HOW DO PRIMARY CARE PROVIDERS INFLUENCE THE EXPERIENCE OF INFORMAL CAREGIVERS CARING FOR PALLIATIVE PATIENTS?

by

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Abstract

Background

Primary care providers face challenges when caring for palliative care patients and their informal caregivers. Many primary care providers have limited understanding and comfort in providing palliative care. The situation is even more complex in rural areas, where access to resources is often challenging. A primary care providers lack of experience can result in inconsistent and inefficient approaches to care.

Method

This integrative review examines research from CINAHL on palliative care as it affects informal caregivers and their experiences. It focuses on the actions of Primary Care Providers (PCPs) and how their interventions impact informal caregivers. CASP checklists and thematic analysis were used to critically analyze and organize the results.

Results

The reviewed studies revealed four themes: support, communication and coordination, post-discharge transition, and holistic, person-centred care. The findings suggested that palliative care does not always need to be interventional but can serve as essential supportive care.

Conclusion

The findings of this review highlight the need for a collaborative team approach in palliative care, which goes beyond the provider-patient dyad. Integrating this approach into palliative care plans can improve care for individuals during palliative care.

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Glossary

Anticipatory care: proactive method of palliative care where identification and care planning are performed in a timely manner (Groenewoud et al., 2021)

Bereavement Support: after a patient's death, follow up care provided to family/informal caregivers addressing emotional, practical and grieving needs (Midlöv et al., 2024)

Community care: care provided outside of long term care facilities and hospital (Community Institute of Health, 2024)

Hospice-At-Home Services: hospice care in a patient's own home, often a subgroup of palliative care services and may or may not be linked with a hospital or hospice organization (Abramhamson et al., 2023)

Informal caregiver: individual providing care to patient who is receiving or deemed to be end-of-life, palliative, or terminal

Palliative Care: patient-centered multidisciplinary approach to care where the main emphasis in on comfort and dignity with focus on physical, psychological and spiritual needs of patients and their family (Xu et al., 2024)

Patient-Carer Dyad: relationship that interweaves the patient and their caregiver (Abrahamson et al., 2023)

Multidisciplinary Care: care coordinated and provided by a team of skilled healthcare professionals (doctors, nurses, social workers, volunteers, and other specialties) (Vinayagamoorthy et al., 2017)

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How do primary care providers influence the experience of informal caregivers caring for palliative patients?

Healthcare in rural environments presents challenges in access to resources and service availability due to the centralization and restructuring of priorities to larger urban centers (Schuurman et al., 2010). Because of centralization, diagnostic, local, and regional resources are known to be more limited in rural areas, which can lead to poorer diagnosis, increased time to treatment, and increased need to travel (Kirby et al., 2016).

Researchers expect that there will be an increased need for palliative care resources as the baby boomer generation ages; this will outpace the availability of resources, and utilization of informal caregivers in community environments and at home will be necessary (Kirby et al., 2016). Informal caregivers are unpaid people who care for patients including those needing palliative care; they are often spouses, family members, friends, or neighbours (Breivik et al., 2024). Rural areas create a greater need for informal caregivers and a broader expectation of the caregiver profile to include friends, community, and cultural networks in a way that is not typical of urban areas (Kirby et al., 2016). Williams et al. (2016) note that a significant physical, emotional, and financial burden is placed on those involved in the process of informal caregiving, a process that does not end with the death of the palliative patient.

Two decades ago, primary care providers (PCPs), such as family physicians and family nurse practitioners' (FNP) areas of practice were projected to be the ideal environment to provide resources and support to individuals in their roles as informal caregivers throughout the palliative stages (Mitchell, 2002). Today, PCPs are general practitioners who can provide care for those with serious illness and aid them in symptom management, care supports and services coordination, condition comprehension and advanced care planning (Health Canada, 2022).

As part of this role, PCPs can also provide support for the informal caregiver. Supportive measures during palliative care often include emotional and psychological well-being and assistance in the provision of physical assistance with mobility, education, and convalescent care (Abrahamson et al., 2023). Informal caregivers were more likely to develop Post-Traumatic Stress Disorder (PTSD) when the palliative patient died in a hospital setting, in comparison to those whose loved one died at home; the theory is that providing palliative care at home prepares informal caregivers for impending death and limiting psychological distress (Wu et al., 2022).

Informal caregivers often struggle with reaching out for support, so it may not be the primary focus of interactions with PCPs in palliative patient appointments (Kirby et al., 2016). However, not meeting or addressing the needs of informal caregivers can lead to dissatisfaction with the PCP therapeutic relationship for the informal caregiver after the palliative patient passes (Mitchell, 2002).

There is an expressed desire for PCPs to learn from current practice and identify ways to improve their practice based on their experiences providing care, ultimately minimizing suffering and pain for future patients and their loved ones (Mahtani et al., 2015). However, many PCPs feel a lack of expertise, training, and infrastructure are barriers preventing them from caring for their patients during the palliative care phase, especially if at-home visits are required (Mahtani et al., 2015). As a result, some PCPs may feel that their patient’s care is better in another more specialized care provider’s hands. Unfortunately, this level of care is not readily available in all communities in B.C.

Despite the demand for palliative care in the community provided by PCPs (Schuurman et al., 2020; Tan et al., 2021) and awareness of the informal caregiver burden (Xu et al., 2024), evidence exists; however, it is not yet widely recognized or acknowledged ways PCPs can aid informal caregivers(Tan et al., 2021). Care of palliative care patients is more complex in rural areas, and a limited understanding of palliative patient and informal caregiver needs may lead to inconsistent approaches and uncertainty for family care providers (Breivik et al., 2024).

This integrative review examines the role of PCPs in influencing the experiences of informal caregivers who are caring for palliative patients. The review will draw on the historical context of palliative care within Canada's healthcare system and important insights related to the aging population of British Columbia (BC), Canada (Kirby et al., 2016). By exploring current themes concerning the experiences of informal caregivers, this review offers evidence-based recommendations and strategies to enhance the support provided to informal caregivers. The guiding question for this examination is: *How do primary care providers influence the experience of informal caregivers caring for palliative patients*?

CHAPTER 1: BACKGROUND

This section will examine the context of the research question and its essential components. Definition and clarity will be provided to understand the environment in which PCPs, including family physicians and nurse practitioners, navigate, particularly regarding resource limitations and challenges of transferring patients for care outside of acute care. Additionally, the goals of palliative care, its clinical relevance, and the education needs that arise in this context will be outlined.

Primary Care Providers

Primary care provider is a term that encompasses a practitioner who provides care for people throughout their lives, across all life stages, and through various health conditions. In this discussion, the term applies explicitly to Family Nurse Practitioners (FNP) and Family Physicians/Doctors.

The FNP role was born in Canada and in other countries, out of a need for primary healthcare delivery; it is distinct in healthcare from previous medical models of care in that the focus of the FNP is not only on the diagnosis and treatment of disease but also on prevention, wellness and education (Schober et al.,2020). Schober et al. (2020) describe FNPs as advanced practice nurses with a foundation in nursing education who have achieved increased levels of competency and capability through formal education. Schober et al. also define an FNP in their ability to apply and explain conceptual frameworks and evidence-based practice, as well as moral, regulatory, legal and practical aspects of care in their role.

Family Physicians (FP) provide comprehensive care in a community environment, within rural and urban settings, this includes medical offices, healthcare facilities and the patient's home (The American Academy of Family Physicians [AAFP], 2024; The College of Family Physicians of Canada [CFPC], n.d.). FPs demonstrate competence and are actively involved in diagnosing, treating and offering preventative care by applying a patient-centred clinical method (AAFP, 2024; CFPC, n.d.). The care FPs provide is similar to NPs in that it encompasses the continuum from birth to senior years, with a defined focus on managing disease and illness while developing patient-specific treatment goals.

A persistent issue in healthcare environments is the workload, scarcity of providers, and the complex needs of patients, exacerbated by decreased patient contact, which affects the overall care for patients in BC and Canada (Rudoler et al., 2022). As a result, there is an increased reliance on pharmacists, physiotherapists and other community primary healthcare providers, such as nurses and nurse specialists (Canadian Institute for Health Information [CIHI], 2024; Mitchell, 2002). Community settings often included medical offices, people’s homes, and environments that are not in residential care or hospital facilities (CIHI, 2024). In 2024, NPs experienced a 3% increase in those practicing in community settings, with indications suggesting that at least 1 in 3 NPs will go to practice in a community setting (CIHI, 2024)—promising for those in the community who require follow-up in palliative care services.

Palliative Care Settings

Schuurman et al. (2010) describe the difficulty in defining palliative care in BC and summarize it as a group of services that include home, hospital, nursing, family doctor, specialist, caregiver, and spiritual care. The focus is on maintaining quality of life and facilitating end-of-life care, which is accomplished by addressing physical, psychological, spiritual, and practical needs. The BC Ministry of Health’s (2010) definition of palliative care is that of specialized care for those who are dying, where the goal is to relieve suffering, not prolong life. In another definition, the Government of Canada (2024) defines palliative care as a broad definition of care from healthcare providers for individuals with serious illnesses. A common thread is that palliative care is not just care given to a dying person but care administered for all ages and stages of illness in various healthcare settings, where support is provided to the palliative patient and informal caregiver. In BC, there is a Palliative Care Benefits program for active members with MSP coverage (BC Ministry of Health, 2024). To qualify, they will be in the end stage of a terminal disease or illness and have a life expectancy of up to six months (Ministry of Health, 2024). The paperwork for this program does have to be submitted by a PCP but covers a variety of medications and healthcare items needed in palliative and end-of-life care.

Funding and legislation aside, palliative care is not as straightforward as indicated by the documents published by the BC government. Rural and marginalized communities often struggle with access to resources due to the ongoing trend of decentralization, where government and organizations have moved more extensive facilities, funding and resources to urban centers (Schuurman et al., 2010). Chronic workforce shortages, worse patient diagnoses, delayed treatment, and lack of locally available resources frequently occur in rural and remote locations (Kirby et al., 2016). Health Canada (2018) developed a framework for Palliative Care in Canada. The primary goals were to enhance the accessibility and quality of palliative care, enhance palliative care training, support PCPs and informal caregivers, and promote research and data collection (Health Canada, 2018). A reassessment by Health Canada in 2023 noted that while progress had been made, improvements were still required in access to palliative care, data collection standardization, education and training with integration of competency frameworks, and informal caregiver support.

Informal caregivers, family and friends support networks were noted to be essential in providing care for palliative and end-of-life patients in rural and remote communities and environments (Kirby et al., 2016). This means that PCPs in these areas must be well-trained and adequately supported in delivering care, particularly symptom management. Their availability is also essential to the overall palliative care support network (Kirby et al., 2016).

A Population Aging

The global population aged 60 and over is expected to nearly double, rising from 12% to 22% between 2015 and 2050 (World Health Organization [WHO], 2024). In Canada, this is reflected in the projection that by 2040, the population of seniors is expected to reach nearly a quarter of the population (Public Health Agency of Canada, 2021). This understanding of the 2022 population statistics is addressed in the Canadian government's planning, aiming to stay ahead of anticipated population demands. Statistics from BC state that 59.5% of people die at home; these statistics only partially cover the province’s population, as Statistics BC notes that not all of BC was properly represented (CIHI, 2022) and the comfort level of individuals and the decision of when and how to die at home were not investigated by researchers. Health Canada (2023) developed several goals ranging from short to long-term (5-10 years). These goals aim to ensure increased awareness of advanced care planning directives, that PCPs have an increased capacity to deliver quality care and that informal caregivers have support to aid in this care (Health Canada, 2023).

PCPs are in the ideal position in the community to monitor and manage this population and begin discussions around end-of-life and palliative care. Palliative care is not just for individuals near the end of their lives (Tan et al., 2021) but for the care of individuals with serious illnesses whose goal is improving overall quality of life (Health Canada, 2022). Kavallieratos et al. (2014) summarize the benefits of palliative care can, in fact, “improve survival, quality of life, symptom burden, and caregiver outcomes, as well as reduce healthcare expenditures, and hospitalizations for patients with serious illness" (p. 1-2). Mahtani et al. (2015) found that, during training family medical residents' training, the residents valued the long-term relationships with their patients. With this in mind, inquiries should be made into how the application of palliative care services could benefit patients to improve patient outcomes and informal caregiver experiences, and whether this can be done while strengthening the longitudinal relationship.

Family practitioners are described as the first point of contact for patients to access healthcare (Mitchell, 2002). However, when it comes to caring for people in the unique and vital twilight of their lives, there was little to no training in bereavement care or communications skills. The FNPs describe that their inexperience is compounded by difficulty correlating what the provider perceived and what the patient reported as far as psychological, emotional and other symptoms beyond pain arose. There is also uncertainty about the role and a functional skills gap, noted by Mahtani et al. (2015), where understanding of funding, on-call systems, and integration of additional resources is misunderstood. FNPs indicated that the functional skills gap, along with other challenges noted with palliative care, leads to and compounds a provider's confidence in their competencies and creates concerns about performance quality (Mitchell, 2002).

