EXPLORING THE EXPERIENCES AND SENSE-MAKING OF PATIENTS AND INFORMAL CAREGIVERS IN THE INPATIENT SPECIALIST PALLIATIVE CARE CONTEXT

Master's Thesis

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A thesis submitted to the University of Ottawa in partial fulfillment
of the requirements for the degree of Master of Science in Health Systems

Telfer School of Management
University of Ottawa
Thesis
January 17, 2022

Abstract

Palliative and end-of-life care (PEOLC) involves the use of an interprofessional approach to improve quality of life for patients facing life-threatening illness, and their informal caregivers (e.g. family, other loved ones). Though many patients with life-threatening illness report desires to die at home, people with PEOLC needs continue to die in hospital settings. Given the considerable differences between inpatient and outpatient PEOLC settings, and the potentially increased future need for inpatient PEOLC services, it is critical to explore how patients and caregivers experience and make sense of illness and care in such settings. To contribute to this gap in the literature, I conducted a scoping review on patient and informal caregiver experiences in inpatient specialist palliative care (SPC) settings and semi-structured interviews with patients and caregivers on the Bruyère inpatient SPC unit. I identified three overarching themes from included studies (n=104), including patient and informal caregiver: i) perceptions of care, the interprofessional palliative care team, and the care environment; ii) communication with the interprofessional team; and iii) impacts of illness and care on quality of life. I conducted interviews with three patients and four informal caregivers. Using an inductive thematic analysis approach, I identified three key themes of patient and informal caregiver experiences within the context of the Bruyère inpatient SPC unit: i) the journey of dealing with life-threatening illness; ii) impacts of the COVID-19 pandemic; and iii) attempts to cope and find peace. Based on my findings, improvements are needed to the provision of person-centred care to address patients' and informal caregivers' supportive needs. Further work is needed to identify reforms to support improved education and awareness about palliative care to patients, informal caregivers, and the general public.

Acknowledgements

Throughout the highs and lows of the past two years, I have received a great deal of support and assistance that made this work possible.

Words cannot express my gratitude for my thesis co-supervisors, Dr. Agnes Grudniewicz and Dr. Shirley Bush, for their guidance, patience, and never-ending support and encouragement both for my thesis work and career aspirations. I can say without a doubt that my thesis would not be what it is today without the countless hours they put into editing my work, suggesting new literature, and ensuring that it 'made sense'. I am truly fortunate to have had the pleasure of having them both as my thesis co-supervisors.

I would like to thank my favourite librarian, Lindsey Sikora, for coaching me through the development of my scoping review search strategy with her extensive knowledge, wittiness, and enthusiasm.

I would like to acknowledge Julie Vizza, Leandra Carino, and Maya Dancey for the extensive time and energy they put into screening title and abstract and full-text records for the scoping review component of my thesis. I truly appreciate their willingness to help me within such a limited timeline while juggling their other commitments.

This thesis would not be possible without the participation of the three patients and four informal caregivers who so openly shared their experiences with me. I sincerely hope that I can contribute to improving other patients' and informal caregivers' experiences through their contributions to this thesis.

I would like to thank the interprofessional palliative care unit team members at Bruyère Continuing Care who took the time to circulate information about my interview study, approach patients for me to contact, and ask about my progress on my thesis project. Based on my prior and current employment in this context, I had always felt lucky to work alongside such genuinely kind and hardworking individuals. Completing research for my thesis in the same setting has reinforced this sentiment.

Thank you to my furry companions, Mini and Biggie, for reminding me to take breaks from my thesis work through their relentless requests for cuddles and preoccupation with creating mayhem.

Finally, I would like to thank my partner, Jon, for his unwavering love, support, and patience. Thanks for always being there for me and, most importantly, never failing to bring me food.

Many, many thanks to you all!

Table of Contents

CHAPTER 1: INTRODUCTION

Palliative care uses an interprofessional approach to improve the quality of life for patients facing life-threatening illness, and their families, through the holistic management of pain and other symptoms, including physical, psychosocial, and spiritual aspects of illness.[1] It has been estimated that approximately 40 million people require palliative care services worldwide every year.[2]

Many patients with life-threatening illness report wanting to die at home, with their caregivers echoing similar preferences.[3, 4] However, many people with palliative and end-of-life care needs continue to die in hospital settings.[5-7] Recent advances in the improved access and provision of palliative care have enabled more people to die in their desired setting.[8, 9] It is predicted that there will be an increased need for inpatient palliative care services given the aging population,[10] greater symptom burden and complexity of chronic illness,[10] and patient care needs surpassing available supports in community settings.[11]

Individuals with life-threatening illnesses, such as cancer, and their informal caregivers have reported unmet supportive needs throughout their experiences in advanced cancer and palliative care settings.[12-18] Supportive care needs can be grouped into four main categories: needs pertaining to the patient's care and well-being, information sharing, caregiving challenges, and emotional support.[12, 19] Patient and informal caregiver supportive needs are well-documented in outpatient or clinic-based palliative care settings,[15-17, 20] where patients typically have a longer prognosis and are living in the community.[21] Conversely, patient and informal caregiver needs are currently poorly characterized in hospital or inpatient palliative and end-of-life care settings where patients are frequently older, typically have shorter lengths of stay until death or discharge, and lower functional status.[12, 22] An additional challenge is that patients in inpatient palliative and end-of-life care settings are particularly vulnerable to rapid changes in cognition and functional status, and the short period of time spent receiving care from the palliative care team may make communication difficult or very limited. Conceptualizing how patients and informal caregivers understand and make sense of their experiences of illness and care will assist palliative care providers to tailor their care to meet patient and informal caregiver needs.[23, 24]

To date, there is a paucity of literature on patient and informal caregiver experiences and associated sense-making in Canadian inpatient specialist palliative care (SPC) contexts. It is critical to explore how patients and caregivers make sense of their experiences and needs for support in such settings given the considerable differences between inpatient and outpatient palliative care,[22] and the unpredictable trajectory of illness in the last weeks to days of life.[25] A 2020 systematic review of palliative care research priorities and an international research agenda identified communication, patient preferences and experience, and cognizance and importance of informal caregiver needs as priority areas for research.[26] This thesis study contributes to addressing these research priorities within the inpatient SPC setting. For the purposes of this thesis study, inpatient SPC settings are those that are designated for the delivery of palliative and end-of-life care with the involvement of SPC providers. Based on this definition, inpatient SPC units, dedicated palliative care beds in hospitals, and inpatient/residential hospices were considered inpatient SPC settings in this study.

1.1. Background

1.1.1. Palliative care: A holistic approach to care

Palliative care uses a team approach to address the needs of patients with life-threatening illness and those of their informal caregivers (e.g., family members, friends, or unpaid caregivers)[1] and is also provided to patients with progressive disease at the end of life, wherein patients are expected to survive "months or less".[27]

The delivery of person-centred care is a hallmark of the palliative care approach.[28] Person-centred care: i) considers and respects individual needs, preferences, beliefs, and values, ii) promotes individuals as being active in their own care, and iii) and ensures the development of a collaborative therapeutic relationship between members of the care team and individuals receiving care.[29] Using this approach, palliative care may be delivered by either generalist or SPC providers alone, or working together in a collaborative partnership.[30] Generalist palliative care providers are non-specialists who care for patients with life-threatening illnesses and are considered a part of the 'primary palliative approach to care'.[31] Examples of these individuals include primary care physicians, oncologists, general acute care nurses, or long-term care home staff. Conversely, SPC providers are formally trained in palliative care through full-time fellowships, or have extra training or experience that resulted in enhanced expertise in palliative care.[31, 32] These clinicians may provide care in inpatient palliative care unit or hospice settings, outpatient clinics, or through consultation-based services in hospitals or in patients' residences in the community.[32]

Specialist palliative and end-of-life care can be delivered in a range of facilities. However, there is an important distinction between hospice care and other palliative care settings, even though these terms are sometimes used interchangeably. In most parts of Canada, inpatient hospice care is typically provided to patients with less complex symptom management needs and who are in the last days or weeks of life compared to patients with more complex symptom management and/or psychosocial needs receiving SPC services on an inpatient palliative care unit.[33]

Effective delivery of palliative care is correlated with improvements in patients' physical and psychological symptoms at the end of life,[31, 34-37] patient quality of life,[31, 37] overall patient and family satisfaction,[38] and bereavement outcomes for informal caregivers.[39] Given the many benefits of palliative care, in 2002, the World Health Organization modified its definition of palliative care by changing all references to "terminal illness" to "life-threatening illness" to establish the applicability of palliative care early on in the disease trajectory.[1, 40, 41] Following this modification, the Bow Tie Model of Integrated Palliative Care was developed as a representation of early palliative care (Figure 1).[41] This model: i) describes the integration of palliative care into medical care as early as when disease management for the life-threatening illness begins, ii) indicates that palliative care should take an increasingly higher precedence throughout the course of the illness, and iii) illustrates the function of palliative care in supporting patients and informal caregivers through to rehabilitation and survivorship, or end-of-life care and bereavement.[41]

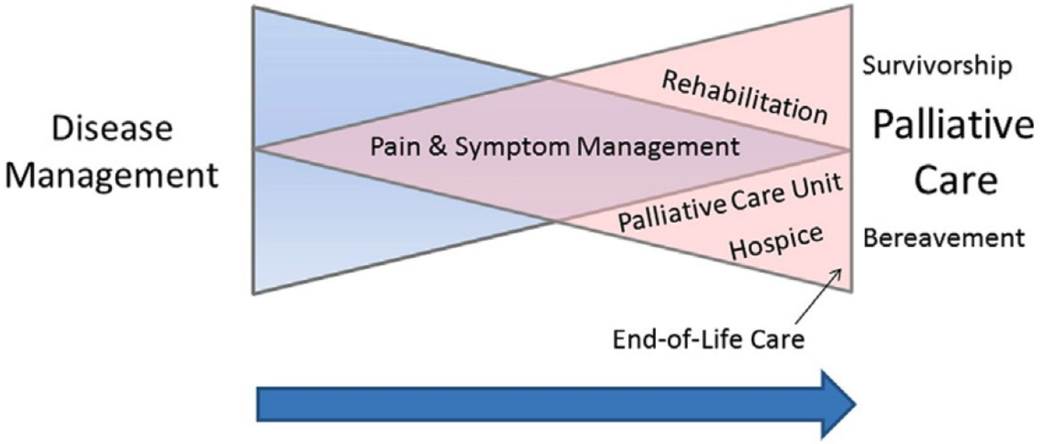


Figure 1. Bow Tie Model of Integrated Palliative Care.[41]

1.1.2. Patient and informal caregiver supportive needs and experiences of palliative and end-of-life care

Ensuring that patients and informal caregivers receive care in accordance with their needs and culture is a core competency of palliative care,[42] and enables the preservation of patient dignity until death.[43] Nonetheless, patients and informal caregivers report unmet supportive needs throughout their experiences within advanced cancer and palliative care contexts. For patients, these can range from information,[13, 14, 44, 45] physical,[13, 44, 45] psychological,[44, 45] spiritual,[13, 14] social,[13, 14] and financial needs.[44] Meanwhile, informal caregivers have reported unmet needs for information,[13, 14] support from the care team to address the patients' needs,[44, 46] physical, spiritual, and psychological support for themselves,[13, 14] guidance and counselling from the care team throughout the illness course,[44] and financial support,[13] among other supportive needs.

Patient and informal caregiver reports of unmet information needs in cancer and palliative care settings are particularly prevalent in the literature.[13-18] Optimal information transfer can lead to patients feeling more involved in their care and that their preferences were considered,[47] while families may feel more capable in their caregiving role.[48, 49] Conversely, unmet information needs in patients receiving palliative or end-of-life care can contribute to anxiety, depression, low quality of life, feelings of loss of control, and dissatisfaction with care.[18, 50-52] Informal caregivers may suffer extensive psychological distress in palliative care contexts, even with the delivery of satisfactory care.[12, 48, 53] These psychological effects may include moderate to severe anxiety and depression,[12, 53] exhaustion,[53] sleep difficulties,[53] feeling isolated,[48] and feelings of loss or the threat of loss.[48] Informal caregiver distress can be further exacerbated with inadequate information provision,[48] and may continue into bereavement.[54, 55] This indicates the importance of understanding patient and informal caregiver experiences of illness and care in palliative and end-of-life care contexts.

1.1.3. Sense-making in the context of incurable illness

Sense-making is defined as a "process through which people work to understand issues or events that are novel, ambiguous, confusing, or in some other way violate expectations."[56] Sense-making is a component of meaning-making,[57] the process of creating meaning, purpose, and a sense of order and consistency in a changing or changed situation.[58] In encountering a complex situation, individuals and groups engage in sense-making to enable a shared understanding of the situation.[59] The sense-making concept can be applied in complex situations to probe and identify patterns, seek multiple perspectives, and then respond to the situation.[59] This process is entrenched in time and space, wherein individuals reflect on and attempt to make sense of their past and present experiences, and prepare for the future.[60] Making sense of an issue or event is a complex phenomenon that involves psychological, social, and cultural components, including emotions, personal desires or motivations, memories, values, and language.[60] Previous literature has examined sense-making in organizational behaviour,[61] education,[62] and human-computer interactions.[63] More recently, the concept of sense-making has been studied in the context of critical and urgent care,[64-66] chronic illness,[67, 68] oncology,[69, 70] and bereavement.[57, 71-75]

The sense-making process in the context of incurable illness can also be described as a process of existential and experiential learning to handle and adapt to an altered or uncertain life situation.[23] Patients, in particular, may move between existential uncertainty and certainty about illness-related changes to their bodies, everyday life, relationships with others, and care situations in the process of learning more about their condition.[76] Making sense of illness at the end of life may involve ongoing searches for knowledge and understanding of the situation to cope with everyday life.[77] In patients' and informal caregivers' quests of making sense of the patient's illness, supportive needs may be uncovered.[78] Patients and informal caregivers may address these needs through self-initiated searches for information, or by consulting others, such as health care providers or patients suffering similar life-threatening illnesses.[77] When patients and informal caregivers are unable to make sense of a particular situation at hand or address their associated needs, this may encumber their ability to cope with the situation.[65]

The struggles that patients and informal caregivers may experience in trying to make sense of illness and the receipt of palliative care require interprofessional team members to act accordingly in communicating with and providing care to patients and informal caregivers.[79] In particular, there is a need for interprofessional palliative care team members to identify and understand patients' and informal caregivers' reasoning in relation to the patient's illness and care, and use this logic to communicate with patients and informal caregivers.[23, 24]

To date, there is limited literature on patient and informal caregiver sense-making in the context of palliative care.[77] Though there is other work that has explored sense-making in outpatient palliative care settings,[23, 24, 77] to my knowledge, there are no previous studies examining patient and informal caregiver sense-making within the context of inpatient SPC. In comparison to outpatient clinic or community SPC offerings, inpatient SPC services involve a significant change in environment (e.g., a patient leaving home).[11, 80] Inpatient SPC settings also typically care for patients with complex and persistent symptoms or psychosocial challenges that cannot be managed in the community setting.[11, 80] It is therefore important to understand how patients and informal caregivers make sense of the patient's illness and care in these settings. Increased knowledge of this process will inform methods of improving existing clinical practices to better align with patient and informal caregiver supportive needs.

1.2. Purpose and Research Questions

The purpose of this thesis study is to describe how patients and informal caregivers experience illness and care, and make sense of these experiences within the inpatient SPC context. For this thesis, I conducted a scoping review and interviewed patients and informal caregivers in an inpatient palliative care setting in Ottawa, Canada to address the following research questions:

1. What is the breadth of the literature on illness- and care-related experiences of patients and informal caregivers in inpatient SPC settings?
2. What are the illness- and care-related experiences of patients and informal caregivers on an inpatient SPC unit?
    a. How do patients and informal caregivers make sense of illness and care in the inpatient SPC context?

In the next chapter, I describe the methods used in this thesis, beginning with the scoping review and followed by the interviews. The results of these two components are presented individually in Chapter 3. In Chapter 4, I summarize both components of this thesis and discuss the implications of my findings, while drawing comparisons with previous literature. I also present the strengths and limitations of the scoping review and interviews along with some recommendations for future work based on my findings in Chapter 4. Finally, I outline the contributions of my thesis to the body of knowledge on how patients and informal caregivers experience and make sense of illness and care in the inpatient SPC context in Chapter 5.

CHAPTER 2: METHODS

2.1. Overall approach and rationale

To answer my first research question, I conducted a scoping review to describe the literature on patient and informal caregiver experiences with illness and care in inpatient SPC settings. To answer my second two-part research question, I collected qualitative data using semi-structured interviews with patients and informal caregivers on an inpatient SPC unit. These interviews were used to understand how patients and informal caregivers experience and make sense of the patient's illness and care, associated supportive needs, and how these needs align with the sense-making process. Additionally, these interviews allowed me to compare qualitative findings from a local setting to my scoping review results in order to examine possible gaps and implications for clinical practices locally and elsewhere in similar settings. The two components of this thesis project were completed concurrently due to the time constraints associated with fulfilling my program requirements.

A pictorial representation of the data sources included in this thesis project and the contributions of these sources towards answering my research questions are depicted in Figure 2.

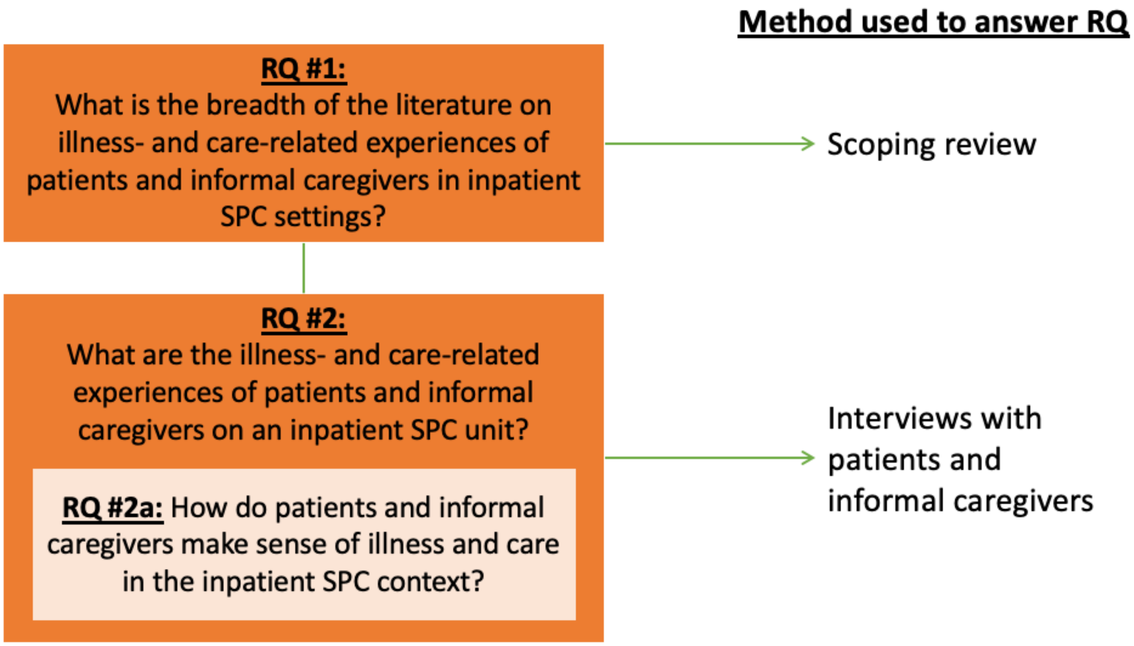


Figure 2. Outline of the components of this thesis project. Abbreviations: RQ: research question, SPC: specialist palliative care.

2.1.1. Rationale for scoping review

Scoping reviews are used to address an exploratory research question and broadly identify the key concepts, main sources, and types of research available on a specific topic area.[81, 82] The purpose of a scoping review is to: i) identify the available evidence for a topic; ii) clarify concepts or definitions across the literature; iii) assess the extent and type of research on a topic area; iv) identify the main characteristics or factors associated to a particular concept; v) act as a precursor to a possible systematic review; and vi) ascertain and analyze potential knowledge gaps.[81, 83, 84] In contrast to both systematic and integrative reviews, scoping reviews are not considered appropriate for answering specific clinical questions,[85] are far broader in scope and have less restrictive inclusion criteria (e.g., inclusion of experimental and non-experimental studies, published and unpublished evidence).[83, 84]

Currently, the volume and nature of literature on patient and caregiver experiences within inpatient SPC settings is unknown. An increased understanding of patient and informal caregiver experiences of palliative and end-of-life care in inpatient settings is needed to facilitate identification of clinical practice domains in need of improvement, and recommendations for further work to support these improvements.[86] Thus, a scoping review is appropriate to understand the breadth and types of research available on this topic, synthesize what has been done, and identify knowledge gaps in existing literature.

I conducted a preliminary literature search on April 16-17, 2020 to identify existing systematic reviews or scoping reviews on patient and informal caregiver experiences in palliative care settings in Epistemonikos, the Cochrane Library, the Joanna Briggs Institute Database of Systematic Reviews, CINAHL and PubMed. Keywords included variations of the terms 'patient', 'caregiver' or 'carer' or 'family', 'experience', and 'palliative care'. These searches did not yield any existing scoping reviews on patient and informal caregiver experiences in a palliative care setting. However, other reviews were found that were relevant to this topic, including:

- a 2014 integrative review of patient and family experiences of palliative care within hospital settings (this review was not specific to inpatient SPC settings but focused on both generalist and SPC delivered within acute care hospitals);[87]
- a 2015 systematic review and meta-synthesis of the communication experiences of patients with palliative care needs (not specific to inpatient SPC units);[88]
- a 2015 systematic review of end-of-life care elements that patients and their families consider to be the most important in hospital settings (excluded inpatient SPC units);[11]

- a 2018 systematic review and meta-synthesis,[89] and a 2010 literature review,[90] of patient and caregiver experiences of transitions during the course of incurable cancer (not specific to inpatient SPC settings);
- a 2019 integrative review of caregiver burden in palliative care (not specific to inpatient SPC settings);[91]
- reviews conducted between 2012 to 2020 of palliative care experiences of patients and/or caregivers from various ethnocultural groups[92] or sexual minorities,[93] as well as those experiencing homelessness,[94] or with the following conditions: esophagogastric cancer,[95] motor neurone disease (amyotrophic lateral sclerosis),[96] or delirium.[97]

None of the above reviews comprehensively summarize the patient and informal caregiver experiences of illness and care within inpatient SPC settings. In the 2014 integrative review listed above,[87] the setting was specific to acute care hospitals, and the delivery of palliative care was not distinguished by provider type. Instead, both generalist and specialist providers were grouped together. Therefore, it is important to explore patient and informal caregiver experiences within inpatient SPC settings, given that the provision of care in inpatient SPC settings may impact patient and informal caregiver experiences of illness and care in different ways. In addition, since the conduct of this integrative review in 2014, there is a need to review and consolidate any recently published evidence. Lastly, this integrative review solely included published peer-reviewed literature. There may be other documents describing patient and informal caregiver experiences within inpatient SPC settings that could be identified through grey literature searches and subsequently included in a scoping review.

In addition to the above, many of the reviews found on my preliminary literature search were also specific to particular patient subgroups in the palliative care population and no reviews specifically examined inpatient SPC settings. Therefore, I conducted a scoping review of published and grey literature to answer this thesis project's first research question: "What are the illness- and care-related experiences of patients and informal caregivers on inpatient SPC settings?".

2.2. Scoping review

For this scoping review, I followed the methods described by the Joanna Briggs Institute Reviewer's Manual.[83] As per best practices for conducting scoping reviews,[83, 98] I developed an *a priori* protocol prior to beginning the scoping review. Given that scoping review protocols cannot be registered in PROSPERO at this time,[99] I uploaded this review's protocol[100] to the Open Science Framework repository (https://osf.io/).

2.2.1. Inclusion criteria

Types of participants: Adults (≥18 years old) receiving care in inpatient SPC settings or their adult (≥18 years old) informal caregivers (e.g., family members, friends) were included.

Concept: The specific concept of focus in this scoping review was patient and informal caregiver 'experience' within the context of inpatient SPC. This is a broad term which encompasses patient and caregiver perceptions, views, or perspectives of illness and care in the inpatient palliative care setting, as well as effects of experiences in this context. The terms 'perceptions', 'views', and 'perspectives' were incorporated in the search strategy to ensure that all possible articles in this topic area could be retrieved. Records that solely reported patients' symptoms using symptom assessment screening tools (e.g., Edmonton Symptom Assessment System) at a single point in time were not included. To manage the number of included articles and the feasibility of the scoping review, all screeners used pre-determined inclusion criteria to identify and include records that specifically involved patient- and/or informal caregiver-reported accounts of their lived experiences and perceptions of the challenges associated with illness and care within the context of inpatient SPC. This inclusion criteria was applied at both title and abstract (Level 1) and full-text (Level 2) screening stages.

Outcomes: Peer-reviewed studies and grey literature examining outcomes related to patient or informal caregiver experience were included, as were interventional studies that reported outcomes related to patient or caregiver experience in inpatient palliative care settings.

Context: This scoping review focused on inpatient settings that are designated for the delivery of palliative and end-of-life care with the involvement of SPC providers. Based on this definition, inpatient SPC units, dedicated palliative care beds in hospitals, and inpatient/residential hospices were included. Palliative care services delivered by generalist palliative care providers (e.g., oncologists, long-term care nurses) were excluded. Outpatient or community palliative and end-of-life care contexts and palliative care consultation services were excluded given that they do not involve care delivery in a designated inpatient SPC context.

