

**THE DEVELOPMENT OF AN END-OF-LIFE GUIDE FOR COMMUNITY-DWELLING
CLIENTS DIAGNOSED WITH ADVANCED CANCER**

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Abstract

BACKGROUND: Advance care planning [ACP] is essential to providing quality end-of-life [EOL] care and promoting the wishes, values, and goals of patients diagnosed with advanced cancer. A lack of community-specific ACP resources, such as guidebooks or EOL resources, was identified as a need for patients diagnosed with advanced cancer through a literature review and by the Palliative Care Community Team [PCCT] in Northumberland County, Ontario.

PURPOSE: The practicum project aimed to develop a community-specific ACP resource to assist patients whom the PCCT supports in ACP discussions.

METHODS: Three methods were used to collect information for this project. Initially, a literature review was conducted to determine the benefits, impacts, and implications of ACP resources for patients. An environmental scan was then performed to determine the currently available resources. Finally, consultations were conducted with palliative care stakeholders to determine what the community would find necessary for inclusion in the resource.

RESULTS: The literature review determined that ACP discussions positively impact quality of life, ensure EOL care is a priority, and that ACP is completed appropriately. The environmental scan showed that resources are available, but the information included was irrelevant to the patients the PCCT supports. Consultations with key palliative care stakeholders in the community were done to determine what information should be included in a resource guide for patients diagnosed with advanced cancer and supported by the PCCT.

CONCLUSION: The need for a community-specific ACP resource was identified, and an ACP guide for patients was developed based on the community's needs. The developed guide will

assist patients diagnosed with advanced cancer in talking about ACP, preparing their families for after their death, and assisting in maintaining quality of life.

KEYWORDS: *Advance Care Planning, End-of-life, Quality of Life, Palliative Care Community Team*

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Introduction

The early integration of palliative care [PC] in oncology care improves quality of life [QOL], reduces depression symptoms, and enhances coping with prognosis and communication of end-of-life [EOL] (Temel et al., 2017). Advanced care planning [ACP] is a process that supports anyone at any age or stage of health to understand and share their personal values, goals, and preferences for when they lose the capacity to make decisions for themselves (Howard et al., 2022) and is an essential part of PC (Advance Care Planning Canada, 2016). ACP aims to prepare caregivers for the patient's wishes, and it should be delivered to ensure optimal patient outcomes and improved QOL (Hui & Bruera, 2016).

As the number of patients diagnosed with advanced cancer increases, the number of resources available also increases. However, most are not relevant to patients who are already diagnosed with advanced cancer. The need for a resource guide for patients diagnosed with advanced cancer has been identified as a need for the Palliative Care Community Team [PCCT] that supports patients diagnosed with advanced cancer in Northumberland County, Ontario, Canada. A resource guide that assists patients in speaking with their families about their ACP wishes, goals, and preferences, as well as planning and communicating wishes, has been identified as a priority. The resource also ensures that all patients receive information and guidance on what they feel is essential to complete and are guided through their disease trajectory. The objective of the practicum project was to identify the need for an advance care planning resource in the workplace and support the need for a resource in the community through reviewing the literature, scanning the environment, and consultations with appropriate stakeholders. Through the creation of the ACP resource, the focus on what is essential for my

patients and families to support them through their EOL journey was identified and attempts to ensure ACP discussions occur early in the disease trajectory.

Objectives

The practicum project aimed to develop an ACP resource for patients diagnosed with advanced cancer whom the PCCT supports. The resource will assist clients in preparing ACP as their disease progresses, guide them through what to expect for EOL, and encourage them to complete tasks that are typically done after death. The resource will ensure the clients can provide their families with information that will assist them in completing post-death tasks and make the bereavement period slightly easier. The guide was developed to give patients peace of mind, allowing their families to feel supported and feel they have contributed to easing the post-death tasks and bereavement period.

The key practicum objectives are:

- To develop an EOL resource guide for clients diagnosed with cancer supported by the PCCT.
- To implement the resource guide into practice and provide it to applicable palliative care providers to implement into their practice.
- To demonstrate the advanced nursing practice competencies of leadership, education, optimizing health systems, and research.

Overview of Methods

Several study methods were conducted to assess and determine the relevancy of a need for an ACP resource in the community. A literature review, an environmental scan and

consultations were completed with community stakeholders. The final drafts of the literature review, the environmental scan, and the consultation report are in the appendices of this report.

Summary of the Literature Review

The literature review was aimed at reviewing research on ACP and the implications of ACP on QOL, which can be found in Appendix A.

Methods

The literature review initially used the Memorial University of Newfoundland Library One Search option and narrowed it to appropriate databases: CINAHL Plus, PubMed, and Cochrane Library. Search terms included *palliative resources*, *end-of-life guide*, *preparing for end-of-life*, *cancer end-of-life guide*, and *guiding families through end-of-life, after-death resources*, *end-of-life cancer*, *advanced care planning guide cancer*, *palliative care in Canada*, *palliative care with cancer*, and *early engagement of palliative care*. The following filters were applied: Primary English language, within the last ten years, within North America or the Western World. The quantitative articles were critically appraised using the Public Health Agency of Canada's [PHAC] Critical Appraisal Toolkit (PHAC, 2014). The qualitative studies were appraised using the Joanna Briggs Institute [JBI] Critical Appraisal Checklist for Qualitative Research (Lockwood et al., 2015) and Lincoln and Guba's Evaluation Criteria for determining trustworthiness (Lincoln & Guba, 1985; Schwandt et al., 2007).