Unfortunately, not only the PCPs are affected by these issues, but also patients and their informal caregivers (Mitchell, 2002). Patients and their informal caregivers also struggle with knowing how involved their PCPs will be, communication insufficiencies and, regrettably, discontent with after-death care.

Regulation & Practice Scope

There are not only personal obligations to consider when there are unfilled expectations in providing care. The focus will be on FNPs for the discussion of this aspect. Practice standard

Duty to Provide Care (British Columbia College of Nurses & Midwives [BCCNM], 2020) discusses that FNPs have a responsibility to provide "safe, competent, and ethical care" (para. 4) to patients in the understanding it is safe and within the provider's scope (BCCNM, 2020). FNPs ignoring this standard willfully engage in the abandonment of the patient if an FNP has done this without discussing with the patient, arranging alternative care, or allowing a reasonable time for an alternative to be found (BCCNM, 2020). In the context of rural or remote environments, the ability to find a substitute PCP is less likely which may result in adverse outcomes for palliative care patients. It may also affect the individual PCP's ability to learn appropriate skills in managing palliative end-of-life care.

There are further reasons to be involved and concerned regarding palliative care. Specifically, for FNPs, the scope of practice includes but is not limited to health promotion and preservation, as well as preventative treatment and palliation of disease and injury (BCCNM, 2024). In addition, FNPs are noted to be competent practitioners with advanced clinical skills that are effective in diagnosing and managing patients (College of Registered Nurses of Nova Scotia, 2016). Health promotion is key to this formulation and is carried out through education, counselling, and disease surveillance (Schober et al., 2020). In literature and research, it can be demonstrated that the FNP role increases access to care and can reduce hospitalization time and healthcare spending (Meddings et al., 2023). With a history of providing care to underserved and underrepresented populations (Schober et al., 2020), FNPs are in a perfect position and primed to step in and provide comprehensive and person-centred end-of-life care for patients in a community and rural setting (Mileski et al., 2020). FNP provision of care can be done in tandem with collaboration and in sync with the current healthcare system, as FNPs are proven collaborative and resourceful healthcare team members (Owens, 2019).

CHAPTER 2: METHODS

This integrative review aimed to address the research question: "*How do primary care providers influence the experience of informal caregivers caring for palliative patients?*" An integrative review methodology (Toronto & Remington, 2020) was selected to synthesize various types of studies, including qualitative, quantitative, and theoretical approaches. To conceptualize the data, a thematic analysis (Naeem et al., 2023) was utilized. The choice of review methodology and analysis permitted a comprehensive understanding of the issue from multiple perspectives and study designs. The goal was to investigate the effect PCPs have on the informal caregivers of palliative patients.

Design

A Population, Situation (PS) framework was used to build the basis of the literature search as this type of search favours a Qualitative research query and investigates the experiences, conditions and circumstances of individuals it investigates; this does not involve a comparison or outcome of an intervention (Health Evidence™, 2009). The goal was to investigate the effect Primary care providers have on the caregivers of palliative patients.

Search Strategy

Databases

A comprehensive literature search was conducted using the CINAHL database to identify relevant studies. Access to CINAHL complete was through the University of Northern British Columbia’s online library. CINAHL complete was used for its availability of primary studies and unique studies that can be accessed with thorough search and proper indexing (Wright et al., 2015). Search terms included keywords related to PCPs, informal caregivers, palliative care, end-of-life care, caregiver settings, and related concepts. Boolean operators combined terms strategically, ensuring the retrieval of studies addressing the research question from diverse angles.

Search Terms

The search terms used were in part due to the research question and mapping as see on appendix A. Search terms are included in Table 1.

Table 1.

Search Strategy

Search terms		Search date
Population/Patient	caregiver*, (famil* or relative* or parent*), N3(caring or care*, "Caregivers”, "Caregiver Support", "Nurse Practitioners", "Physicians, Family"	12/2024
Situation	"Terminal Care", "Palliative Care", "Hospice Care", terminal* or palliat* or hospic*, N3(ill* or patient* or care), ("end of life" OR end-of-life OR "dying"), "Caregiver Attitudes", "Caregiver Burden", "Support, Psychosocial", "Family Support"	
Limitation	NOT ("Pediatric Care+") OR ("Child+") OR pediatric*)	
Total Data Sources Retrieved		93

Note. The asterisk is a wildcard search function to capture variations of the words it is associated with. In addition, Proximity operator used to “N3”

Inclusion and Exclusion Criteria

The inclusion of Nurse Practitioners and Family Physicians ensured that PCPs were covered and represented for relevance and application of findings. Studies that discussed other community-based practitioners were excluded because of their vast and differing roles and scopes of practice.

Articles were not limited based on their country of origin due to the potential for generativity of data and the interest in qualitative data in the context of the provider–informal caregiver relationship. In this same rationale, studies were not limited to community care alone, but a narrowing of dates and locations may have occurred due to the use of nurse practitioners, family physicians, and related terms. In addition, the terms “nurse practitioner” and “family physician” are not necessarily universally used titles and this additionally narrowed the search to countries that do use those terms in similar context. A timeline of 2014-2024 was selected to ensure the research reflected the current climate, any technological nuance, policy changes, best practice guidelines, and evidence-based practice within healthcare.

Pediatrics were excluded from this review to keep focus scope and avoid adding complexity to the data. The role of the primary decision maker, family dynamics, caregiver experiences, and developmental and healthcare pathways differed in pediatric patients and their inclusion may have confounded the data beyond the scope of this review. I did not intentionally exclude quantitative data, but in sorting through the literature with a focus on nuanced perspectives and contextual factors may have inadvertently eliminated quantitative design studies. Articles that were not in English or had an English translation available were not included because of the absence of translational technology and I primarily speak English.

Study Selection Process and Quality Appraisal

To organize articles, I sorted them based on inclusion and exclusion criteria guided by the Preferred Reporting Items for Systematic Reviews (PRISMA) (Page et al., 2021) guidelines. The PRISMA guidelines were not strictly adhered to, but rather I utilized them as a guiding framework to support a systematic process of selecting studies during the integrative review process. I then combined the PRISMA framework (Page et al., 2021) and the Critical Appraisal Skills Programme (CASP) (CASP, 2024) to sort articles at each identification, screening, and selection step. In the final stage of assessing for eligibility the information was sorted based on criteria, eliminating articles based on setting, outcomes, intervention, and study design. The CASP tool (CASP, 2024) was used in tandem with this process to authenticate validity of studies.

To identify phenomena in the context of PCPs and informal caregiving, I utilized unstructured data observations to gain insights into the thoughts, values, and behaviours that affect informal caregivers during palliative care and how these factors shape their needs. Each study was evaluated for methodological approach and rigour using the qualitative studies checklist CASP tool (CASP, 2024). This tool assessed aspects such as validity, results, ethical considerations, trustworthiness, relevance, and key concepts in the papers. I applied the CASP to both qualitative and mixed-methods research to provide a consistent approach to evaluation across all studies included in the paper. Covidence systematic review software (Veritas Health Innovation, 2024), a web-based platform, was utilized to identify and remove duplicate articles, while I sorted the remaining articles manually. In addition, I used Covidence features to organize and manage the information. Since I was the only reviewer involved, a formal conflict resolution process was unnecessary.

Data Extraction

During research I manually extracted data from the selected studies to gather additional information for discussion. I was able to then organize the data sets into a matrix table (Toronto & Remington, 2020) to arrange relevant data known and unknown about informal caregivers' needs and how the experience is changing or evolving with the current healthcare climate. See Table 2.

Table 2 *Data Extracted*

Data Extracted			
Year of publication	Country of origin	Research design	Recruitment methods

Sample size and sampling methods	Inclusion and exclusion criteria	Data collection methods	Key findings and recommendations
Identified Study Limitations			

Data Synthesis

Thematic analysis was used to synthesize the qualitative data and mixed methods, focusing on key themes and patterns related to the experiences of informal caregivers and the role of PCPs (see Appendix D). Toronto and Remington (2020) outline a process of thematic analysis where the researcher engages with the data to define and name themes. I was required to adopt a qualitative synthesis approach to accommodate the diversity of the studies for this integrative review. I then synthesized the findings and data, integrating insights from qualitative and mixed-methods studies to understand the topic comprehensively.

Ethical Considerations

The review did not require ethical approval because it utilized secondary data from publicly available studies. Further ethical review was not necessary to ensure adherence to ethical standards.

CHAPTER 3: FINDINGS

Reflecting on the question "*How do primary care providers influence the experience of informal caregivers caring for palliative patients?*", a broad approach focused on primary care providers was necessary. During literature accrual, I did not find a comprehensive understanding by narrowing the focus exclusively to FNPs. In the analysis of the included studies, four themes emerged when investigating the experiences of informal caregivers during the palliative/end-of-life period. Palliative care patients and their informal caregivers frequently discuss needs that fall under themes of support, coordination of communication, holistic and person-centred care, and discharge transitions, which directly affect the care provided to palliative care patients. Subsequently, an outline of studies will be included for clarity of context, providing a comprehensive understanding of the research.

Search Results

A total of 6 studies were reviewed, most were from 2024, with two from 2023 and one from 2017. The type of study varied, and half were qualitative (Xu et al., 2024; Vinayagamoorthy et al., 2017; Midlöv et al., 2024), and half used mixed methods (Groenewoud et al., 2021; Abrahamson et al., 2023; McCoy et al., 2024). Research settings varied from primary care to community-based palliative care across countries with differing healthcare systems. Three studies applied theoretical frameworks: Abrahamson et al. (2023) used Normalisation Process Theory (Mishuris et al., 2019) and Realist Evaluation (Butler et al., 2022); McCoy et al. (2024) adapted the Double Diamond framework (Ball, n.d.) for their ACEPATH intervention; and Xu et al. (2024) applied Transition Theory (Meleis, 1975) to caregiver experiences in end-of-life discharge planning. This variety allowed for breadth in the following analysis.

Variants of Support

The underpinning of research in these studies reveals a need for several types of support (Abrahamson et al., 2023; Groenewoud et al., 2021; McCoy et al., 2024; Midlöv et al., 2024; Vinayagamoorthy et al., 2017; Xu et al., 2024) which fell under the greater categories of instrumental support, emotional and psychological support, and information and continuity of care support and were essential in enabling informal caregivers the ability to care for palliative care patients.

Instrumental Support

Several studies highlighted the practical aspects needed to ensure informal caregivers felt adequately supported in practical caregiving skills education to provide end-of-life care. For the purpose of this review, the criteria defined for instrumental support are physical care, practical skills training, and economic support. Abrahamson et al. (2023) interviewed informal caregivers and utilized a realist evaluation with mixed methods for their study design to capture the function of their study while maintaining a holistic understanding (Holly et al., 2022). Despite excluding participants with no PCP, which may have narrowed the scope of the study, researchers found that education highlighting hands-on care and understanding the dying process were noted by informal caregivers to be helpful during palliative care (Abrahamson et al., 2023). Similar findings were reflected by Groenewoud et al. (2021); in their study examining the use of a palliative care pathway where general practitioners were recruited to identify and coordinate care for palliative care patients. Groenewoud et al. produced their research from a combination of primary care practices (13 intervention, 8 control) and hospital departments (oncology and geriatrics). In addition, Groenewoud et al. collected data from a combination of patient assessment, GP and family questionnaires, and healthcare utilization records- including measures of anxiety, care needs, caregiver burden, palliative care quality, healthcare service use, and medication patterns. The data the researchers collected informed three outcome categories, physician reported outcomes, family member experience, and healthcare utilization (Groenewoud et al., 2021). Groenewoud et al. had non-randomized participants, which ran the risk of underrepresentation of the population; despite this selection bias (Holly et al., 2022), the data collected by researchers was representative of the general results found in this review. The researcher's results discussed multiple support types, but specifically how practical home visits, symptom management, and coordination of care contributed to improved informal caregiver satisfaction and may have contributed to decreased acute out-of-hours consultations (Groenewoud et al., 2021).

Emotional and Psychological Support

The theme of emotional and psychological support that emerged from the review can be defined as psychological, social, and individualized support. In qualitative descriptive research, Vinayagamoorthy et al. (2017) evaluated a community-based palliative care service by interviewing patients, caregivers and medical staff. They assessed a previously established home care service linked to a palliative care program. Despite purposeful sampling that could have affected the negative feedback report, the researchers concluded that part of the program's success can be credited to supportive measures such as psychosocial care and moral and social support. Vinayagamoorthy et al. also noted that the support provided significantly improved well-being, dignity and resilience in the palliative patient and their informal caregiver. Midlöv et al.'s (2024) study that investigated improvements needed for support of palliative patients, utilized a qualitative descriptive design and collected data via surveys, finding that informal caregivers require specific types of support. Despite using open-ended surveys and the potential for response limitation, Midlöv et al. noted that both informal caregivers and palliative care patients wanted holistic care. The participants, who were informal caregivers, discussed the need for personalized support, counselling, more honest conversations regarding the prognosis of the palliative patient, and post-death communication in addition to bereavement visits with the PCP for improved palliative care experience.

