et al. (2012)	Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients	Australia	Mixed methods; literature review, focus groups, and structured interviews	To develop clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients	n=5 stakeholders participated in a focus group, 9 participated in an interview, and 2 provided written feedback; n=26 survey respondents	Beyond blue: the national depression initiative	High
Hudson et al. (2013)	Reducing the psychological distress of family caregivers of home-based palliative care patients: Short-term effects from a randomised controlled trial	Homes in Australia	Quantitative; 3 arm, randomized control trial	To prepare caregivers for the role of supporting a patient with advanced cancer receiving home-based palliative care by offering a one-to-one psycho-educational intervention	n=298 caregivers	NH & MRC Grant, Commonwealth Department of Health & Aging	Moderate
Hughes et al. (2019)	What do patients and family-caregivers value from hospice care? A systematic mixed studies review	Hospice in the UK	Systematic review; sequential exploratory design	To explore patients' and their family carers' views and experiences, to determine what they valued about adult hospice care in the UK	n=34 studies reviewed	Knowledge Economy Skills Scholarship (KESS2)	High
Hutchinson and Van Wissen (2017)	Home to die from the intensive care unit: A qualitative descriptive study of the family's experience	Patient homes and ICU in New Zealand	Qualitative; unstructured interviews	To gain insight into family members' experiences when an adult ICU patient is taken home to die	n=4 participants from 2 different families whose family member was taken home from the ICU to die.	No specific funding	High
Jack et al. (2014)	Supporting family carers providing end-of-life home care: A qualitative study on the impact of a hospice at home service	Hospice at home service in the UK	Qualitative; semi-structured interviews	To explore patients' and family caregivers' experiences and perceptions of Hospice at Home care	n=41 patients and family caregivers involved with a hospice at home service	Merseyside & Cheshire Palliative & End of Life Care Network	High
Jack et al. (2016)	Supporting older people with cancer and life-limiting conditions dying at home: A qualitative study of	Hospice at Home service in the UK	Qualitative; semi-structured interviews	To explore bereaved family carers' perceptions and experiences of a hospice at home service	n=20 family carers	Cheshire and Merseyside Palliative and End-of-life Care Network	High

(Continued)

Table 2. Continued

Author(s)/Year	Title	Setting of Care/ Location	Method	Aim of Project	Sample Description (N)	Funding	Quality Assessment
	patient and family caregiver experiences of Hospice at Home care						
Knighting et al. (2015)	Gaining consensus on family carer needs when caring for someone dying at home to develop the Carers' Alert Thermometer (CAT): A modified Delphi study	Caregivers homes in the UK	Mixed methods; multi-phased modified Delphi study and instrument development	To identify the priority areas for inclusion in an alert screening tool for carers providing support to someone dying at home	n=111 carers, n=93 health care professionals	National Institute for Health Research (NIHR) - Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0909-20188)	High
Kobayakawa et al. (2016)	Family caregivers require mental health specialists for end-of-life psychosocial problems at home: A nationwide survey in Japan	Home hospice in Japan	Quantitative; questionnaire	To find out how best to support caregivers at home	n=628 caregivers	Japan Hospice Palliative Care Foundation	High
Lee et al. (2013)	Providing hospice home care to the terminally ill elderly people with cancer in Taiwan: Family experiences and needs	Homes in Taiwan	Qualitative; semi-structured interviews	To explore caregivers' experiences and needs when providing hospice home care to their terminally ill elderly patients with cancer in Taiwan	n=44 caregivers	No financial support	High
Lum et al. (2016)	Neighborhood support and aging-in-place preference among low-income elderly Chinese city-dwellers	Homes in China	Quantitative; face-to-face interviews using various questionnaires	To investigate the preferences for aging-in-place and its contributing neighborhood factors among low-income Chinese elderly in a metropolitan city	n=400 low-income older adults	Hong Kong Housing Society	High
Milligan et al. (2016)	Unpacking the impact of older adults' home death on family caregivers' experiences of home	Homes in England, UK	Qualitative; interviews	To elicit an in-depth understanding of how facilitating a home death can create an ambiguity of place for carers	n=59 bereaved family caregivers who cared for someone dying at home	Marie Curie Cancer Care	High
Mills et al. (2015)	Building community capacity for end of life: An investigation of community capacity and its implications for health-promoting palliative care in the Australian capital territory	Community in Australia	Qualitative; in-depth semi-structured interviews	To identify and examine both organizational and community-based activities focused on building community capacity around death, dying, and end-of-life care	n=10 caregivers	Australian Catholic University (Faculty of Health Sciences) Honours Student Support Scheme	High
Mogan et al. (2018)	The facilitators and challenges of dying at	Patient homes in the UK	Literature review; narrative synthesis	To identify and understand the challenges to and facilitators of providing end-	n=7 studies met all eligibility criteria	Economic and Social Research Council (ESRC)	High

(Continued)