Types of studies: No restrictions were placed on study type. Books were excluded due to the extensive amount of time required to review these data sources. Conference abstracts were included if they met the eligibility criteria. Only articles in the English language were included at Level 1 and 2 screening stages.

2.2.2. Search strategy

I consulted with a University of Ottawa Health Sciences librarian for assistance with search strategy development and translation into various databases. Searches were developed and tested to ensure that relevant records that had already been found in my preliminary searches were captured. I conducted searches within the following databases: Medline and Medline in Process (via Ovid; 1966 to September 17, 2020), Embase (via Ovid; 1947 to September 17, 2020), CENTRAL (via Ovid; 1991 to September 17, 2020), PsycINFO (via EBSCOhost; 1887 to September 17, 2020), Cumulative Index of Allied Health and Nursing Literature (CINAHL; 1937 to September 17, 2020), Cochrane's Database of Systematic Reviews (via Ovid; 2005 to September 17, 2020), Database of Abstracts of Reviews of Effects (DARE; via Ovid; 1991 to 2005). All databases were searched from the date of database inception to September 17, 2020. No language restrictions were applied on the database searches, except for CINAHL. Limitations selected for the CINAHL search included 'English' and 'Inpatients' for feasibility purposes and to fit the short timeline for this thesis project. All searches were restricted to humans.

The reference lists of included full-text studies were citation-searched to identify relevant articles that were not captured in my searches across databases. Iterative citation-searching (i.e., searching the reference lists of included citation-searched studies) was not completed due to timeline considerations for this thesis. The final search strategy for Medline, CENTRAL, Cochrane's Database of Systematic Reviews, and DARE are presented in Appendix A. I searched for grey literature on February 24, 2021 using a template for locating and documenting grey literature,[101, 102] and applied three recommended strategies.[102] I used various combinations of the terms 'patient', 'caregiver' or 'carer' or 'family', 'experience', 'inpatient' or 'hospital', and 'palliative care' for these searches. First, I searched the websites of specific organizations that typically publish documents related to palliative care: the Agency for Healthcare Research and Quality (AHRQ), National Institute for Health and Care Excellence (NICE), Canadian Society of Palliative Care Physicians (CSPCP), National Hospice and Palliative Care Organization, Canadian Hospice Palliative Care Association (CHPCA), Canadian Virtual Hospice, CareSearch (Caresearch.com.au), Palliative Care Australia, All Ireland Institute of Hospice and Palliative Care, Pallium Canada, and Hospice Palliative Care Ontario (HPCO). Second, I searched grey literature databases (e.g. ProQuest Dissertations & Theses Global, OpenGrey, WorldWideScience.org), and screened the first 100 results in each database. Lastly, I searched Google using the advanced search feature, and examined the first 100 results for each combination of terms. The search strategy for the grey literature is presented in Appendix B.

2.2.3. Study selection

The titles and abstracts of all references were entered into Covidence, a software that enables efficiency and collaboration for systematic and scoping reviews.[103] Duplicates were removed first using EndNote^{TM},[104] and then in Covidence. A set of inclusion and exclusion criteria for screening was developed and piloted by all reviewers prior to each level of screening using 10 randomly selected articles per round of pilot testing. Two rounds of pilot testing were completed per level of screening. Screening started once there was at least 70% consensus between all reviewers on the pilot test of the inclusion and exclusion criteria. My thesis co-supervisors (AG and SHB), two graduate students, and I independently conducted title and abstract (Level 1) screening in duplicate. In Level 1 screening, options for each reference were 'include', 'exclude', or 'maybe'. Disagreements in screening decisions were resolved through discussions between the screeners for a particular reference. If needed, my thesis co-supervisors were consulted to make the final determination for a reference. My thesis co-supervisors, one graduate student, a research volunteer, and I independently completed full-text (Level 2) screening. In Level 2 screening, we refined, tested, and applied the selection criteria to full-text articles for which abstracts received ‘include’; or ‘maybe’ decisions in Level 1 screening. The decisions for full-text screening were ‘include’ or ‘exclude’ (with a reason for exclusion). The consensus and disagreement resolution processes were the same for Level 2 screening as Level 1.

2.2.4. Data charting

A preliminary data extraction form was developed as part of this review’s protocol, and refined prior to the data charting process. Data charting included the following items: full citation, year(s) of study, country of origin (locations of study conduct, or if not available, corresponding author’s location of affiliation), publication type, number of centres (single-centre or multi-centre), study methodology (qualitative, quantitative, or mixed methods), purpose of study, study design (as described by authors), intervention type (if applicable), intervention comparators (if applicable), inpatient health care setting (inpatient SPC unit, dedicated palliative care beds in a hospital, inpatient/residential hospice, combination, other), community type (as described by authors; metropolitan, urban/suburban, small town, rural or remote, not reported, other), study population (patient and/or informal caregiver characteristics: age, sex/gender, ethnicity, marital status, employment status, other demographic characteristics), patient diagnosis (cancer, non-cancer, mixed), sample size, measures/scales/validated tools used to capture experience, key elements of patient or informal caregiver experience (not captured using measures/scales/validated tools), results of measures/scales/validated tools, and key results that were not captured using measures/scales/validated tools.

I charted data using the final version of the data extraction form from included full-text articles. To verify the accuracy of the data extraction process, one of the graduate student reviewers verified approximately 10% (10/104) of the records.

2.2.5. Data analysis

According to published scoping review guidance, descriptive qualitative content analysis is an acceptable approach to analyzing articles included in scoping reviews.[83, 105] Therefore, I used this approach in analyzing all included qualitative studies, the qualitative results of mixed methods studies, and an autobiographical article. First, I coded these articles in NVivo 12[106] to organize and aggregate concepts from the qualitative, mixed methods, and autobiographical articles included in this scoping review into themes. One of my thesis co-supervisors (SHB) reviewed and verified my coding for approximately 20% (9/48) of these articles. Quantitative studies were solely aggregated using frequency counts of key concepts or characteristics.

2.2.6. Presentation of results

The results of the scoping review are presented using charts, tables, and a narrative synthesis. General study characteristics (e.g., year of publication, country of origin, study methodology, study design, health care setting, participant characteristics) of the included articles are presented in tables. Results from quantitative studies are presented using numerical summaries, while results from qualitative studies are consolidated by themes.[105] The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist[98] was used to report this review's results.

2.3. Interviews with patients and informal caregivers

2.3.1. Rationale for interviews with patients and informal caregivers

The aim of qualitative research is to understand, explore or explain issues or phenomena.[107] In this approach, participants can be viewed as individuals who are knowledgeable of their thoughts, intentions, and actions, while researchers both elicit these contributions from participants and accurately report on the patterns they interpret from participant data.[108] The interviews in this study contribute to an understanding of patient and informal caregiver experiences and sense-making within an inpatient SPC unit in Ottawa, Canada. Therefore, the qualitative approach aligns with the goals of this thesis project.

2.3.2. Philosophical approach

In the interviews conducted for this thesis, I used a constructivist paradigm to examine patients' and informal caregivers' experiences and sense-making in the inpatient SPC unit context. The constructivist approach posits that reality is socially constructed and is uniquely perceived by individuals,[109] and that the development of theory occurs through co-construction between researchers and participants.[110] In constructivist research, "the investigator and the object of investigation … are interactively linked so that 'findings' are literally created as the investigation proceeds".[109] In using this approach, my goal was to understand patient and informal caregiver experiences and sense-making within the inpatient SPC unit context, and create meaning through my interactions with participants and my perspective of participants' reported experiences throughout my analysis. Given that I was an active participant in the data collection and analysis processes as a researcher, I have detailed my reflexive account of my position as a researcher as it relates to the conduct of this study in section 2.3.10.

2.3.3. Setting

The setting for this interview study was the 31-bed inpatient SPC unit at Bruyère Continuing Care in Ottawa, Canada. The Bruyère Continuing Care SPC unit is located in an academic sub-acute hospital and is the largest academic inpatient SPC unit in Canada.[111] This unit provides bilingual SPC to patients in need of complex symptom management and/or end-of-life care in a hospital setting, and their families.[111] The interprofessional inpatient SPC unit team consists of

SPC physicians, residents and medical students, bedside nurses (registered practical nurses and registered nurses), a nurse practice leader, a practice support nurse, a social worker, a pharmacist, a spiritual care worker, unit clerks, volunteers, and a clinical manager. The goal of the interprofessional palliative care team is to use a holistic approach (including addressing psychosocial and spiritual components of well-being) with the aim of improving the quality of life and symptom relief for individuals suffering from life-threatening illness, as well as supporting their families.[33]

However, the COVID-19 pandemic presented significant challenges as I began recruiting patients and informal caregivers. All admissions had to be approved by the hospital infection prevention and control team, with patients undergoing COVID-19 isolation requirements. Visitation was also restricted. At the start of the pandemic, fewer patients were admitted to the Bruyère SPC unit due to a drop in referrals from external providers. Many patients who were admitted had a reduced performance status (Palliative Performance Scale ≤ 20%) and therefore did not meet my eligibility criteria for interviews (see section 2.3.5: Eligibility criteria). As a result, I was not able to recruit patient and informal caregiver dyads, so I recruited as many eligible patients and informal caregivers as possible between November 2020 and mid-February 2021, given the limited amount of time I had to complete this work to fulfill my program's requirements.

Access to the Bruyère inpatient SPC unit was obtained through my existing professional connections to this institution. Senior leadership members from the Bruyère Department of Palliative Care were enthusiastic about supporting this thesis project.

2.3.4. Interview procedures

Patients and informal caregivers on the Bruyère inpatient SPC unit were invited to participate in one telephone or video (e.g., via Zoom) interview given isolation precautions. Patients and/or informal caregivers who were unable to participate in a telephone or video interview (e.g., due to technological barriers, or personal preference) were also offered the option of an in-person interview within the patient's room on the inpatient SPC unit. Bereaved informal caregivers who have previously experienced care on the Bruyère inpatient SPC unit were also interviewed. Interviews with bereaved informal caregivers in the community solely took place via phone or video conferencing software. These interviews explored how patients and informal caregivers experienced the patient's illness and care within the context of the inpatient SPC unit, as well as the sense-making that arose from these experiences.

Following the principles of semi-structured interviews, questions were open-ended, using language and prompts that were responsive to the participant's accounts.[112] Each semi-structured interview was based on a written interview guide (Appendix C). The final version of the interview guide provided in Appendix C was adapted iteratively over the course of interviews to further examine specific issues of interest. Question order was flexible to allow the interview to be led by the participant rather than the interviewer. Patients and informal caregivers were asked to participate in interviews for 30-45 minutes to reduce participant burden, while enabling me to obtain a rich understanding of their experiences. Interviews were audio-recorded with two digital recording devices to prevent data loss, and transcribed verbatim.

2.3.5. Eligibility criteria

Eligible patients included adults (≥18 years) who were: rated ≥30% on the Palliative Performance Scale[113] (a scale that is used to assess patients' functional ability in palliative care);

able to speak English; receiving care on the Bruyère inpatient SPC unit; and able to provide informed consent to participate in research.

The patient's circle of care assessed the patient's eligibility and cognitive capacity to participate in this thesis project. Patients with mild to moderate cognitive impairment or dementia were eligible if, based on the opinion of the clinical care team, patients could provide informed consent to participate in the research project and contribute meaningfully. Patients experiencing delirium, severe cognitive impairment, or otherwise deemed too unwell to participate in this thesis project by their clinical care team (e.g., actively dying, somnolent, unresponsive, or anxious due to a recent admission to the unit) were excluded. Late exclusions occurred after the initial consent process if the patient's condition deteriorated or if they were considered to be no longer competent of providing ongoing informed consent to participate in research, based on the opinion of the clinical care team. This method of determining patient eligibility for participation in clinical research is the typical approach for studies that take place on the Bruyère inpatient SPC unit and is also deemed acceptable by the Bruyère Research Ethics Board.

Informal caregivers of previous and current inpatients on the Bruyère SPC unit were eligible if they were able to communicate in English, were at least 18 years of age or older, and provided informed consent. If the condition of a current inpatient deteriorated or death occurred, I liaised with the informal caregiver to confirm their interest in still participating in an interview and to provide the option to postpone or withdraw from this project to minimize the potential for undue burden during a distressing time in their lives.

Bereaved informal caregivers who experienced the loss of a family member or friend at least 3 months to 2 years prior to the date of my first contact with them were also eligible to participate. This timeframe is in keeping with similar studies that have recruited bereaved informal caregivers from 1 or 2 months[54, 114] to 3 years[115] post-bereavement. I screened all potential bereaved informal caregiver participants via telephone using the Bereavement Risk Assessment Tool (BRAT)[116]. The BRAT is a 40-item list of both risk factors (36 items) and protective factors (4 items) that predicts the level of risk of issues arising around bereavement for a person who has been bereaved.[116] A researcher or clinician uses the tool to assign values of 1 to 5 to each risk factor or protective factor, each of which reflect lower or higher relative risk. Specific total scores identify five cumulative levels of risk: i) no known risk, level 1; ii) minimal risk, level 2; iii) low risk, level 3; iv) moderate risk, level 4; v) high risk, level 5. If potential participants were found to be at moderate or high risk (level 4 or 5) using the BRAT, I did not proceed with an interview, and instead provided them with grief and bereavement resources available in the community.

2.3.6. Sampling considerations

Recommendations for sampling procedures in the palliative care population include recruiting as many participants as possible to ensure a representative and diverse sample of the population.[117] These considerations made convenience sampling, a technique that enables the sampling of accessible and available individuals of a population,[118] particularly applicable for this thesis study. The advantage of this sampling technique was that it allowed for the recruitment of as many patients and informal caregivers as possible through the Bruyère inpatient SPC unit, due to broad eligibility criteria and sampling based on availability or accessibility of participants.

2.3.7. Recruitment

Previous research within the palliative care context has extensively documented the difficulties of recruiting patients from this setting.[117, 119-122] The palliative care patient population is prone to high attrition rates due to unpredictable disease trajectories, mental and physical exhaustion, impaired function due to progressive disease, and death.[119] These factors are even more prevalent within an inpatient SPC context due to high symptom burden, which increased the difficulty of recruitment within this patient population. As previously mentioned, the COVID-19 pandemic contributed to recruitment challenges as patients who were closer to the end of life were being admitted on the Bruyère inpatient SPC unit.

Recruitment procedures included a member of the patient's primary circle of care informing eligible patients of the opportunity to participate in this thesis project. This occurred at least 48-72 hours post-admission to the inpatient SPC unit to avoid overwhelming the patient and/or their informal caregivers. This member of the circle of care asked the patient if they agreed to provide contact information (e.g. name and room number) to me for the purpose of discussing the project in more detail. Informal caregiver(s) were recruited using posters that I placed throughout the inpatient SPC unit, or through word-of-mouth via patients after my first visit with them. A maximum of one informal caregiver per patient on the inpatient SPC unit was recruited for participation in this project. Patients were recruited for participation in interviews regardless of whether they had an informal caregiver who was available to take part in an interview. If patients were unable to participate in interviews due to symptom burden or declined to participate, informal caregivers were still invited to participate in interviews.

If a patient agreed to provide their contact information, the member of the circle of care forwarded the patient's contact details to me in a secure manner (i.e., password-protected voicemail on Bruyère office phone and/or using encrypted Bruyère email). If the member of circle of care who approached the patient was not their attending physician, I informed the attending physician of the patient's participation in the project based on accepted research procedures on the Bruyère SPC unit and according to the Bruyère Research Ethics Board.

Informal caregivers on the inpatient SPC unit contacted me directly using the contact information that I provided on posters throughout the unit or were introduced to me through patients. I then contacted patients and informal caregivers by telephone to discuss the project in more detail and obtain informed consent. After patients and/or their informal caregivers reviewed and verbally consented to participating, a phone or video interview was scheduled at the convenience of participants. I notified participants that taking part in this thesis project was voluntary, and that they could withdraw from participating in the project at any time.

Informal caregivers in the community were also provided information about the study and my contact information via virtual posters that I circulated within the Ottawa community (e.g., on Facebook). Mail-outs informing bereaved informal caregivers about the study were also sent out. Bereaved informal caregivers who cared for a patient on the inpatient SPC unit are mailed a quality improvement survey by the Bruyère Patient Safety and Quality Department at least 3 months after the patient's death. In order to reach bereaved informal caregivers, this department agreed to include the study recruitment poster to this mailout between November 3, 2020 and February 1, 2021 (total of 45 mailouts). Both informal caregivers from the community and bereaved informal caregivers contacted me directly if they were interested in participating in the study. After explaining the study and screening bereaved informal caregivers with the BRAT, I obtained verbal consent from them over the phone.

During the conceptualization of this thesis project, I aimed to recruit participants for interviews until I reached code saturation. I had anticipated that I would reach code saturation within 8-12 interviews with patients and informal caregivers.[123, 124] Code saturation is defined as the point in a qualitative study when there are no new issues identified and the codes included in the codebook have stabilized.[123, 124]

2.3.8. Analytic approach

I conducted analysis of the interview data concurrently with data collection.[125] As a preliminary analytical step following each interview, I created a contact summary form.[125] These contact summary forms allowed me to begin preliminary analysis by recording the most salient concepts, themes, issues and questions from each interview, and enabled me to plan for future interviews with other participants.[125]

Interview audio recordings were transcribed verbatim by a professional transcriptionist and de-identified, using participant codes to identify speakers.[126] I also listened to interview audio recordings to check for transcription errors and made corrections as needed. Transcripts were imported into NVivo 12,[106] a qualitative data analysis software program. Themes were identified from the qualitative interview data using an iterative, inductive thematic analysis approach.[127, 128] Using this approach,[127] I:

- Read and re-read through the transcripts to gain an understanding of the data;
- Created initial codes based on responses from interviewees, generating as many codes as possible while staying close to the data;
- Aggregated codes into potential overarching themes, using mind-maps;
- Reviewed themes for similarities or dissimilarities, combining and separating themes as necessary;
- Described and further revised themes for clarity and simplicity, ensuring that themes were coherent with regards to the coded extracts; and finally,
- Generated a final account of the data, incorporating quotations as necessary to describe each theme and relationships between themes.

In the initial coding phase, I coded approximately 20% of the interview data (one patient and one informal caregiver transcript) in duplicate with a co-supervisor (AG) to determine preliminary codes and to develop a precursory codebook. My other co-supervisor (SHB) attended coding meetings to provide their SPC expertise throughout the coding process. We piloted the initial codebook on a third informal caregiver interview transcript and made corresponding revisions to the codebook. I coded the remaining interview transcripts using the most updated version of the codebook, and made iterative changes to the codebook in consultation with my thesis co-supervisors to refine the names and descriptions of themes, subthemes, and codes as I coded new material.

Once coding was complete, prominent themes were identified from the qualitative dataset to explore patients' and informal caregivers' experiences of the patient's illness and care within the context of the Bruyère inpatient SPC unit. Each theme, and relationships between themes, were analyzed iteratively throughout the analytic process. The use of an inductive thematic analysis for this thesis project's qualitative results enabled the systematic recognition of common patterns or themes pertaining to patient and caregiver experiences of illness and care across the qualitative dataset.[127] Following this inductive process, I used the sense-making concept to identify and compare relationships between themes. Specifically, I identified and grouped processes that were described by patients and informal caregivers as existential or experiential learning,[23] such as their accounts of attempting to adjust or adapt to events, uncertainty, or other issues throughout their experiences of patients' illnesses and care based on their understanding of themselves, and the world around them.[57] Examples of existential or experiential learning included patients' or informal caregivers' ongoing searches for knowledge or understanding of the situation to cope with everyday life within the context of illness,[77] which may have resulted in supportive needs being uncovered.[78]

2.3.9. Assessing trustworthiness of data collection and analysis

To ensure trustworthiness of the data collection and analysis, I scheduled debriefing meetings with my thesis co-supervisors (AG and SHB) on a weekly basis to enable their review of the data collection and analysis process.[129, 130] For the qualitative data collected using interviews in this thesis project, it was not appropriate to employ positivist assessments of reliability and validity as data collection and analysis varied based on individual perspectives and worldviews.[129] Instead, I aimed to generate rich, thick descriptions of each contact with participants[129, 130] and used assessment techniques specific to qualitative research[129] throughout interviews and data analysis in this thesis project to determine:

- *Credibility:* Does it make sense for patients or informal caregivers to have such experiences of their illness and care, and have these supportive needs?
- *Transferability:* Can my findings of patient and caregiver experiences of illness and care, and their supportive needs, be transferred or generalized to the inpatient palliative care context in Ottawa, Canada and elsewhere in Canada?
- *Dependability:* Would a variety of different patients and informal caregivers have similar experiences of illness and care that participants in this thesis study did? Do other patients and informal caregivers (e.g., based on the literature) express similar supportive needs that participants in this study described?
- *Confirmability:* Do my thesis co-supervisors (AG and SHB), based on their review of the data, data collection and analysis processes, and one co-supervisor's

(SHB) experience providing SPC, think that my findings of patient and informal caregiver experiences and associated supportive needs make sense?

2.3.10. Reflexivity throughout the research process

In the constructivist paradigm, researchers are active in the research process and intrinsically bring their own values and ideas into the work being conducted, meaning that researchers cannot be independent of their research.[109] Therefore, in this section, I explain my academic and personal background, and then describe how I came to this work involving patients and informal caregivers receiving palliative and end-of-life care on the Bruyère inpatient SPC unit and reflect on how these experiences may have influenced the study.

For nearly six years during my undergraduate studies and thereafter, I worked in a family medicine clinic. As a medical assistant, and then assistant clinic manager, I acted as point of first contact and a liaison between patients and family physicians. In many cases, I became enveloped in the lives of patients through the stories they shared with me, and from being involved in their care. The relationship and trust I built with many patients often led to them sharing details about their personal or familial struggles with life-threatening illnesses and associated emotional challenges. These experiences contributed to my interest in finding effective means of providing empathetic support to patients dealing with their own or a family member's illnesses, and may have contributed to my sensitivity to challenges described by patients and informal caregivers within this study.

My academic background was mostly unrelated to palliative care in the beginning; my undergraduate degree was in biology and psychology. Even still, my interest in death and dying was piqued after taking a psychology course on the topic in my third year of undergraduate studies. During this degree, I completed a co-op placement at the Cochrane Collaboration's Bias Methods Group (then headquartered in Ottawa). This experience contributed to my understanding that research was not only conducted in laboratories. Rather, I began to understand research as an endeavour that could involve patient and informal caregiver recruitment and engagement, two groups that I was already particularly interested in based on my experiences in the family medicine clinic.

My interest in understanding the experiences of patients and informal caregivers in the inpatient palliative care context come from two parts of my life: my experiences as a primary caregiver for my younger sister and my knowledge of my partner's experiences with inpatient palliative care. Towards the end of my undergraduate degree, my younger sister suffered a severe traumatic brain injury, leading to successive emergency surgeries, a two-week coma, and almost three months of inpatient care for rehabilitation. Though these experiences were not in the palliative care setting, I realized through my personal experiences as an informal caregiver in the hospital and home setting that caregiving is an immense and often overwhelming undertaking, especially while balancing school and work. Without the supports offered by the hospital, community, and my older sister and brother-in-law, providing care for my hospitalized younger sister would have been insurmountable. Several months later, I met my partner. As we got to know each other, he shared stories of his single mother's battle with cancer, and as the cancer progressed and became untreatable, her subsequent experiences in an inpatient SPC unit. He had a poor experience on the SPC unit, and to compound the issue, lost his only parent in early adulthood, leaving him to care for a younger sister with limited support when he was only beginning to learn to care for himself. These experiences made him feel let down by the palliative care context and the health care system as a whole.

My experiences, both personal and second-hand, intensified my goal of understanding and improving patient and informal caregiver experiences in the hospital, now with a focus on palliative and end-of-life care. As a result of these experiences, unconsciously, I may have been more sensitive and attuned to challenges or negative experiences expressed by patients and informal caregivers in interviews. Nonetheless, I tried my best to keep my probing questions as open-ended as possible to ensure that I was capturing participants' experiences as much as possible, rather than my own perspectives of their experiences.

In addition, my professional experiences may have impacted my role as a researcher in this study. I was fortunate enough to be able to start working at the Bruyère Research Institute with the Division of Palliative Care as a research assistant, and then as a research coordinator. Shortly after beginning to work at Bruyère in 2016, I also began to volunteer on the inpatient SPC unit, initially providing general support, such as company to patients or feeding patients who were not able to feed themselves. After a year or so, I continued to volunteer on the inpatient SPC unit in the new role of Good Night Ambassador, during the evenings to support the newly implemented delirium clinical practice guideline on the unit. In this role, I used nonpharmacological interventions such as drawing curtains closed, dimming lights, offering beverages, and providing earplugs and eye-masks to patients to encourage a healthy sleep-wake cycle, the lack of which may contribute to delirium. These experiences allowed me to become familiar with many patients and informal caregivers over my weekly volunteering shifts and allowed me a glimpse of patient and informal caregiver experiences on the Bruyère inpatient SPC unit.

Throughout my time as part of the research support team for the Division of Palliative Care and volunteering, I was able to form relationships with many of the interprofessional palliative care team members, including physicians, nurses, spiritual care workers, and social workers, as well as SPC unit management. In my working role, I was able to contribute to several clinical research studies, and recruited and interviewed patients, informal caregivers, and members of the interprofessional palliative care team.