Information and Continuity of Care Support:

Continuity of care and provision of information was another supportive measure that informal caregivers desired. In this theme, information and continuity of care support are categorized as information provision and communication support. Xu et al. (2024) performed their research through semi-structured face-to-face interviews and, despite using only one hospital care site, determined that informal caregivers require more support in caring for palliative care patients post-discharge. Xu et al. also noted that informal caregivers more easily developed coping and psychological resilience when provided with additional support. McCoy et al. (2024) collected data for their co-design through virtual, audio, and video recordings translated into transcripts for review. Despite their narrow population characteristics (English speaking, white, high socioeconomic status), which may have introduced population bias, McCoy et al. received feedback echoed in other studies that informal caregivers experience a large amount of administrative burden and felt they did not receive enough emergency health and readiness information.

Coordination of Communication

A concept that consistently emerges as important to informal caregivers is the coordination of communication (Xu et al., 2024; Midlöv et al., 2024; Abrahamson et al., 2023). The focus varied from communication and coordination between the interdisciplinary team

(McCoy et al., 2024; Vinayagamoorthy et al., 2017) across service/healthcare providers to the informal caregivers (Abrahamson et al., 2023; Groenewoud et al., 2021; Xu et al., 2024). Communication coordination ensures integrated information sharing, which is vital in multidisciplinary care teams. Abrahamson et al. (2023) investigated the family carer's experience of hospice care at home through qualitative interviews with carers and service providers. Qualitative interviews allowed caregivers to share their experiences and give authentic contextual insight (Melnyk & Fineout-Overholt, 2023).

Lived Experiences

Midlöv et al. (2024), found in their explorative study, that there was a need for improved communication between PCPs, palliative patients, their informal caregivers, and other healthcare providers. Midlöv et al. utilized open-ended survey questions in a qualitative approach with a descriptive design, focusing on direct summary and limited interpretation. Surveys used by Midlöv et al. were open-ended, allowing informal caregivers to produce their own answers, thereby collecting detailed narrative data based on personal experience and emotions. Vinayagamoorthy et al. (2017) also discuss coordination of communication as a need, during their community-based palliative care program development. They found that key feedback for improving their communication skills and requests for further education and development of relationship-building skills in communication derived from semi-structured interviews. Using a semi-structured face-to-face interview, Xu et al. (2024) recognized communication gaps in discharge, continuity of care, and the support provided to informal caregivers. Other studies only reinforce the importance of care delivery in a transparent, compassionate, informed manner, particularly during end-of-life discussions.

Intervention and Improvement

In their research, Groenewoud et al. (2021) assessed the implementation of an integrative palliative care pathway using a quasi-experimental design. This design employed a clustered approach, grouping data based on care setting (participating or control), with partial control as data only collected from palliative care patients enrolled in the program. In their findings, Groenewoud et al. (2021) found increased communication in their palliative care pathway, which they attribute to reduced emergency and out-of-hours visits. Their research highlights the importance of coordinating communication with palliative care patients and their informal caregivers. The conclusions are similar to findings in McCoy et al. (2024) who utilized the initial stages of codesign to develop an intervention they identified as Advancing the Care Experience for patients receiving Palliative care as they Transition from hospital to Home (ACEPATH). Researchers chose a codesign for this intervention as it requires participation from stakeholders as equal partners to address a specific need and continuous feedback testing with stakeholders (Peters et al., 2024). ACEPATH aims to develop interventions that improve hospital-to-home transitions for palliative care patients and their caregivers (McCoy et al., 2024). The researchers wanted this intervention to meet the unique needs and challenges of transitioning home within the Canadian healthcare system while maintaining flexibility and adaptability to local settings and contexts across Canada. The researchers determined key communication challenges from feedback provided by participating administrators, primary healthcare providers, patients receiving palliative care, and informal caregivers. McCoy et al. found that there was a need for improved communication, specifically regarding medications, planning, and requests for clarity. Based on the findings, the researchers suggested incorporating a communications expert in the care team to address gaps in communication.

Comprehensive Systems View

Through realist evaluation, Abrahamson et al. (2023) could discern the mechanism of the caregiving role in the context of at-home care and still conceptualize the relationship between the caregiver and the palliative patient. Abrahamson et al.'s approach was unique in this review as their focus was the analysis of a broad systemic approach focused on service delivery with multiple stakeholder perspectives and a holistic view of care experiences. Abrahamson et al. identified collaboration at both the organizational and operational levels as integral to providing efficient and cohesive care and producing a background understanding of the patient experience.

Coordination of Communication Views

Researchers generally agreed on the essential communication components, but there are disagreements on specific aspects of this communication. Midlöv et al. (2024), Xu et al. (2024) and McCoy et al. (2024) discussed the need for comprehensive communication and transparent information sharing. However, Abrahamson et al. (2023) found that healthcare providers cautioned against information overload and overwhelming palliative patients and their caregivers, while Groenewoud et al. (2021) suggested a more balanced approach with expectations outlined on what information is to be shared. In interdisciplinary communication, McCoy et al. (2024), Groenwould et al. (2021), and Vinayayagamoorthy et al. (2017) found adequate interprofessional collaboration, while authors Midlöv et al. (2024), Xu et al. (2024) and Abrahamson et al. (2023) pointed out issues in communication between interdisciplinary teams and indicated issues in communication. The difference could be due to the difference in the focus of the study.

Discharge Transitions

Transitions in care are crucial for patients and their informal caregivers, as there is a shift in treatment settings, providers, and supportive systems (Levoy et al., 2022). Informal caregivers describe anxiety and distress in times of transition, and this can involve care location dynamics (Abrahamson et al., 2024), caregiver role transition (McCoy et al., 2024), and across all levels of care (Groenewoud et al., 2021). Regardless of the type of transition, it is a point of focus for many palliative care patients and their informal caregivers.

Hospital-To-Home

McCoy et al. (2024) identified specific transitional issues for informal caregivers in their study that developed low-fidelity prototypes for transitions in palliative care; in this study, The researchers were able to describe several instances in which transition can be identified and supported through psychological, practical, and systemic transitions. McCoy et al. produced this study in Canada in the context of the COVID-19 pandemic as such, was limited in in-person contact but gleaned important feedback. They noted three critical phases in transitions to home where issues often occurred: waiting for discharge, the first 48 hours at home, and stabilization at home. The co-design also revealed four key needs in the home transition: emergency and health readiness, logistics and set up of personal care, psychosocial preparation, and life at home post-discharge. Abrahamson et al. (2023) synthesized similar themes from their qualitative interview styles with informal caregivers—surprising trends given the study's backdrop of an English hospice home service. In the Abrahamson et al. study, the transition from hospital to home caused difficulties with a lack of preparedness and support; informal caregivers increased responsibilities and emotional strain, and inconsistencies in services available. Another transition Abrahamson et al. discuss is when the palliative patient dies; informal caregivers experience "double grief" (p. 1536) where after the death of the palliative care patient, informal caregivers feel the combined loss of their loved one and the loss of their care team. The care team in this context includes healthcare assistants, nurses, service leads, volunteer coordinators, fundraising managers, and senior managers (Abrahamson et al., 2023). The care team noted by Xu et al. (2024) in their study caused additional stress during the transition due to the absence of a detailed discharge plan with clear instructions from the healthcare team. Xu et al. also note that informal caregivers feared leaving the controlled familiar environment of the hospital for home, with specific concerns regarding managing emergencies, the palliative patients' personal care, and facing palliative care in a home setting. The informal caregivers' fear sometimes leads to resistance to discharge home and extended hospital stays (Xu et al., 2024).

Systemic Care in Study

Vinayagamoorthy et al. (2017) discuss the anxieties of informal caregivers in transitions concerning inadequate resources for transition. The study's community-based palliative care program relied on interdisciplinary collaboration between palliative care providers; it was noted that there was a request from informal caregivers for further resources such as physiotherapy and housing assistance to make the transition a more straightforward process. Transitions within the care system are another stress point for informal caregivers and palliative care patients; there are many factors, and often, just as many healthcare team members are involved. Groenewoud et al. (2021) note that in their research intervention pathway when PCPs are more proactive in identifying palliative care patients, the patient is more prepared for end-of-life transition. It was also important for Groenewoud et al. to note that transitions were not just about the palliative care patient but also the informal caregiver. In the researcher's pathway, it was often found that informal caregivers experienced increased emotional pressure after the death of the palliative care patient; this may be the result of an abrupt end of service or absence of follow-up (Groenewoud et al., 2021).

Relational/Emotional in Transition

Care transitions do not just occur from physical place to place; they also occur in multidimensional pathways that are dynamic and require careful observation (Midlöv et al., 2024). Aspects of care transitions were discussed by Midlöv et al. (2024) who found that limited information and preparation to transition home led to increased stress and anxiety. Despite the potential for selection bias as some invited to participate refused, findings were comprehensive, with researchers discovering where challenges arose during the hospital-to-home transition. Informal caregivers reported limited guidance for post-discharge preparation; during their struggle to organize their home for the palliative care patient, they spent a lot of time running errands and missing time with their loved ones.

It can be generalized that all researchers included in this review agree that transitions are multifaceted and logistically and emotionally challenging for informal caregivers and palliative care patients, requiring comprehensive support (Abrahamson et al., 2023; Groenewoud et al., 2021; McCoy et al., 2024; Midlöv et al., 2024; Vinayagamoorthy et al., 2017; Xu et al., 2024). During these transitions, comprehensive, compassionate support ensures the palliative care process is positive for both the informal caregiver and the palliative patient (Abrahamson et al., 2023; Midlöv et al., 2024; Xu et al., 2024).

Researchers had different views on the role of volunteers in transitional support for palliative care patients and their informal caregivers. Vinayagamoorthy et al. (2017) reported a need for volunteers and for them to have a more active role, viewing them as essential to creating a self-sustaining model of transitional care, recommending their recruitment from their community to aid in service expansion and adding to the continuity of care. Abrahamson et al. (2023) had different results, stating that use in functioning and sustainability was present but would not be used in hands-on transitional care. There is a concern from informal caregivers and employees of the hospice-at-home program regarding professional boundaries and palliative patient comfort with volunteer involvement.

Holistic and Person-Centred Care

Holistic care is understood to be a focus on comfort and dignity while addressing physical, physiological, economic, and spiritual needs (McCoy et al., 2024; Vinayagamoorthy et al., 2017; Xu et al., 2024). In the context of informal caregivers, this acknowledges the patient and care provider together as a unit (Abrahamson et al., 2023; Midlöv et al., 2024) and aims to ensure the dyad is equipped with individualized care support in a way that preserves the dignity and autonomy of the individuals involved (Groenewoud et al., 2021).

Relational approach

Abrahamson et al. (2023) focused on care provided at home by informal caregivers and found that holistic aspects of care were most desired and successful for palliative care patients and informal caregivers in coping with the end-of-life process. The researchers noted that of the 58 informal caregivers interviewed, 58% were female, and 60.4% were identified as spouses or partners of the palliative patient. Abrahamson et al.'s results were fulsome and representative of overall themes found in the included studies; despite the absence of ethnicity as a collected demographic, researchers indicated that providing comprehensive palliative care included ensuring the informal caregiver and the palliative patient felt valued in the interaction, and did not feel rushed. Palliative care patients and their informal caregivers value aspects of holistic care, such as developing skills to empower their day-to-day care, acknowledging family unit dynamics, and respecting individual preferences (Abrahamson et al., 2023). Vinayagamoorthy et al. (2017) describe their community-based palliative care service as a multidimensional approach that includes physical management, psychological support, social support, emotional care with family, and community engagement. Informal caregivers in this study were largely female (68%), and ages ranged from 13-65 years old. Despite the smaller sample size of participants, which may affect the overall nuance of the community care program, holistic care was highlighted in their desire to follow guidelines in communication that ensured adequate care was provided for palliative care patients (Vinayagamoorthy et al., 2017). The researchers' desire to meet this need originates from informal care providers and palliative care patient dissatisfaction in other studies. Elevated communication can ensure that the physical and non-physical psychosocial needs of the palliative patient and their informal caregivers are met with compassionate care that values family needs and relationship development (Vinayagamoorthy et al., 2017).