Table 2. Continued

Author(s)/Year	Title	Setting of Care/ Location	Method	Aim of Project	Sample Description (N)	Funding	Quality Assessment
	home with dementia: A narrative synthesis		of qualitative and quantitative data	of-life care at home for people with dementia			
Morris et al. (2015)	Family carers providing support to a person dying in the home setting: A narrative literature review	Homes in the UK	Narrative literature review; database search including grey literature	To review the literature relating to the perspectives of family carers providing support to a person dying at home	n=28 studies were included	No specific funding	High
Nicholson et al. (2013)	The experience of living at home with frailty in old age: A psychosocial qualitative study	Homes in England	Qualitative; observation, psychosocial narrative analysis	To understand the experience over time of home-dwelling older people deemed frail, in order to enhance the evidence base for person-centred approaches to frail elder care	n=15 frail older adults	The Health Care Foundation via the Health Care Consortium	High
Oliver (2010)	The relevance of psychosocial indicators in community palliative care: A pilot study	Community palliative care service in Australia	Qualitative; interviews	To discuss a framework in psychosocial care in community palliative care and the outcomes of a pilot study	n=6 participants composed of palliative care nurses and allied health professionals	School of Nursing & Midwifery at the University of Western Sydney, endorsed by the Australian Practice Nurses Association	High
Perner et al. (2012)	Quality of life and satisfaction of family caregivers in palliative care—Results of postmortem interviews with bereaved family members	Outpatient palliative care in Germany	Qualitative; interviews	To evaluate quality of life and satisfaction with medical care in bereaved family members	n=44 bereaved family caregivers	Else Kröner-Fresenius Foundation	High
Phongtankuel et al. (2016)	Why do home hospice patients return to the hospital? A study of hospice provider perspectives	Patient homes and hospital in New York City, USA	Qualitative; semi-structured focus groups	To understand the reasons for hospitalization among home hospice patients through the perspectives of hospice interdisciplinary team (IDT) members	n=73 home hospice interdisciplinary team members from a not-for-profit hospice agency in New York City	National Institute on Aging (P30AG022845), the National Institute on Drug Abuse (R21DA038163), the Howard and Phyllis Schwartz Philanthropic Fund (DA038163), the John A. Hartford Foundation, and the Empire Clinical Research Investigator Program	High
Pleschberger and Wosko (2015)	Informal non-kin support for elderly people living alone and end of life care: Literature review	Care at home with non-kin, informal caregivers	Scoping review	To investigate how non-kin carers support older people living alone; e.g., to fulfill their preference for dying at home	n=12 articles included in final review	Austrian Federal Ministry of Social Affairs, Health, Care and Consumer Protection	High

(Continued)

Table 2. Continued

Author(s)/Year	Title	Setting of Care/ Location	Method	Aim of Project	Sample Description (N)	Funding	Quality Assessment
Robinson et al. (2017)	Caring at home until death: enabled determination	Caregivers' homes in BC, Canada	Qualitative; semi-structured interviews in-person and over the phone	To describe the experiences of bereaved family caregivers whose terminally ill family members with advanced cancer were successful in achieving a desired home death	n=29 bereaved adult family caregivers (≥19 years of age) who had provided care for a family member with advanced cancer and experienced a home death	British Columbia Cancer Foundation (no. 62R17410)	High
Sims-Gould and Martin-Matthews (2010)	We share the care: Family caregivers' experiences of their older relative receiving home support services	Homes in BC, Canada	Qualitative; in-depth interviews	To extend our understanding of the salient issues in delivery of home support from the perspective of family caregivers, and to examine the contributions and dynamics between family caregivers and home support workers	n=52 family caregivers who have or had an older relative receiving home support services in BC in the past 12 months	Not declared	High
Sixsmith et al. (2019)	Ageing-in-place for low-income seniors: Living at the intersection of multiple identities, positionalities, and oppressions	Homes in Metro Vancouver, BC, Canada	Mixed methods; in-depth interviews	To provide recommendations for place-based policy and practice in order to inform guidelines for future senior housing projects	n=25 older, low income male and female tenants transitioning into an affordable housing development	Vancouver Foundation	High
Totman 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	Inner-city home hospice in London, UK	Qualitative; semi-structured interviews	To explore the emotional challenges faced by home caregivers, and their experiences of health care professionals, from the perspective of existential psychology	n=15 recently bereaved adult relatives (age ≥21) of cancer patients who cared for their family member at home	No specific funding – part of doctoral thesis	High
Turner and Flemming (2019)	Socioeconomic factors affecting access to preferred place of death: A qualitative evidence synthesis	Care homes and community in the UK	Literature review; database search	To systematically synthesize the existing qualitative evidence for socio-economic factors affecting access to preferred place of death in the UK	n=13 articles related to UK health system were included in the synthesis	No financial support	High
Vassal et al. (2011)	Return home at the end of life: Patients' vulnerability and risk factors	Hospital in France	Quantitative; multi-centric, observational, prospective, exhaustive, and longitudinal epidemiological study	To clarify how the return home is influenced by the vulnerability of the patient at the end of life, and by that of the family and caregivers	n=46 patients hospitalized at the end of their lives desiring to return home	No specific funding	High
Waling et al. (2019)	Experiences and perceptions of residential and home care services among	Residential care and homes in Australia	Qualitative; semi-structured interviews	To explore participants' perceptions and experiences of residential-care and home-care	n=33 cisgender gay men and lesbian women	Australian Research Council (LP160100221)	High