My prior personal, academic, and professional experiences have all contributed to my interests in pursuing this research and may have contributed to the potential for bias in this study. On the other hand, my previous experiences conducting research on the Bruyère inpatient SPC unit have contributed to my knowledge of this context. I used this knowledge to my advantage throughout this thesis project. For example, in interviews with patients and informal caregivers, I asked probing questions about issues, such as the receipt of person-centred care, that I knew to be important to patients and informal caregivers included in other research studies through my experience. My prior experiences were also integral to making inferences about items patients and informal caregivers mentioned during their interviews. For instance, one informal caregiver referred to having access to “those really nice kitchens” on the inpatient SPC unit. Based on my prior experiences conducting research and volunteering on the inpatient SPC unit, I knew that the informal caregiver was referring to the three family rooms that are on the unit. Therefore, my prior experiences also served to enrich and expand on the data collected for this thesis project, allowing me to gain a more comprehensive understanding of my participants’ experiences.

Nevertheless, my experiences working in the context of the Bruyère inpatient SPC unit may have introduced an overly positive bias to my interview findings given my personal views of the setting, as well as my relationships with the members of the interprofessional palliative care team. Though I was an active participant in the interviews using the constructivist approach of creating meaning through my interactions with patients and informal caregivers, I made a conscious effort to retain the integrity of patient- and informal caregiver-reported experiences throughout my data collection, analysis, and finding generation processes. Specifically, I used open-ended questions during interviews with participants to avoid leading them to respond in a specific way, and attempted to stay true to the explicit ideas that participants expressed throughout the processes of analyzing and generating findings from these interviews using an inductive approach. In this way, I aimed to minimize my own experiences, views, and biases from influencing my findings.

2.3.11. Ethical considerations

The Bruyère inpatient SPC unit provides its services to a vulnerable patient population. Thus, as a researcher seeking to recruit participants for interviews in this context, I had to be conscious of changes in patient functional status by ensuring an open line of communication with the patient's interprofessional circle of care.

Given the unpredictability of the illness trajectory in palliative care populations, it was important that patient and informal caregiver participants were aware that participation in this thesis project was voluntary. I informed participants that they could decline to participate or choose to withdraw from the project at any time, and could also choose to continue their interview at a later time if they felt particularly fatigued or unwell after an interview had commenced.

Research ethics board (REB) approval was obtained from the Bruyère REB (#M16-20-037) on July 7, 2020, Ottawa Health Sciences Network REB (#20200503-01H) on July 21, 2020, and the University of Ottawa REB (#H-07-20-6006) on July 24, 2020.

CHAPTER 3: RESULTS

This chapter presents the results of the two components of my thesis. First, I provide the results of the scoping review of literature on patients' and informal caregivers' experiences within inpatient SPC settings, followed by my findings from the interviews I conducted with patients and informal caregivers on the Bruyère inpatient SPC unit.

3.1. Scoping review

3.1.1. Search results and study characteristics

Electronic databases were searched on September 17, 2020. These searches yielded 4087 records. Citation searching of the included records added a further 95 records. I removed duplicate records (n=773) first using Endnote™,[104] a reference management software. The remaining 3407 records were uploaded to Covidence[103], where remaining duplicates (n=79) were removed. Records from electronic database (n=3237) and citation searches (n=93) were screened independently and in duplicate at the title and abstract level. After exclusions, full-texts were retrieved for 488 database-searched and citation-searched reports. A grey literature search of relevant organizations' websites and grey literature databases was conducted on February 24, 2021. I included six reports from these grey literature searches and added another two reports which I found as incidental findings while reading relevant literature. I included eight reports from these additional sources for screening at the full-text screening level. Following the review of the full-text reports, 392 were excluded and 104 were included in this review. A PRISMA flow diagram for the search process is depicted in Figure 3.

Quantitative methods were used in 56 studies,[53, 55, 131-184] qualitative methods in 36 studies,[46, 185-219] and mixed methods in 11 studies.[220-230] One study involved an autobiographical account of the author's experiences of their family member's stay in a dedicated palliative care bed.[231] Patients were the sole participants in 26 studies,[132, 136, 137, 144, 154, 167, 172-175, 183, 184, 195, 196, 199, 201, 202, 205, 208, 212, 214, 216, 219, 224, 229] and informal caregivers were the only participants in 54 studies.[46, 53, 133-135, 138-140, 142, 143, 145, 147-151, 153, 156, 158-164, 166, 168, 170, 171, 176-181, 185-187, 191, 192, 200, 203, 206, 207, 213, 215, 217, 220, 221, 226-228, 230, 231] In 24 studies, both patients and informal caregivers were participants.[55, 131, 141, 146, 152, 155, 157, 165, 169, 182, 189, 190, 193, 194, 197, 198, 204, 209-211, 218, 222, 223, 225] Studies were most commonly conducted in the United Kingdom (n=20),[143, 149, 154, 165, 173-175, 180, 181, 185, 189, 190, 193, 195, 215, 216, 220-222, 224, 227, 228] Canada (n=15),[55, 142, 161, 179, 186, 188, 194, 197, 201, 209, 213, 218, 223, 230, 231] Japan (n=12),[139, 140, 147, 151, 163, 167, 170, 172, 176-178, 217] United States (n=9),[46, 135, 149, 157, 159, 168, 169, 175, 229] Australia (n=8),[132-134, 202, 205, 214, 226] and Germany (n=8).[53, 131, 138, 158, 162, 164, 198, 204]

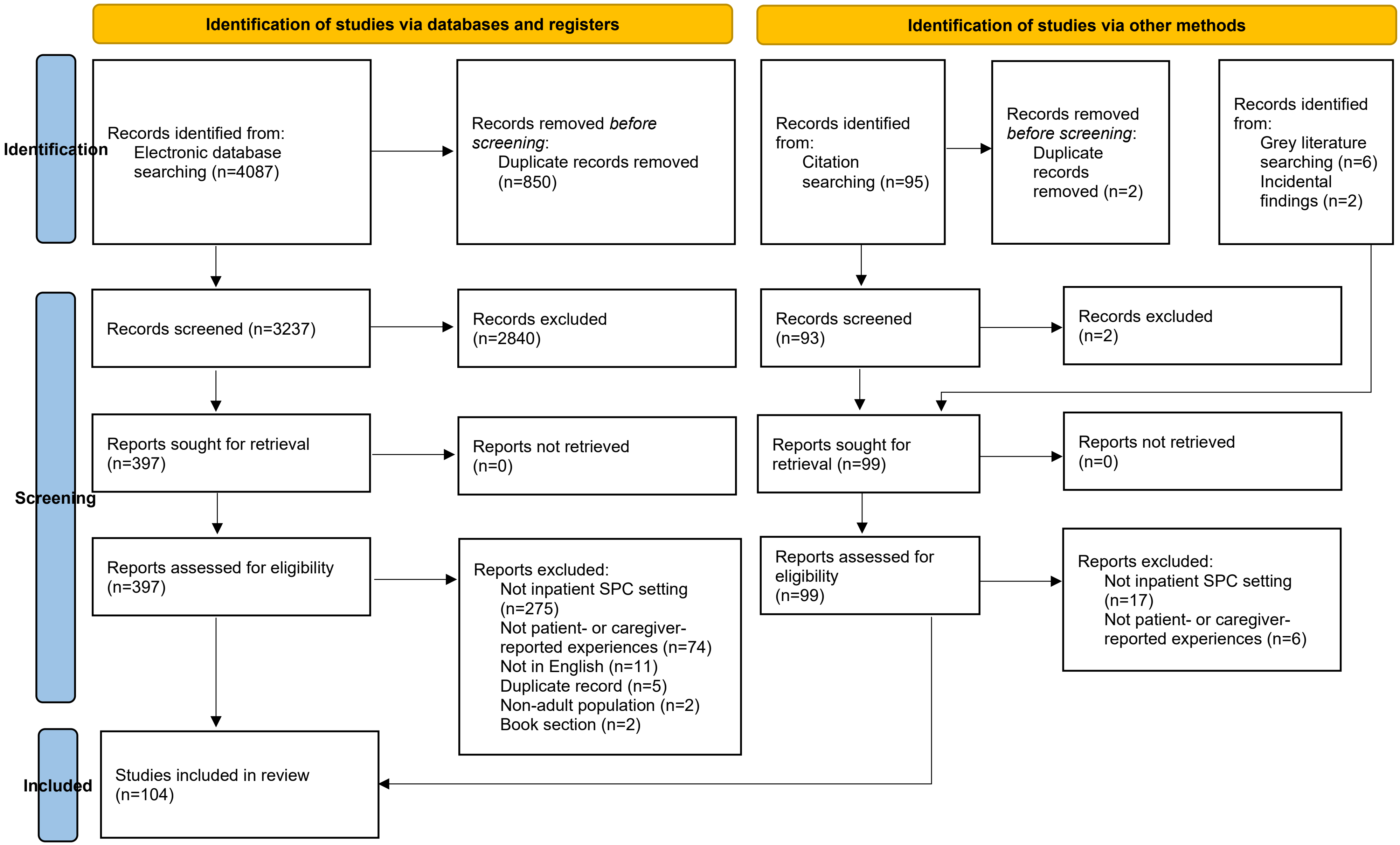
As studies included in this scoping review either discussed patients only, informal caregivers only, or both patients and informal caregivers, it was difficult to present the results by population. Instead, the results are presented by theme, and patient and informal caregiver perspectives are reported within each theme whenever results for each population were available. An overview of the studies reporting on each population (patients only, informal caregivers only, or both patients and informal caregivers) are presented in Table 1.

An overview of the characteristics of the included quantitative, qualitative, and mixed methods studies are presented in Appendix D.

Table 1. Overview of studies including patients only, informal caregivers only, and both patients and informal caregivers by the themes and sub-themes identified in this scoping review.

Theme/sub-theme	**Number of studies reporting on:**		
	Patients only	**Informal caregivers only**	**Both patients and informal caregivers**
Perceptions of:			
• Care	8[183, 188, 202, 205, 208, 212, 214, 219]	31[46, 53, 135, 140, 142, 143, 148, 150, 153, 159, 161, 163, 166, 176, 177, 179, 181, 185-187, 191, 200, 203, 206, 207, 213, 217, 220, 227, 230, 231]	7[149, 190, 193, 197, 198, 218, 222]
• The interprofessional palliative care team	4[188, 201, 208, 219]	17[140, 142, 143, 156, 157, 159, 161, 176, 180, 186, 191, 200, 203, 207, 213, 217, 227]	4[198, 204, 218, 222]
• The care environment	7[173, 188, 202, 205, 208, 214, 219]	10[139, 153, 186, 203, 213, 217, 220, 221, 227, 231]	5[165, 193, 194, 218, 230]
Communication with the interprofessional palliative care team	5[137, 202, 212, 219, 224]	23[135, 142, 143, 150, 151, 153, 156, 158, 170, 177, 178, 185, 186, 191, 200, 203, 213, 217, 220, 221, 226, 228, 230]	8[138, 169, 189, 198, 210, 218, 222, 223]
Impacts of illness and care on quality of life	4[132, 136, 188, 214]	2[160]	2[55, 190]
• Physical elements	6[132, 136, 172, 188, 219, 224]	16[91, 140, 143, 156, 161, 177, 179, 180, 186, 187, 192, 200, 213, 217, 221, 228]	4[146, 193, 209, 222]
• Psychological or emotional elements	17[132, 136, 154, 167, 172, 174, 188, 196, 202, 205, 208, 212, 214, 216, 219, 224, 229]	34[46, 53, 133, 134, 138, 140, 142, 145, 147, 150, 151, 156, 158, 160, 164, 171, 177-181, 185, 186, 192, 197, 200, 203, 207, 213, 220, 221, 226, 230, 231]	10[55, 139, 146, 155, 184, 190, 193, 204, 211, 223]
• Social or cultural elements	10[137, 154, 172, 188, 195, 199, 205, 208, 212, 219]	12[46, 147, 150, 166, 185, 192, 200, 207, 217, 220, 227, 230]	7[141, 146, 182, 193, 194, 209, 223]
• Spiritual or existential elements	5[167, 172, 175, 202, 208]	7[150, 156, 166, 168, 179, 206, 228]	5[146, 152, 182, 211, 225]

Figure 3. PRISMA flow diagram[232] for scoping review search process reported using the PRISMA extension for Scoping Reviews Checklist.[98] Abbreviation: SPC: specialist palliative care.



3.1.2. Experiences of illness and care in inpatient specialist palliative care (SPC) contexts

Three main overarching themes of patient and informal caregiver experiences were evident: i) perceptions of care, the interprofessional palliative care team, and the care environment; ii) communication with the interprofessional palliative care team; and iii) impacts of illness and care on quality of life.

3.1.2.1. Perceptions of care, the interprofessional palliative care team, and the care environment

Using a descriptive qualitative content analysis approach, I divided this overarching theme into three sub-themes detailing patients' and informal caregiver perceptions of: i) care, ii) the interprofessional palliative care team, and iii) the care environment in inpatient SPC settings.

Perceptions of care

Forty-six studies described patient and/or informal caregiver views on the care they received from inpatient SPC settings.[46, 53, 135, 140, 142, 143, 148-150, 153, 159, 161, 163, 166, 176, 177, 179, 181, 183, 185-188, 190, 191, 193, 197, 198, 200, 202, 203, 205-208, 212-214, 217-220, 222, 227, 230, 231] Patients and informal caregivers most commonly reported being satisfied with the care and support provided within the inpatient SPC context.[53, 135, 140, 142, 149, 153, 159, 161, 163, 166, 168, 176, 179, 183, 187, 188, 198, 200, 208, 213, 218, 219, 222, 226, 227, 230] In three studies, informal caregivers reported dissatisfaction with aspects of care in inpatient SPC settings.[150, 198, 217] Reasons for dissatisfaction with care included feeling that the care was ineffective,[198] not person-centred or individualized,[217] involved less medical staff than thought to be necessary,[150, 217] and did not provide adequate medical treatment or psychological care.[217] Though patients did not expressly report being dissatisfied with care, three articles described patient frustration with the inaccessibility of medical assistance in dying or euthanasia in the inpatient SPC setting.[46, 202, 214]

Patient and informal caregiver views of the inpatient SPC context were distinct from one another. One article found that patients felt their time on the inpatient SPC allowed them to tie up loose ends and say goodbye to their friends and family, while also relieving care burdens for their informal caregivers.[5] While there were no studies on patient perspectives of the timing of their admission to an inpatient SPC setting included, three studies including informal caregivers showed that they viewed the admission as occurring too late,[46, 213, 217] while others perceived it to have taken place at an appropriate time.[148] In addition, when informal caregivers perceived that the referral to the inpatient SPC setting occurred at the appropriate time, they reported that the patient was more comfortable both physically and psychologically.[153]

With the receipt of inpatient SPC, informal caregivers felt assured that the patient was safe,[191, 203] treated with dignity,[143] and that the care provided was respectful of patients' and informal caregivers' preferences[149, 159] and their culture or traditions.[193] Moreover, informal caregivers viewed this type of care as being compassionate,[206, 218] holistic in its approach to caring for the patient and family as a unit,[213, 222, 227] amenable to their visitation needs,[203, 213, 227] tailored to patients' and informal caregivers' needs,[191, 222] and enabling good quality of life for the patient until death.[166] With respect to care offerings, informal caregivers felt that clinically-assisted hydration for patients should be a minimum standard of care within the inpatient SPC context.[177] Informal caregivers emphasized that if patients were well-supported and competently cared for, then by extension, they were also supported and cared for.[186, 200] The need for respite care was identified by informal caregivers.[190] For those who received respite care in an inpatient SPC setting, this care was viewed as allowing informal caregivers to rest and have a break from caregiving.[220]

Several studies reported patient and informal caregiver misunderstandings about inpatient SPC care.[163, 202, 212, 214, 217, 219, 220] Patients believed that receiving inpatient SPC meant that they were reaching the end of their lives.[202, 212, 214, 219] However, after their stay on an inpatient SPC setting, some patients reported understanding the purpose of this context as providing appropriate care for their illness, and that this type of care could be provided to those who were not imminently dying.[219] These views of inpatient SPC settings were not reported in the literature for informal caregivers. Informal caregivers perceived inpatient SPC as only for individuals who were dying, and that this type of care hastened death.[163, 217, 220]

Nine articles also examined patients' and informal caregivers' involvement in their care in the inpatient SPC context.[143, 181, 185, 187, 197, 200, 207, 218, 222] In one study, patients desired more involvement in care decisions.[183] In contrast, informal caregivers reported being involved in decisions about the patient's care as much as they wanted to be in inpatient SPC settings.[143, 181, 187, 218, 222] Informal caregivers described feeling a sense of duty to the patient and strong desires to be involved in patients' care,[200, 207] and demonstrated this through contributing to patients' physical and personal care,[185, 197] as well as being present at the bedside.[197]

Both patients and informal caregivers reported feeling uncertainty within the context of illness and care on an inpatient SPC setting.[46, 151, 188, 196, 197, 200, 205, 214, 218, 224, 230] For patients, this uncertainty was associated with being admitted to an inpatient SPC setting,[205, 214] as well as what the future held for them with respect to the end-of-life process and death.[188, 196, 218, 224] Informal caregivers relayed that their uncertainty was associated with the patient's disease trajectory and end-of-life care,[46, 151, 197, 200] the amount of pain medications patients were receiving,[46] when and who to expect updates from on the patient's condition,[230] and their role in the inpatient SPC setting.[200]

Perceptions of the interprofessional palliative care team

Twenty-five studies described patients' and/or informal caregivers' views of the interprofessional palliative care team.[140, 142, 143, 156, 157, 159, 161, 176, 180, 186, 188, 191, 198, 200, 201, 203, 204, 207, 208, 213, 217-219, 222, 227] In these studies, the interprofessional care team included but was not limited to nurses, physicians, psychologists, chaplains, social workers, and art, music, or pet therapists.

Twenty-two studies reported patients and informal caregivers having a high regard for their interprofessional palliative care team and being satisfied with the care delivered from this team.[142, 143, 157, 159, 161, 176, 180, 186, 191, 198, 200, 201, 203, 204, 208, 213, 218, 219, 222, 227] Patients perceived the interprofessional palliative care team as being best able to meet their needs over other care providers (e.g., family physicians or nurses in other hospital settings).[201, 208] They also viewed the care team as being competent,[208] warm, and reassuring.[188, 198, 219] The relationships that patients had with members of the interprofessional palliative care team contributed to feeling loved and cared for.[188] Correspondingly, informal caregivers indicated that the care team was knowledgeable,[222] compassionate and empathetic,[186, 213, 227] respectful,[191] and persistent in their goals of minimizing patient suffering.[156, 203, 204] Both patients and informal caregivers praised the cohesiveness,[198, 204, 218, 219] accessibility and approachability,[191, 200, 203, 222, 227] attentiveness,[188, 203] and proficient communication of their interprofessional palliative care teams.[198]

Two studies described patient dissatisfaction with members of the interprofessional palliative care team.[218, 219] Sources of dissatisfaction included perceiving certain members of the care team to be less responsive than desired,[218] or too many members of the care team visiting patient rooms in a short period of time.[219] Three studies reported on informal caregiver dissatisfaction with the interprofessional palliative care team.[191, 213, 217] Reasons included informal caregivers being upset with the team's assumptions that the patient would not recover and perceiving the team to view the patient's death as "routine work".[217] In these studies, informal caregivers perceived members of the care team to be uncompassionate or incompetent,[213, 217] changing too frequently,[217] not interacting with informal caregivers,[191] or not considering the patients' or informal caregivers' preferences in care decisions.[217]

Perceptions of the care environment

Twenty-two studies reported patient and/or informal caregiver perceptions of the inpatient SPC environment.[139, 153, 165, 173, 186, 188, 193, 194, 202, 203, 205, 208, 213, 214, 217-221, 227, 230, 231] Overall, both patients and informal caregivers perceived the care environment in inpatient SPC settings to be pleasant.[186, 188, 193, 194, 202, 203, 208, 213, 214, 218-220, 227, 231] Specifically, patients and informal caregivers perceived the care environment in inpatient SPC settings to be peaceful,[194, 208, 213, 214, 231] comforting,[139, 153, 193, 213, 231] positive or cheerful,[186, 193, 203, 208, 218-220] mostly home-like,[194, 203] customizable,[218] and safe for the patient.[203, 208, 214] Patients described having access to the resources they desired within the inpatient SPC environment, including medical procedures (e.g., blood tests, imaging) or specialists providing consultation services, equipment (e.g., lifts, wheelchairs, specialty beds), and sophisticated technology.[218] Access to such resources contributed to patient satisfaction with the inpatient SPC setting.[218] Patients and informal caregivers also perceived the inpatient SPC setting to be the most appropriate place for the patient to be receiving end-of-life care, and eventually, for the patient's death.[188, 193, 221, 227] Meanwhile, though most studies including informal caregivers reported their positive views of the inpatient SPC environment, some were dissatisfied with the location of the hospice,[217] or doubted that it was the appropriate place of care due to its physical location (i.e., housed within an oncology unit).[231] Informal caregivers also conveyed frustration with visitation policies during the COVID-19 pandemic, feeling that these policies should be more lenient for patients at the end of life.[230]

Patients described the care environment as enabling a sense of living life while dying, and reducing burden on their informal caregivers.[202, 214] They also perceived the inpatient SPC environment as allowing them to regain control over their daily life and care,[188, 194, 214] which included but was not limited to maintaining existing and creating new rituals, having guests, and making their own food choices or morning routines.[194] On the other hand, patients conveyed that in some ways, the inpatient SPC care setting was unlike home in that family intimacies could not necessarily be replicated in the institutional environment.[205] They perceived their admission required a period of adjustment to become used to the new environment,[194] or also commented on the upsetting nature of experiencing other patients' deaths and disruptive behaviour in the inpatient SPC setting.[221] Patients also described their preferences for types of rooms, with a 2014 (i.e., pre-pandemic) study showing a comparable split between those who preferred shared or single rooms.[165] In contrast, two studies reported patients mostly preferring single rooms for the privacy and quiet,[173, 218] while one study reported most informal caregivers preferring single rooms for the same reasons.[165]

3.1.2.2. Communication with the interprofessional palliative care team

Thirty-six studies described the process of communication and information provision between patients, informal caregivers, and the interprofessional palliative care team.[135, 137, 138, 142, 143, 150, 151, 153, 156, 158, 169, 170, 177, 178, 185, 186, 189, 191, 198, 200, 202, 203, 210, 212, 213, 217-224, 226, 228, 230] Numerous factors impacted patient desires for communication or lack thereof. Two studies reported patients having little desire to discuss their diagnosis and end-of-life topics.[137, 169] Patients who had previously engaged in communication about end-of-life topics prior to their current admission on an inpatient SPC setting were less likely to report feeling hopeless, depressed, or having a lower quality of life.[169] However, patients who expressed desiring more communication on end-of-life topics or who were provided indirect information about their life-threatening diagnosis (e.g., physician avoidance of the word 'cancer' in explaining their diagnosis) were more likely to report being distressed.[169, 212] Upon their admission to an inpatient SPC setting, some patients described feeling overloaded with information.[222] Nevertheless, as their physical condition improved, patients engaged in more communication with the interprofessional palliative care team[222] and reported discussing topics pertaining to their illness and end of life if their family members expressed wishes to do so.[169]

Overall, patient needs and preferences for communication and information on their diagnosis and prognosis varied widely across studies. Some patients reported wanting to limit their awareness of their diagnosis and prognosis to make it more manageable to handle,[224] while others wished to be informed fully to help them come to terms with approaching the end of life.[189, 212] In some cases, patients did not want to be informed about their diagnosis or discuss end-of-life issues due to cultural taboos surrounding these topics,[137] or reported avoiding the use of certain terminology or topics, such as the word 'death' and topics related to death, due to perceiving them as inappropriate.[212, 224] On the other hand, other patients felt that their medical professionals withheld information due to their shared cultural norms.[212] Other patients reported unmet information needs on their diagnosis and prognosis,[210, 212] the purpose of the inpatient SPC setting and the services it offered (prior to admission)[219] and assisted death (particularly due to the religious affiliations of their particular inpatient SPC setting).[202] Some patients viewed informal caregiver decisions to limit the amount of information that the interprofessional palliative care team was able to provide to patients as a contributing factor to their unmet information needs.[210]

Eleven studies reported on informal caregivers describing the process of information exchange, or communication, with the interprofessional palliative care team as easy to understand and to their satisfaction.[135, 142, 143, 170, 178, 191, 200, 203, 218, 221, 230] There was no comparative information on patients' level of satisfaction or dissatisfaction with communication. Informal caregivers reported desiring consistent and sufficient communication about the patient's condition,[135, 150, 186] which was associated with informal caregivers' satisfaction with care.[135] Moreover, when informal caregivers perceived being provided good communication about the possible outcomes of patients' illness trajectories, they perceived the patient to be in greater physical and psychological comfort.[153]

Six studies reported on informal caregivers' preferences for how information exchange occurred with the interprofessional palliative care team.[185, 186, 191, 203, 218, 230] They described desires of more frequent communication,[230] individualized information exchange according to their needs,[203, 218] open communication about their role,[185] nurses relaying their observations of patients,[191] and distressing updates to be delivered face-to-face instead of via telephone calls.[186] Informal caregivers perceived technology use,[223, 230] family meetings,[226] online access to patients' medical charts,[230] and implementation of care pathways[156] as facilitating communication with the interprofessional palliative care team.