Systematic and Integrated

Groenewoud et al. (2021) found outcomes relevant to physicians, family members, and healthcare utilization in their research on the effects of an integrative palliative care pathway. Researchers examined questionnaires from 99 participants who were palliative care patients and who had a mix of primary diagnoses from cancer to congestive heart failure. Outcomes were positive despite low response rates from families. Groenewoud et al. also emphasized holistic care through the lens of anticipatory care, advocating this approach enhanced the overall palliative care experience for the patient and their informal caregiver. A measure of this improvement is that more palliative care patients died at home (97.3%) as opposed to in a hospital when compared to control practices (77.5%), indicating a meaningful shift toward preferred end-of-life settings. Xu et al. (2024) also focused on transitions from the hospital to home for informal caregivers and their palliative patients, focusing on palliative care as patient-centred and multidisciplinary, a repeating definition of holistic care. In this study, researchers highlight the experience by interviewing 15 family caregivers and analyzing the data through thematic analysis using Colaizzi's (1978) method. A thematic analysis with this method of analysis was useful for researchers as Colaizzi's method is grounded in phenomenology and understanding the meaning of experiences of those who lived them, how the informal caregivers feel, think, and cope, not just their actions (Sanders, 2003). Through this method, Xu et al. (2024) echo sentiments previously discussed by other researchers in this review: that palliative care is not just medical treatment but supporting the human experience of palliative care patients and their families, with emphasis on support for families, not just the patient, there is an acknowledgement of the palliative care patient's caregiver environment.

Caregiver and Family Centered

Midlöv et al. (2024) found that in their population of informal caregivers, spouses/partners, adult children, and other forms of relatives/friends, informal caregivers desired tailored supportive interventions. Researchers provided informal caregivers with the opportunity to provide feedback through mail-in surveys that housed open-ended questions, allowing the qualitative method to interpret experiences and understand suggestions for improvement (Midlöv et al., 2024). Although researchers did not address reflexivity, the findings present similarly to other studies with clear reflexive research practice. Midlöv et al. noted that informal caregivers request timely, individualized interventions that are relevant to their stage in the caring trajectory. In their finding, Midlöv et al. note that informal caregivers often feel overlooked and request PCPs engage with them and honor their experience as the palliative patience informal caregiver.

These are the hallmarks of holistic care McCoy et al. (2024) endeavour to address in their codesign intervention for transitions to home for palliative patients. McCoy et al. had a primary focus of enhancing the experience of the patient beyond medical treatment, emphasizing an interprofessional approach to reduce the symptoms burden while addressing the psychological, spiritual, and emotional needs of palliative care patient and their informal caregiver. Despite the smaller population size of 15 participants, McCoy et al. developed a tentative pathway aimed at supporting palliative patients and their caregivers to succeed in their palliative care transition. This pathway at its core emphasized holistic care as support for the palliative care patient and the caregiver's capacity and meeting unmeet emotional needs.

Points of Agreement and Difference

The concept of holistic care was established as a theme, and generally authors agreed on its importance. Authors consistently recommended tailoring support, providing timely interventions, with focus on the palliative care patient and the informal caregiver would improve holistic care and the experience during palliative care (Abrahamson et al., 2023; Groenewoud et al., 2021; McCoy et al., 2024; Midlöv et al., 2024; Vinayagamoorthy et al., 2017; Xu et al., 2024). Two authors highlight complementary findings: informal caregiver are essential to the success of home-based care, unpaid care (Abrahamson et al., 2023), but often face significant challenges, including poor mental health (Midlöv et al., 2024). It is generally agreed that there is a need for a multidisciplinary approach involving multiple healthcare providers to aid in the complex process of transition, and community care of the palliative patient and their informal caregiver (Abrahamson et al., 2023; Groenewoud et al., 2021; McCoy et al., 2024; Midlöv et al., 2024; Vinayagamoorthy et al., 2017; Xu et al., 2024).

Many elements of the research aligned in regard to holistic care, however variations occurred in practical implementation. Xu et al. (2024) described holistic care in multiple dimensions and conceptualized that addressing all of these dimensions simultaneously defines success. Groenewoud et al. (2021) validated their holistic approach with systematic and comprehensive assessments and tools, such as a distress thermometer, hospital anxiety and depression scale and caregiver burden questionnaire. These were psychometric assessment tools used to validate and screen distress and caregiver burden. Abrahamson et al. (2023) in their study had a more direct focus on the interpersonal dynamics, the patient-informal caregiver relationship, emotional support, continuity of care, and staff-palliative patient interaction. Scope of holistic care was interpreted through different philosophical and practical lenses but coalesced to important aspects of comprehensive care.

CHAPTER FOUR: DISCUSSION

This integrative review aimed to determine "*How do primary care providers influence the experience of informal caregivers caring for palliative patients?*". The findings offer the potential to boost PCPs' confidence in care for palliative patients by outlining methods to support palliative care patients and their informal caregivers while also improving the experience for the palliative patient and their informal caregiver. The themes discovered through literature synthesis included coordinating communication, support needs, transitions, and holistic care. These findings emphasize informal caregivers' burden and highlight the opportunities for PCP-lead improvement and support.

Effective Approaches to Coordinating Communication

A key finding was that PCPs must proactively communicate and coordinate their ongoing care efforts to prevent accidental harm and ensure adequate care (Groenewoud et al., 2021; Midlöv et al., 2024). However, gaps in coordination of communication lead to fragmented experiences for the palliative patient and their informal caregivers. The WHO (2023) also notes that communication breakdowns within the healthcare team (which includes patients and their families) can lead to patient harm. McCoy et al. (2024) suggest that PCPs can overcome gaps with checklists, reference sheets, and workbooks, focusing on transition communication support. In current healthcare practices, an overwhelming number of handover tools have been developed with the aim of improving communication coordination in healthcare teams but despite this, communication gaps still exist (Müller et al., 2018). In their systematic review, Riesenberg et al. (2009) found 24 different mnemonics including SBAR and DeMIST that can be utilized for handoff in healthcare environments, however they could not find adequate evidence to reach a clear recommendation of which handoff mnemonic to utilize. Canadian Partnership Against

Cancer & Health Canada (2021) developed a competency framework but it only advises on interpersonal communication. Since no specific tool is utilized in BC by community PCPs with other healthcare providers, an opportunity exists to develop a tool to meet the recommendations discussed by the authors in this review. A tool that could address the support needs of informal caregivers (Midlöv et al., 2024; Xu et al., 2024; Abrahamson et al., 2023), enable comprehensive patient assessments (Abrahamson et al., 2023; Groenewoud et al., 2021; McCoy et al., 2024; Xu et al., 2024), and incorporate checklists and reference sheets to support delivery of care (McCoy et al., 2024; Abrahamson et al., 2023; McCoy et al., 2024; Midlöv et al., 2024; Xu et al., 2024), and promote improved communication between providers (Abrahamson et al., 2023; Midlöv et al., 2024; Xu et al., 2024). A standardized community-based palliative care communication model could also ensure that all rural locations can coordinate, communicate, and ensure continuity of care between the community and acute care locations. Communities could use this process's basic structure and policy/procedure as a template to build more specific plans. Xu et al. (2024) heavily emphasized the concept of close coordination with healthcare institutions, and Midlöv et al. (2024) emphasized this as key in ensuring that palliative care dyads are well-informed and information flow is maintained.

Addressing Support Needs

Palliation can be stressful and full of changes that put additional pressure on informal care providers. Improved caregiver support can improve the overall experience (Xu et al., 2024). PCPs know what a stressful time palliation is for informal caregivers but may need to be more aware of how to offer moral support and aid informal caregivers in navigating emotional complexities during end-of-life care. Support could be provided by connecting to resources outside the PCP office or reassuring them during stressful caregiving periods (Vinayagamoorthy et al., 2017). To assist in particularly challenging times, PCPs should ensure informal caregivers have access to individuals who can provide palliative care or connect informal caregivers with methods to learn palliative care skills (ambulation, medication administration) (McCoy et al., 2024).

Informal caregivers must first feel comfortable in that role to address support needs. Novice PCPs can view palliative care as a specialty service that community PCPs are not equipped to manage, resulting in discomfort, perception of absent palliative care skills, and insufficient clarity regarding its integration into practice (Mahtani et al., 2015). Rural and remote areas have limited access to healthcare at baseline (CIHI, 2024). However, the number of FNPs in rural areas is increasing faster than the growth rate of family physicians (CIHI, 2024). With rural FNPs stepping in to fill a healthcare crisis gap, there is a need for a method of education that prepares FNPs for a rural practice environment (Owens, 2019), especially in the context of palliative care and support for informal caregivers (Mahtani et al., 2015). Continuing Professional Development (CPD) would be a method to fill in this perceived knowledge gap and increase PCP's confidence in practice (Wright et al., 2024). Groenewoud et al. (2021), included in this review, discuss the need for proactive and anticipatory palliative care, which they conclude can be determined using assessment tools. A model for an anticipatory palliative care tool that PCPs can use with confidence due to CPD can perhaps be modelled after the following study. Lynn et al., (2024) investigated Human immunodeficiency viruses (HIV) testing rates, theorizing that CPD indicatives could increase the frequency of PCP HIV testing rates. The study, conducted in BC, had transferability in its context of location and had the participation of 25% of rural PCPs (Lynn et al., 2024). Through multimodal CPD sessions, PCPs reported improved comfort, knowledge, and proactive HIV testing behaviour, which resulted in ongoing increased rates of HIV testing, which implies effective knowledge transfer (Lynn et al., 2024).

As demonstrated in the above study, CPD is generally well-received and effective and can have versatile delivery methods, online/self-directed, live courses, or hybrid models (Wright et al., 2024). Kelley et al. (2020) performed a systematic review examining CPD for PCPs in palliative care. Researchers in this study found increased confidence, knowledge, and skills across palliative care practice areas. Kelley et al. did note that findings related to the impact of the provision of care CPD were limited. It should be noted that increased confidence could help PCPs participate more readily in palliative care (Mahtani et al., 2015).

While admittedly not bedside interventions, FNPs can advocate in their educational programs, when stepping into teaching roles, for improvements to the FNP program that ensure FNPs are prepared for the unique challenges and responsibilities of working in rural settings (Owens, 2019). As an FNP, there is also the opportunity to encourage partnerships between rural clinics and the FNP schools to both foster a sense of community and provide ongoing rural education programs (Owens, 2019).

Navigating Transitions

The transitional period for palliative patients and their informal caregivers is an intertwined theme within elements of the discussed themes. Xu et al. (2024) discovered that during transitional phases, informal caregivers required support to limit anxiety during transition. McCoy et al. (2024) discussed that transitions are stressful for informal caregivers and palliative patients; this can be made worse by poor communication between the informal care provider and the healthcare team. In 2017 Health Canada made commitments to improve palliative care through a national framework, which was developed with input from stakeholders. Health

Canada (2018) prioritized improving access to palliative care especially for underserved groups, and discussed living well until death through education, training, PCP support and further research into palliative care. Then in 2023, Health Canada outlined their plan to expand on palliative care interventions and improve upon training and education for PCPs, development of Project Echo, a continuing education program, and eiCompass project, for the development of training and tools for healthcare workers. for the interest of training and tools for healthcare workers. The above strategies have been recommended by authors in this review for improvement of palliative care.

The feasibility of a more structured palliative care transitional pathway is still in development; however, Markle-Reid et al. (2020) found in their study to determine the feasibility of a transitional care intervention in Hamilton, Ontario, that such a tool could exist for those who have suffered a stroke. Markle-Reid et al. state that transitional care aims to establish continuity and coordination of care for patients transferring across healthcare settings and support reintegration into the community. Researchers outlined four main aims in their research, "(i) home visits or telephone calls by an IP team from the hospital-based outpatient rehabilitation centre, (ii) monthly case conferences where the providers discuss individual patients, (iii) care coordination/system navigation by the OT, and (iv) our web-based app 'My Stroke Team (MyST)" (Markle-Reid et al., 2020, p. 5). This study indicated that hospital readmissions dropped dramatically, and reductions in hospitalizations, ER visits, and other emergency services noted additional cost savings.

Transitions are areas of care where gaps in support, discharge planning and communication are noted between providers (Midlöv et al., 2024). Transitional gaps contribute to patient and caregiver anxiety, resistance to change, and uncertainty in the transition process

(Xu et al., 2024). Informal caregivers find the transitional process is further complicated by their evolving role, which is to adapt and produce adjustments in the home environment (McCoy et al., 2024). Groenewoud et al. (2021), in their advocacy for proactive and anticipatory approaches to transition, promote early identification of palliative care needs, multidisciplinary coordination, and care planning to ensure a smoother and more holistic transition and optimization of healthcare utilization.