(Continued)

Table 2. Continued

Author(s)/Year	Title	Setting of Care/ Location	Method	Aim of Project	Sample Description (N)	Funding	Quality Assessment
	older lesbian women and gay men in Australia			services, and the rationale behind current and future decision processes in accessing (or not accessing) aged-care services			
Wilson and Birch (2017)	Moving from place to place in the last year of life: A qualitative study identifying care setting transition issues and solutions in Ontario	Hospice, hospital and homes in Ontario, Canada	Qualitative; semi-structured interviews and observation	To identify current issues or problems with care setting transitions during the last year of life as well as potential or actual solutions for these problems	n=38 health care professionals, caregivers and patients	Law Commission of Ontario	High
Woodman et al. (2015)	The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of- life. A systematic review and thematic synthesis of the qualitative evidence	Hospice, hospitals, and homes in the UK	Systematic review	To systematically search and synthesize the qualitative literature exploring the preferences and perspectives of family caregivers towards place of care for their relatives at the end of life	n=28 articles included	Marie Curie Cancer Care core grant funding to the Marie Curie Palliative Care Research Centre, Cardiff University School of Medicine (MCCC-FCO-14-C and MCCC-FCO-14-C), National Institute for Health Research (NIHR) Health Technology Assessment (HTA) clinical trial (ALICATref. 10/145/01)	Moderate
Wright et al. (2010)	Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health	Hospitals and homes in the USA	Quantitative; structured clinical interviews	To determine whether the place of death for patients with cancer is associated with patients' quality of life at the end of life, and psychiatric disorders in bereaved caregivers	n=342 patients with advanced cancer and their caregivers	National Institute of Mental Health (MH63892), National Cancer Institute (CA106370), National Cancer Institute (5R25CA092203), and the ASCO Cancer Foundation Young Investigator Award	High

were frequently seen as problematic and resulted in many caregivers foregoing support altogether (Hughes et al., 2019).

Relating to others. Loss of mobility associated with physical decline evoked an emotional response from patients, sometimes expressed as a sense of shame. For example, this feeling could, in turn, result in perceived social isolation, as patients avoided going outside because of their sense of shame about requiring walking aids (Nicholson, Meyer, Flatley, & Holman, 2013). Loneliness and isolation were very common for aging and dying persons and their caregivers. These two commonly related experiences were compounded by the absence of a support network, frequently constituting the main barrier to aging and dying at home (Turner & Flemming, 2019). In general, these issues were inadequately addressed, with very little or no preparation for what was ahead (Hammond & Baxter, 2019; Mogan et al., 2018; Morris et al., 2015; Pleschberger & Wosko, 2015; Sixsmith et al., 2019; Totman et al., 2015; Woodman et al., 2015).

...like that first night we came home from the hospital [...] I was really sad, because suddenly when we left the hospital I realised we were on our own (Caregiver, Totman et al., 2015, p. 501).

Losing the relationship once held with the dying person and grieving before the death was particularly challenging for caregivers (Totman et al., 2015). On the other hand, patients did not wish to become a burden for caregivers, and this influenced their decisions regarding whether to remain at home (Turner & Flemming, 2019). Maintaining personal autonomy was particularly important for members of marginalized populations such as lesbian and gay older adults, who expressed concerns about discrimination, hostility, and potential elder abuse (Waling et al., 2019).

In many instances, having to advocate strongly for their loved one's interests may have exacerbated the emotional distress experienced by caregivers (Totman et al., 2015). In addition, family caregiver disagreements around decision making could add another layer to the emotional distress experienced by families of persons aging and dying at home (Wilson & Birch, 2017; Woodman et al., 2015).

Information and resources. Many patients aging and dying at home and their caregivers felt lost, and they were not always aware of the supportive resources available to them (Bainbridge & Seow, 2018; Dionne-Odom et al., 2017; Ewing & Grande, 2012; Hashem et al., 2020; Morris et al., 2015; Woodman et al., 2015). General information needs (Wilson & Birch, 2017) and equipment retrieval and instruction in the home (Ewing et al., 2013; Ewing & Grande, 2012; Hashem et al., 2020; Mogan et al., 2018; Robinson et al., 2017), as well as answers to questions related to legal proceedings and finances (Ewing et al., 2013; Ewing & Grande, 2012; Hashem et al., 2020; Knighting et al., 2015; Sixsmith et al., 2019; Wilson & Birch, 2017) were broadly highlighted as neglected aspects of care, adding to the burden of suffering and caregiving. DiGiacomo et al. (2013) reported that the loss of financial resources had an impact on the physical and mental well-being of widows, consequently having a negative impact on bereavement.