Eight studies reported informal caregiver satisfaction with their information needs being met.[143, 156, 200, 203, 213, 217, 222, 226] Some informal caregivers reported having knowledge or awareness of specific palliative care topics (e.g., opioid use for pain relief, palliative sedation).[177, 178] Others conveyed having high information needs,[150] and reported concerns about possible gaps in information provision.[198] In particular, informal caregivers desired information and education about the patient's illness, care, and end-of-life process.[138, 150, 169, 189] Specific topics where their information needs were perceived to have not been met included: the concept of palliative care,[217] the patient's prognosis,[158, 213, 217, 228] the patient's test results,[217] when to expect symptoms,[138, 158] updates on patients' social activity and mood,[230] how to care for the patient at home,[158] and the availability of services (e.g., respite care, community services) to meet their needs.[213, 217, 220] During the COVID-19 pandemic, informal caregivers desired more information on hospital regulations and procedures, visitation restrictions, how to communicate with patients during visitation restrictions, and whether items from home could be brought into the inpatient SPC setting.[230]

3.1.3. Impacts of illness and care on quality of life

Seven studies reported on patients' and/or informal caregivers' views of their overall quality of life in inpatient SPC settings.[55, 132, 136, 160, 188, 190, 214] Patients perceived the meaning of quality of life as living while dying,[188, 214] accepting their new capabilities and limitations,[190] having the freedom to do what they desired without physical restrictions,[188, 190] and extending life as long as possible.[188] They described their quality of life being impacted positively by their relationships with informal caregivers, and affirmations from the interprofessional palliative care team of their control over their own care.[188] Other studies reported patients' life-threatening illnesses having a greater impact on their quality of life in the inpatient SPC context compared to other settings (e.g., home),[132] with informal caregivers perceiving patients' quality of life to be lower in inpatient SPC settings.[160] However, another study reported that inpatients did not perceive receipt of inpatient SPC as negatively impacting their quality of life.[136] Patients viewed the following factors as enabling the maintenance of quality of life: continuing normal activities (e.g., interaction with family),[188] having religion or spirituality,[188] and low symptom distress.[55]

The overarching theme of impacts on quality of life has been divided into four sub-themes for the purposes of reporting: i) physical, ii) psychological or emotional, iii) social or cultural, and iv) spiritual or existential.

3.1.3.1. Physical elements

Twenty-six studies included patient and/or informal caregiver perceptions of physical components of their quality of life.[91, 132, 136, 140, 143, 146, 156, 161, 172, 177, 179, 180, 186-188, 192, 193, 200, 209, 213, 217, 219, 221, 222, 224, 228] In 18 studies, patients and informal caregivers reported being satisfied with the management of the patient's physical symptoms in the inpatient SPC setting, in some cases due to improved symptom management in this setting.[140, 143, 146, 153, 156, 161, 177, 179, 180, 186-188, 193, 200, 213, 219, 221, 222, 228] In other cases, patients felt that inpatient SPC or psycho-spiritual interventions (e.g., life review interviews) had no effect on their physical symptoms (e.g., constipation, insomnia),[136, 172] and that in general, their physical health was poorer in the inpatient SPC setting due to disease progression.[132] Patients also reported that their most salient concerns were associated to symptoms of their illness and pre-existing issues related to their age.[224] Informal caregivers were dissatisfied with the patient's pain control in one study,[192] and described feeling no impacts on their own physical health with respect to caregiving within the inpatient SPC context.[192]

3.1.3.2. Psychological or emotional elements

Sixty-one studies reported on patients' and/or informal caregivers' perspectives on the psychological or emotional aspects of their quality of life.[46, 53, 55, 132-134, 136, 138-140, 142, 145-147, 150, 151, 154-156, 158, 160, 164, 167, 171, 172, 174, 177-181, 184-186, 188, 190, 192, 193, 196, 197, 200, 202-205, 207, 208, 211-214, 216, 219-221, 223, 224, 226, 229-231] For patients, the psychological and emotional effects of illness and care within the context of inpatient SPC were varied and quite extensive. Some patients reported feeling anxiety, depression, or general distress due to their illness diagnosis or trajectory, and concern for their family.[154, 174, 212, 224] Patients also reported a multitude of other psychological and emotional aspects associated with the receipt of care in the inpatient SPC context, and their life-threatening illness. These included: anger,[192, 197, 212, 214] acceptance of their illness and death,[202, 211, 212, 224] helplessness or hopelessness,[188, 212, 214, 224] guilt associated with perceiving themselves to be a burden on their families,[202, 205, 208, 214] fear and stigma,[205, 214] relief,[205, 214] a sense of losing one's identity,[208, 214] loss of control,[132, 188] loneliness,[208] and resistance to the inpatient SPC concept of "dying well".[202] Informal caregivers similarly perceived patients to be angry,[190] and experiencing considerable anxiety and overall distress.[156, 178]

Patients also conveyed their perceptions of a "good death" and perceived the following to be important: dying naturally,[139, 224] being respected as an individual and held in dignity,[139, 224] physical comfort,[139] psychological comfort,[139, 224] being religious or spiritual,[216, 224] having achieved acceptance of their death,[224] dying in their preferred location,[224] and having their culture considered.[216] Patients also reported having experienced end-of-life dreams and visions that were filled with personal meaning and emotional significance, which reassured patients.[229] Patients perceived improvements to their ability to achieve a good death from participating in a short life review interview intervention.[167] Meanwhile, informal caregivers perceived patients to have experienced a lower quality of death if the patient preferred to have a home death but died in the inpatient SPC setting.[147]

Patients described the effects of art therapy,[184] music,[196] life review,[167, 172] and communication or information technology[223] interventions on their psychological and emotional well-being in the inpatient SPC context. These interventions improved their psychological or emotional well-being,[167, 172, 184, 196, 223] fostered a sense of hope,[167, 196] alleviated boredom,[196] and encouraged reminiscence.[196] In one study, patients reported being more aware of their loss of autonomy as a result of participating in an intervention.[196]

Care offerings, such as psychological support from the interprofessional palliative care team, also impacted perspectives on patients' psychological aspects of quality of life. Some patients and informal caregivers reported that the psychological supports offered to patients in this context were inadequate,[142, 146] did not worsen patients' psychological or emotional well-being,[136] or were satisfactory.[179] Despite these diverse views, some patients described improvements in their psychological symptoms,[219] while other informal caregivers described patients being less distressed in the inpatient SPC context compared to other institutions.[177]

Overall, informal caregivers experienced complex psychological effects of caregiving and receiving care within the inpatient SPC context. They reported significant burdens, including: moderate to severe anxiety and general distress,[46, 53, 55, 158, 192, 204, 207] discomfort or anguish witnessing the patient's physical changes or suffering,[46, 186, 192, 197, 200] concerns associated to the patient's use of pain medication or palliative sedation,[46, 145, 171, 178] feeling helpless or hopeless,[46, 138, 158, 192] mental fatigue,[150, 160, 220] having to manage the patient's psychological or emotional state,[192, 207] feeling a sense of loss,[46] and having difficulty accepting the patient's impending death.[46, 221, 231] Informal caregivers also reported substantial psychological burden from high levels of unmet social and information needs.[150] Even still, informal caregivers described being less anxious in inpatient SPC settings compared to other contexts,[160, 180, 181, 193, 205] and feeling relief when patients were admitted to a inpatient SPC setting.[205, 213] Reasons for this included the decreased psychological burden associated with no longer having to manage the patient's pain and other symptoms, suffering,[205] medication regimen,[193] as well as the increased level of support in the inpatient SPC setting.[160] Informal caregivers perceived their involvement in patients' personal care as not being onerous,[192] emphasized the importance of empowering patients as much as possible,[185] and perceived providing this care as not being onerous. Through their involvement in patients' care, informal caregivers relayed feeling valued,[140] and satisfied in their accomplishments.[160] Informal caregivers also reported being aware and accepting of patients' impending death.[156, 197, 200]

Informal caregivers evaluated the effects of participating in several interventions, including psycho-educational programs,[133, 134] shortened existential behavioural therapy,[164] and family meetings.[226] These interventions were perceived to have no impact on informal caregiver psychological well-being,[133, 134, 164] but contributed to fewer unmet needs,[133, 134] increased competency and preparedness for caregiving,[133, 134] and feeling supported.[226]

3.1.3.3. Social or cultural elements

Twenty-nine studies reported on patient and informal caregiver views of social or cultural aspects of their quality of life within the inpatient SPC context.[46, 137, 141, 146, 147, 150, 154, 166, 172, 182, 185, 188, 192-195, 199, 200, 205, 207-209, 212, 217, 219, 220, 223, 227, 230] For patients, the social and relational impacts of illness were far-reaching. Patients reported being concerned about the impacts that their illness and end-of-life trajectory would have on their daily life (e.g., loss of independence or mobility limiting the completion of everyday tasks),[154] and on their informal caregivers, particularly with respect to how informal caregivers were coping with the patient's illness.[154, 188, 199, 205, 208]

Patients discussed the social support, or lack thereof, they received from their informal caregivers in the inpatient SPC setting in seven studies.[182, 188, 194, 195, 200, 205, 230] Patients viewed support from their informal caregivers as mostly positive, where informal caregivers advocated for patients' choices in their end-of-life care,[200, 205] encouraged patients to continue coping with the situation,[195, 205] enabled patients to take part in activities,[194] improved patients' mood,[188] and maintained the patients' sense of normality and identity.[195] Patients reported receiving continued support from informal caregivers throughout the COVID-19 pandemic through virtual and window visits.[230] However, in some cases, it was difficult for some patients to communicate with their informal caregivers virtually due to patients' functional decline.[209] Conversely, patients also recounted the lack of physical presence or support from their informal caregivers, which also affected them negatively.[205, 212] Both patients and informal caregivers also reported family conflict being common throughout the end-of-life process.[195, 205]

Only two studies assessed interventions that impacted patients' social well-being, one using the life review interview,[172] and another using communication and information technology.[223] Life review interviews were not useful in reducing patients' concerns about their family members' well-being or decreasing family conflict,[172] while patients viewed the communication and information technology intervention allowing the maintenance of social contact with their informal caregivers, and alleviating boredom.[223]

Cultural elements also impacted patients' experiences of illness and care in the inpatient SPC setting. Patients reported declining or not requesting information about their condition,[137, 212] and both patients and their informal caregivers reported that informal caregivers kept patients unaware of their diagnosis and prognosis based on cultural considerations.[166, 192, 193, 212] Patients also believed that suffering was a part of life, even if they feared pain and suffering, and avoided requesting assistance from interprofessional palliative care team members due to their cultural practices of not inconveniencing others.[208]

For informal caregivers, being present at the patients' bedside or virtually visiting the patient were methods of maintaining their social relationship with the patient within the inpatient SPC setting. Informal caregivers' reported being able to be more present at the patient's bedside until death in the inpatient SPC context compared to other inpatient settings.[227] The ability to be present at the bedside allowed informal caregivers to cope, feel reassured, and demonstrate their support to the patient.[192, 200] However, during the COVID-19 pandemic, informal caregivers reported feeling distressed or frustrated from being unable to visit or communicate with patients,[46, 230] and feared that the patient would die unaccompanied.[230] Informal caregivers viewed virtual visits to be comforting in this instance, and used these as a method of visually assessing the patient's condition.[230]

To fulfill their own social needs, informal caregivers also accessed support from other family members. Overall, informal caregivers were satisfied with the support that was provided from other family members during the patient's time in the inpatient SPC setting.[166, 192, 200] However, they perceived social support as ineffective for coping with loneliness that may be experienced when caregiving for a patient with a life-threatening illness,[182] and criticized the lack of adequate ongoing support after experiencing bereavement in an inpatient SPC context.[217]

Informal caregivers also reported caregiving burdens that impacted their social well-being. They viewed caregiving as having a major impact on their daily lives,[166, 185, 207, 217, 220] and highlighted the importance of maintaining normal routines within the inpatient SPC setting as a coping mechanism.[185, 194] Caregiving was perceived to lead to sleep deficits,[141] while informal caregivers described the inability to continue to provide practical care for the patient in the home context as a major contributor to patients' admission to an inpatient SPC setting.[141, 147] Informal caregivers also recounted feeling burdened by their social needs (e.g., counselling, financial support) remaining unaddressed.[146, 150, 217]

3.1.3.4. Spiritual or existential elements

Patients and informal caregivers described aspects of their spiritual or existential well-being in 17 studies.[146, 150, 152, 156, 166-168, 172, 175, 179, 182, 202, 206, 208, 211, 225, 228] Patients' spiritual and religious well-being was an important determinant to their experiences of illness and care within inpatient SPC settings. Patients' reports of low spiritual well-being were correlated with their experiences of end-of-life despair and desires for an accelerated death.[175] Improvements in patients' spiritual well-being were seen with visits from clergy members, based on the perspective of informal caregivers,[228] and with patient participation in interventions such as life review interviews.[167, 172]

Patients' spirituality and religion also influenced their experiences of illness and care in the inpatient SPC context. Some patients perceived their religiosity as contributing to hope[208] and acceptance of death.[211] Patients also described being encouraged to seek existential closure prior to their death by their informal caregivers, and this support was associated with patients' eventual acceptance of spiritual care.[202] Some patients described receiving spiritual care from interprofessional palliative care teams in the inpatient SPC context, while others reported that their interprofessional palliative care teams did not attend to or discuss their spiritual well-being.[146] Overall, patients' spirituality and religion influenced their care choices (e.g., choosing to receive end-of-life care rather than aggressive curative treatment due to views of death as natural and inevitable based on their spiritual or religious beliefs),[211] and comfort with spiritual care assessments by members of the interprofessional palliative care team.[225]

Nine studies reported on informal caregiver perceptions of their own spirituality or religion, and their spiritual or religious care needs.[150, 152, 156, 166, 168, 179, 182, 206, 225] Informal caregivers described using their spirituality and religion to cope with the patient's illness trajectory, in addition to loneliness.[166, 182, 206] Within the inpatient SPC setting, informal caregivers reported higher levels of spiritual care needs compared to patients in one study,[152] while another study highlighted the association of unmet spiritual or religious needs with increased caregiver burden.[150] In cases where spiritual care was provided by the interprofessional palliative care team, informal caregivers reported their satisfaction with this spiritual support.[168] Informal caregivers perceived the implementation of a care pathway as improving their ability to discuss existential issues with the interprofessional palliative care team.[156] Informal caregivers described receiving spiritual support from nurses and physicians within the inpatient SPC setting.[152, 179] However, in some cases, informal caregivers described spiritual care and the assessment of spiritual needs as not being the responsibility of certain members of the interprofessional palliative care team (i.e., nurses).[225]

3.2. Interviews

This section details the results from the interviews I conducted with patients and informal caregivers who received care on the Bruyère inpatient SPC unit.

3.2.1. Participant characteristics

From the eligible patients and informal caregivers approached by their interprofessional palliative care team, a total of 21 provided their verbal consent to be contacted for this study. Of the 15 patients approached, 12 patients did not take part in an interview due to their condition declining (n=5), deciding not to participate (n=5), or death or discharge during the recruitment process (n=2). Of the six informal caregivers approached, four did not participate in an interview due to the patient dying on the inpatient SPC unit (n=2), non-response (n=1), or deciding not to participate (n=1). One informal caregiver experienced the death of their friend on the inpatient SPC unit, however, still indicated their interest in participating in this study approximately six weeks into bereavement.

Forty-five bereaved informal caregivers were mailed information about the study. Of these, three bereaved informal caregivers contacted me to indicate their interest in participating. One of these informal caregivers were screened as being at higher risk of issues arising around bereavement using the Bereavement Risk Assessment Tool (BRAT), and was therefore unable to participate in an interview.

I conducted interviews with three patients and four informal caregivers between November 2, 2020 and February 26, 2021. Interviews lasted between 44 to 53 minutes with patients, and 52 to 113 minutes with informal caregivers. All patients interviewed were admitted on the inpatient SPC unit at the time of the interview. Of the informal caregivers interviewed, three were bereaved and one was caring for a patient currently on the inpatient SPC unit at the time of the interview. Given that all my participants had experienced care on the unit during the pandemic, each of their experiences were impacted in some way by the pandemic. A flow diagram describing the recruitment and enrolment of participants in this interview study is depicted in

Figure 4. The characteristics of patients and informal caregivers who participated in interviews are presented in Table 2.

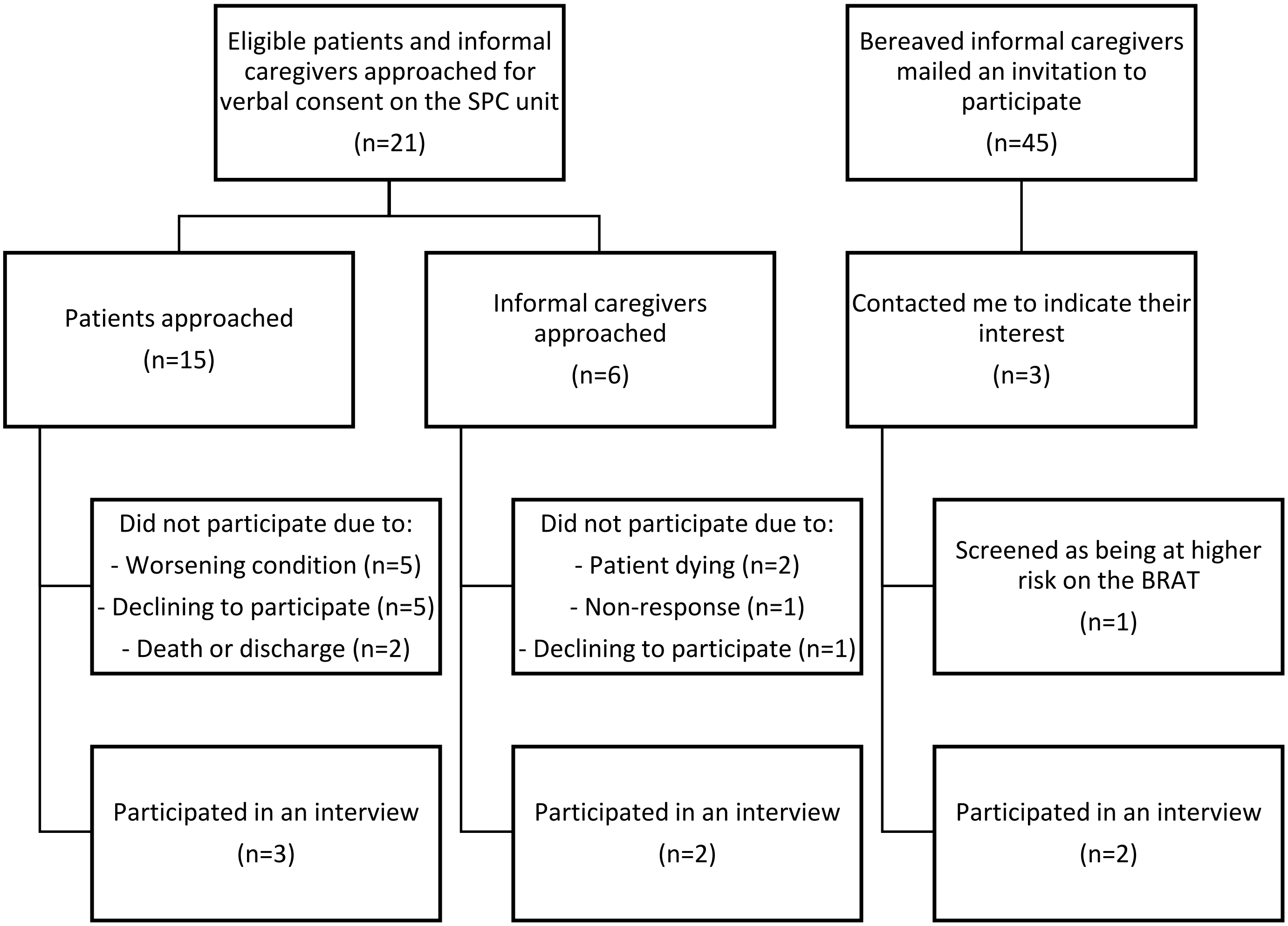


Figure 4. Flow diagram of recruitment and enrolment of patients and informal caregivers who were receiving care on the Bruyère SPC unit at the time of the interview, and bereaved informal caregivers who had previously experienced care on the SPC unit.

Table 2. Characteristics of patients and informal caregivers who participated in interviews (n=7).

Participant type	**Characteristics**	**n (% of participant type)**
Patients		3 (100)
	Age (years), mean (SD)	60.3 (SD 7.4)
	Sex	
	Female	1 (33)
	Male	2 (67)
	Diagnosis, cancer	
	Lung	1 (33)
	Diagnosis, non-cancer	
	End-stage kidney failure	1 (33)
	Congestive heart failure	1 (33)
	Days on the inpatient SPC unit, range	9-76
	Location prior to SPC[a] admission	
	Acute care hospital	2 (67)
	Home	1 (33)
Informal caregivers		4 (100)
	Age (years), mean (SD)	65.5 (SD 11.6)
	Sex	
	Female	4 (100)
	Male	0
	Patient's diagnosis, cancer	
	Lung	1 (25)
	Breast	1 (25)
	Esophageal	1 (25)
	Patient's diagnosis, non-cancer	
	Recurrent pneumonia due to dysphagia	1 (25)
	Relationship to patient	
	Spouse	2 (50)
	Child	1 (25)
	Friend	1 (25)
	Bereavement status	
	Bereaved	3 (75)
	Not bereaved[b]	1 (25)
	Days on the inpatient SPC unit, range	69.5 (13-213)
	Patient's location prior to SPC admission	
	Acute care hospital	3 (75)
	Home	1 (25)

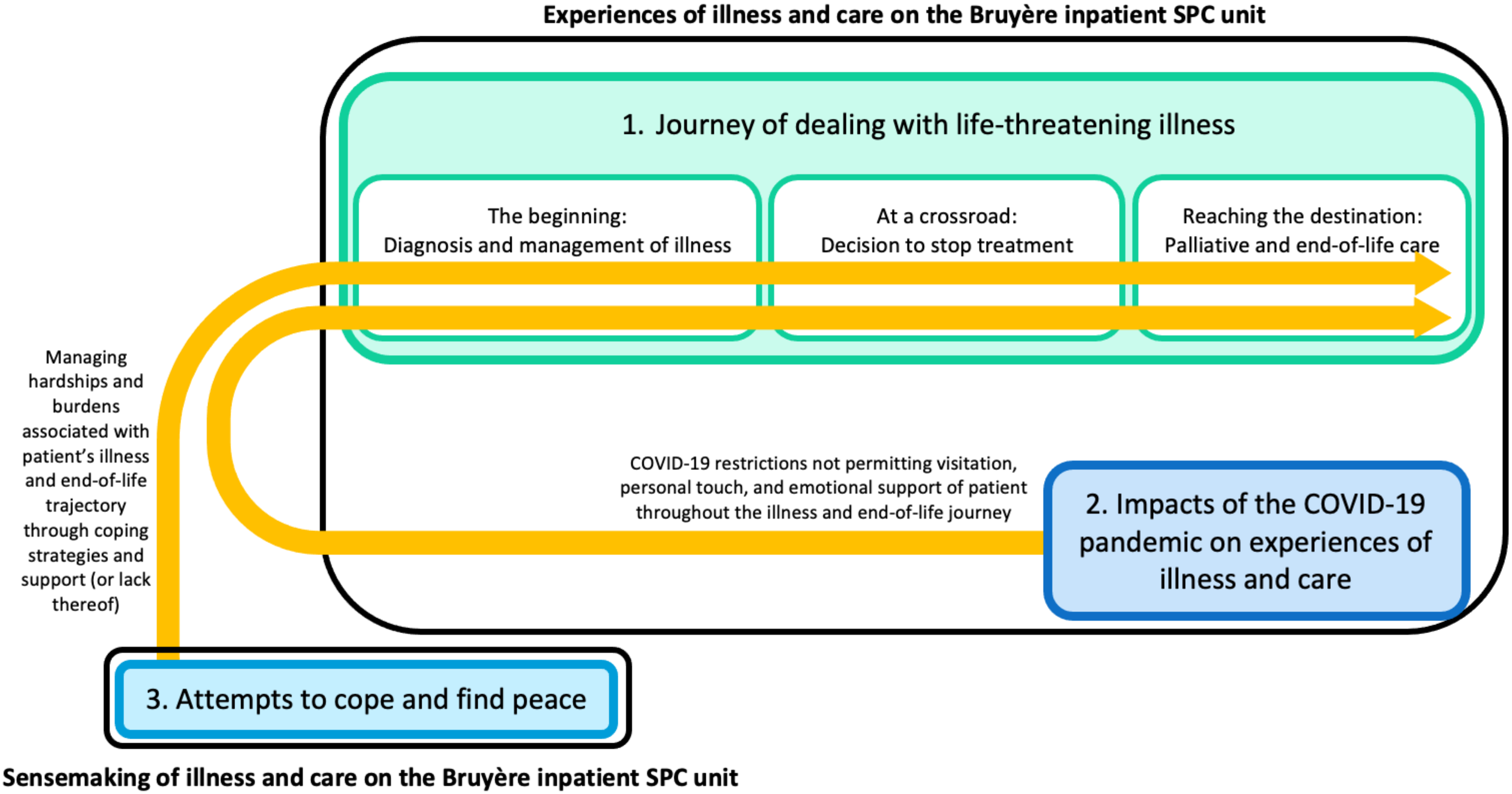
[a] SPC: specialist palliative care

[b] Patient actively receiving care on the inpatient SPC unit at the time of the interview

3.2.2. Organization of themes

I identified three overarching themes across all interviews: (1) the journey of dealing with life-threatening illness, (2) impacts of the COVID-19 pandemic on experiences of illness and care, and (3) attempts to cope and find peace. Themes 1 and 2 described patient and informal caregiver experiences within the Bruyère inpatient SPC unit (research question #2), while theme 3 captured patient and informal caregiver sense-making within this context (research question #2a). A conceptual model depicting each of these themes and the relationships between them is presented in Figure 5.

Figure 5. Conceptual model of the three themes and relationships between each theme from the qualitative analysis of patient and informal caregiver interviews.