A Whole Person Lens

Holistic care emerged as a central theme across this integrative review literature, reflecting a growing recognition of the need to treat the person, not just the condition. This theme included the informal caregiver as part of the palliative care patient, inseparable from the needs during end-of-life care (Abrahamson et al., 2023; McCoy et al., 2024; Xu et al., 2024). Holistic principles in care delivery enhance caregiver wellbeing (Abrahamson et al., 2023; Groenewoud et al., 2021) and contribute to compassionate models of care, which is essential in the shift to home and community-based palliative care (Groenewoud et al., 2021; McCoy et al., 2024; Xu et al., 2024)

In their study on the hospice experience at home, Abrahamson et al. (2023) voiced that volunteers play a crucial role in hospice services. The importance of volunteers is echoed by Midlöv et al. (2024), who suggest that volunteers could support domestic tasks, post-bereavement care, and reduce the caregiver burden. Johnson et al. (2024)'s research provides insight into the effectiveness of peer support demonstrated successfully in a level 3 trauma center in the southeastern United States (USA). The findings in this research are contextually specific to healthcare workers taking on peer support roles; it shows strong evidence that the successful integration of trained volunteer peer supports was effective and, in addition, was well received by the healthcare workers, as it met a need and is a model for other peer-led emotional supports (Johnson et al., 2024). Researchers recruited volunteers based on interpersonal skills, leadership capabilities, and communication skills. As a need indicated by informal caregivers is post-bereavement support (Abrahamson et al., 2023), skilled volunteers can successfully fill the role of peer support workers. Ramchand et al. (2017) found a nuanced success in peer integration in their systematic analysis that examined peer support interventions in promoting health and wellness. The reviewers included information from 116 randomized control trials using evidence mapping to catalogue the search visually (Ramchand et al., 2017). Researchers found that with peer integration, outcomes were mixed overall, with more null than positive effects regarding health promotion. Researchers reported that outcomes measured related to engagement, knowledge and psychosocial wellbeing were noted to be effective (Ramchand et al., 2017). Peer support can enhance coping and resilience while building emotional connection and trust and even providing contextually relevant support (Johnson et al., 2024; Ramchand et al., 2017).

Implications

Clinical implications exist for PCPs in rural areas required to care for palliative care patients and support the informal caregiver in the process. The overarching themes guide the need for changes across practice, policy and research.

Interdisciplinary collaboration

PCPs and other disciplines' inconsistent communication was identified as a barrier to informal caregivers' ability to care for the palliative care patient effectively. To overcome inefficient communication a focus on interdisciplinary collaboration needs to be established for improved information sharing systems and clearer communication protocols (Groenewoud et al., 2021; McCoy et al., 2024; Vinayagamoorthy et al., 2017; Xu et al., 2024). To effectively achieve optimal communication, PCPs will need interventions in their practice, policy and for further research to be performed on their behalf. Enhancing skills in communication and collaboration will aid PCPs in handling the complex and targeted conversations that are required during palliative care (Abrahamson et al., 2023; McCoy et al., 2024; Vinayagamoorthy et al., 2017; Xu et al., 2024). Advocacy for policy, regional or even local changes should be aimed at implementing standardized hand off tools, or care coordination pathways. McCoy et al. discuss a transition care coordinator who would be in charge of communication coordination and interventions, findings consistent in Groenewoud et al. (2021) and Abrahamson et al. research that supports the opinion that one person should be in charge of care coordination, demonstrating a need for a structured communication pathway for improved information transfer. Further research should as be performed as discussed by McCoy et al. in developing pathways to improved transitional communication pathways.

Limitations

Overall, the studies included high methodological quality, as all research established clear research aims, used appropriate methodologies, and adhered to ethical considerations. Using the CASP tool (CASP, 2024) combined with the PRISMA framework (Page et al., 2021) allowed for a thorough quality appraisal of all included research articles. In the review process, I did note limitations that could affect the interpretation of the data. Firstly, only English-language studies were included, which may have limited the scope of findings and curbed the transference of implications obtained in other data; the overall value of the data may have been depreciated for unincluded good quality data (Mao & Li, 2020). In previous steps studies were excluded based on inadequate rigour. In the included studies; a limitation noted across multiple was a limited diversity and representation of the included population (Abrahamson et al., 2023; McCoy et al., 2024; Xu et al., 2024). McCoy et al. (2024) acknowledged the significant limitation on participant diversity: they were primarily white, English-speaking, and had a higher socioeconomic status. There was no collection of participants' education levels or literacy, and this would contribute to barriers for marginalized groups. Xu et al. utilized a single healthcare institution and had no information gathered on participant ethnicity or other key data that may influence responses in specific ways. Abrahamson et al. could not recruit non-English speaking participants and did not collect data on participants' ethnicity. CINAHL was the only search tool used. I did note that publication bias may inadvertently be present, as I did not include unpublished or grey literature. Mitra-Majumdar and Kesselheim (2022) discuss publication bias and conclude that publication bias can create an incomplete picture and that positive outcomes are favourably published, limiting negative or null results. A publication bias for this integrative review may affect the interpretation and understanding of this topic. In addition, due to the limiters noted above, dates were not manually limited. I may have forced a narrowing of dates and timelines through data selection, which could have limited other foundational or seminal work that did not meet other criteria. There is a chance for current data to represent early-stage findings (Helbach et al., 2022).

As I was the only data extractor and individual conducting the synthesis; interpretation bias may have occurred when identifying and selecting themes (Kaptchuk, 2003). I did not restrict articles based on the study type or method; consequentially, methodological heterogeneity can be attributed to difficulty synthesizing findings and confusing central themes (Helbach et al., 2022). Despite the limitations discussed, I believe that this integrative review provides valuable insights into its goals and highlights key themes that can be used to inform future research, policy, and clinical practice.

The results of this review provided a comprehensive outline of methods in which PCPs can effectively intervene to improve the experience of informal caregivers. The included articles also discuss areas where PCPs can improve their caregiving role. However, shortcomings should be acknowledged in the ability to obtain region-specific data and literature and in the narrower scope to find rural initiatives that may be effective. The review obtained rich insight from qualitative and mixed-method studies but including quantitative data in the future would aid in the generalizability of the findings while allowing for a broader look into trends.

Implications for FNPs

The FNP scope, with a background in nursing, focuses on care goals directed at holistic and person-centred care. This project's scope was intended to be interventions PCPs could perform daily to ensure ease of transition for palliative care patients and their informal caregivers and provide a sense of security and knowledge in those efforts. This integrative review aims to improve primary care and develop care pathways that prioritize using a community's strengths. Utilizing strengths in a community is within the FNP wheelhouse and is the usual care method for their patients. FNPs possess a collaborative base and are experts in providing and ensuring education progression and ongoing research (Schober et al., 2020). All of these are essential in bringing more significant interventions to fruition.

Conclusion

This integrative review highlights the many facets of the experience of informal caregivers caring for palliative care patients. Four central themes emerged: coordinating communication, addressing support needs, navigating transition, and providing holistic care. The central themes demonstrated significant opportunities and challenges in how PCPs could intervene to affect the informal caregiver's experience. These challenges can be worsened in a rural context where limited access to resources, geographic isolation, and workforce limitations can exacerbate informal caregiver strain.

It should be noted that this research illuminates intervention points for PCPs in the experience of informal caregivers during palliative care, the next step is action. FNPs and FNP focused researchers should aim to develop clear protocols and guidelines around palliative care patients' supportive, transitional, communication coordination, needs with an aim to ensure holistic care is honored. This integrative review highlights the importance of the informal caregiver in the palliative care experience and can help PCPs identify ways to involved them in care.

The lens of a rural PCP is important to understanding how BC's rural and remote areas can shape informal caregiver experience and expectations. The research shows that informal caregiving is a complex, emotionally, and physically demanding occupation that requires strategic interventions from the PCP and their team of community care providers. The benefit of improving the informal care provider experience is increased satisfaction and improved outcomes for the informal care provider and the palliative care patient. Addressing the barriers to improving the informal care providers' experience should be a PCP goal. Methods to achieve this success lie in the ability to enhance communication pathways and find ways to honour the emotional, social, and spiritual needs of both patient and informal caregivers holistically while supporting the transitions taking place in the palliative care experience. For rural PCPs, responsive, localized and flexible care strategies are essential. PCPs who apply person-centred principles while considering rural realities can empower informal caregivers, improve the experience, and foster dignity for palliative care patients in their journey. It is only by utilizing these key concepts that rural PCPs can fully realize and utilize the informal caregivers’ role to enhance overall patient care and experience.

References

Abrahamson, V., Wilson, P., Barclay, S., Brigden, C., Gage, H., Greene, K., Hashem, F., Mikelyte, R., Rees-Roberts, M., Silsbury, G., Goodwin, M., Swash, B., Wee, B., Williams, P., & Butler, C. (2023). Family carer experiences of hospice care at home: Qualitative findings from a mixed methods realist evaluation. *Palliative Medicine*, *37*(10), 1529–1539. https://doi.org/10.1177/02692163231206027

Ball, J. (n.d.). *The Double Diamond: A universally accepted depiction of the design process*. Design Council. Retrieved March 23, 2025, from https://www.designcouncil.org.uk/our-resources/archive/articles/double-diamond-universally-accepted-depiction-design-process/

Breivik, E., Ervik, B., Kitzm&uuml, G., & ller. (2024). Ambivalent and heavy burdened wanderers on a road less travelled: A meta-ethnography on end-of-life care experiences among family caregivers in rural areas. BMC Health Services Research, 24(1), NA-NA. https://doi.org/10.1186/s12913-024-11875-3

British Columbia College of Nurses & Midwives. (2024, April). *Nurse Practitioners Scope of Practice Standards, Limits, Conditions*. https://www.bccnm.ca/Documents/standards_practice/np/NP_ScopeofPractice.pdf

British Columbia College of Nurses & Midwives. (2020). *Duty to Provide Care*. Practice Standards. https://www.bccnm.ca/NP/PracticeStandards/Pages/dutytoprovidecare.aspx

British Columbia Ministry of Health. (2010). *A provincial framework for end-of-life care* (1–1 online resource (14 pages)). Ministry of Health. https://www.deslibris.ca/ID/223821

British Columbia Ministry of Health. (2024, July 9). *Palliative Care (Plan P)—Province of British Columbia*. Province of British Columbia.

https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/pharmacare/plans/plan-p-bc-palliative-care-benefits-program

Butler, C., Wilson, P., Abrahamson, V., Mikelyte, R., Gage, H., Williams, P., Brigden, C., Swash, B., Rees-Roberts, M., Silsbury, G., Goodwin, M., Greene, K., Wee, B., & Barclay, S. (2022). Optimum models of hospice at home services for end-of-life care in England: A realist-informed mixed-methods evaluation. *Health and Social Care Delivery Research*, *10*(24). https://doi.org/10.3310/MSAY4464

Canadian Institute for Health Information. (2022). *Death at Home or in Community · CIHI*. https://yourhealthsystem.cihi.ca/hsp/inbrief?lang=en#!/indicators/096/death-at-home-or-in-community/;mapC1;mapLevel2;provinceC9001;trend(C1,C9001);/

Canadian Institute for Health Information. (2024). *While family physician growth has slowed, pan-Canadian data indicates primary health care workforce is expanding | CIHI*. https://www.cihi.ca/en/news/while-family-physician-growth-has-slowed-pan-canadian-data-indicates-primary-health-care-workforce

Canadian Partnership Against Cancer and Health Canada. (2021). The Canadian interdisciplinary palliative care competency framework. Toronto, ON.

Canva. (n.d.). Canva (Version 2025) [Computer software]. https://www.canva.com/

Colaizzi, P. (1978). Psychological research as a phenomenologist views it. In: Valle, R. S. & King, M. (1978). Existential Phenomenological Alternatives for Psychology. Open University Press: New York.

College of Family Physicians of Canada. (n.d.). Vision, mission, values, and goals. https://www.cfpc.ca/en/about-us/vision-mission-principles

College of Registered Nurses of Nova Scotia. (2016). Nurse Practitioner-Sensitive Outcomes 2016 Summary Report. https://albertanps.com/wp-content/uploads/2017/12/NP-Sensitive-Outcomes-2016-Report.pdf

Critical Appraisal Skills Programme (2024). *CASP Qualitative Studies Check*list. https://casp-uk.net/casp-tools-checklists/qualitative-studies-checklist/

Groenewoud, A. S., Wichmann, A. B., Dijkstra, L., Knapen, E., Warmerdam, F., De Weerdt-Spaetgens, C., Dominicus, W., Akkermans, R., & Meijers, J. (2021). Effects of an Integrated Palliative Care Pathway: More Proactive GPs, Well Timed, and Less Acute Care: A Clustered, Partially Controlled Before-After Study. *Journal of the American Medical Directors Association*, *22*(2), 297–304. https://doi.org/10.1016/j.jamda.2020.10.025

Health Canada. (2018). Framework on palliative care in Canada. Government of Canada. https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada/framework-palliative-care-canada.pdf

Health Canada. (2022, October 13). Palliative care. Government of Canada. https://www.canada.ca/en/health-canada/services/health-services-benefits/palliative-care.html

Health Canada. (2023, December 14). *The Framework on Palliative Care in Canada—Five Years Later: A Report on the State of Palliative Care in Canada* [Report on plans and priorities]. https://www.canada.ca/en/health-canada/services/publications/health-system-services/framework-palliative-care-five-years-later.html

Health Evidence™ (2009). *Developing an efficient search strategy using PICO*. National Collaborating Center for Methods and Tools. McMaster University. http://www.healthevidence.org/practice-tools.aspx

Helbach, J., Pieper, D., Mathes, T., Rombey, T., Zeeb, H., Allers, K., & Hoffmann, F. (2022). Restrictions and their reporting in systematic reviews of effectiveness: An observational study. BMC Medical Research Methodology, 22, 230. https://doi.org/10.1186/s12874-022-01710-w

Holly, C., Salmond, S. W., & Saimbert, M. (2022). *Comprehensive Systematic Review for Advanced Practice Nursing, Third Edition: Vol. Third edition*. Springer Publishing Company.