Remaining at home required support with housework, physical care, and navigating various systems. A lack of support in these areas negatively affected patients' and caregivers' ability to cope, and caused distress (Ewing et al., 2013; Ewing & Grande, 2012; Knighting et al., 2015; Morris et al., 2015; Woodman et al., 2015). Some caregivers, however, had difficulty accepting help out of a sense of personal responsibility to their dying loved one, and

occasionally felt judged as inadequate by direct observations from paid health care providers (Jack et al., 2014, 2016; Robinson et al., 2017). Persons aging and dying at home reported choosing to manage without help for many reasons, including the fear of losing autonomy, confidence, and personhood (Nicholson et al., 2013; Turner & Flemming, 2019).

The meaning of home. An additional challenge was the need to change the overall home environment when the decision was made to care for a loved one at home. Home was described as more than a physical space in some articles; it was viewed as a site of intimate personal and socio-emotional relationships (Milligan et al., 2016; Morris et al., 2015). Caregivers reported that the home environment changed negatively as unfamiliar items such as commodes and lifts became part of their life (Morris et al., 2015). There was a loss of privacy expressed by caregivers, and a feeling that their personal space shrank (Morris et al., 2015; Woodman et al., 2015). Caregivers' relationship with their home could change again after the death of their loved ones. Many people avoided some parts of the home or felt the need to redecorate to cope with the absence of the deceased (Milligan et al., 2016; Morris et al., 2015). DiGiacomo et al. (2013) pointed out that the death of a husband could directly affect the widow's living arrangement (needing to move, for example) causing stress, anxiety, and depression.

Lack of attention to the whole person

Symptom management. Although the review's focus was on the psychosocial aspects of care, much of the reviewed literature emphasized that the need to address physical symptoms of patients and caregivers was directly related to supporting the psychosocial aspects of aging and dying in place. Difficulties with managing patients' symptoms were overwhelming for caregivers (Phongtankuel et al., 2016; Woodman et al., 2015), and discomfort in dealing with medications and administering opioids was particularly challenging (Ewing et al., 2013; Ewing & Grande, 2012; Hashem et al., 2020; Morris et al., 2015)

[...] Symptom management is crucial as this is integral to psychosocial care because you can't separate the physical from the patient's psyche; it is the holistic aspects of care that results in quality psychosocial care (Healthcare provider, Oliver, 2010, p. 25).

Psychological support. In general, the challenge of managing crises at home was a common reason for emergency department admissions and hospitalizations, as caregivers felt the emotional burden of providing care in these situations (Ewing et al., 2013; Ewing & Grande, 2012; Gomes et al., 2015; Hughes et al., 2019; Mogan et al., 2018; Phongtankuel et al., 2016; Robinson et al., 2017; Wilson & Birch, 2017). Although psychosocial distress was commonly reported and may have required mental health professionals to support caregivers (Kobayakawa et al., 2016), this support was not always provided (Perner, Köhler, Brähler, & Götze, 2012).

Having a specific point of contact for assistance, especially during times of crisis, provided reassurance while remaining at home; however, having someone to turn to was not always a reality (Ewing et al., 2013; Ewing & Grande, 2012; Gomes et al., 2015; Hashem et al., 2020; Hughes et al., 2019; Knighting et al., 2015; Mogan et al., 2018). Moreover, a lack of supports during times of transition, such as from hospice to home, was particularly detrimental to caregivers' ability to cope, and took away from continuity of care (Bainbridge & Seow, 2018; Danielsen et al., 2018; Ewing &

Grande, 2012; Hashem et al., 2020; Hutchinson & Van Wissen, 2017; Jack et al., 2016; Phongtankuel et al., 2016; Robinson et al., 2017; Wilson & Birch, 2017; Woodman et al., 2015).

Spiritual support. Spiritual suffering, accompanied by a loss of confidence and feelings of guilt, was relatively common for patients (Vassal et al., 2011). Support to maintain spiritual well-being, however, was not always available (Bainbridge & Seow, 2018; Ewing et al., 2013; Ewing & Grande, 2012; Morris et al., 2015; Totman et al., 2015). Acknowledging dread and being supported through fear was a critical issue mentioned in the literature. Bainbridge and Seow (2018) found that a large number of close to 400 patients receiving end-of-life care rated satisfaction with spiritual support lower than satisfaction with other forms of support, independent of care setting.

You know, if you're so gripped with fear about everything, you're already kind of dead. (Caregiver, Totman et al., 2015, p. 502).

Lack of collaborative and trusting relationships

Communication. Caregivers often felt unsupported, overlooked, and let down by health care providers when caring for people at home (Totman et al., 2015; Woodman et al., 2015). Communication was particularly linked to the ability to age and die in place, and a lack thereof, negatively impacted the psychosocial well-being of patients and caregivers alike. Both groups highlighted poor communication with health care providers, which was worsened, in many instances, by a lack of empathy, avoidance of difficult conversations, and professionals failing to acknowledge patients' and families' preferences (Danielsen et al., 2018; Hashem et al., 2020; Mogan et al., 2018; Morris et al., 2015; Perner et al., 2012; Totman et al., 2015; Wilson & Birch, 2017). This posed a major barrier to continuity of care and effective coping during the end-of-life process (Danielsen et al., 2018; Hashem et al., 2020; Totman et al., 2015; Wilson & Birch, 2017).