3.2.3. Experiences of illness and care on the Bruyère inpatient SPC unit

The two themes broadly describe patient and informal caregiver experiences related to the complex journey of dealing with a life-threatening illness both leading up to and within the inpatient SPC unit, and the impacts of the COVID-19 pandemic on their overall experiences.

3.2.3.1. Theme 1: Journey of dealing with a life-threatening illness

Patients and informal caregivers described their experiences of the patient's life-threatening illness as having a distinct beginning, middle, and end, which I conceptualized as a journey. It began with the diagnosis of the illness and continued through disease management. Once it was clear that the illness was no longer curable, the journey led to the receipt of palliative and end-of-life care to provide comfort and symptom management. This process was complex, filled with uncertainties and the need to prepare for death.

The beginning: Diagnosis and management of illness

Diagnosis and management of illness was the beginning of the journey for the patients and informal caregivers interviewed. For some informal caregivers, this preliminary period began with suspicions of illness, particularly as early signs and symptoms of illness made themselves known, and sometimes denial. These experiences were raw and were seemingly ingrained in one informal caregiver's memories as she looked back and analyzed past events related to the patient's illness trajectory and their thoughts at the time:

> "… so I was looking after [patient's name] for depression … I noticed she started withdrawing and [patient's name] kept declining my requests to take her to the doctor. And you know, [patient's name] was getting to be a bit eccentric, well more eccentric than normal. I started to get more and more worried and wondered whether it was more

> than eccentricity, but you know, I didn't want to go anywhere near the territory of dementia. I guess looking back, it was probably denial, it was denial and I felt it … And then after that, I feel like [patient's name] just kept deteriorating – and looking back now, I feel that this was a sign that I should have noticed." *Informal caregiver 1*

In contrast, other patients and informal caregivers recounted details of the diagnosis frankly, without much emotion, regret, or retrospective analysis of past thoughts or incidents pertaining to the diagnosis of illness. For these patients and informal caregivers, it appeared that they had come to terms with the onset of the patient's life-threatening illness.

At a crossroad: Decision to stop treatment

At the middle of the journey, which I have termed a crossroad, patients and informal caregivers realized that the patient's condition would not improve and that they would have to choose between continuing curative interventions or choosing a palliative care approach. Some patients felt that they were no longer able to continue curative treatment and trying to get better, or viewed deterioration in their condition as inevitable. Once patients realized that the illness was terminal, all of them prioritized quality of life and comfort over quantity of life, which they perceived as being potentially achievable through palliative treatment. One patient described his decision-making eloquently:

> "For a number of years now, I've been sort of gradually decaying. This condition of mine basically eventually leading to death one way or another. It became a question ultimately, if I want to have some sort of a decent sort of quality of life, I'm dealing with symptom management and trying to be as comfortable as possible, or do I go out of my way to increase my stress levels, change my lifestyle around a whole lot – that sort of thing, try to tack on an extra number of years, that really would just be more miserable for me

> given my stress and then doing all that has to be done … And in the long run, I basically decided that conservative management was more the direction for myself. Having weighed all the pros and cons." *Patient 1*

This turning point, where increasing the patient's quality of life was ultimately chosen as the priority, sometimes included the patient's admission to the Bruyère inpatient SPC unit. The admission to the unit took place for a number of reasons from the patient perspective: being unable to administer their own pain medication or feed themselves, or becoming less independent; experiencing severe symptoms that could not be managed at home; and lacking the desire to pursue more treatment to improve their condition. On the other hand, informal caregivers reported deciding to admit their family member or friend to the inpatient SPC unit because they did not want the patient to suffer at home and wanted the patient to be comfortable at all times, which they perceived to be difficult to manage at home.

Patients and informal caregivers described their perceptions of the transition from their previous care setting into the inpatient SPC unit in terms of their level of preparedness. In some cases, informal caregivers felt unprepared for the transition to the unit due to limited receipt of information about the unit before their arrival. One informal caregiver elaborated:

> "I think when I was at [other acute care hospital], I was given my options and the lady there was really, really good, don't get me wrong, but I don't think I had a lot of information going in. … So the one thing I would say is I really didn't know what to expect going in [to the Bruyère inpatient SPC unit] … I think it's one of those things that because it's such an emotional day, like that's a really tough day the day you come that it's really just an emotional thing. So I don't know that you can really prepare yourself, but in terms of information I would say that I don't know if it would be relevant to have a

> conversation with someone before you come from the [acute care] unit. I don't even know if they'd have the time or the resources to do that … then from the moment I got there, the [inpatient SPC unit] staff kind of take care of you and [family member] and get you all settled." *Informal caregiver 2*

This informal caregiver suggested that information about the unit in the form of a conversation or leaflet would improve caregiver preparation for admission to the unit. Another informal caregiver also described her family member having trouble adjusting to the unit:

> "When [patient's name] was first admitted to the Bruyère [inpatient SPC unit], I knew Dr. [Staff Physician] was not hopeful that he was going to live very much longer … by the time he got into a bed, he was out of control, just crazy. He didn't know where he was. He didn't know anybody. He'd never met any of the doctors or nurses at Bruyère. He'd just spent an hour in an ambulance and I couldn't come with him. So the first couple of days was hard for him. I think it was all the changes and a new situation, and plus he was in a lot of pain because he had just had radiation treatment a week before they took him to Bruyère." *Informal caregiver 3*

Once patients and informal caregivers were able to settle in, they reported being in a better position to evaluate the care received from the unit, and palliative care as a whole. A common thread of acceptance, both for the diagnosis itself as well as the prognosis, was evident throughout this point in the journey for both patients and informal caregivers. Initially some patients were in denial, but found that meeting and talking with others who also had cancer contributed to acceptance of their diagnosis and its associated trajectory and reduced distress. For one patient, a lengthy illness journey resulted in acknowledging that death could occur at any point, but he felt that this was acceptable because he had lived long enough. This patient used an analogy to describe why he felt this way:

> "People asked me a long time ago in terms how do I define having lived a fulfilling life and, and I said, it has nothing to do with how long you live, per se, and to me it's t-shirts … And people wondering saying, 'T-shirts? How is it t-shirts?' with quizzical looks … there's an expression, 'I've done that and got the t-shirt'. And eventually, you feel like your wardrobe is sufficient. You know, you don't need any more t-shirts, per se, and when that does, the time when life is coming to a point of meaning you've lived long enough. … A different way of thinking, too, but I think I've lived long enough."
>
> *Patient 1*

Similarly, another patient who was in the early stages of her illness trajectory described acceptance of her condition and being at ease with her decision to pursue supportive care through the inpatient SPC unit to be more comfortable. She eschewed the idea of curative treatment for her condition given her circumstances at the time because she associated it with discomfort.

For informal caregivers, the decision to stop curative treatment and solely pursue symptom management through the inpatient SPC unit was a trying point in this journey. However, acceptance was also seen to have an important impact on the overall experience on the palliative care unit. One informal caregiver elaborated about their family member:

> "I think probably, in all honesty, the hardest day was finding out that she [family member] was ready to stop trying to get better. That was a really, really difficult day, but it's her life and it was her choice and we were going to get to that at a certain point … she just wanted to accept what was going to come … I think because people had kind of prepared me and I had to accept it – that's the other thing … everybody deals with it

> differently, right? We accepted what the doctors told us and trusted what they were telling us and accepted how [family member] felt … but the critical part, too … is that the family has to be accepting… So I think the level of acceptance that we had with where [family member]'s condition was, where she was going really had a big impact on that [experience]." *Informal caregiver 2*

In other cases, informal caregivers described being accepting of the shift to a palliative care approach due to feeling overwhelmed while trying to cope with the situation at home:

> "I was noticing her cognitive state more at this point, it was getting to be more noticeable. I'd been overwhelmed for so long that once Bruyère palliative care came in and ultimately knowing that there is no bringing [patient's name] back home, then, okay, as long as I didn't have any major or any small concerns about [patient's name]'s care and that she was safe, then I was accepting of it all because it was good." *Informal caregiver 1*

Informal caregivers viewed the Bruyère inpatient SPC unit as a space to allow them to focus on coping, particularly once it became clear that the patient's condition was not going to improve.

Though I did not explicitly ask interviewees about what palliative care meant to them, patients and informal caregivers shared their perceptions of what this type of care entailed. Both patients and informal caregivers described palliative care as enabling patients to be more comfortable in their current situation. One patient elaborated on the evolution of her understanding of palliative care:

> "So, and when palliative care showed up, they said, would I come, and I said, well, of course I'd come, but I don't think I'm there. And they said, well, no, it's not quite what everybody thinks it is. It's not just end of life. It's support. We make you comfortable as

> we can for that … So, palliative care doesn't quite mean what it meant to me before. I always thought you go there to die. That's what I thought. And I told them, I said, 'Well, everybody in my family, including me, doesn't really want to die in the hospital if I don't have to. I'd like to die at home. It's my choice, you know.' Like they accept what my choices are … they understood that. …. So, they explained to me what palliative care is really about and, yes, they can be end of life of course. But it also just means they're taking care of me, [making] me more comfortable in my own skin, [the] situation that I'm in right at present." *Patient 3*

This patient's time on the unit changed her misconceptions of palliative care and led to the realization that palliative care meant supportive care and symptom management, irrespective of where the patient was in their illness trajectory. In some cases, patients and informal caregivers viewed palliative care to be an alternative to offerings from acute care hospitals, since they viewed the acute care setting as solely providing treatment for the patient's life-threatening illness. Informal caregivers also described palliative care as a type of care that could be provided within the patient's home, enabling patients to stay and die at home. Intriguingly, one informal caregiver perceived the receipt of palliative care to mean the culmination of medical interventions (e.g., radiation therapy) for the patient's life-threatening illness. However, they also noted palliative care enabling a shift in focus to comfort and controlling the patient's symptoms:

> "They [care team at other acute care hospital] suggested palliative care, not rehab, but actual palliative care and that means no radiation … It keeps him as comfortable as he can until he's not with us anymore." *Informal caregiver 3*

Another informal caregiver described the importance of palliative care overall due to its goal of providing compassionate care until death, particularly in the absence of family members at the bedside:

> "I think palliative care needs to be there permanently for anything. Palliative care is the last thing that a patient will see before they go, it is the nurses, the staff and that, and if you stay kind and gentle and even if … you're not able to [do] your other work and you're holding a patient's hand and that patient dies in your care while you're there, that person is not alone … especially if [patients] have no family." *Informal caregiver 4*

This informal caregiver viewed the interprofessional palliative care team as an integral component to the delivery of palliative care.

Reaching the destination: Palliative and end-of-life care

This phase of the journey involved receipt of palliative and end-of-life care from the inpatient SPC unit, and for some patients and informal caregivers, preparing for the patient's last days to weeks of life. After experiencing care on the unit, patients and informal caregivers mostly described the quality of care delivered to them as being excellent or high-quality. One patient stated:

> "The care is unbelievable. It's super. Out of 10 stars, I'd give it 15 to 20, that's how good it is." *Patient 2*

Both patients and informal caregivers perceived the level of care provided as making a difference in the patient's comfort and symptom control (e.g., pain), and the patient's overall condition (e.g., independence in completing activities of daily living). In turn, these improvements enhanced patients' mood, or gave them hope. One patient elaborated:

> "… for the first few days it [nausea and vomiting] was horrible, I couldn't keep anything down and they even bedpanned me so I wouldn't have to get up, and I still got sick. But I haven't been sick probably now for the last four days or so maybe. I don't feel like I'm going to be sick. I managed to eat a little bit of everything on my tray … So that's encouraging too and the nurses say, 'Hey, we do see a difference in you.' … every day that I don't get sick I feel a little bit better. So there's some more hope." *Patient 3*

Despite a difficult transition on their arrival to the inpatient SPC unit, one patient still perceived the unit positively. He felt that care and nursing support was available in a reliable and timely manner in this care context, which increased his feelings of comfort and safety. This patient stated:

> "It [care from the unit] impacted overall how I'm feeling … I'd probably say that yes, it has helped quite a bit … it is just good to be able to have a sort of service where they were demonstrating to be more reliable and timely than I had with any sort of call service that I had before when I was not in the hospital … Or at least a lot faster than I would be getting— like there were times when I was living out in my apartment, like before I got to the hospital, if I needed a nurse for something, I could be waiting for over an hour for someone to show up. Whereas, here, it's pretty quick … I feel a little more secure about various problems when they come up … If I were to fall, for instance, and if someone could be here within a couple of minutes, as opposed to some long convoluted way of waiting for someone at my apartment or whatnot." *Patient 1*

In addition to enhancing feelings of comfort and safety, the care offered from the inpatient SPC unit was instrumental for some patients in regaining as much independence as possible in their circumstances, which many patients desired. Achieving a higher degree of independence enabled patients to feel happier and increased feelings of self-efficacy due to greater personal control over their daily living activities. One informal caregiver perceived her family member feeling more at ease due to his increased independence with feeding himself:

> "He's enjoying his food … He's using both his arms now. For a while there he couldn't use either one of them because he has [metastases] in both arms. So he's able to feed himself now. He doesn't mind if I help him, but he also can do it himself. I bring yogurt with fruit in it and if I turn around and have a chat with the nurse or something, I'll come back and the yogurt's gone… He has more control over his limbs now, so he's in charge now and he likes that … and he can still take mostly all of them orally, which is good … And [patient's name] is content to be there." *Informal caregiver 3*

Informal caregivers also described feelings of gratitude for the quality of care offered on the Bruyère inpatient SPC unit. They felt their family member or friend was safe and not suffering (e.g., due to pain), and was cared for with dignity. Another informal caregiver described her expectations of the care being met by the unit:

> "Comfort and cleanliness and softness—I think it plays a huge part in anybody that is ill no matter what degree of illness or awareness the individual has because whether they can communicate or not, they know what's going on. As long as there's light, that person knows that bad things are not happening to them. Good things are happening to them, and that's what I wanted for [patient's name]. I wanted her safe and not in pain and I wanted her to be held in respect. And that all happened at Bruyère [inpatient SPC unit]."
> *Informal caregiver 1*

In assessing care provided from the interprofessional palliative care team, patients and informal caregivers perceived the care team as compassionate and competent in remaining on top of patient care tasks. Members of the interprofessional palliative care team were seen as promoting a welcoming, joyful, and non-judgmental atmosphere. One patient described her experiences of nursing members of the interprofessional palliative care team exceeding her expectations:

> "Oh, the nurses are wonderful … they're always very accommodating … Some go the extra mile than others, but all in all they're very, very good … I mentioned something about there being a muffin and some cheese in the fridge … they weren't any, but the nurse stops at Tim Horton's and got me one. You know, she got me a muffin … Stuff like that, you see. In ways, when they clean every day and then brush my teeth and they wash out my personal areas… and then they take a brush to my hair and tell me I have nice hair … Things they don't have to do, right? They can do what they've got to do and go."
>
> *Patient 3*

This patient perceived the interprofessional palliative care team going beyond what she considered to be their mandated tasks. Similarly, an informal caregiver illustrated her perceptions of the level of care from the interprofessional palliative care team as being holistic, and taking care of patients and informal caregivers as a unit:

> "You could see right from the get-go the staff is bending over backwards … they would always check in with me … I had numerous nurses say to me, 'If you don't have food, we almost always order extra meals up from the kitchen. If there's something you need, let us know.' If I stayed overnight, they were always obliging with blankets and, you know? So, from my perspective, they really go out of the way to make sure that the family is doing okay … They look out for the whole person and they literally ask you how you're doing … they're taking care of you as a unit." *Informal caregiver 2*

Patients and informal caregivers also viewed members of the interprofessional palliative care team as being knowledgeable in their approach to care, treating patients with dignity and respect, and for the most part, providing person-centred care that was individualized according to patient and informal caregiver needs. One patient relayed their experience:

> "No, I don't feel that [uninvolved in care] at all because my team of doctors come and talk—and they say … 'We think this… if we up the steroids and maybe that will make you not as nauseous. How do you feel about it?' And so I said, 'Well, the way I look at it, if I'm here and you guys experiment with me, okay.' … So I kind of leave myself in their hands, but they never once, not asked me to be involved in my care. Never once. Not my team anyway." *Patient 2*

In cases where patients and informal caregivers described having received person-centred care from the interprofessional palliative care team, they gave examples of the members of the care team listening to their concerns (e.g., informal caregivers perceiving the patient to be confused and physicians and nurses responding to these observations) and respecting patients' decisions (e.g., patient not wanting to take a bath). In contrast, one patient felt that his prior experiences with caring for himself were not acknowledged by some members of the interprofessional palliative care team at first:

> "… there are a certain staff who are very open to consulting me about what kind of care I would give myself under certain circumstances. Then there are others who just go by whatever's on the official doctor's orders and if they're on the doctor's orders, you're taking it, you're doing it, whatever and that's it, that's all there is to it … Eventually, though, it's panned out that some of the people here actually have started listening to what I was trying to say about what worked for my care and with gradual demonstration

> of those aspects working, they've suddenly decided to support it over the course of the weeks. It was quite the fight to get to." *Patient 1*

Though this patient's input into his own care was taken into consideration after some time, the initial inability to contribute to his care due to resistance from the interprofessional palliative care team was frustrating for him. This demonstrates a disparity in patient experiences of person-centred care from the interprofessional palliative care team.

Patients and informal caregivers also discussed communication with the interprofessional palliative care team. The team was seen as observant, anticipating information needs, addressing patient and informal caregiver queries when they arose, and providing information when their family member's or friend's condition changed. An example of this was provided by one informal caregiver:

> "… it's [maintaining communication with the interprofessional care team] not hard to do there. It's so easy to do because nurses, half the time, were sitting outside [family member]'s door at their station. Right? And they're very, very approachable which is critical, right? I never got a 'I can't talk to you right now.' I'd be like, 'Listen, this is what's going on. I'm just letting you know.' 'We'll be in as soon as we can.' It was very good that way." *Informal caregiver 2*

These interactions reassured informal caregivers, and informal caregivers relayed patients also appreciating the level of information exchange according to their needs. One informal caregiver described this:

> "The doctors, if I have a question they'll answer it. And they'll be frank and I ask it when [patient's name] is in the room because he wants to know. He doesn't want a big surprise pop up one morning. He wants to know what could be coming. So we've been asking a

> lot of questions and the doctors have frankly given us the answers. Worst case scenario, what could happen, this might not happen…" *Informal caregiver 3*

However, in another circumstance, one informal caregiver felt that while they were kept informed according to their needs, the interprofessional palliative care team did not always use lay language when speaking with the patient:

> "So when they came out with certain words, I'd be saying, '[Patient's name], this is what they mean.' I would explain to him in layman's terms what they were saying. So I had to finally tell the nurses, 'Listen, he's not getting this. You're not explaining to him in easy words. You're going to have to come down. He doesn't understand what's going on.'" *Informal caregiver 4*

Thus, instances where the interprofessional care team did not provide information using clear and simple language resulted in informal caregiver burden. One patient emphasized the need for individualized communication from the interprofessional palliative care team to address this issue. Nonetheless, this patient felt that his informal caregiver's and his own experiences communicating with the interprofessional palliative care team were satisfactory.

Overall, although one gap (i.e., lack of person-centred care) was identified in the care provided by the interprofessional palliative care team, patient and informal caregiver perceptions of the care team were by and large positive. Moreover, the amenities and equipment available within the care environment of the unit supported patient comfort. For example, an informal caregiver described accessibility to "top-quality" equipment that facilitated patient comfort, such as a hoist for patient transfers, an inflatable air pressure mattress to prevent bed sores, and extra pillows if needed. Patients and informal caregivers also reported being pleased with the quality of the food on the unit.

For one patient, the care environment contributed to their sense of alienation. He described himself as cognitively sound and having a higher degree of functional ability than others on the unit, but yet still suffering from a life-threatening condition. Based on his observations of other patients admitted on the inpatient SPC unit, this patient felt that the unit and the care it delivered contributed to his feelings of not belonging on the unit due to his end-of-life trajectory and overall presentation being dissimilar to that of other inpatients:

> "I suppose what struck me the most is how the feeling of belonging in this unit is not a matter so much of prognosis or classification, seemingly, as it is by what I would say whether someone is languishing in those final days. If you really are someone who when dying has lost all sense of the … Problems with cognition type things … other difficulties like that. Yes, the palliative care ward seems to be the place to be, but the thing is, it seems though when you have someone like myself …who's not languishing, but who could technically have a heart attack or stroke at any time and just fall over dead. Do we treat this individual in palliative care, or do we treat this person in some other category… If I was lying in bed all day just moaning in pain I'd be fitting in without a problem."
>
> *Patient 1*

Both participant groups perceived services and supports provided by spiritual care and volunteers, and communal activities as integral to care. In particular, patients and informal caregivers noted the accessibility of spiritual care on the inpatient SPC unit, which contributed to feeling supported and enabled patients to cope with their life-threatening illness:

> "I'm fairly spiritual, quite spiritual and that has helped me so much. Even talking to the pastor yesterday helped me so much because it's going one way or the other. Either I'm

> going to die soon from this, or I'm going to be healed from this. … So, my attitude has been really good." *Patient 3*

Patients and informal caregivers also shared positive experiences with social activities available on the unit, while others commented on the pandemic's impact on their availability. Volunteers were seen as offering support mechanisms through spiritual offerings (e.g., communion provided by a nun) and companionship. One informal caregiver felt that these activities helped distract patients from their illness or find peace of mind. Patients and informal caregivers said they wanted some activities that were provided by volunteers prior to the pandemic (e.g., virtual travel and reminiscence program, pet therapy, social gatherings on the unit), as well as those that had not been provided on the inpatient SPC unit to date (e.g., group games such as bridge, euchre or cribbage).

While care was mostly viewed positively, the end-of-life trajectory was shrouded in some uncertainty for both patients and informal caregivers. One patient described being aware of their end-of-life trajectory, but being uncertain of when and how his death would come about:

> "I know I'm heading toward death. I just don't know when … I don't know how it's going to happen and the funny thing is, I've been having so many of these little scares and so many of these years to prepare for this in a sense that, to me, it's more of a curiosity as opposed to anything to actual I feel fear with." *Patient 1*

Instead of feeling fearful of this uncertainty that he faced, this patient expressed a sense of curiosity about when and how he would die. Other patients felt less uncertain due to their spiritual beliefs, and the knowledge that the interprofessional care team would provide symptom relief as needed. On the other hand, informal caregivers reported feeling uncertainty due to the unpredictability of their family member's or friend's illness trajectory, and as a result, found it difficult to decide whether to remain at the bedside or not. One informal caregiver summed this uncertainty up:

> "You know where my biggest uncertainty came from: should I stay, or should I go home. So at that point, I'm like, well, I had the conversation with the nurse and I said, 'What should I be looking for in terms of these change you're telling about?' And so she was very clear on telling me, 'This is what you'd be looking for' and that kind of thing and that helped. Once I understand where we're heading, it helps to prepare you emotionally as much as you can." *Informal caregiver 2*

For this informal caregiver, talking with the interprofessional palliative care team reduced some uncertainty and helped her emotionally prepare for the end-of-life trajectory. In contrast, another caregiver recounted feeling more confident and prepared for her mother's illness and end-of-life trajectory due to her current and prior experiences caring for other cancer patients as a volunteer.

There were opposing beliefs about how to prepare for the end of life among participants. Some informal caregivers believed that there was no way to truly prepare for the end of life or prevent feelings of uncertainty. Other informal caregivers posited that preparation was possible and should occur early on before the patient's condition declines, with one suggesting that a lack of education and the taboo nature of discussing end of life contributed to informal caregivers feeling unprepared and overwhelmed. In this case, preparation was viewed as a necessary precursor to having a more positive experience in receiving palliative and end-of-life care.

Regardless of their level of preparedness for the end-of-life trajectory, patients and informal caregivers described tasks that were directly or indirectly preparing for the patient's death. These included creating a will and power of attorney, patients mending rifts with family members, spending more time with family members, organizing funeral arrangements, pre-selecting the patient’s outfit for the funeral, and patients arranging for gifts for important people in their lives. Carrying out these tasks contributed to a sense of peace of mind for patients and informal caregivers.

Preparation also included choices of the location of the patient’s end-of-life care and death. Some informal caregivers were not comfortable with a home death, fearing the patient may suffer without quick access to a physician. They preferred the care offered within the inpatient setting where their family member or friend would be able to access care rapidly when needed. For other informal caregivers, even though they and the patient wanted to remain at home for the patient’s last days, it became clear that the supports available at home were not sufficient to meet the patient’s needs. Barriers to keeping the patient at home included insufficient home nursing and personal support worker care and patients needing more pain management and assistance with eating than what was feasible at home.

3.2.3.2. Theme 2: Impacts of the COVID-19 pandemic on experiences of illness and care

The COVID-19 pandemic impacted patient and informal caregiver experiences of illness and care, in particular because of visitation restrictions. At the Bruyère inpatient SPC unit, no visitors were allowed at the start of the pandemic unless patients were imminently dying. Informal caregivers were primarily left to communicate with patients through telephone or virtually during the initial phases of the pandemic, until the development of revised visitation rules permitted patients who were not imminently dying to have one informal caregiver visit per day. The volunteer presence on the inpatient SPC unit, which was fairly robust prior to the pandemic, was stopped for over a year during the pandemic. In addition, newly admitted patients were isolated to their room for the first 14 days of their admission.