Johnson, B., New, L., Ballister, M., Brown, C., & Scott, S. (2024). Implementing a Peer Support Program for Second Victims. AJN The American Journal of Nursing, 124(9), 44. https://doi.org/10.1097/01.NAJ.0001050816.14247.78

Kaptchuk, T. J. (2003). Effect of interpretive bias on research evidence. BMJ : British Medical Journal, 326(7404), 1453–1455.

Kavalieratos, D., Mitchell, E. M., Carey, T. S., Dev, S., Biddle, A. K., Reeve, B. B., Abernethy, A. P., & Weinberger, M. (2014). "Not the 'grim reaper service'": An assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. Journal of the American Heart Association, 3(1), e000544–e000544. https://doi.org/10.1161/JAHA.113.000544

Kelley, L. T., Coderre-Ball, A. M., Dalgarno, N., McKeown, S., & Egan, R. (2020). Continuing Professional Development for Primary Care Providers in Palliative and End-of-Life Care:

A Systematic Review. Journal of Palliative Medicine, 23(8), 1104–1124. https://doi.org/10.1089/jpm.2020.0060

Kirby, S., Barlow, V., Saurman, E., Lyle, D., Passey, M., & Currow, D. (2016). Are rural and remote patients, families and caregivers needs in life-limiting illness different from those of urban dwellers? A narrative synthesis of the evidence. *Australian Journal of Rural Health*, *24*(5), 289–299. https://doi.org/10.1111/ajr.12312

Levoy, K., Rivera, E., McHugh, M., Hanlon, A., Hirschman, K., & Naylor, M. (2022). Caregiver Engagement Enhances Outcomes among Randomized Control Trials of Transitional Care Interventions: A Systematic Review and Meta-Analysis. Medical Care, 60(7), 519–529. https://doi.org/10.1097/MLR.0000000000001728

Lynn, B. M., Barrows, J. A., Lam, V. W. Y., & Curran, V. R. (2024). Effect of a multimodal continuing professional development initiative on HIV testing in primary care in British Columbia, Canada. *AIDS Research & Therapy*, *21*(1), 1–8. https://doi.org/10.1186/s12981-024-00688-3

Mahtani, R., Kurahashi, A. M., Buchman, S., Webster, F., Husain, A., & Goldman, R. (2015). Are family medicine residents adequately trained to deliver palliative care? *Canadian Family Physician / Médecin de Famille Canadien*, *61*(12), e577–e582.

Mao, C., & Li, M. (2020). Language Bias Among Chinese-Sponsored Randomized Clinical Trials in Systematic Reviews and Meta-analyses—Can Anything Be Done? JAMA Network Open, 3(5), e206370. https://doi.org/10.1001/jamanetworkopen.2020.6370

Markle-Reid, M., Valaitis, R., Bartholomew, A., Fisher, K., Fleck, R., Ploeg, J., Salerno, J., & Thabane, L. (2020). Feasibility and preliminary effects of an integrated hospital-to-home transitional care intervention for older adults with stroke and multimorbidity: A study protocol. Journal of Comorbidity, 9. https://doi.org/10.1177/2235042X19828241

McCoy, M., Shorting, T., Mysore, V. K., Fitzgibbon, E., Rice, J., Savigny, M., Weiss, M., Vincent, D., Hagarty, M., MacLeod, K. K., Ernecoff, N. C., Pattison, R., Kornberg, M., Bruni, A., Bush, S. H., Kuluski, K., Fiset, V., Li, C., Parsons, H. A., & Lalumière, G. (2024). Advancing the Care Experience for patients receiving Palliative care as they Transition from hospital to Home (ACEPATH): Codesigning an intervention to improve patient and family caregiver experiences. *Health Expectations*, *27*(2), 1–22. CINAHL Complete. https://doi.org/10.1111/hex.14002

Meddings, J., Gibbons, J. B., Reale, B. K., Banerjee, M., Norton, E. C., & Bynum, J. P. W. (2023). The Impact of Nurse Practitioner Care and Accountable Care Organization Assignment on Skilled Nursing Services and Hospital Readmissions. Medical Care, 61(6), 341. https://doi.org/10.1097/MLR.0000000000001826

Meleis, A. I. (1975). Role insufficiency and role supplementation: A conceptual framework. Nursing Research, 24(4), 264–271.

Melnyk, B. M., & Fineout-Overholt, E. (2023). *Evidence-based practice in nursing & healthcare: a guide to best practice* (Fifth edition). Wolters Kluwer.

Midlöv, E. M., Lindberg, T., & Skär, L. (2024). Relative’s suggestions for improvements in support from health professionals before and after a patient’s death in general palliative care at home: A qualitative register study. *Scandinavian Journal of Caring Sciences*, *38*(2), 358–367. ccm. https://doi.org/10.1111/scs.13239

Mileski, M., Pannu, U., Payne, B., Sterling, E., & McClay, R. (2020). The Impact of Nurse Practitioners on Hospitalizations and Discharges from Long-term Nursing Facilities: A Systematic Review. Healthcare, 8(2), 114. https://doi.org/10.3390/healthcare8020114

Mishuris, R. G., Palmisano, J., McCullagh, L., Hess, R., Feldstein, D. A., Smith, P. D., McGinn, T., & Mann, D. M. (2019). Using normalisation process theory to understand workflow implications of decision support implementation across diverse primary care settings. BMJ Health & Care Informatics, 26(1). https://doi.org/10.1136/bmjhci-2019-100088

Mitchell, G. K. (2002). How well do general practitioners deliver palliative care? A systematic review. *Palliative Medicine*, *16*(6), 457–464. https://doi.org/10.1191/0269216302pm573oa

Mitra-Majumdar, M., & Kesselheim, A. S. (2022). Reporting bias in clinical trials: Progress toward transparency and next steps. PLoS Medicine, 19(1), e1003894. https://doi.org/10.1371/journal.pmed.1003894

Müller, M., Jürgens, J., Redaèlli, M., Klingberg, K., Hautz, W. E., & Stock, S. (2018). Impact of the communication and patient hand-off tool SBAR on patient safety: A systematic review. BMJ Open, 8(8), e022202. https://doi.org/10.1136/bmjopen-2018-022202

Naeem, M., Ozuem, W., Howell, K., & Ranfagni, S. (2023). A Step-by-Step Process of Thematic Analysis to Develop a Conceptual Model in Qualitative Research. International Journal of Qualitative Methods, 22, 16094069231205789. https://doi.org/10.1177/16094069231205789

Owens, R. A. (2019). Nurse Practitioner Role Transition and Identity Development in Rural Health Care Settings: A Scoping Review. Nursing Education Perspectives, 40(3), 157. https://doi.org/10.1097/01.NEP.0000000000000455

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, *372*, n71. https://doi.org/10.1136/bmj.n71

Peters, S., Guccione, L., Francis, J., Best, S., Tavender, E., Curran, J., Davies, K., Rowe, S., Palmer, V. J., & Klaic, M. (2024). Evaluation of research co-design in health: a systematic overview of reviews and development of a framework. Implementation Science : IS, 19(1), 63. https://doi.org/10.1186/s13012-024-01394-4

Public Health Agency of Canada. (2021, July 14). *Aging and chronic diseases: A profile of Canadian seniors* [Education and awareness]. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/aging-chronic-diseases-profile-canadian-seniors-report.html

Riesenberg, L. A., Leitzsch, J., & Little, B. W. (2009). Systematic Review of Handoff Mnemonics Literature. American Journal of Medical Quality, 24(3), 196–204. https://doi.org/10.1177/1062860609332512

Rudoler, D., Peterson, S., Stock, D., Taylor, C., Wilton, D., Blackie, D., Burge, F., Glazier, R. H., Goldsmith, L., Grudniewicz, A., Hedden, L., Jamieson, M., Katz, A., MacKenzie, A., Marshall, E., McCracken, R., McGrail, K., Scott, I., Wong, S. T., & Lavergne, M. R. (2022). Changes over time in patient visits and continuity of care among graduating cohorts of family physicians in 4 Canadian provinces. *CMAJ*, *194*(48), E1639–E1646. https://doi.org/10.1503/cmaj.220439

Sanders, C. (2003). Application of Colaizzi's method: Interpretation of an auditable decision trail by a novice researcher. Contemporary Nurse, 14(3), 292–302. https://doi.org/10.5172/conu.14.3.292

Schober, M., Lehwaldt, D., Rogers, M., Steinke, M., Turale, S., Pulcini, J., Roussel, J., & Stewart, D. (2020). *Guidelines on advanced practice nursing*. International Council of Nurses. https://www.icn.ch/system/files/documents/2020-04/ICN_APN%20Report_EN_WEB.pdf

Schuurman N, Crooks VA, & Amram O. (2010). A protocol for determining differences in consistency and depth of palliative care service provision across community sites. *Health & Social Care in the Community*, *18*(5), 537–548. https://doi.org/10.1111/j.1365-2524.2010.00933.x

Schuurman, N., Martin, M. E., Crooks, V. A., & Randall, E. (2020). Where to enhance rural palliative care? Developing a spatial model to identify suitable communities most in need of service enhancement. BMC Health Services Research, 20, 168. https://doi.org/10.1186/s12913-020-5024-y

Tan, A., Spice, R., & Sinnarajah, A. (2021). Family physicians supporting patients with palliative care needs within the patient medical home in the community: An appreciative inquiry study. BMJ Open, 11(12), e048667. https://doi.org/10.1136/bmjopen-2021-048667

The American Academy of Family Physicians. (2024). *The Speciality of Family Medicine*. https://www.aafp.org/about/dive-into-family-medicine/family-medicine-speciality.html

Toronto, C. E., & Remington, R. (2020). *A step-by-step guide to conducting an integrative review* (1–1 online resource (xii, 106 pages) : illustrations, tables). Springer International Publishing.

https://search.ebscohost.com/login.aspx?direct=true&scope=site&db=nlebk&db=nlabk&AN=2375735

Veritas Health Innovation. (2024). Covidence systematic review software [English; Covidence]. Veritas Health Innovation. www.covidence.org

Vinayagamoorthy, V., Suguna, E., & Dongre, A. R. (2017). Evaluation of Community-based Palliative Care Services: Perspectives from Various Stakeholders. *Indian Journal of Palliative Care*, *23*(4), 425–430. ccm. https://doi.org/10.4103/IJPC.IJPC_80_17

Williams, A. M., Wang, L., & Kitchen, P. (2016). Impacts of care-giving and sources of support: A comparison of end-of-life and non-end-of-life caregivers in Canada. *Health & Social Care in the Community*, *24*(2), 214–224. https://doi.org/10.1111/hsc.12205

World Health Organization. (2023). *Patient safety*. https://www.who.int/news-room/fact-sheets/detail/patient-safety

World Health Organization. (2024). *Ageing and health*. https://www.who.int/news-room/fact-sheets/detail/ageing-and-health

Wright, K., Golder, S., & Lewis-Light, K. (2015). What value is the CINAHL database when searching for systematic reviews of qualitative studies? *Systematic Reviews*, *4*(1), 104. https://doi.org/10.1186/s13643-015-0069-4

Wright, M. M. M., Kvist, T. A., Imeläinen, S. M., & Jokiniemi, K. S. (2024). Continuing education for advanced practice nurses: A scoping review. Journal of Advanced Nursing, 80(8), 3037–3058. https://doi.org/10.1111/jan.15911

Wu, E. X., Collins, A., Briggs, S., Stajduhar, K. I., Kalsi, A., & Hilliard, N. (2022). Prolonged Grief and Bereavement Supports Within a Caregiver Population Who Transition Through a

Palliative Care Program in British Columbia, Canada. *American Journal of Hospice and Palliative Medicine®*, *39*(3), 361–369. https://doi.org/10.1177/10499091211030442

Xu, Y., Liu, Y., Kang, Y., Wang, D., Zhou, Y., Wu, L., & Yuan, L. (2024). Experiences of family caregivers of patients with end-of-life cancer during the transition from hospital to home palliative care: A qualitative study. *BMC Palliative Care*, *23*(1), 1–9. ccm. https://doi.org/10.1186/s12904-024-01559-4