Rapport. Lack of rapport with the at-home care team negatively affected the ability of patients and caregivers to form trusting relationships (Danielsen et al., 2018; Kobayakawa et al., 2016; Mogan et al., 2018; Morris et al., 2015; Perner et al., 2012). Health care providers' attention to cultural and religious differences was also a gap in various situations, complicated by language barriers or needs related to faith-specific practices, for example (Morris et al., 2015; Sixsmith et al., 2019; Totman et al., 2015).

Death literacy. Lack of broad discussions regarding death, dying, and advance care planning, commonly addressed as "death literacy", was considered a gap (Bainbridge & Seow, 2018; Ewing et al., 2013; Gomes et al., 2015; Hashem et al., 2020; Wilson & Birch, 2017), as was support in decision making (Ewing & Grande, 2012; Knighting et al., 2015; Robinson et al., 2017; Woodman et al., 2015). That, in turn, had an impact on patients' and caregivers' lack of understanding about illness progression and often led to difficulties when discussing life expectancy, which caused additional worry and distress to caregivers (Ewing & Grande, 2012; Hutchinson & Van Wissen, 2017; Robinson et al., 2017). Preparing for the future was of utmost importance for both caregivers and patients (Fukui et al., 2011; Hatano et al., 2017; Hudson et al., 2012; Totman et al., 2015):

...although you know kind of in the background, sometimes it helps when someone says it, you know, this is what you can expect (Caregiver, Totman et al., 2015, p. 502).

Facilitating caregiving at home

Community resources. Maintaining social networks was very important for aging persons and caregivers alike, and these networks included not only family and friends but also community groups (Hughes et al., 2019; Mills et al., 2015; Sixsmith et al., 2019; Totman et al., 2015). Their support went beyond emotional support for caregivers through connection and empowerment including, in many cases, practical support such as assistance with financial planning and navigation (Mills et al., 2015). DiGiacomo et al. (2013), however, pointed out that social support is not a one-size-fits-all construct, and satisfaction with its availability may vary depending on individuals' unique needs and contexts.

Empowering opportunities for social connection offered the potential for meaning making among patients and caregivers or between caregivers (Mills et al., 2015; Nicholson et al., 2013; Totman et al., 2015). Consistent, reliable social networking promoted connectedness and facilitated staying at home at the end of life (Lum et al., 2016; Mogan et al., 2018; Woodman et al., 2015). Community resources focused on grief and bereavement represented an option to address anticipatory grief (Mills et al., 2015). Further, bereavement support groups and interventions in the community may positively influence bereavement outcomes (DiGiacomo et al., 2013; Gauthier & Gagliese, 2012). Finally, public education initiatives focused on death and dying, particularly advance care planning, could prevent transition problems between care settings (Wilson & Birch, 2017).

Care at home. The presence of high-quality home care was a major facilitator of aging and dying in place, whereas poor quality of home care or inappropriate home environments were detrimental (Turner & Flemming, 2019). Care at home was provided mostly by nurses and health care support workers who may or may not be connected to a hospice. Establishing close collaboration among health care professionals, caregivers, and patients early in their trajectory was reported to be essential (Danielsen et al., 2018; Hughes et al., 2019). Trusting relationships with formal support networks based on reciprocal empathy and maintaining normality were seen as crucial. Such relationships had a positive impact on patients' emotions and on caregivers' ability to cope with their role (Danielsen et al., 2018; Hashem et al., 2020; Hudson et al., 2013; Hughes et al., 2019; Jack et al., 2014; Sims-Gould & Martin-Matthews, 2010; Woodman et al., 2015).

I would say that one of the biggest ones [supports] for my mom is the companionship. Conversation, having a tea or coffee... they sit down. They have a cup of tea... she does what she needs to do but she's also very good company for my mother (Caregiver, Sims-Gould & Martin-Matthews, 2010, p. 419).

Active general practitioner (GP) engagement in end-of-life care was seen as important in supporting the physical and mental well-being of the patient with whom they had a long-standing, trusting relationship. Home care teams also valued GPs' long-term knowledge of the patients' health, which enhanced continuity of care (Danielsen et al., 2018; Gomes et al., 2015; Hashem et al., 2020). Mogan et al. (2018) highlighted that, "no matter the model of care provided, regular contact with a healthcare professional, and not necessarily a palliative care specialist, might play an important role in end-of-life care at home for people with dementia" (p. 1049). Care at home could be enhanced by professionals conducting systematic needs assessments with caregivers (Hammond & Baxter, 2019; Hudson et al., 2012; Wilson & Birch, 2017). These

assessments should include psychological and physical health, social, spiritual, cultural, financial, and practical elements (Aoun, Breen, et al., 2018; Hudson et al., 2012; Jack et al., 2014). Aoun, Breen, et al. (2018) found that bereaved caregivers who received a nursing intervention that assessed needs before the death reported benefits. They perceived their support needs as being better met and experienced less strain than the control group who did not receive equivalent interventions.