Both patients and informal caregivers perceived visitation restrictions and isolation periods as unpleasant and distressing for everyone involved, including patients, caregivers, and the interprofessional palliative care team. Patients perceived visitation restrictions and the inability to leave the unit for a cigarette, take a walk or longer outings as particularly difficult when they knew they were near the end of life. For one patient, the pandemic presented an obstacle to being able to spend his remaining days with his spouse:

> "It's a little hard because it's the end-of-life phase. I wish this pandemic wasn't here because I'd like to – before I pass away, I'd like to take [spouse] out for a nice dinner somewhere … and just being able to spend more time with her. I know she's already booked off a whole bunch of hours and stuff like that, and she has to come from downtown all the way here. So it's just often a lot." *Patient 2*

Informal caregivers expressed that visitation restrictions left them feeling more strained during an already stressful time. They recounted feeling distressed because visitation restrictions removed what little emotional or other supports that they could provide to the patient on the inpatient SPC unit. In some cases, informal caregivers felt that visitation restrictions contributed to cognitive issues (e.g., delirium) for patients, and magnified uncertainty and fears of missing out on the last days of quality interaction with the patient. While the interprofessional palliative care team was able to provide some reassurance and support to informal caregivers who expressed these feelings, a sense of helplessness and anxiety remained due to being unable to be at the patient's bedside.

Both participant groups viewed physical touch as an important component to supporting patients with life-threatening illness. Patients reported that personal touch and the informal caregiver presence made a positive impact on their stay on the inpatient SPC unit. Though some patients did not feel that they needed physical touch or have visitors during their 14-day isolation, patients and informal caregivers did describe visitation as being important for others on the unit who were closer to the end of life. For one informal caregiver, being unable to hug and hold her friend in his home due to COVID-19 public health orders was frustrating, and this tension remained once he was admitted to the inpatient SPC unit. She was upset that the mandated 14-day isolation upon being admitted to the unit meant that she still could not hold her friend. Patients and informal caregivers reported that the interprofessional team tried to make up for the loss of visitation and personal touch by spending time at the bedside chatting with patients, even if it meant having to go through extra procedures such as putting on a gown and face shield.

Both participant groups also commented on the plight of the interprofessional palliative care team caring for them during the pandemic. Patients and informal caregivers perceived the interprofessional palliative care team as being fatigued and strained due to providing care with little support and reprieve but also emphasized that even if team members felt fatigued, they continued to provide excellent care.

3.2.4. Sense-making of illness and care on the Bruyère inpatient SPC unit

Patients and informal caregivers engaged in sense-making, a process of existential and experiential learning needed to manage a changing or uncertain life situation,[23] throughout their experiences on the Bruyère inpatient SPC unit. Specifically, patient and informal caregiver attempts to make sense of the complexities of their situations contributed to them identifying strategies that facilitated coping with the hardships and burdens associated with the patient's illness and end-of-life trajectory or make peace with the situation at hand. The intricacies of this process are described in the third overarching theme of finding ways to cope and feel at peace.

3.2.4.1. Theme 3: Attempts to cope and find peace

Coping with the illness and end-of-life journey was a complex component of the sense-making process for both patients and informal caregivers. Patients described not being particularly concerned with their proximity to the end of life, but rather, were more focused on comforting their informal caregivers. With respect to coping with the uncertainty of illness, patients shared that talking to others helped lift their spirits, however, they became fatigued very quickly when socializing. Patients also found support from their informal caregivers as helpful in coping with their illness and end-of-life trajectory. In some cases, this support involved informal caregivers accepting the patient's end-of-life care decisions despite their disapproval, or simply being present at the bedside.

Some patients described coping well with their proximity to the end of life due to their lack of fear of death, their faith in God, or feeling as though they had lived a full life already. On the other hand, one patient suggested that keeping a positive outlook was also important while coping with a life-threatening illness:

> "I think a negative outlook, we all get that from time to time. We're only human beings, right? But if we stayed in a negative frame of mind, it doesn't help me heal. It just makes you worse and I don't want to get worse…" *Patient 3*

Patients also described drawing on their willpower and ability to fight to make it through the challenges that their illness presented for them. In contrast, another patient described getting frustrated with their condition and their informal caregiver, but then acknowledged the burden that these reactions placed on their informal caregiver:

> "I got angry at [spouse name] and I said, 'Sometimes I just think maybe I should just roll over and die,' and she's like, 'Oh, don't say that … Don't make me cry.' And I said, 'You know, I'm just tired. I know it's hard on you.'" *Patient 2*

Accordingly, some informal caregivers described feeling overwhelmed and carrying a heavy burden throughout the patient's illness journey. One informal caregiver explained:

> "[I was] beyond overwhelmed. I just figured as long as [patient's name] was being looked after well, and she was, and everything that could be done for her comfort was being done, it was, so… I just carried on like a robot, in a way … I cried a lot … my type of crying that I'm referring to is the crying of despair where you just don't… I wasn't anywhere near my emotional best to begin with and I just kept getting hit with the horrors of reality. … I felt mostly when I was at the palliative care unit, I was just trying to mostly keep myself going until I could get to the point where I'd have a rest." *Informal caregiver 1*

Coping strategies used by informal caregivers to address the emotional burdens of caregiving included focusing on one task at a time, solely depending on the information provided from the patient's interprofessional palliative care team to inform care decisions, or using meditative energy work (e.g., Qi Gong) for stress management. Good communication with the patient about the patient's wishes for their end-of-life journey also helped informal caregivers handle the patient's last weeks to days of life. Coping with, and therefore, making sense of the patient's illness journey was fundamentally linked to feeling peace of mind. Informal caregivers appeared to associate this sense of peace with feelings of having done everything they could to ensure that the patient was cared for and honoured to the best of their ability.

Informal caregivers also viewed support from their other family members as impacting their ability to cope and make sense of the situation at hand. Informal caregivers' family members provided support by being present, offering rides to the hospital, and encouraging the primary informal caregiver to take care of themselves. One informal caregiver gave an example of the support that her family members provided to her throughout her spouse's stay on the inpatient SPC unit:

> "… we have grown-up kids, so my son came home from [another city across the country] to here … and then my daughter … came from [another city across the country] a couple of days later … we were all there again, sort of, taking turns visiting him because only one person could go and see him each day. It was hard. I mean, it's still hard … It was a big help to have the kids home and they staggered their visits a little bit … That was a big help." *Informal caregiver 3*

When support was not available from other family members or other community supports, informal caregivers reported feeling fatigued and burdened. Moreover, conflict with other family members contributed to informal caregiver burden, particularly in cases where family members contested power of attorney arrangements made by the patient. These hindrances complicated the journey of coping and making sense of the patient's illness and end-of-life trajectory. Fortunately, informal caregivers viewed the admission to the inpatient SPC unit as helping with easing their burden overall. They also perceived the admission to the unit as facilitating coping by allowing them to attend to their practical needs and emotional well-being while the unit provided care to the patient.

Thus, though informal caregivers experienced significant burden throughout the patient's illness and end-of-life journey, they also reported being able to manage these hardships using specific coping strategies, and support from their family members and the interprofessional palliative care team on the inpatient SPC unit. These strategies and support contributed to their ability to make sense of and adjust to the patients' illness and care within the inpatient SPC context.

CHAPTER 4: DISCUSSION

In this chapter, I summarize my findings and describe the strengths and limitations of the two components of this thesis: first the scoping review and then the interview study. I conclude with recommendations for future work based on my findings from both parts of this thesis.

4.1. Scoping review

4.1.1. Summary of findings

This scoping review synthesizes 104 studies that describe patient and informal caregiver experiences of illness and care in inpatient SPC settings. I identified three overarching themes of complex and diverse patient and informal caregiver experiences, including i) their perceptions of care, the interprofessional palliative care team, and the care environment; ii) communication with the interprofessional palliative care team; and iii) impacts of illness and care on quality of life. Overall, within the included studies, both patients and informal caregivers reported being satisfied with the care provided, their interprofessional team, and the care environment in inpatient SPC settings. Patients described specific preferences and unmet needs with respect to communication with the interprofessional palliative care team, while informal caregivers reported their satisfaction with communication, as well as unmet needs. Lastly, the impacts of the inpatient SPC context on patients' and informal caregivers' quality of life were well-characterized. Though patients and informal caregivers mostly reported positive impacts of inpatient SPC on their quality of life, both groups reported feeling distressed in this setting, whether due to patients' illness trajectory or caregiving burdens for informal caregivers.

Both patients and informal caregivers mostly reported being satisfied with the care offerings, interprofessional team, and care environment within inpatient SPC settings in this scoping review. However, informal caregivers also described dissatisfaction with some elements of the inpatient SPC setting (e.g., lack of person-centred care, inadequate staffing, no curative interventions). These findings reflect those of a previous systematic literature review on patient and informal caregiver satisfaction or preferences with respect to SPC, which largely reported their satisfaction with the receipt of SPC in the inpatient and community context, though a wide range of sources of dissatisfaction were also described.[233] Patient perceptions of the quality of care provided in SPC contexts,[234] and the specialist as opposed to generalist approach to palliative care,[38] have been identified as contributors to patient and informal caregiver satisfaction with the care offered in SPC settings. Informal caregivers reported desiring person-centred care in the studies included in this scoping review. Patients and informal caregivers viewed care that was tailored to their needs and preferences in inpatient SPC settings as reducing potential gaps in communication and improving delivery of culturally insensitive care. This approach to care is well-supported in the palliative and end-of-life care literature, given that an inherent characteristic of person-centred care involves acknowledgement and respect for patients' and their families' preferences, values, and fears.[43, 235]

Patients reported a wide range of preferences and needs, including unmet information needs, with respect to communication with the interprofessional palliative care team in the inpatient SPC context. Many informal caregivers reported satisfaction with the communication they received, but also reported unmet information needs. These descriptions of patient and informal caregiver unmet information needs in the inpatient SPC context are comparable to those described in inpatient, outpatient, home-based, and mixed palliative and cancer care settings.[13, 14, 44, 45] Cultural considerations also impacted the amount of information desired by patients and informal caregivers, as well as how transparent members of the patient's care team were with patients about their illness. However, in the studies included in this scoping review, the majority of patients and informal caregivers felt the care delivered in the inpatient SPC setting was respectful of their culture. This finding is in contrast with that of a recent systematic review that described South Asian patient and informal caregiver perceptions of a lack of culturally sensitive care from inpatient palliative care settings in the United Kingdom, United States, Australia, Canada, and Scotland.[236]

In this scoping review, the physical, psychological, social, and spiritual aspects of patients' and informal caregivers' quality of life were described in numerous included studies. Patients and informal caregivers mostly reported positive impacts, such as improved patients' physical symptoms, and overall quality of life, and reduced informal caregiver anxiety within inpatient SPC settings. Nonetheless, some gaps were also identified. These included patients and informal caregivers reporting that they needed more psychological and spiritual support than what was provided during the receipt of inpatient SPC care. Patients' psychological distress appeared to be mostly associated with their illness and its trajectory, while informal caregivers' psychological burdens were due to caregiving, distress at witnessing patients' declining condition, and unfulfilled social and information needs. These findings are supported by previous literature describing lower patient quality of life and increased symptom burden due to illness in the end-of-life phase within inpatient SPC settings,[237] and informal caregiver psychological distress in palliative care contexts.[12, 48, 238] Other studies have reported provision of better psychological supports in SPC settings compared to other care settings,[233] and SPC teams identifying patient and informal caregiver needs more proficiently compared to generalist care teams.[38] However, these care offerings may only provide a mild mitigating effect, given that this scoping review has identified distress and quality of life impacts reported by patients and informal caregivers in inpatient SPC settings. These findings confirm the extensive caregiving burdens that have been reported within the palliative care context broadly, and highlight the immense need for effective holistic support for informal caregivers,[91] given that these burdens may continue into bereavement.[54, 55]

This scoping review found the following gap in the literature for patient experiences in the inpatient SPC context. While informal caregiver experiences have been reported in numerous included studies, there was less literature on patients' perspectives of inpatient SPC settings. As an example, there were some areas where literature was available for informal caregivers but not for patients (e.g., level of satisfaction with communication from the interprofessional palliative care team, perspectives of the timing of the admission to the inpatient SPC setting). These gaps in the literature may be due to the disparity in the number of available studies for patient versus informal caregiver perspectives. Specifically, in contrast to the 54 studies reporting on informal caregiver experiences in this scoping review, there were only 26 studies on patients' experiences. In addition, there was a wide range in patient preferences for and satisfaction with communication from their interprofessional palliative care teams in inpatient SPC settings, which was complicated further by cultural norms and taboos surrounding illness and end-of-life discussions. To compound this problem, one included study described patients with life-threatening illnesses experiencing significant levels of distress, but being unable to communicate this in order to elicit care to address their distress.[239] Further research is needed to fill the gap in the literature on patient-reported experiences in inpatient SPC settings (see Section 4.3: Synthesis of findings, recommendations, and clinical practice implications). It is imperative that these experiences are self-reported by patients in future studies given that informal caregivers have been found to be unreliable proxies for reporting patients' subjective experiences of their illness or care, including quality of life or symptoms such as pain, depression, or anxiety.[87, 240-242]

4.1.2. Strengths and limitations

The strengths of this scoping review are that it comprehensively summarizes the available literature on patient and informal caregiver experiences within inpatient SPC settings. To my knowledge, there is no published scoping review on this topic to date. Moreover, this scoping review contributed to the identification of clinical practices in need of improvement and areas in which further work is needed (see Section 4.3: Synthesis of findings, recommendations, and clinical practice implications). I followed established scoping review methods to maintain rigour in the conduct and reporting of this review.[83, 98]

Possible limitations of this scoping review include that some studies may not have been captured in searches, despite the use of a comprehensive search strategy in multiple databases and grey literature searches. Moreover, studies that were not in English were excluded in Level 1 and 2 screening, and one database search (CINAHL) was limited to the English language due to feasibility and timeline considerations. As a result, it is possible that some relevant non-English studies were not included in this scoping review. Lastly, though there were mechanisms in place to ensure data charting and analysis accuracy, in which approximately 10% of charted articles and 20% of coded articles were verified by a second reviewer, I was the sole reviewer completing data charting and coding. This approach was taken to make the scoping review feasible within the limited timeline for this degree, however the use of only one reviewer may have impacted the rigour of this work.

4.2. Interviews

4.2.1. Summary of findings

4.2.1.1. Experiences of illness and care on the Bruyère inpatient SPC unit

The qualitative findings from the three patient and four informal caregiver interviews conducted as part of this thesis reflected the intricacies of patient and informal caregiver experiences within an inpatient SPC unit in Ottawa, Canada. I identified three overarching themes from the interview results: i) patients' and informal caregivers' experiences of the patients' life-threatening illness and care before and during their admission to the inpatient SPC unit; ii) impacts of the COVID-19 pandemic on these experiences, and iii) their attempts at making sense of their experiences through coping and finding peace. The first two themes are discussed in relation to existing literature in this section, while the third theme is discussed in section 4.2.1.2 to correspond to my research questions. The beginning of the illness journey was rife with emotional challenges for some patients and informal caregivers, while other patients and informal caregivers seemed to have come to terms with the initial diagnosis and management of the patient's illness. When patients and informal caregivers realized that the patient's illness was incurable, this signified a crossroad in their journey, and ultimately led to patients and their informal caregivers choosing to prioritize the patient's quality of life. The final destination in patients' and informal caregivers' experiences of the illness journey involved the receipt of palliative and end-of-life care from the Bruyère inpatient SPC unit and, for some, preparation for the patient's last days to weeks of life.

Some patients felt angry, sad, and in denial at the beginning of their journey of dealing with a life-threatening illness. Meanwhile, some informal caregivers who participated in interviews reported suspecting the onset of illness and had difficulty accepting the patient's increasingly discernable decline. Correspondingly, the emotional difficulties associated with the diagnosis of illness is widely reported in the literature, both from patient[192, 197, 212, 214] and informal caregiver[20, 46, 221, 231] perspectives.

Both participant groups described the process of accepting the nature of the patient's illness, and the inevitability of the patient's deterioration until death as being an intrinsic part of the admission to the inpatient SPC unit. This finding is confirmed by previous literature describing patients and informal caregivers coming to terms with the patients' illness and prognosis leading up to and within the inpatient SPC context.[156, 197, 200, 211, 224] In contrast to the results of this interview study, a previous study in an inpatient SPC setting reported patients feeling pressured by their families to accept or find peace with their impending death when they were not ready to do so.[202]

During their stay on the Bruyère inpatient SPC unit, one informal caregiver described not knowing what to expect due to a lack of information about the unit prior to the patient's admission, which reflects a gap also described in a study conducted in an Austrian inpatient SPC unit.[219] This finding suggests the need for improved communication and education about palliative care and the role of the SPC unit prior to the transition to an inpatient SPC setting. As a result of their stay on the inpatient SPC unit, patients and informal caregivers conveyed understanding the concept of palliative care more fully. However, one informal caregiver described palliative care to mean no medical interventions (e.g., radiation therapy) for the patient's life-threatening illness, which is a widely held misconception across patients and informal caregivers in other inpatient SPC care settings.[163, 202, 212, 214, 217, 219, 220] The prevalence of limited knowledge of palliative care, especially among those who were already receiving palliative care on an inpatient SPC unit, highlights the need for more widespread education among patients and informal caregivers about this topic (see Section 4.3: Synthesis of findings, recommendations, and clinical practice implications).

After experiencing care on the Bruyère inpatient SPC unit, patients and informal caregivers reported feeling satisfied with improvements in the patient's physical symptoms, which they viewed as contributing to their improved mood or hopefulness. These results provide support for the strong association between symptom distress and quality of life reported in other work.[55] Both participant groups also described receiving holistic care on the inpatient SPC unit, which is in keeping with the remit of palliative care.[1]

Patients and informal caregivers reported on the detrimental impacts of the COVID-19 pandemic on receiving inpatient SPC care at the end of life, particularly with respect to the social isolation they experienced. This finding reflects the currently available literature on the negative effects of the pandemic in inpatient and outpatient palliative care settings.[230, 243] Patients and informal caregivers who participated in interviews reported finding ways to cope with the impacts of the pandemic as well as the patient's illness and end-of-life trajectory, as detailed in the next section.

Nonetheless, informal caregivers still reported extensive psychological and social burdens, which echoes previous research in the inpatient SPC context.[46, 53, 55, 141, 146, 147, 150, 158, 160, 166, 185, 192, 203, 204, 207, 217, 220] Though informal caregivers viewed the Bruyère inpatient SPC unit as a way to ameliorate some of their burdens, these findings suggest that more supports (see Section 4.3: Synthesis of findings, recommendations, and clinical practice implications) are needed for informal caregivers caring for patients with life-threatening illness.

4.2.1.2. Sense-making of illness and care on the Bruyère inpatient SPC unit

The process of sense-making was woven through patients' and informal caregivers' journeys, from the beginning, crossroads, and into the destination for their receipt of inpatient palliative and end-of-life care: the Bruyère inpatient SPC unit. Patients and informal caregivers attempted to make sense of the patient's complex illness and end-of-life journey in the context of the unit through learning and identifying strategies to cope or adjust to the situation. Ultimately, for some patients and informal caregivers, their experiences of coping with the patient's illness and care on the unit led to finding peace of mind.

In the context of life-threatening illness, such as cancer or other serious health conditions, sense-making may involve seeking out additional information to help individuals understand their situations, and learn to manage uncertainty.[23, 78] In this interview study, patients reported coping with the uncertainty of their illness by talking to their interprofessional palliative care team or informal caregivers. Patients in this interview study reported that having social interactions with members of the interprofessional palliative care team or informal caregivers improved their mood and a sense of hope, which in turn allowed them to adjust to the uncertainty presented by their illness. This finding is in contrast to previous studies which described patients interacting with interprofessional palliative care team members to solely elicit information,[23, 78] but similar to another study where patients pursued pleasurable social connections with their families, friends and other informal caregivers to alleviate feelings of suffering or loneliness due to the uncertainties of illness.[77] In the current interview study, informal caregivers reported relying on information from the patient's interprofessional palliative care team to inform their care decisions for patients, which subsequently contributed to their ability to cope with the patient's illness journey and feel peace of mind.

As reported by a single study in the community SPC setting, making sense of a traumatic experience such as impending death or bereavement may be facilitated when individuals feel lower levels of distress prior to the traumatic event, have spiritual or religious beliefs, or view death as a predictable or natural part of life.[57] Correspondingly, the patients interviewed on the Bruyère inpatient SPC unit reported coping well with their proximity to the end of life due to their faith in God, or lacking a fear of death. Unfortunately, I was not able to assess patient and informal caregiver levels of distress prior to their palliative and end-of-life care experiences in the inpatient SPC context and the associated impacts on their sense-making processes in my interviews with them as this was outside the scope of my interview study. Further research may be warranted to examine how patients' and informal caregivers' levels of distress impact their sense-making processes in relation to the patient's illness and care within the inpatient SPC context.

Two out of three patients on the Bruyère inpatient SPC unit appeared to perceive their informal caregivers as more distressed than themselves in coping with the patient's impending death. This led patients to try to comfort their informal caregivers. Though patients in my interview study were not explicit in how they comforted their informal caregivers, another study identified cancer patients avoiding the use of fear-inducing language (e.g., "clot in the brain" instead of "tumour") in speaking to their informal caregivers about their own illness to improve comfort and minimize distress for their informal caregivers.[23] Patients described this behaviour of protecting or comforting their informal caregivers through the use of "neutral" language when they perceived the informal caregiver to be unable to cope with the patient's declining condition, even when patients knew with certainty that they were close to the end of life.[23] Such examples illustrate the importance of finding effective means to help informal caregivers cope with patients' illnesses in order to alleviate unwanted burdens on patients nearing the end of life.

Overall, informal caregivers on the Bruyère inpatient SPC unit reported feeling overwhelmed due to being bombarded by the "horrors of reality" throughout the patient's illness journey, and perceiving a lack of support from their other family members. This contributed to informal caregivers having difficulty adjusting to their situations and therefore feeling psychologically burdened. These findings correspond to a study of informal caregivers from the intensive care unit context, wherein informal caregivers who experienced difficulties with making sense of the patient's illness also encountered barriers in their ability to cope effectively with the situation as a result.[65] Previous literature from the community SPC context demonstrates that informal caregivers who were able to make sense of the patient's impending death and their own bereavement were in in turn more capable of coping with the death of the patient up to six months into bereavement.[57] Moreover, informal caregivers who were able to move past sense-making and into perceiving benefits (referred to as 'benefit-finding') in their experiences of loss were more likely to be able to adjust to their loss on a long-term basis.[57] Given that informal caregivers on the Bruyère inpatient SPC unit reported more difficulties adjusting to the patient's illness and end-of-life trajectory compared to patients, these findings demonstrate the importance of identifying methods of supporting informal caregivers in their attempts to make sense of the patients' illness and end-of-life trajectory within the inpatient SPC context.

4.2.2. Strengths and limitations

A key strength of the interview component of this thesis included the recruitment of both patients and informal caregivers for a broader understanding of their experiences while on the Bruyère inpatient SPC unit, and how they made sense of their illness and care within this setting. Based on my scoping review results, patient and informal caregiver experiences within other inpatient SPC contexts have been described in many articles, with many using a qualitative approach as I have done. However, to my knowledge, there is no study to date on the sense-making processes undertaken by patients and informal caregivers in the inpatient SPC context. Therefore, this thesis's interview findings represent a novel contribution to the literature. Moreover, I conducted in-depth interviews with participants, which allowed me to provide a rich, thick descriptions of patient and informal caregiver experiences and sense-making processes.[129, 130] Lastly, this interview study also represents a novel contribution to the growing body of literature on patient and informal caregiver illness and care experiences in inpatient contexts during the COVID-19 pandemic.

The following limitations to the interview findings need to be considered. Firstly, patient and caregiver perceptions, feelings, experiences, and needs may evolve over time, and interviews conducted at a single point in time will only capture some of these variations. In addition, interviews were conducted with only three patients and four informal caregivers. This small sample size reflects both the well-documented challenges of recruiting patients and informal caregivers for research in palliative care,[117, 119-122, 244] and the impacts of the COVID-19 pandemic. These challenges meant that I was unable to meet my goal of 8-12 interviews with patients and informal caregivers to reach code saturation.[123, 124] Therefore, my findings may not fully reflect the breadth of patient and informal caregiver sense-making in the inpatient SPC context. Even still, I attempted to ensure that recruitment rates were as high as possible during the pandemic, and used previously established recruitment strategies for the palliative care context, including: ensuring ongoing communication with the clinical care team (i.e., showing up to weekly team rounds on the Bruyère inpatient SPC unit),[122] increasing promotion of this study to participants (e.g., using posters, through the interprofessional palliative care team),[122] and performing continuous monitoring of the recruitment rate.[119]

Given the difficulties of recruitment in the palliative care context, I used convenience sampling to find participants for interviews. A key disadvantage in using this sampling method is that the sample may not be representative of the patient and informal caregiver population on the inpatient SPC unit, and as a result, may result in lower transferability to the broader patient and informal caregiver patient population within this specific setting, or other similar settings.[118, 245] Only patients with higher functional status (Palliative Performance Scale >30%) were included as patients who were closer to the end of life or with lower functional status (Palliative Performance Scale ≤30%) were not able to participate in research. This issue was likely compounded by the COVID-19 pandemic, given that many patients were being admitted to the Bruyère inpatient SPC unit later in their illness trajectory, meaning that they were often closer to the end of life.

It is also possible that individuals who were more interested in sharing their experiences on the Bruyère inpatient SPC unit, whether positive or negative, may have been more likely to participate in this study. As a result, the experiences reported may not fully reflect the breadth of patient and informal caregiver experiences within the unit. I attempted to reduce this self-selection bias by explaining to all potential participants that the interviews were intended to capture their experiences, regardless of the quality of their experiences (e.g., positive, negative, or somewhere in between). It is also possible that bereaved informal caregivers who participated in interviews may have experienced recall bias due to the passage of time since experiencing illness and care on the inpatient SPC unit. In addition, bereaved informal caregivers' experiences of the patient's death and the subsequent grieving process may have influenced informal caregivers' perceptions of their time on the unit in ways that could not be assessed as part of this study.