Appendix A

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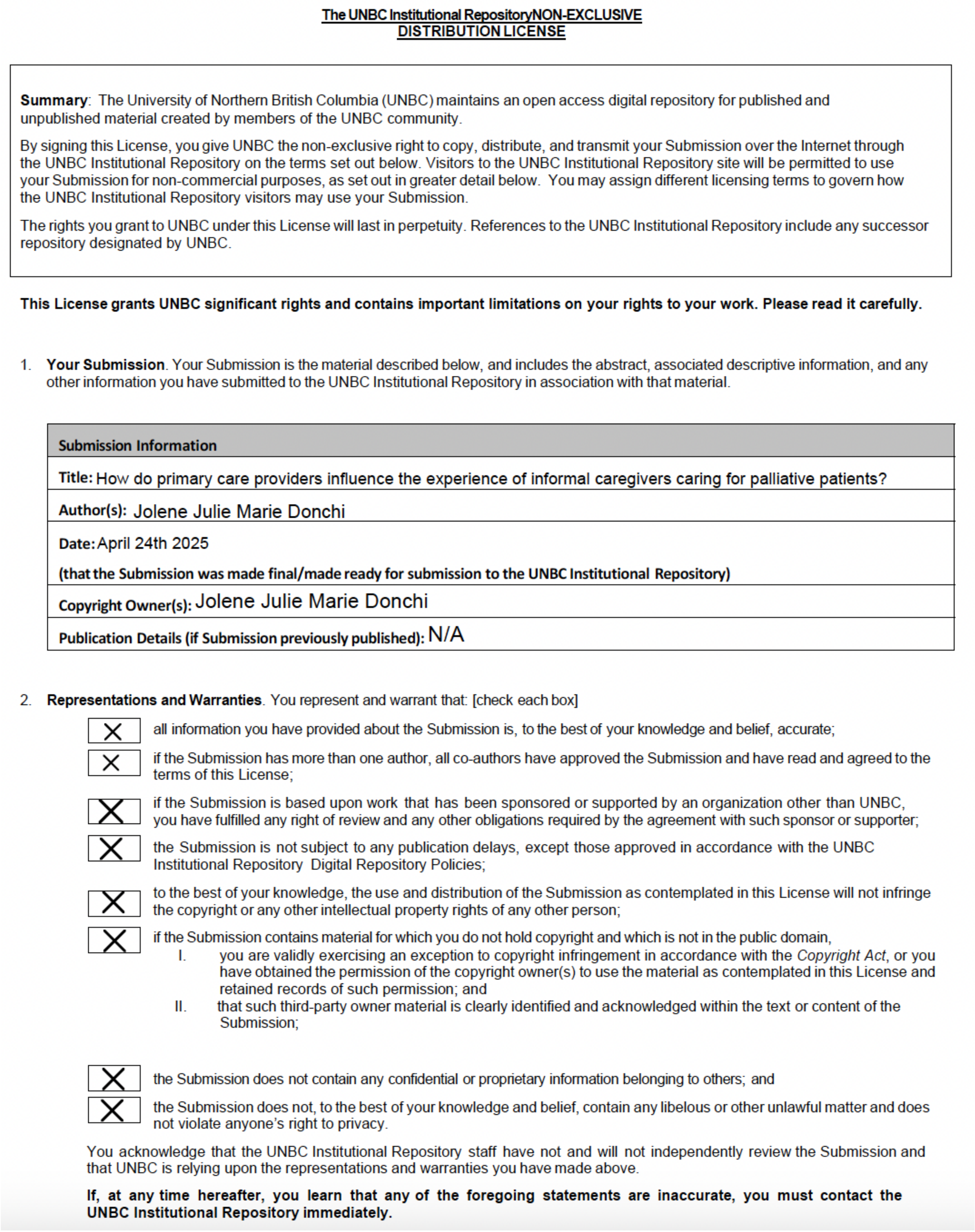

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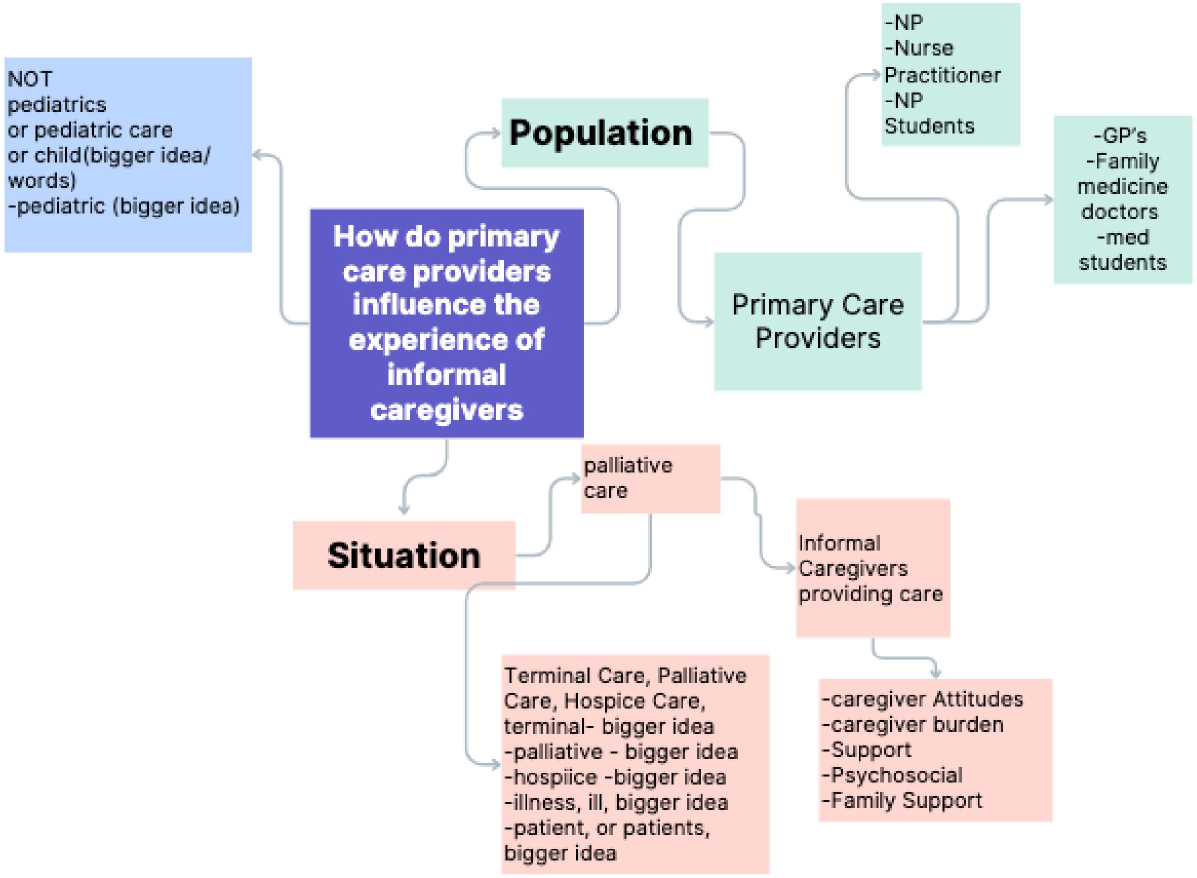
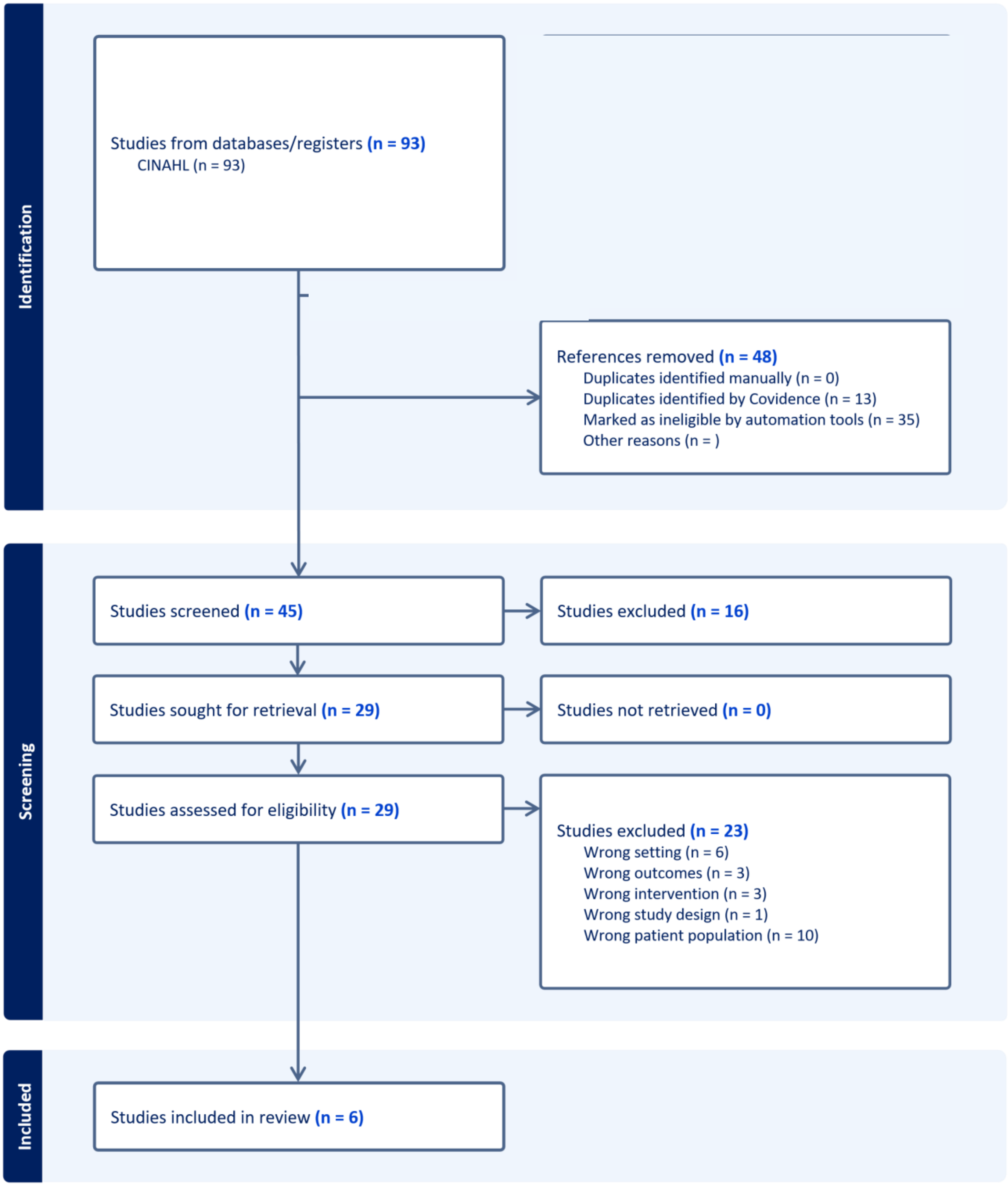
Appendix B
Brainstorming Map



Note. This mind map is the course used to develop search terms with Canva (n.d)

Appendix C



Note. PRISMA flow diagram is by Veritas Health Innovation (2024)