Caregivers pointed out that proactive equipment training provided by the health care team would help them support their loved one's desire to die at home (Ewing et al., 2013; Ewing & Grande, 2012; Hashem et al., 2020; Mogan et al., 2018; Robinson et al., 2017). They reported feeling reassured particularly when they received validation from formal caregivers related to the task that they were doing (Jack et al., 2014).

Made me feel that we were doing everything we should do, there's always a doubt in your mind that "oh, what if?," "should I do this; should I do that?," but they allowed you to stand back and think "actually, there isn't anything else that we can do; this is the best it is" (Caregiver, Jack et al., 2014, p. 135).

Hospice care. Hospice at home, hospice day care, or community-based hospice programs were highlighted as successful facilitators of aging and dying in place (Bainbridge & Seow, 2018; Hashem et al., 2020; Hughes et al., 2019; Jack et al., 2014, 2016; Mogan et al., 2018; Woodman et al., 2015). Hospice clinical staff teams were recognized as highly trained to support not only the medical needs, but also the psychosocial needs of patients and caregivers (Hashem et al., 2020; Jack et al., 2014, 2016). Features such as the emotional and practical support to caregivers offered by night-sitting services (e.g., reassurance and peace of mind that patients were being looked after) were reported to be integral supports for caregivers (Hashem et al., 2020; Hughes et al., 2019; Jack et al., 2014).

The support of a palliative care team for caregivers supporting their loved ones at home gave them the ability to continue with normal life as much as possible (Jack et al., 2014, 2016; Morris et al., 2015). Hospice at home helped to relieve the strain on caregivers, gave people time to balance their own lives with new duties, and had positive effects on bereaved caregivers' mental health (Jack et al., 2014, 2016; Wright et al., 2010).

She did the ironing for me – it sounds like such a simple little thing – but it meant the next day instead of sitting doing the ironing I took mum out for the day, and just being able to do that was just ... it was just so nice. (Caregiver, Jack et al., 2014, p. 136).

Direct telephone lines for support (Hashem et al., 2020; Hughes et al., 2019; Mogan et al., 2018) as well as crisis intervention teams (Danielsen et al., 2018; Mogan et al., 2018; Phongtankuel et al., 2016) were opportunities identified for future exploration. Caregivers pointed out that initiation of respite care or increased hours of respite services could also better support their caregiving role by allowing them to address their own need for rest (Ewing et al., 2013; Ewing & Grande, 2012; Hashem et al., 2020; Hughes et al., 2019; Jack et al., 2014; Knighting et al., 2015; Robinson et al., 2017). Anticipatory rather than reactive care was referenced as an opportunity to prevent distress and reduce hospital admissions (Hashem et al., 2020; Hughes et al., 2019).

Figure 2 summarizes the challenges and opportunities we identified.

Discussion

We set out to identify psychosocial aspects of aging and dying in place that would point to gaps in programs and services, in preparation for a discussion with key stakeholders within the British

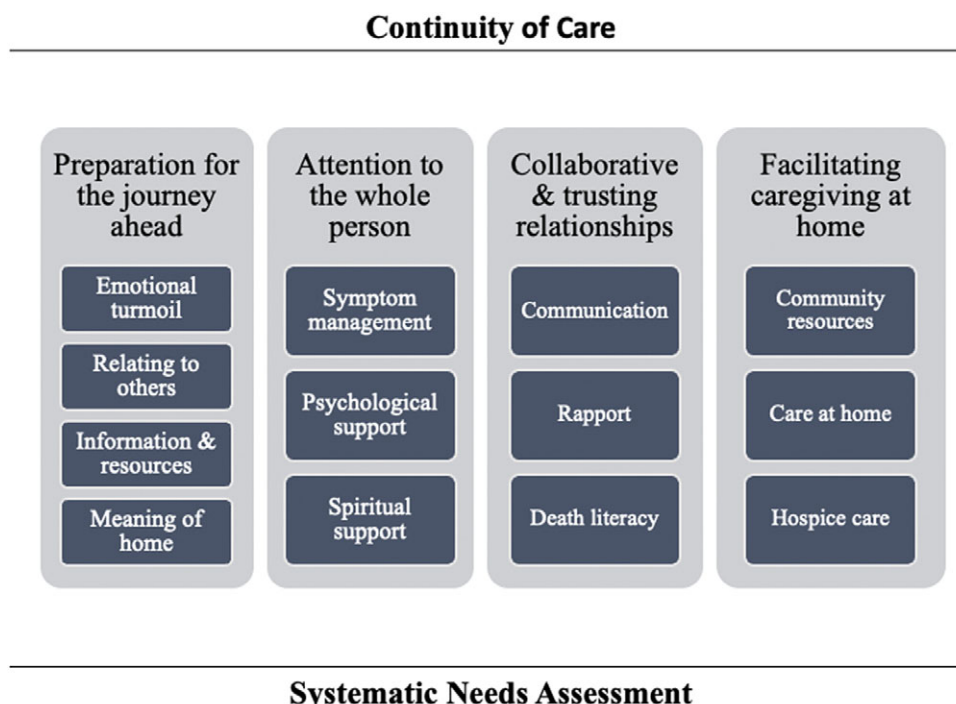


Figure 2. Summary of Semantic Analysis Results.