Despite these limitations, the interviews conducted as part of this thesis project provide a starting point to describing how patients and informal caregivers experience and make sense of illness and care within the context of an inpatient SPC unit.

4.3. Synthesis of findings, recommendations, and clinical practice implications

Based on the findings from both the scoping review and interviews, patients and informal caregivers identified similar areas in need of improvement. Both patients and informal caregivers reported unmet information needs, and distress, uncertainty, or difficulty coping due to the patient's illness or end-of-life trajectory. Moreover, they emphasized the need for person-centred care delivery within the inpatient SPC setting, which in interviews, informal caregivers described as extending to the use of patient-friendly language. The use of a person-centred approach may enable interprofessional palliative care teams to deliver improved care to address patient and informal caregiver needs, such as those for information or psychological support. One method of improving the delivery of person-centred care in inpatient SPC settings may include tools such as question prompt lists, a list of questions that patients and informal caregivers may wish to have answered by their care team. Patients and informal caregivers have found question prompt lists to be helpful in addressing their supportive needs in outpatient palliative care and medical oncology settings.[246-254] In order to enable patients and informal caregivers to elicit information and care according to their needs within the inpatient SPC context, similar tools could be adapted for this context and provided to patients and informal caregivers upon admission. Overall, the findings from the scoping review demonstrated that there is less literature on patient-reported experiences of the inpatient SPC setting in comparison to informal caregiver-reported experiences. Further research on patient experiences of such settings is needed to contribute to this gap in the literature.

In both components of this thesis, patients and informal caregivers also reported misunderstandings about palliative and end-of-life care. Specifically, both groups felt unsure about the applicability of care offered from the inpatient SPC setting to the patient's situation and were often under the impression that palliative care was solely for patients who were close to the end of life, or actively dying. This lack of clarity highlights the ongoing need for educating patients and informal caregivers about the palliative care approach, and its applicability early in the disease trajectory, even as curative interventions for the patient's life-threatening condition are initiated.[41] Moreover, when discussing palliative care, health care providers should also be mindful of the language used to communicate to patients, their families, and colleagues to avoid perpetuating the misconception that palliative care is only for those patients who are dying when all other curative interventions have failed.[255] Though some studies promote the use of the term 'supportive care' rather than 'palliative care' due to negative connotations that may be associated with the use of the latter term,[256, 257] other studies have emphasized the need to educate the general public and raise awareness about palliative care using mechanisms such as media campaigns.[258] Interestingly, most patients and informal caregivers who participated in interviews noted only understanding the meaning of palliative care once they began experiencing care on the Bruyère SPC unit. This finding suggests that patients and informal caregivers may lack adequate information about the palliative care approach prior to their transition to the inpatient SPC setting. Therefore, further work is needed to identify changes that may support improved education and awareness about palliative care prior to care transitions to such settings.

CHAPTER 5: CONCLUSION

5.1. Contributions to knowledge

This thesis study has contributed to the current body of knowledge on how patients and informal caregivers experience illness and care within inpatient SPC settings and make sense of these experiences. To my knowledge, there are no published reviews that comprehensively summarize the literature on patient and informal caregiver experiences in inpatient SPC settings. The scoping review that was undertaken as part of this thesis study contributes to this gap in knowledge and has identified recommendations for clinical practices in need of improvement and areas for future work to support these improvements. The findings from the qualitative portion of this thesis study may contribute to changes in clinical practice with respect to improving patient- and caregiver-tailored care and information provision within the Bruyère inpatient SPC unit, as well as elsewhere nationally or internationally. Specifically, further research demonstrating how patients and informal caregivers experience and make sense of illness and care within the inpatient SPC setting may enable decision-makers and clinicians in such contexts to improve and individualize care offerings according to patient and caregiver needs.

Results from this thesis study will be shared with participants upon request, presented in local and international presentations and conferences, and published in an academic peer-reviewed journal.

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APPENDICES

Appendix A. Search strategy for Medline (via Ovid), CENTRAL (via Ovid), Cochrane's Database of Systematic Reviews (via Ovid, and Database of Abstracts of Reviews of Effects (DARE; via Ovid).

1. Palliative Care/
2. Terminally Ill/
3. exp Terminal Care/
4. Hospice Care/
5. palliat*.tw.
6. hospice*.tw.
7. (last year of life or LYOL).tw.
8. (terminal* adj3 (car* or ill* or diseas*)).tw.
9. (terminal-stage* or terminal stage* or dying or (close adj4 death)).tw.
10. (end* adj3 life).tw.
11. ((end-stage* or end stage* or incurable or advanced) adj5 (diseas* or ill* or care or cancer* or malignan*)).tw.
12. (dying adj3 (care or comfort or relief or strateg* or plan or intervention or pain)).tw.
13. or/1-12
14. Hospitalization/
15. Inpatients/
16. ((hospital* adj2 patient*) or (stay* adj3 hospital*) or "hospital patient*" or "hospitalised patient*" or "hospitalized patient*" or "inhospital patient*" or "in-hospital patient*").tw.
17. or/14-16
18. (experien* or perspective* or view* or comprehen* or perception* or understand* or opinion* or belief* or believ* or preference*).tw.
19. family/ or grandparents/ or nuclear family/ or exp parents/ or siblings/
20. (sibling* or sister* or brother*).tw.
21. Caregivers/
22. (famil* or mother or mothers or father or fathers or parent* or caregiver* or care giver* or carer*).tw.
23. (grandparent* or grandm* or grandfather* or grandpa*).tw.
24. (family adj1 member*).tw.
25. (substitute adj2 decision mak*).tw.
26. or/19-25

Appendix B. Grey literature search strategy and results for search conducted on February 24, 2021.

Database/ Organization (Abbreviation; Country)	**Website**	**Search terms (using Google as search engine)[a]**	**Number of records retrieved[b]**	**Number of records reviewed[b]**	**Number of relevant records**	**# of duplicate records**
Agency for Healthcare Research and Quality (AHRQ; United States)	https://www.ahrq.gov/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.ahrq.gov/	5	5	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.ahrq.gov	5	5	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.ahrq.gov	5	5	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:ahrq.gov	20	20	0	0
National Institute for Health and Care Excellence	https://www.nice.org.uk/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.nice.org.uk/	236	100	0	0

(NICE; United Kingdom)		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.nice.org.uk	205	100	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.nice.org.uk	229	100	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:nice.org.uk	208	100	0	0
Canadian Society of Palliative Care Physicians (CSPCP; Canada)	https://www.cspcp.ca/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.cspcp.ca/	0	0	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.cspcp.ca	0	0	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.cspcp.ca	0	0	0	0

		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:cspcp.ca	0	0	0	0
National Hospice and Palliative Care Organization (NHPCO; United States)	https://www.nhpco.org/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.nhpco.org/	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.nhpco.org	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.nhpco.org	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:nhpco.org	1	1	0	0
Canadian Hospice Palliative Care Association	https://www.chpca.ca/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.chpca.ca/	0	0	0	0

(CHPCA; Canada)		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.chpca.ca	0	0	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.chpca.ca	0	0	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:chpca.ca	0	0	0	0
Canadian Virtual Hospice (Canada)	https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx	0	0	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.virtualhospice.ca	5	5	0	0

		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.virtualhospice.ca	5	5	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:virtualhospice.ca	5	5	0	0
CareSearch (Australia)	https://www.caresearch.com.au/Caresearch/Default.aspx	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.caresearch.com.au/Caresearch/Default.aspx	0	0	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.caresearch.com.au	9	9	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.caresearch.com.au	9	9	0	0

		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:caresearch.com.au	9	9	0	0
Palliative Care Australia (Australia)	https://palliativecare.org.au/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://palliativecare.org.au/	3	3	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://palliativecare.org.au	3	3	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:palliativecare.org.au	3	3	0	0
All Ireland Institute of Hospice and Palliative Care (Ireland)	https://aiihpc.org/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://aiihpc.org/	1	1	0	0

		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://aiihpc.org	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:aiihpc.org	1	1	0	0
Pallium Canada (Canada)	https://www.pallium.ca/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.pallium.ca/	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.pallium.ca	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.pallium.ca	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:pallium.ca	2	2	0	0

Hospice Palliative Care Ontario (HPCO; Ontario, Canada)	https://www.hpco.ca/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.hpco.ca/	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://www.hpco.ca	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.hpco.ca	1	1	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:hpco.ca	1	1	0	0
ProQuest Dissertations & Theses Global[a] (International)	https://search-proquest-com.proxy.bib.uottawa.ca/pqdtglobal/index?accountid=14701	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life")	40070	100	2	0
OpenGrey (Europe)	http://www.opengrey.eu/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:http://www.opengrey.eu/	0	0	0	0

		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:http://www.opengrey.eu	0	0	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:www.opengrey.eu	0	0	0	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:opengrey.eu	0	0	0	0
WorldWideScience.org (International)	https://worldwidescience.org/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://worldwidescience.org/	2260	100	2	0
		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:https://worldwidescience.org	1910	100	1	1

		(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life") site:worldwidescience.org	1910	100	1	1
Google (using advanced search feature)	https://www.google.ca/	(patient or caregiver or carer or family or "family member") and (experience or perception or views or perspective) and (inpatient or hospital) and (palliative or "palliative care" or "end of life" or "end-of-life")	592000	100	6	4
		Total	**639130**	**1002**	**12**	**6**
		<u>Total screened at Level 2</u>				**6**

[a] ProQuest Dissertations & Theses Global was not searched using Google since access to this database was only available via institutional access through the University of Ottawa.

[b] In the event that there were more than 100 records retrieved from a search, only the first 100 were reviewed.

Appendix C. Interview guide for patients and informal caregivers.

Informed consent

The consent form details information about the study, including how the information you will be providing today in interview will be used in the study. [Review consent form, if not already reviewed and signed by participant]

Do you have any questions about the consent form or any of the information you received from me?

Background

During this interview, I would like to hear about your experiences on the palliative care unit at the Élisabeth Bruyère Hospital.

I know that everyone has slightly different experiences given that there are so many unique aspects of both your/your loved one's illness and the journey that led you here.

Given the distinctiveness of each individual's experiences, <u>there are no right or wrong answers</u>.

Audio recording

I will be audio-recording this interview.

> Any information that identifies you will be removed in order to maintain confidentiality. I might use quotes from your interview for reports that I will prepare as part of this study, but I will ensure that your name or other details that could trace your responses back to you will not be included.

Do you have any questions before I turn the audio-recorders on?

<u>Participant's understanding of illness/care on the palliative care unit</u>

1. Can you please tell me about your experience on the palliative care unit?
    a. Probe: What is your/your loved one's diagnosis?
    b. Probe: Where were you/was your loved one receiving care for your/their illness before you/they were admitted to the palliative care unit?
    c. Probe: Have you/your loved one previously received palliative care services before (e.g. hospital consultation services or community services)?

2. What was it like for you when you found out about your/your loved one's illness?
    a. Probe: How did you deal with this? Can you give me an example?

3. How have you come to understand your/your loved one's illness?
    a. Probe: How has your understanding changed over time?
    b. Probe: How has being here on the palliative care unit impacted your understanding of your/your loved one's illness?

4. How have you understood the care that is provided to you/your loved one here on the palliative care unit?
    a. Probe: What purpose do you think palliative care plays for your/your loved one's illness?
        i. Probe: Can you give me an example?

5. Dealing with a life-threatening illness can result in a lot of uncertainty. How have you managed this uncertainty?
    a. Probe: What have you done to address the unknown aspects related to your/your loved one's illness or care?
        i. Additional probe: Can you give me an example?
    b. Probe: How has this uncertainty affected decision-making in relation to your/your loved one's illness or care?

<u>Information or communication needs related to understanding illness and care on the palliative care unit</u>

6. What are some things that you had (or still have) questions about or wanted more information about your/your loved one's illness or care?
   [If patient/caregiver still has unanswered questions, ask if it is okay to let the attending physician know so that they may address these information needs]
    a. Probe: What did/do you want to know specifically about your/your loved one's illness or care?
    b. Probe: What were things you wanted to know about, but didn't ask or look into by yourself?

7. How have you managed your needs for information or knowledge throughout this journey with your/your loved one's illness?
    a. Probe: How have you addressed these needs here on the palliative care unit?
    b. Probe: How have these needs changed during your time here on the palliative care unit?
    c. Probe: What was your experience with addressing your needs for information or communication before you were here on the palliative care unit?

8. What information do you think would have made you feel more prepared for being on the palliative care unit as a patient/caregiver?
    a. Probe: How would this information have helped you?
    b. Probe: When would you have wanted this information?
    c. Probe: How would you suggest that this information be provided?

9. What would you change or improve on the palliative care unit to better address your needs for information about your/your loved one's care or illness or care?

Concluding questions

10. Is there anything else you would like to add to what we discussed today?
11. What did I not ask you that I should have asked?
12. If I have any other questions or need clarifications, can I contact you again?

Thank you very much for your willingness to open up to me about your experiences here on the palliative care unit. Your contributions will help me understand the needs for information that patients and their loved ones may have on the palliative care unit, as well as what can be done to help address these needs.

Please don't hesitate to get in touch with me if you wanted to ask me any questions or add anything you may not have already mentioned today.

Appendix D. Characteristics of studies (n=104) included in this scoping review.

Table 1. Characteristics of included quantitative articles (n=56).

Author (year)	**Publication type**	**Country**	**Setting**	**Sample (in inpatient specialist palliative care setting only)**	**Patients' medical diagnoses**	**Aim of study**	**Data collection method[a]**
Abbey, 2008[169]	Dissertation	United States	Hospital specialized in palliative care (n=1)	Patients (n=67), informal caregivers (family only; n=46)	Cancer	To examine cancer patients' desires to communicate about topics pertaining to the end of life with their family members, and the impacts of having such discussions	Questionnaires: • Patient-Family Illness Questionnaire • Beck Hopelessness Scale • Hospital Anxiety and Depression Scale • Chabot Pursuer-Distancer Movement Scale • McGill Quality of Life Questionnaire
Abesadze, 2009[137]	Conference abstract	Georgia	Inpatient palliative care unit (n=1)	Patients (n=346)	Cancer	To determine the frequency of information provision to cancer patients about their diagnosis and prognosis	Chart review
Addington-Hall, 2009[143]	Original research article	United Kingdom	Inpatient hospices, acute care hospitals (n's not reported)	Informal caregivers (family only; n=40)	Cancer	To compare bereaved family member perceptions of hospice inpatient care and hospital care	Postal questionnaire: • Views of Informal Carers – Evaluation of Services questionnaire
Ando, 2007[172]	Original research article	Japan	Inpatient palliative care unit (n=1)	Patients (n=12)	Cancer	To assess the efficacy of life review interviews on cancer patients' spiritual well-being and to compare patients who showed clinical benefits to those that did not	Questionnaires: • Overall Quality of Life score • Skalen zur Erfassung von Lebens qualitat bei Tumorkranken—Modified Version

Ando, 2010[167]	Original research article	Japan	Inpatient palliative care units (n=2)	Patients (intervention group: n=34, control group: n=34)	Cancer	To assess the efficacy of Short-Term Life Review on enhancing cancer patients' sense of meaning, and to examine the effects of this intervention on anxiety, depression, and elements of a good death	Questionnaires: • Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (Japanese version; Meaning of life domain) • Good Death Inventory (Hope, Burden, Life Completion, and Preparation for death domains) • Hospital Anxiety and Depression Scale (Japanese version)
Bainbridge, 2018[161]	Original research article	Canada	Residential hospices (n=22)	Informal caregivers (family only; n=1153)	Mixed (cancer and non-cancer)	To examine bereaved family caregiver perspectives on residential hospice patients' end-of-life care experiences across several settings	Survey: • CaregiverVoice survey (based on Views of Informal Carers—Evalution of Services questionnaire)
Carlsson, 2003[141]	Original research article	Sweden	Inpatient hospice (n=1), advanced palliative care team providing care at home (n=1)	Patients (n=69), informal caregivers (family only; n=45)	Cancer	To examine the differences between patients who died at home compared to those who died at an inpatient hospice, including sociodemographic variables, informal caregiver burden, and reasons for accessing hospice care	Chart review and questionnaire (Likert-style responses or dichotomized responses of Yes/No)
Carlsson, 2009[160]	Original research article	Sweden	Inpatient palliative care units providing home or institutional care (n=7)	Informal caregivers (family only; n=56)	Cancer	To understand fatigue experienced by family members of patients in palliative care settings	Questionnaires: • Multidimensional Fatigue Inventory-20 • Karolinska Sleep questionnaire

Casarett, 2010[157]	Conference abstract	United States	Acute care ward, intensive care unit, inpatient hospice unit, nursing home (n's not reported)	Informal caregivers (family only; n=3897)	Not reported	To examine the quality of care provided by palliative care teams across the health care system in the United States	Chart review for patient data and 14-item survey administered via telephone interview for informal caregiver perceptions of care
Choi, 2013[153]	Original research article	Korea	Inpatient palliative care unit (n=40)	Informal caregivers (family only; n=570)	Cancer	To ascertain the factors associated with the quality of death and dying in inpatient palliative care units for cancer patients with life-threatening illness, from the perspective of bereaved informal caregivers	Questionnaires: • Care Evaluation Scale • Good Death Inventory
Collette, 2014[184]	Conference abstract	Spain	Inpatient palliative care unit	Patients (n=38), informal caregivers (relationship not specified, n not reported)	Cancer	To assess the effect of an art therapy intervention in adult cancer patients receiving care from an inpatient palliative care unit, and their primary caregivers.	Single question of whether intervention helped patients and how
Ekeström, 2014[156]	Original research article	Sweden	Inpatient palliative care unit (n=1), general geriatric ward (n=1)	Informal caregivers (family only; pre-Liverpool Care Pathway, n=26; after Liverpool Care Pathway, n=23)	Not reported	To understand how family members experienced care in the patient's end-of-life care on a palliative care unit and a general geriatric ward before and after implementation of the Liverpool Care Pathway	Study-specific questionnaire designed based on the goals of the Liverpool Care Pathway
Frade, 2014[166]	Conference abstract	Portugal	Inpatient palliative care unit (n=1)	Informal caregivers (family only; n not reported)	Mixed (cancer and non-cancer)	To understand the key characteristics of informal caregivers in palliative care	Chart review; caregiver burden assessed using the following instruments: • ZARIT Burden Interview

							• Family Relationships Index
Hagerstown, 2014[159]	Conference abstract	United States	Inpatient palliative care unit (n=1), palliative care consult team (n=1)	Informal caregivers (family only; n=60)	Not reported	To compare bereaved family caregiver satisfaction with care, perceptions of the quality of care, and advantages or disadvantages to inpatient and consultative specialist palliative care	Telephone interviews (no other details provided)
Heaven, 1998[154]	Original research article	United Kingdom	Inpatient hospice (n=1)	Patients (n=87)	Cancer	To describe hospice inpatients' concerns, the level of their psychological distress, and the relationship between their concerns and psychological distress	Questionnaires administered via semi-structured interviews: • Concerns Checklist • Hospital Anxiety and Depression Scale • Spielberger State Anxiety questionnaire
Howard, 2014[165]	Original research article	United Kingdom	Inpatient specialist palliative care units (n=2)	Patients (n=77), informal caregivers (family only; n=51)	Not reported	To understand patient and family caregiver preferences of single or shared rooms	Questionnaire survey on preferences of single or shared rooms (no validated instruments used)
Hudson, 2011[133]	Conference abstract	Australia	Inpatient specialist palliative care units (n=4)	Informal caregivers (family only; n=126)	Not reported	To assess the effectiveness of a psycho-educational group programme created to prepare family caregivers for supporting patients receiving inpatient palliative care	Questionnaires: • Family Inventory of Needs • Preparedness for Caregiving Scale • Caregiver Competence Scale • General Health Questionnaire
Hudson, 2012[134]	Original research article	Australia	Inpatient specialist palliative care units (n=5)	Informal caregivers (family only; n=126)	Not reported	To assess the effectiveness of a psycho-educational group programme created to prepare family members for supporting	Questionnaires: • Family Inventory of Needs

						patients receiving inpatient palliative care	• Preparedness for Caregiving Scale • Caregiver Competence Scale • General Health Questionnaire
Jasinska, 2010[136]	Original research article	Poland	Inpatient palliative care unit (n=1)	Patients (n=41)	Cancer	To determine the effectiveness of palliative care for patients receiving inpatient palliative oncological, end-of-life care for the most common cancers (lung, breast, colon, or prostate)	Questionnaire completed by patients every week during the study: • Core Quality of Life Questionnaire
Jho, 2015[148]	Original research article	Korea	Inpatient hospice palliative care units (n=40)	Informal caregivers (family only; n=383)	Cancer	To understand bereaved family caregiver perceptions of the timeliness of referral to an inpatient hospice palliative care unit, and associated factors	Questionnaire: • Question on timeliness of referral • Good Death Inventory
Jihyeon, 2017[150]	Original research article	Korea	Inpatient hospice palliative care units (n=4)	Informal caregivers (family only; n=101)	Not reported	To examine bereaved family caregivers' experiences of care and associated needs, as well as the relationship between unmet needs and care burdens for informal caregivers of inpatient hospice patients	Questionnaires: • Comprehensive Needs Assessment Tool for Cancer-Caregivers • Burden-of-care tool
Kirk, 2004[15]	Original research article	United Kingdom	Inpatient hospices (n=2)	Patients (n=24)	Not reported	To understand hospice patients' preferences of single or shared rooms, and factors that may impact a change in these preferences	Structured interview
Kristjanson, 1996[55]	Original research article	Canada	Inpatient palliative care unit (n=1)	Patients (n=36), informal caregivers (family only; n=80)	Cancer	To examine variables that may contribute to family caregivers' satisfaction with care, and to identify variables that predict informal caregivers' health and family functioning pre- and post-bereavement	Questionnaires: • Patients: ○ Symptom Distress Scale ○ Quality of Life Scale • Family members: ○ Family Inventory of Needs

							○ F-Care Expectations Scale ○ F-Care Perceptions Scale ○ FAMCARE Scale ○ Self-Report Family Inventory ○ Symptoms of Stress Inventory
Kühnel, 2020[164]	Original research article	Germany	Inpatient palliative care unit (n=1)	Informal caregivers (family and friends; intervention group: n=75, control group: n=82)	Mixed (cancer and non-cancer)	To assess the effectiveness of shortened existential behavioural therapy compared to a non-directive psychological intervention (control) using a randomised controlled trial study design	Questionnaires: - General Anxiety Disorder Questionnaire - Distress Thermometer - General Health Questionnaire - Positive and Negative Affect Schedule - Satisfaction with Life Scale - World Health Organization Quality of Life Questionnaire
Kyung-Ah, 2020[152]	Original research article	Korea	Inpatient national hospice institutions (n=4)	Patients (n=226), Informal caregivers (family only; n=219)	Cancer	To determine the sociodemographic, disease, and spiritual needs-related characteristics of cancer patients and their family members, and to determine differences between and factors that influence scores on the Spiritual Interests Related to Illness Tool	Questionnaire: - Spiritual Interests Related to Illness Tool
Le Fevre, 1999[174]	Original research article	United Kingdom	Inpatient hospice (n=1)	Patients (n=79)	Mixed	To compare the screening performance of the Hospital Anxiety and Depression Scale and General Health Questionnaire	Questionnaires followed by psychiatric interviews: - Hospital Anxiety and Depression Scale

							- General Health Questionnaire - Semi-structured psychiatric interview using Revised Clinical Interview Schedule
Lin, 2000[145]	Original research article	Taiwan	Inpatient palliative care units (n=2)	Informal caregivers (family only; n=80)	Cancer	To identify Taiwanese family caregiver attitudes that were barriers to cancer pain management, and to determine how these barriers impacted informal caregiver hesitancy to report pain and administer analgesics, and adequacy of analgesics used by patients	Questionnaire: - Barriers Questionnaire-Taiwan
Loh, 2006[146]	Original research article	Malaysia	Community palliative care ward (n=1)	Patients (n=30), informal caregivers (family only; n=30)	Cancer	To collect information from patients to enable the team to improve their efforts in delivering holistic end-of-life care	Survey on patients' and informal caregivers' views of the care they received in four major areas: physical, psychological, social and spiritual
McClain, 2003[175]	Original research article	United States	Palliative care hospital (n=1)	Patients (n=160)	Cancer	To examine the relationship between spiritual well-being and end-of-life despair in terminally ill cancer patients	Standardized questionnaires administered via interview: - Functional Assessment of Chronic Illness Therapy—Spiritual well-being scale - Hamilton Depression Rating Scale - Beck Hopelessness Scale - Schedule of Attitudes toward Hastened Death - Duke-UNC Functional Social Support Questionnaire
Miyashita, 2008[139]	Original research article	Japan	Inpatient palliative care unit	Patients (n=165); informal	Cancer	To compare between inpatient palliative care units and general wards in the achievement of a	Medical chart review (for patients) and questionnaire for informal caregivers:

			(n=1), General wards (n not reported)	caregivers (family only; n=165)		good death, and to explore patient and family caregiver factors that may contribute to a good death from the bereaved informal caregiver perspective	• Good Death Inventory
Miyashita, 2015[140]	Original research article	Japan	Designated cancer centres (n=56), inpatient palliative care units (n=100), home hospices (n=14)	Informal caregivers (family only; n=5312)	Cancer	To understand bereaved family member perspectives on end-of-life cancer care in designated cancer centres, inpatient palliative care units, and home hospices in Japan, with a focus on care satisfaction and achievement of a good death	Questionnaire: • Good Death Inventory
Mori, 2018[151]	Conference abstract	Japan	Inpatient hospices (n=71)	Informal caregivers (family only; n=818)	Cancer	To understand bereaved family members' perceptions of improvements needed in discussions about patients' impending death, and associated factors	Survey on families' experiences of discussions pertaining to impending death from inpatient hospice care teams, and the need for improvements in these discussions
Mori, 2018[170]	Original research article	Japan	Inpatient palliative care units and inpatient hospices (n=71; n's for each setting not reported)	Informal caregivers (family only; n=513)	Cancer	To understand bereaved family members' perceptions of improvements needed in discussions about patients' impending death, and associated factors (e.g., timing of discussion)	Questionnaire survey developed by the authors based on a systematic literature review and discussions among the authors
Morita, 2002[176]	Original research article	Japan	Inpatient palliative care units (n=37)	Informal caregivers (family only; n=640)	Not reported	To understand advanced cancer patient experiences of hope using a hope assessment framework	Questionnaire: • Satisfaction scale for Family members receiving Inpatient Palliative Care

Morita, 2004[178]	Original research article	Japan	Inpatient palliative care units (n=7)	Informal caregivers (family only; n=185)	Cancer	To explore family members' experiences and evaluation of palliative sedation, and factors influencing their evaluations	Questionnaire survey developed by the authors based on a literature review, in-depth interviews with bereaved family members, and preliminary questionnaire surveys of bereaved family members
Morita, 2006[177]	Original research article	Japan	Inpatient palliative care units (n=12), other institutions (n not reported), home care (n not reported)	Informal caregivers (family only; n=548)	Cancer	To understand bereaved family members' knowledge and beliefs related to legal options, pain medications, communication with members of the care team, and hydration or nutrition at the end of life; and to examine the association between the end-of-life care patients experience and their beliefs based on reports from their family members	Questionnaire survey developed by the authors based on a literature review and discussions among the authors
Oechsle, 2013[131]	Original research article	Germany	Inpatient palliative care unit (n=1)	Patients (n=33), informal caregivers (family and friends; n=33)	Cancer	To examine the prevalence of anxiety and depression in the informal caregivers of cancer patients, and assess influential factors for anxiety and depression	Self-report questionnaires. Patients: • Single-question regarding their subjective overall condition on a five-grade scale Informal caregivers: • General Anxiety Disorder scale (German version) • Patient Health Questionnaire (German version) • Single question regarding the patient's subjective overall condition on a five-grade scale

Oechsle, 2018[158]	Conference abstract	Germany	Inpatient palliative care units (n=2)	Informal caregivers (relationship not specified; n=232)	Cancer	To explore the supportive care needs of family caregivers for advanced cancer patients, and the association of these needs with psychosocial distress, anxiety, and depression	Questionnaires: • Family Inventory of Needs • Distress Thermometer • General Anxiety Disorder scale • Patient Health Questionnaire
Oechsle, 2019[53]	Original research article	Germany	Specialist inpatient palliative care wards (n=2)	Informal caregivers (family and friends; n=232)	Cancer	To identify distress, depressive and anxiety symptoms in informal caregivers of advanced cancer patients, and to identify factors associated with mental burden	Questionnaires: • Distress Thermometer (German version) • General Anxiety Disorder (German version) • Patient Health Questionnaire (Depression module; German version) • Family Carer Satisfaction with Palliative Care scale (German version) • Integrated Palliative Care Outcome Scale (German version)
Ong, 2016[135]	Original research article	United States	Inpatient hospice (n=1), home hospice care (n=1)	Informal caregivers (family only; n=368)	Mixed	To understand the elements of hospice care that are linked to greater overall family satisfaction, and to determine whether the correlates of family satisfaction with care vary by care setting	Questionnaire: • Family Evaluation of Hospice Care
Parkes, 1979[180]	Original research article	United Kingdom	Inpatient hospice (n=1), other hospitals (n not reported)	Informal caregivers (family only; n=34)	Cancer	To describe surviving spouses' self-reported experiences of inpatient care at St Christopher's Hospice and other hospitals nearby	Standard interview schedule and questionnaires: • Checklist of 6 common accompaniments of anxiety • "Worry Score"

							• Checklist of symptoms and features of emotional reaction to bereavement
Parkes, 1984[181]	Original research article	United Kingdom	Inpatient hospice (n=1), other hospitals (n not reported)	Informal caregivers (family only; 1967-69: n=227, 1977-79: n=164)	Cancer	To assess changes of inpatient care at St Christopher's Hospice and other hospitals nearby over a period of 10 years since 1969	Semi-structured interviews (results were presented as quantitative summaries with p-values)
Peters, 2006[132]	Original research article	Australia	Inpatient palliative care centres (n=3) and home-based palliative care services (n=4)	Patients (inpatients: n=32, home-based care recipients: n=26)	Cancer	To compare between inpatient and home-based palliative care services in cancer patients' symptom experience, physical and psychological health status, level of personal control over illness, and quality of life; and to examine factors that are associated with patient quality of life	Medical checklist and questionnaire administered by personal interview: • European Organization for the Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire • Hospital Anxiety and Depression Scale • 3 single-item scales (control over daily symptoms, control over the course of the illness, control over medical care and treatment)
Rokach, 2007[182]	Original research article	Israel	Inpatient oncological hospice (n=1)	Patients (n=37), informal caregivers (relationship not specified; n=78)	Cancer	To understand how changing life circumstances affect patients in coping with the loneliness of dying and their informal caregivers	Questionnaire: • The Loneliness Questionnaire
Roza, 2014[149]	Conference abstract	United States	Inpatient palliative care unit (n=1), palliative	Informal caregivers (family only; inpatients: n=30;	Not reported	To assess the impact of an inpatient palliative care unit with a palliative care consultation service on quality	Questionnaire administered via telephone interview: • Bereaved Family Survey

			care consultation service (n=1)	consultation service: n=30)		of care at a tertiary care hospital	
Roza, 2015[168]	Original research article	United States	Inpatient palliative care unit (n=1), palliative care consultation service (n=1), usual hospital care (n=1)	Informal caregivers (family only; inpatient palliative care unit: n=31, palliative care consultation service: n=28, usual hospital care: n=49)	Mixed	To determine the impact of an inpatient palliative care unit on bereaved family members' perceptions of quality of end-of-life care at a tertiary care hospital	Questionnaire administered via telephone interview: • Bereaved Family Survey
Sandsdalen, 2016[183]	Original research article	Norway	Inpatient hospices (n=2), hospice day-care centres (n=2), palliative units in nursing homes (n=2), home care districts (n=2)	Patients (inpatient hospice: n=72, hospice day care: n=51, palliative units in nursing homes: n=30, home care: n=38)	Mixed	To assess and compare patients' perceptions of the quality of palliative care within various settings, including perceptions of care received and their subjective importance	Questionnaires (self-reported or administered via interview): • Quality from the Patient's Perspective instrument • EQ VAS from the EQ-5D-3 L questionnaire by the EuroQOL group • The Sense of Coherence scale
Sanjo, 2008[163]	Original research article	Japan	Inpatient palliative care units (n=12)	Informal caregivers (family only; n=513)	Not reported	To assess bereaved family members' and the Japanese general populations' awareness and perceptions of inpatient palliative care units, compare between these two groups, and explore the association between bereaved family members' perceptions of inpatient palliative care units	Questionnaire developed using a literature review, expert consensus among authors, and based on a previous study

						and overall satisfaction with care	
Sato, 2017[147]	Original research article	Japan	Inpatient palliative care units (n=95)	Informal caregivers (family only; n=407)	Cancer	To examine bereaved family members' perceptions of available and preferred places of care, perspectives on the contributions of quality of care to enabling patients to experience a comfortable end of life and good death, and reasons for patients preferring to live at home but not being able to do so	Questionnaire (no details provided)
Seow, 2017[179]	Original research article	Canada	Homecare organizations (n=6), residential hospices (n=16)	Informal caregivers (family only; hospice: n=576; homecare: n=330)	Mixed	To validate the CaregiverVoice questionnaire across hospice, homecare, and hospital settings	Questionnaire: • CaregiverVoice Survey
Serpentini, 2010[144]	Conference abstract	Italy	Inpatient palliative care unit (n=1)	Patients (n=290)	Cancer	To psychologically evaluate cancer patients' condition upon admission to the inpatient palliative care unit	Evaluation administered via semi-structured interview
Shen, 2018[171]	Original research article	Taiwan	Inpatient oncology palliative care unit (n=1), intensive care units (n=6)	Informal caregivers (family and others; palliative care unit: n=41; intensive care unit: n=31)	Cancer	To assess and compare family experiences of palliative sedation therapy use in specialized palliative care units and intensive care units	Questionnaires: • Family Concerns about Palliative Sedation Therapy instrument • Texas Revised Inventory of Grief
Stajduhar, 2017[142]	Original research article	Canada	Inpatient palliative care units (n=2), extended care	Informal caregivers (family only, n=155)	Mixed	To understand bereaved family members' perceptions of the quality of end-of-life care based on the place of patients' death	Questionnaires: • Canadian Health Care Evaluation Project Instrument

			units (n=3), intensive care units (n=2), medical care units (n=3)				• Texas Revised Inventory of Grief • Life Orientation Test • Resilience scale
Tu, 2007[155]	Original research article	Taiwan	Inpatient hospice (n=1)	Patients (n=58), informal caregivers (n=58)	Cancer	To examine patients' and their family caregivers' ratings of the patient's life satisfaction and global pain, and to assess whether culture is a factor in these ratings	Questionnaire developed by authors based on literature review, and administered via interview
Ullrich, 2018[162]	Conference abstract	Germany	Specialist inpatient palliative care wards (n not reported)	Informal caregivers (family only; n=226)	Cancer	To assess the comorbidity of distress and psychological issues, and other influential factors, among family caregivers of advanced cancer patients receiving care from an inpatient specialist palliative care ward	Questionnaires: • Distress Thermometer • General Anxiety Disorder scale • Patient Health Questionnaire (Depression module)
Ullrich, 2021[138]	Original research article	Germany	Specialist inpatient palliative care wards (n=2)	Informal caregivers (family only; n=232)	Cancer	To examine family caregivers' perceptions of the importance and satisfaction of their needs upon the patients' initial receipt of specialist inpatient palliative care, near the patients' death, and throughout bereavement; to identify factors associated with important and needs that were addressed; and to assess family caregivers' use of psychosocial and bereavement supports	Questionnaires: • Family Inventory of Needs • The Distress Thermometer • Patient Health Questionnaire (Depression module) • General Anxiety Disorder scale • Integrated Palliative Care Outcome Scale • Family Carer Satisfaction with Palliative Care scale

[a] This table only includes data collection methods that provided information on patient/informal caregiver experience. Thus, symptom assessment screening tools (e.g., Edmonton Symptom Assessment System) with a focus on patient symptoms completed at a single point in time were not included.

Table 2. Characteristics of included mixed methods studies (n=11).

Author (year)	**Publication type**	**Country**	**Setting**	**Sample (in inpatient specialist palliative care setting only)**	**Patients' medical diagnoses**	**Aim of study**	**Data collection method**[a]
Cornish, 2020[222]	Original research article	United Kingdom	Inpatient hospice units (n=2)	Patients (n=5), informal caregivers (family only; n=5)	Not reported	To examine patient, family and staff perceptions of wound care by non-registered nursing staff in an inpatient hospice	Interviews, questionnaires (no details provided), and observations
Forbat, 2018[226]	Original research article	Australia	Palliative care inpatient ward (n=1)	Informal caregivers (family and friends; Interviews: n=13, CARE measure: n=47, Family Inventory of Need: n=64)	Mixed	To understand relational empathy as an outcome of regular family meetings in the context of a palliative care inpatient ward	Interviews and pre-post self-reported questionnaires: • CARE measure • Family Inventory of Need
Guo, 2017[223]	Original research article	Canada	Inpatient palliative care unit (n=1)	Patients (n=13), informal caregivers (family and friends; n=38)	Mixed	To assess the feasibility of palliative care inpatients use of internet-based communication and information technologies, and patient, informal caregiver and health care provider experiences with these technologies	Interviews and scales: • Blessed Orientation-Memory-Concentration test • Self-rated quality of life and satisfaction with quality of life on a scale • UCLA Loneliness Scale • Multidimensional Scale of Perceived Social Support

Kerr, 2014[229]	Original research article	United States	Inpatient hospice (n=1)	Patients (n=59)	Mixed	To describe end-of-life dream and vision experiences in hospice patients approaching the end of life; to assess the content and significance of end-of-life dreams and visions; and to examine the prevalence, content and significance of end-of-life experiences over time until the patient's death	Semi-structured interviews with closed and open-ended questions
Kim, 2021[230]	Original research article	Canada	Inpatient palliative care unit (n=1)	Informal caregivers (relationship not specified, n=19)	Mixed	To describe information needs of informal caregivers of inpatients at a palliative care unit during COVID-19 visitation restrictions	Telephone survey developed by the authors
Parkes, 1979[228]	Original research article	United Kingdom	Inpatient hospice (n=1), other hospitals (n not specified)	Informal caregivers (family only; n=34)	Cancer	To assess the impacts of inpatient care at the St Christopher's Hospice with a matched cohort of patients dying in other local hospitals from the spouse's perspective	Systematic and semi-structured interviews
Payne, 1996[224]	Original research article	United Kingdom	Inpatient palliative care unit (n=1)	Patients (n=67)	Cancer	To examine the impact of patients' deaths on other patients' anxiety and depression, perceived distress and/or reassurance; and to understand patients' awareness of impending death	Semi-structured interview, scale, and checklist: • Hospital Anxiety Depression Scale • Events Checklist
Seale, 1997[221]	Original research article	United Kingdom	Inpatient hospice (n=1), other hospitals (n not specified)	Informal caregivers (family only; n=33)	Cancer	To assess the quality of care for inpatients in St Christopher's Hospice and nearby hospitals from the spouse's perspective, and compare with earlier studies in the same setting	Structured interviews using fixed choice items and open questions
Seamark, 1998[227]	Original research article	United Kingdom	Inpatient hospice (n=1), other	Informal caregivers	Cancer	To evaluate the perceptions of the closest lay caregivers of cancer inpatients in community	Structured interview, or questionnaire based on interview proforma

			hospitals (n not specified)	(family and others; n=70)		hospitals compared to an inpatient hospice	
Skilbeck, 2005[220]	Original research article	United Kingdom	Inpatient hospice respite unit (n=1)	Informal caregivers (family only; n=25)	Mixed	To describe family caregivers' expectations and experiences of respite services from one inpatient hospice unit, particularly with respect to caring for their relative, their understanding of respite services, and the receipt of respite care	Interviews and Likert scale: • Resilience Stress Scale Inventory
Taylor, 2013[225]	Original research article	New Zealand	Inpatient hospice (n=1)	Patients (n=34), informal caregivers (family only; n=32)	Not reported	To understand patients' and family caregivers' perspectives about spiritual assessments conducted by nurses	Questionnaire: • Spiritual Assessment Questionnaire (created by study team from literature review)

[a] This table only includes data collection methods that provided information on patient/informal caregiver experience. Thus, symptom assessment screening tools (e.g., Edmonton Symptom Assessment System) with a focus on patient symptoms completed at a single point in time were not included.

Table 3. Characteristics of included qualitative (n=36) and autobiographical (n=1) studies.

Author (year)	**Publication type**	**Country**	**Setting**	**Sample (in inpatient specialist**	**Patients' medical diagnoses**	**Aim of study**	**Data collection method[a]**

				palliative care setting only)			
Andruccioli, 2007[210]	Original research article	Italy	Inpatient hospices (n=2)	Patients (n=100), informal caregivers (family only, n not reported)	Cancer	To assess patients’ awareness about their diagnosis and prognosis, and family members’ and hospital staffs’ perceptions of patient awareness	Semi-structured interviews, which were used by psychologists to complete a questionnaire
Andruccioli, 2012[192]	Original research article	Italy	Inpatient hospice (n=1)	Informal caregivers (family only, n=24)	Not reported	To understand how caregivers manage the death representation of hospice inpatients	Semi-structured interviews
Bainbridge, 2018[213]	Original research article	Canada	Residential hospices (n=16)	Informal caregivers (family and others; n=550)	Mixed	To examine patients’ end-of-life care experiences across a range of palliative care settings from the perspective of bereaved informal caregivers	Survey with open-text questions and questionnaire: • CaregiverVoice Survey
Bascioni, 2014[187]	Conference abstract	Italy	Inpatient hospice (n=1)	Informal caregivers (family only; n=63)	Cancer	To understand family caregivers’ attitudes towards patients’ enrolment in inpatient hospice care	Semi-structured telephone interviews
Bolton, 2016[203]	Original research article	New Zealand	Inpatient hospice unit (n=1)	Informal caregivers (family only; n=10)	Non-cancer	To describe experiences of care within an inpatient hospice unit for patients with dementia, delirium and cognitive impairment, from the perspective of family carers	Interviews
Broom, 2011[214]	Original research article	Australia	Inpatient hospice (n=1)	Patients (n=20)	Not reported	To examine patients’ experiences of care delivered in an inpatient hospice	Interviews
Broom, 2012[202]	Original research article	Australia	Inpatient hospice (n=1)	Patients (n=20)	Not reported	To explore patient’s experiences of care delivered in an inpatient hospice, and the resources available for dying in hospice	Interviews

Broom, 2013[205]	Original research article	Australia	Inpatient hospice (n=1)	Patients (n=20)	Not reported	To examine patients' perspectives and experiences in the end-of-life, including those related to their families	Interviews
Chapple, 2011[193]	Original research article	United Kingdom	Inpatient hospices (n not specified), among other care settings	Patients (n=32), informal caregivers (family only; n=8)	Cancer	To explore patient preferences for end-of-life care and death at home, hospice, nursing home or hospital, and associated decision-making processes	Semi-structured interviews
Frank, 2014[231]	Auto-biographical article	Canada	Oncology unit with dedicated palliative care beds (n=1)	Patient (n=1), informal caregivers (family only, n=2)	Cancer	To share the author's observations of their mother's experiences in a dedicated palliative care bed in an oncology unit	Autobiographical account
Gourdji, 2009[188]	Original research article	Canada	Inpatient palliative care unit (n=1)	Patients (n=10)	Cancer	To describe the meaning of a quality life from the perspective of patients receiving care on an inpatient palliative care unit	Open-ended, unstructured interviews
Grothe, 2015[191]	Original research article	Norway	Inpatient palliative care unit (n=1)	Informal caregivers (family only; n=6)	Not reported	To explore relatives' lived experiences of care delivered in an inpatient palliative care unit	Unstructured interviews
Guo, 2016[209]	Original research article	Canada	Inpatient palliative care unit (n=1)	Patients (n=2), informal caregivers (family only; n=7)	Not reported	To assess the acceptability of internet-based communication and information technologies for patients receiving care on an inpatient palliative care unit	Focus groups, interviews, and drop-in consultations
Hong, 2012[208]	Original research article	Singapore	Inpatient hospice (n=1)	Patients (n=15)	Cancer	To describe and interpret the lived experiences of older Singaporean Chinese patients with life-threatening illnesses who were receiving palliative care in an inpatient hospice	Interviews

Kehl, 2009[46]	Original research article	United States	Inpatient hospice facility (n=1), skilled nursing facility (n=1), managed care community support program (n=1)	Informal caregivers (family only; n=10)	Not reported	To explore the challenges experienced by family caregivers of patients receiving end-of-life care in three settings	Semi-structured interviews using questions from the Family Interview Guide
Kristjanson, 1986[186]	Original research article	Canada	Inpatient palliative care unit (n=1)	Informal caregivers (family only; n=33)	Not reported	To examine indicators perceived to be helpful or not helpful in the care of cancer patients and their family caregivers, from the perspective of family caregivers	Face-to-face group interviews
Mak, 2001[212]	Original research article	China	Inpatient hospice (n=1)	Patients (n=33)	Cancer	To understand the meaning of a good death from the perspectives of Chinese patients receiving inpatient hospice care	Semi-structured interviews
Masel, 2016[219]	Original research article	Austria	Inpatient palliative care unit (n=1)	Patients (n=20)	Cancer	To describe patients' knowledge of palliative care, their needs and expectations, and concept of a good palliative care physician within the context of a palliative care unit	Semi-structured interviews
McClement, 2003[197]	Original research article	Canada	Inpatient palliative care unit (n=1)	Patients (n=13), informal caregivers (family members; n=23)	Cancer	To contribute to theory development on describing the social processes associated with family interactions with patients and health care providers regarding nutritional	Semi-structured interviews and participant observation

						care in an inpatient palliative care unit	
McPherson, 2018[215]	Original research article	Scotland	Hospice inpatient unit (n=1)	Informal caregivers (family only; n=10)	Not reported	To describe informal caregivers' perspectives of their role in providing personal care to a family member during their stay in a hospice inpatient unit	Interviews
McPherson, 2020[185]	Original research article	Scotland	Hospice inpatient unit (n=1)	Informal caregivers (family only; n=10)	Not reported	To understand informal caregivers' views, attitudes, and preferences regarding providing personal care to a family member during their stay in a hospice inpatient unit	Interviews
Mossin, 2011[200]	Original research article	Norway	Inpatient oncology/ palliative ward (n=1)	Informal caregivers (family only; n=8)	Cancer	To describe spouses' experiences of their presence on an inpatient oncology/palliative ward during patients' last days before death	Interviews
Needham, 2004[190]	Original research article	United Kingdom	Hospice inpatient unit (n=1)	Patients (n=97), informal caregivers (relationship not specified; n=74)	Not reported	To explore patient and carer goals for admission to a hospice inpatient unit, measure outcomes of goals on discharge or death, and identify where goals had differed between patients, carers and staff	Audit forms placed in patient charts
Niedzielski, 2016[194]	Original research article	Canada	Residential hospice (n=1)	Patients (n=4), informal caregivers (relationship not specified; n=4)	Cancer	To understand the ambient and sensory experiences of a residential hospice, and to identify methods of improving these experiences	Observations and semi-structured interviews
Norman, 2001[201]	Original research article	Canada	Inpatient palliative	Patients (n=25)	Cancer	To examine factors that impact the integrity of patients' relationships with their family	Semi-structured interviews

			care wards (n=2)			physicians, and to determine their perceptions of their family physicians' roles in their care during their time on the inpatient palliative care ward	
Ohnsorge, 2012[211]	Original research article	Switzerland	Inpatient hospice (n=1)	Patients (n=2), informal caregivers (family only; n=2)	Cancer	To understand patients' experiences on an inpatient hospice and meaning-making at the end of life, along with nurses' roles in these processes	Semi-structured interviews
Payne, 1996[216]	Original research article	United Kingdom	Inpatient palliative care unit (n=1)	Patients (n=18)	Cancer	To examine patients' and palliative care professionals' perspectives on death	Semi-structured interviews
Phillips, 2018[199]	Conference abstract	Australia	Inpatient palliative care unit (n=1)	Patients (n=19)	Not reported	To determine whether palliative care inpatients are concerned about the bereavement needs of individuals other than their families; and to assess the feasibility, acceptability, safety, and practicability of prospective bereavement follow-up conversations for patients approaching the end of life	Semi-structured interviews
Pommeret, 2019[196]	Original research article	France	Inpatient palliative care unit (n=1)	Patients (n=10)	Cancer	To understand the patients' experiences of a musical intervention on an inpatient palliative care unit	Interviews
Rhondali, 2014[207]	Original research article	France	Inpatient palliative care unit (n=1)	Informal caregivers (family only; n=15)	Cancer	To examine caregivers' perceptions of depression and the role they envision in the management of the patients' illness	Interviews

Rocha, 2018[206]	Original research article	Brazil	Inpatient palliative care unit (n=1)	Informal caregivers (family only; n=20)	Cancer	To explore the spiritual needs of family caregivers of cancer patients receiving palliative care	Interviews
Shiozaki, 2005[217]	Original research article	Japan	Inpatient palliative care units (n not reported)	Informal caregivers (family only, n=22)	Not reported	To determine the reasons for dissatisfaction with inpatient palliative care from the perspective of bereaved family caregivers	Interviews
Spencer, 2018[189]	Conference abstract	United Kingdom	Inpatient hospices (n=2)	Patients (n not reported), informal caregivers (relationship not specified; n not reported)	Not reported	To assess the acceptability of a prognostic tool to patients, caregivers, and palliative care professionals, and to determine any barriers or facilitators for its use	Semi-structured interviews
Thomas, 2001[195]	Original research article	United Kingdom	Inpatient palliative care unit (n=1)	Patients (n=6)	Cancer	To describe six patients' experiences of visitation	Semi-structured interviews
Ullrich, 2017[198]	Conference abstract	Germany	Inpatient palliative care unit (n=1)	Patients (n=12), informal caregivers (family only; n=10)	Not reported	To identify benefits and challenges associated with multiprofessional teamwork in specialized inpatient palliative care from the perspective of patients, family caregivers, and multidisciplinary team members	Semi-structured interviews
Ullrich, 2018[204]	Conference abstract	Germany	Specialist inpatient palliative care ward (n=1)	Patients (n=12), informal caregivers (relationship not specified; n=10)	Not reported	To explore patients', informal caregivers', and multidisciplinary team members' perceptions on specific professions' roles	Interviews

Wentlandt, 2016[218]	Original research article	Canada	Specialized palliative care units (n=4)	Patients (n=23), informal caregivers (relationship not specified; n=23)	Cancer	To examine inpatients', informal caregivers', and health care professionals' perspectives on quality of care and patient satisfaction in inpatient palliative care units.	Interviews and focus groups

[a] This table only includes data collection methods that provided information on patient/informal caregiver experience. Thus, symptom assessment screening tools (e.g., Edmonton Symptom Assessment System) with a focus on patient symptoms completed at a single point in time were not included.