Appendix D
Extraction and Analysis

Study ID	Title	Authors	Journal	Year	Country	Research Design	Data Collection	Sample Size	Sampling Method	Inclusion Criteria	Exclusion Criteria	Method of Recruitment	Key Findings	Recomendations	Limitations
Groenewoud et al., 2021	Effects of an Integrated Palliative Care Pathway: More Proactive GPs, Well Timed, and Less Acute Care: A Clustered, Partially Controlled Before-After Study	Groenewoud, A. S., Wichmann, A. B., Dijkstra, L., Knapen, E., Warmerdam, F., De Weerdt-Spaetgens, C., Dominicus, W., Akkermans, R., & Meijers, J.	Journal of the American Medical Directors Association	2021	Europe	Quasi-experimental design: clustered, partially controlled before-and-after approach	-Questionnaire (for GP, Family Member) -Electronic Patient Record -Hospital administrative data -pharmaceutical data	99 patients	-not fully randomized	-terminally ill patients (identified by GP's, Medical Specialist) -RADboud indicators for PAlliative Care Needs (RADPAC) -Supportive and Palliative Care Indicators Tool (SPICT)	Not specifically indicated but through implication: -not end of life -unable to provide consent -not within the geographical area	-13 Interventional general practices -located in Sittard, Netherlands	1. Proactive not reactive care: early identification of palliative care patients, needs assessment, multidisciplinary coordination 2. Holistic patient-centred Approach: care domains addressed (physical needs, social care, psychological support, spiritual consideration), personalized care planning, respect and dignity for the patient 3. Healthcare utilization changes: reduced out-of-hours care, increased primary care provider interaction, strategic hospital engagement, medication management optimized 4. Family and Informal Caregiver support: burden assessment, improved end-of-life communication, postmortem support, emotional and practical support	Implementation strategies: -early identification -multidisciplinary frameworks -outcome monitoring Future research: -larger sample sizes, direct patient involvement, long-term outcome tracking, refined measurement strategy Practical Care: proactive care planning, enhanced communication, holistic patient care, cycle of integrated care and management	-non-randomized, limited direct involvement, potential bias in questionnaires, small sample size -low response rates, incomplete data across domains -non-randomized, exclusive physician-driven, lack of patent trajectory, no comparison of those who "opted out"
Vinayagamoorthy et al., 2017	Evaluation of Community-based Palliative Care Services: Perspectives from Various Stakeholders	Venugopal Vinayagamoorthy, Elayaperumal Suguna, Amol R Dongre	Indian Journal of Palliative Care	2017	Other	Qualitative descriptive	-Semi-structured interviews	25 (patients: 4 (16%), Caregivers: 7 (28%), Medical Social Workers: 2 (8%), Nursing Staff: 6 (24%), Medical Interns: 6 (24%))	-Purposive sampling	-stakeholders involved with Community-based palliative care service	Not explicitly discussed but implied through process: -participants who were not available during data collection -unwilling or unable to participate in collection	purposeful sample: -vocal and willing, service providers with experience to ensure a variety of views and evidence	1. Physical management: consultations on co-morbidities, laboratory services, nursing care, free drug provision 2. Psycholigical care: moral support, stress reduction 3. Social support: care for family members, economic support, improved community interaction 4. Efficient Teamwork: trained service providers, preplanned monthly schedules, supportive decision-making	For success needs -local volunteer recruitment -train caregivers -community funding -community engagement	-purposive sampling resulting in the exclusion of alternate opinions and adding a potential for bias -participant availability resulted in not all opinions collected causing a limited understanding of all opinions
Abrahamson et al., 2023	Family carer experiences of hospice care at home: Qualitative findings from a mixed methods realist evaluation	Abrahamson, V., Wilson, P., Barclay, S., Brigden, C., Gage, H., Greene, K., Hashem, F., Mikelyte, R., Rees-Roberts, M., Silsbury, G., Goodwin, M., Swash, B., Wee, B., Williams, P., & Butler, C.	Palliative Medicine	2023	Europe	Realist evaluation with mixed methods	-Qualitative interviews with carers and service providers	339 patient/carer dyads, 284 patients died during study period, 58 carers interviewed	-convenience sampling	Patient Criteria: -had an informal care provider that provided daily care at home -the patient was admitted to a hospice-at-home service Informal Care Provider: -Willing to participate -able to provide informed consent and actively involved in care	Was not explicitly stated but can be implied: -patients who did not have an informal care provider -non-English speaking -unable to provide consent	-hospice staff invited dyads -research team provided training on recruitment -variable written consent -personal/nominated consulted process for patients lacking capacity	1. Integration and Coordination: carers appreciated hospice staff taking over care, out-of-hours support 2. Knowledge and skill: skilled professionals, unique care approach, expertise in death and dying 3. Support for Informal Care Providers: home-based care, patient/caregiver dyad service, education, service expectations 4. Volunteers: reluctance from staff and informal care providers about volunteers 5. Bereavement support: caregivers experienced double grief, current services were (not matching preference, lacked personalization, and relied on self-referral)	Hospice at home services require: -staff experienced in hospice specific care -allow for time and flexibility to personalize support and care -inter-service and interdisciplinary coordination and collaboration -informal caregiver support strategies	-Reliance on informal care providers indicating an inability to directly interview patients and the potential for recall bias or emotional interpretation -Could only recruit members with a care provider, excluded patients without an informal caregiver, limited representation for care scenarios -No translation service indicated diversity was not achieved and nuance could have been lost -Ethnic backgrounds not collected, cultural variations and nuance not achieved -English hospice at home services, health region-specific characteristics -Emotional and memory bias, incomplete narrative -Subjective interpretation of material
McCoy et al., 2024	Advancing the Care Experience for patients receiving palliative care as they Transition from hospital to Home(ACEPATH): Codesigning an intervention to improve patient and family caregiver experiences	McCoy, M., Shorting, T., Mysore, V. K., Fitzgibbon, E., Rice, J., Savigny, M., Weiss, M., Vincent, D., Hagarty, M., MacLeod, K. K., Ernecoff, N. C., Pattison, R., Kornberg, M., Bruni, A., Bush, S. H., Kuluski, K., Fiset, V., Li, C., Parsons, H. A., et al.	Health Expectations : An International Journal of Public Participation in Health Care and Health Policy	2024	Canada	Codesign methodology using the Double Diamond Framework	-virtual workshop -audio and video recording -transcripts -demographic questionnaire -prompt cards for facilitators	3 patients, 7 caregivers, 5 healthcare providers	-Purposive sampling	-patients and caregivers: experienced hospital-to-home transition while receiving care, age 18+, able to communicate in English or French, palliative performance scale between 30-50% (bedbound at 30%)	Not specifically stated but inferred: -under 18yo -non-English or French speakers -not experiencing a hospital-to-home transition -Palliative Performance Scale below 30% or above 50%	-The team approached potential participants -16 organizations were contacted -was presented virtually to stakeholders	1. Emergency and Health Needs Readiness: not knowing who to call in emergencies, lack of equipment, concerns managing health needs, uncertainty over DNR protocols 2. Logistics: home equipment selection issues, arranging home care difficulties, medication management issues, home layout 3. Psychosocial Preparedness: not prepared for the unknowns, learning caregiver basics, managing emotional changes, coping with caregiver burden, dealing with a lack of resources 4. Home Life: feeling prepared, needing education, understanding ongoing care requirements	Intervention: specific and simple documentation, develop patient/ caregiver-centered support tools, easy to use written resources (checklists, reference sheets, workbook Approaches: empower patient and caregiver, provide clear navigation support, create written documentation, capacity for long-term care management	-recruitment was low, limited abiity to be selective in participant selection -predominantly white English speaking, high socioeconomic status, limited representation from other other populations -sampling bias due to the exclusion of marginalized groups -COVID-19 impact forced virtual workshops, restricted direct interaction, shortage of community healthcare, potential skewing of participant experience
Midlöv et al., 2024	Relative's suggestions for improvements in support from health professionals before and after a patient's death in general palliative care at home: A qualitative register study	Elina Mikaelsson Midlöv RN, PhD, Terese Lindberg RN, PhD, Lisa Skär RN, PhD, Professor	Scandinavian Journal of Caring Sciences	2023	Europe	Qualitative descriptive design	-Swedish Register of Palliative Care (SRPC) survey	160	-Adult relatives involved in general palliative care at home across Sweden	-adults relatives of patients who died -relatives involved in palliative care at home	-not explicitly set	-Health professionals invited relatives to complete the survey -invitation sent withing 3 months after patient's death -survey collected between March 2016-March 2022	1. Increased Access to Health Professionals: 24/7 support desired, help during evenings & weekends, pain relief assistance, care from same provider 2. More Information: a noted lack of information, no guidance about support services, missed details about care, insufficient communication between healthcare professionals 3. Improved Communication: difficulty in discussing end-of-life status, more conversations about condition, help contacting counsellors, coordination between professionals 4. Inddivualized support: listen, holistic individualized care, support tailored to individual needs, follow up after death	-Person centered care for health professionals -support protocols that are comprehensive -24/7 support system for caregivers -implement follow-up processes	-Open-ended survey: impose response limitation, lack conceptual depth, restrict detailed explanation -Sampling gaps: relatives who were invited but declined were excluded from the data pool, limited demographic details,
Xu et al., 2024	Experiences of family caregivers of patients with end-of-life cancer during the transition from hospital to home palliative care: a qualitative study	Yanan Xu, Yahui Liu, Yubiao Kang, Danruo Wang, Yujie Zhou, Ligui Wu and Ling Yuan	BMC Palliative Care	2024	Other	Descriptive phenomenological approach	-Semi-structured face-to-face interviews	15 family caregivers	-Purposive sampling at a tertiary cancer hospital	-providing care to patients for more than 4 hours a day -aware that the patient has end-of-life cancer -receiving palliative care as an inpatient -transitioning from hospital to home -consent	-significant organic disease -language impairment -cognitive impairment	-hospital leadership identification -screened against criteria -invitation extended to matching participants	1. Transition Process: anxiety about uncertainty, resistance to transition 2. Discontinuity in Care: insufficient discharge guidance, insufficient communication 3. Post-Discharge Continuous Care Needs: a need for home-care knowledge, need for social and emotional support, desire for grief counselling 4. Personal Growth and Gains: noted were enhanced coping ability, an increase in psychological resilience	1. Provide psychological support 2. Training of skills for caregivers 3. Improve communication from the hospital to the community 4. Establish a network of support 5. Telemedicine services?	-only one site used -small sample size -potential for bias

Appendix E
Thematic Conceptual Framework

Quotations	Key Words	Codes	Themes
"Family caregivers need support and assistance from professional institutions, healthcare providers, and other social resources during home palliative care." (Xu et al., 2024)	Support and assistance, social resources	Healthcare Utilization	Support
"The relatives expressed a desire for improved communication with the HPs to support them, as communication with the HPs was not working optimally." (Midlöv et al., 2024)	increas. PCP involvement		
Finally, our findings regarding medication prescriptions (more comforting medication was provided to patients who were included into the pathway) are underpinned by other studies that also found an increase in prescribed symptom-specific medication and a reduction in medication prescribed for comorbid disease, if appropriate palliative care was given(Groenewoud et al., 2021)	homecare, medication, home arrangements	Preparedness	
“Moulding care around the dyad also involved equipping carers with the necessary knowledge and skills to develop confidence in their own abilities. One hospice ran a carers' course which included sessions on mobility, nutrition, finances and the process of dying which most found helpful" (Abrahamson et al., 2023)	caregiver morale, bereavement, training		
“the engagement of patients and caregivers has created opportunities to challenge long-standing concerns in medicine where the voices of healthcare providers (HCPs) take precedence over those with lived experience”(McCoy et al., 2024)	unique needs, personalized care, needs assessment	Individualized Support	Holistic and Person Centered Care
“guide patients and caregivers problem-solving, coping, decision-making, advance care planning, symptom management, self-care, and communication, in turn reduce the burden on family caregivers” (Xu et al., 2024)	Care planning, recognizing the individual journey		
“Since the relatives involved in PC at home have unmet support needs, a person-centred perspective might contribute to understanding how to meet these needs and improve the support to them” (Midlöv et al., 2024)	meeting needs, person centered	Holistic Care	
Studies done across the world, which used various guidelines, showed that an effective Community Based Palliative Care model comprises seamless coordination, holistic care, communication and relationship development, and empathy and understanding of the patients and carers (Vinayagamoorthy et al., 2017)	holistic care, communication, relationship develop., outcome monitoring		
Successful care at home depended heavily on the family carer. In strong services, care was moulded around the dyad, combining co-ordinated processes with high quality care. Notable was the use of 'family' as metaphor, used by both carers and staff." (Abrahamson et al., 2023)	Explicit focus, collaborative working	Team Integration and Coordinatoin	Communication and Coordination
I had no direction as to what to expect before and after we came home. I am struck by the poor coordination and the system that is not patient-centred, nor supportive of caregivers."(McCoy et al., 2024)	Skill based communication, training in communicatoin skills		
“The study found that interdisciplinary collaboration is essential to ensure continuous and consistent care, necessitating close cooperation among medical teams, family caregivers, and community resources to develop personalised care plans” (Xu et al., 2024)	interdisciplinary understanding	Improved Communication	
They requested more conversations about the patient's condition and described that improvements in support could be made in raising and discussing difficult topics regarding death, as they found it difficult to communicate about it and accept that the patient would die.(Midlöv et al., 2024)	clarity in instructions		
During the patient's discharge or transfer process, healthcare professionals should promptly provide detailed information to both the patient and the caregiver, including treatment plans, care plans, and potential risks(Xu et al., 2024)	Post discharge dynamics	Transition and Discharge Process	Transition Post Discharge
“Family carers were often responsible for co-ordinating care prior to hospice involvement and were relieved when hospice staff took over responsibility” (Abrahamson et al., 2023)	Discharge preparation issues		
“caregivers reported experiencing an additional administrative load as they were often responsible for coordinating many of the physical supports (e.g., setting up equipment, obtaining medical supplies) before discharge home.” (McCoy et al., 2024)	dynamics of care and environment of caregiving	Continuity of Care Post Discharge	
In addition, the relatives suggested improved communication with and between different HPs to coordinate care so that they would not have to contact different healthcare institutions (Midlöv et al., 2024)	Care support and challenges		

Note. Conceptual Framework (Naeem et al., 2023) with Canva (n.d)