Columbia hospice palliative care sector. That discussion would explore how hospices can best support British Columbia's communities through the ongoing and accelerating demographic shifts. The multitude of psychosocial, practical, and medical issues emerging from an aging population demonstrates the current shortfall in programs and services but, conversely, highlights promising opportunities to address those gaps. Lack of attention to the whole person (dying person and caregivers), lack of preparation for the journey ahead, and lack of collaborative and trusting relationships were gaps affecting the psychosocial well-being of patients and caregivers that permeated most of the reviewed literature. We believe that a blend of initiatives in the community to maintain and expand social networks, combined with an integrated palliative approach to care within the health care system and an expansion of HPC in the community, can better support patients and caregivers alike, and mitigate some of the challenges that currently limit options for aging and dying in place.

The importance of community networks to support people experiencing loneliness, isolation, and the demands of caregiving highlighted in the literature we reviewed, was not a surprise. The Compassionate Communities and Compassionate Cities (CCC) movement, which started in the late 1990s, brought health promotion ideas to palliative care, building on community development strategies to support the dying person and their families (Kellehear, 2013). CCC normalizes seeking and accepting emotional, social, and practical help from members of the community (family, friends, neighbours, schools, and workplaces – also called “informal social support”), encouraging the development of local caring social networks to support end-of-life care (Aoun, Breen, et al., 2018; Kellehear, 2013). Aoun, Breen, et al. (2018) pointed out that informal social support helps with emotional bonds, provides practical assistance, and improves the perceived sense of belonging for bereaved caregivers. Although CCC strategies may better prepare people for the journey ahead and positively impact their psychosocial well-being, Librada-Flores, Nabal-Vicuña, Forero-Vega, Muñoz-Mayorga, and Guerra-Martín (2020) recently showed that there is little and low-quality evidence about CCC development and assessment models. As the CCC movement is consolidated as an important approach to supporting the psychosocial well-being of the dying person and their caregivers, we echo Librada-Flores et al. (2020)'s call for a systematic documentation of the processes involved in CCC implementation and the development of an evaluation framework to measure CCC's impact and effectiveness.

Attending to the needs of the whole person, integrating physical, psychosocial, and spiritual aspects of patient and family care is central to HPC (Hammond & Baxter, 2019). HPC aims to relieve suffering and improve the quality of living and dying (Canadian Institute for Health Information, 2018). A recent report from the Canadian Institute for Health Information highlights that community palliative care increases the likelihood that older people will remain at home; few Canadians, however, receive palliative care at home in their last year of life (Canadian Institute for Health Information, 2018; Tanuseputro, Budhwani, Bai, & Wodchis, 2017). In the last 15 years, to address the changes in illness trajectories (i.e., people are living longer with life-limiting illnesses), the HPC concept has been expanded, shifting from a specialized service available to few at the end of life to an integrated approach to care, available to people living at home and in the community with life-limiting illnesses, at any point in their trajectory (Hammond & Baxter, 2019). An integrated palliative approach to care focuses on meeting patients' and their families' full range of

needs—physical, psychosocial, and spiritual—throughout the course of an illness, or the process of aging, and in all settings where they live and receive care (Canadian Hospice Palliative Care Association, 2015). The approach does not imply, however, the need for increased specialist palliative care delivered upstream in the illness trajectory but, rather, enhancing supports embedded in the everyday care processes, wherever people happen to be and whoever their health care providers are (Sawatzky et al., 2016). The integration of a palliative approach to care into generalist practice and the expansion of community palliative care could, and perhaps should, address the demand for innovative approaches to support people who wish to age and die in place.

An important gap that we pinpointed was in communication among patients, families, and health care providers, which was directly linked to poor continuity of care, affecting patient and caregiver coping and the establishment of trusting relationships. Although the literature we reviewed has not directly linked training and strong communication skills, enhancing training in this area is a feasible opportunity to improve the exchange of information for all concerned. Paladino et al. (2019) caution, however, that education alone will not be a sufficient measure to address the need to improve, for example, conversations about serious illness between health care providers and patients and families. They argue that system-level changes must support the integration of these conversations into clinical practice, which in turn will improve trust and support coping.

Expanding HPC in the community through “Hospice at Home” programs may be another important part of the system-level changes necessary to improve the psychosocial well-being of patients and caregivers at end of life, while also supporting the desire to age and die in place. “Hospice at Home” is not a novel concept (Ahn et al., 2019; Rees-Roberts et al., 2019; Shepperd, Gonçalves-Bradley, Straus, & Wee, 2016); Shepperd et al. (2016) demonstrated that it increased the likelihood of people dying at home. However, not all “Hospice at Home” programs are made equal. Hashem et al. (2020) argue that these programs are composed of a diverse range of services based on local needs and adapted to different contexts. These researchers highlight some key areas of service that match the results of our own rapid review: access to medications, the support of skilled staff that includes rapid response, continuity of care, anticipatory care, and attention to caregivers through practical and emotional support (including mentorship in the use of equipment and help through crisis). Health care providers' having excellent communication skills is paramount to the success of “Hospice at Home” programs.

HPC is especially tailored to address coping and distress associated with life-limiting illnesses (Hammond & Baxter, 2019), both of which were major gaps pointed out in the literature that we reviewed. An important feature of HPC is the engagement of volunteers. Since its inception, volunteers have been fundamental to the HPC movement (Morris et al., 2015). They fulfill many roles, such as providing companionship or practical and emotional support, including bereavement support and advocacy, both in the community and in institutional settings (Claxton-Oldfield, 2015; Diamond, Llewelyn, Relf, & Bruce, 2012; Pesut, Hooper, Lehbauer, & Dalhuisen, 2014; Vanderstichelen et al., 2018). Caregivers reported that bereavement volunteers helped them gain perspective and hope for the future by exploring strategies to overcome difficulties, providing insight, and building a consistent, trusting relationship outside the caregivers' regular social networks. Certain social traits of bereavement volunteers also contributed to the overall satisfaction felt by caregivers, such as listening skills,

encouraging reflection, and remaining non-judgemental (Diamond et al., 2012).

Hospice volunteers often receive education and training, and in most cases, it is a mandatory prerequisite to taking on any role in assisting with end-of-life care (Diamond et al., 2012; Woitha et al., 2015). When investigating the impact of volunteers in hospice care, Block et al. (2010) demonstrated that hospice programs with high use of volunteers per patient, per day had high ratings in terms of overall quality, as perceived by bereaved family members. On the other hand, Kellehear (2013) described a CCC initiative adopted by a Hospice in England in which volunteers were recruited to support frail and vulnerable people, including those with life-limiting illnesses. The hospice provided a short training in care, and volunteers from the community committed to regularly visiting people at home. Although this network of volunteers was established to address loneliness and isolation, early audits and evaluations revealed reduction in use of unscheduled health care services by people receiving the volunteer support. Despite the positive impact of volunteers described in the literature, Claxton-Oldfield (2015) stated that hospice-trained volunteers are underutilized in Canada and that more needs to be done to promote their value to patients and families.

We suggest that a network of hospice-trained volunteers in the community has the potential to address many of the challenges related to psychosocial care identified in the literature. Volunteers can act as a point of contact for patients and families, helping local networks to access the resources they need, thus supporting continuity of care, an underlining gap voiced by patients and families alike that affects their psychosocial well-being. To this end, our organization is currently developing a volunteer-led program to support caregivers in the community.

A key strength of this RR is its practical application, an inherent goal of RRs. Our results were presented at the PHWG roundtable event held on November 2019, and they contributed meaningfully to the decisions made by participating British Columbia HPC stakeholders. The quality of the research included in the review was generally high, which suggests high validity and reliability for our findings. RRs have limitations, however, as components of the systematic review process were simplified or omitted to produce information in a timely manner (Khangura, Konnyu, Cushman, Grimshaw, & Moher, 2012). Tricco et al. (2015) highlights that poor quality of reporting is one major pitfall for RRs. We addressed this issue by recording, and therefore reporting, our approach in detail, allowing reproducibility of the research. Limiting the search to three databases may have introduced publication bias, thereby incidentally omitting relevant publications. And yet, expanding searches to include articles written in three languages partially overcame this limitation. The majority of articles included in the current RR were qualitative studies or had a qualitative component to them, potentially limiting the generalizability of our results.

Final Considerations and Implications for Practice

As the senior population grows, our health care system faces new challenges to support a great number of Canadians who desire to age and die at home. The present study identified a number of challenges related to psychosocial aspects of aging and dying in place. Equally important, however, were the opportunities we identified to overcome these challenges. We then identified ways to leverage these opportunities:

- Expansion of the CCC movement encouraging the development of local caring social networks to support end-of-life care
- Implementation of an integrated palliative approach to care, which includes training of nurses, GPs, and health care support workers in palliative care principles
- Health care provider (HPC professionals and non-HPC professionals) education and training focused on communication skills and the psychosocial and spiritual aspects of end-of-life care
- Caregiver education related to end-of-life topics, including resilience, coping, and death literacy
- Expansion of “Hospice at Home” programs focused on preparation for the future and response to crisis (use of validated tools to identify patients’ and caregivers’ holistic needs)
- Expansion of hospice-trained volunteer networks in the community including providing support to local caring social networks

We would also argue that all stakeholders, including caregivers, should be involved in the development of any initiative to overcome challenges affecting opportunities for living and dying at home, and that initiatives should document processes and develop an evaluation framework to measure their impact and effectiveness.

Although the BC Care Providers Association forecasts a high demand for new long-term care beds with the expected demographic shifts in our province, enhancing supports to local caring networks, implementing an integrated palliative approach to care, and expanding HPC in the community may mitigate this demand and ease the path toward Canadians’ widely preferred choice of aging and dying at home.

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Authors’ contributions. Both authors contributed to the design and execution of the review, synthesis, interpretation of results, and reporting. Both authors read and approved the final manuscript.

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