Literature Review Results

After reviewing the articles' abstracts and identifying the appropriate articles, fourteen qualitative, nine quantitative, and one mixed-methods study were included in the literature review. The literature search included the benefits of ACP, the prevalence of ACP resources in

the community, the required content to be included in the development of ACP resources, and the gaps identified in the literature.

ACP is an essential aspect of PC; therefore, the prevalence of PC in Canada was explored. The Canadian Institute for Health Information reported that 58% of Canadians who died in 2021-2022 received some form of PC, an increase from 52% in 2016-2017 (Health Canada, 2023). In 2021-2022, 13% of Canadians died at home with PC support, reflecting improved PC at home and meeting wishes of remaining at home for EOL, as only 7% received PC in 2016-2017 (Health Canada, 2023). ACP discussions are essential for ensuring the quality of life [QOL] is maintained, values are identified, and integral to providing effective PC. The increase in the number of patients receiving PC in Canada requires more ACP resources. Despite the increase in PC usage in Canada, there is minimal information and research on the actual usage of ACP in practice in Canada. However, the occurrence of ACP discussions is challenging to study due to the subjective nature of the discussions and the fact that ACP discussions are usually only done near EOL.

The contributing factors of decreased ACP discussions were identified as a lack of public education on the benefits of ACP, the lack of time healthcare providers must spend with patients, and the impact that different cultures have on ACP. Common themes identified in the studies leading to poor ACP discussions are the lack of public understanding of ACP, access to the healthcare system, confidence in the substitute decision-makers [SDM]'s ability to make decisions, and the limited time healthcare providers spend with patients (Biondo et al., 2019; Taneja et al., 2019). The healthcare system in Canada requires patients to make decisions on complex life-sustaining measures without the benefit of having prior ACP discussions, suggesting that engagement in ACP should be done before becoming sick (Taneja et al., 2019).

Culture should be considered when having ACP discussions with patients, and recognize when ACP discussions are not beneficial to the patient as their culture may impact the ability to be beneficial (Kelly et al., 2021; Vashisht et al., 2023).

The involvement of ACP discussions in care improves the reported QOL of individuals and the number of medical treatments patients experience after being diagnosed with cancer (Bakitas et al., 2009; Temel et al., 2017; Temel et al., 2010; Vanbutsele et al., 2018). Additionally, the involvement of ACP discussions reduces the number of medical treatments. ACP ensures goals of care conversations are documented in the chart, reducing the number of unnecessary medical treatments experienced by patients diagnosed with advanced cancer (Ahluwalia et al., 2015; Aller et al., 2024).

The content of ACP discussions varies, and the literature suggests including a review of the current health situation, ensuring fears are identified, establishing a preferred place of death, identifying SDM, conversations on finances, estate planning, and funeral arrangements in ACP programs (Carlozzi et al., 2018; Fritz et al., 2020). Four primary themes that are important to providing effective PC and ACP were identified: introducing ACP early in the disease trajectory, adequate preparation of patients and families for ACP discussion, ensuring flexible conversation timing, and documentation of ACP discussions (Carlozzi et al., 2018; DeCoursey et al., 2021; Fritz et al., 2020). These identified themes should be considered in developing ACP programs and assist in ensuring wishes, values, and goals.

As a result of the findings of the literature review, it was determined that there is a need for an ACP resource for the community. The content that I must include and consider in the development was identified. The literature review results identified the community's need for an

ACP resource guide. The information and research identified that a structured ACP intervention is not beneficial to patients as each requires a personalized approach to the conversation (Korfage et al., 2020). ACP discussions require providers to meet patients where they are and individualize each conversation, therefore ensuring the developed resource will provide open-ended questions to promote conversation and encourage patients to discuss with their healthcare providers and families. The review yielded no specific research on the style and format of resources.

Summary of Environmental Scan and Consultations

An environmental scan and consultations were conducted to determine the resources available in the community and what is needed in Northumberland County. The complete environmental scan and consultation report is found in Appendix B.

Environmental Scan Methods

The environmental scan aimed to find resources online, as well as those utilized by organizations that support similar patients. The other PCCTs in Ontario were contacted to determine what resources they use with their patients, but no reply was received. The environmental scan reviewed the available resources to determine what information is beneficial for health providers who support patients with advanced cancer. The environmental scan reviewed what is available and what information is being provided to the public by those who support patients similarly to those the PCCT supports.

The websites searched included: Hospice Palliative Care Ontario, Princess Margaret Cancer Centre, Hospice Toronto, Government of British Columbia, Advance Care Planning Ontario, and Advance Care Planning Canada. After reviewing each website, further sources were reviewed as the resources they use were found through other organizations. These include Plan

Well Guide, the Government of British Columbia, and Canadian Virtual Hospice. Many organizations utilize the same resources, and all documents available to clients on the website were reviewed.

Consultation Methods

The consultations were completed using an online survey format as not all participants were available in person, and it allowed participants to complete them on time. An online survey was sent to multiple stakeholders who provide palliative care in Northumberland County. These stakeholders were three palliative physicians, seven PCCT members, and twenty-six clinical staff. The survey responses were collected, and the common responses and themes identified are essential to include in developing the ACP resource. The information collected from the stakeholders is essential as they support the same clients as the PCCT and have identified needs and resources that are missing in the community.

Environmental Scan Results

The environmental scan provided several online resources from various organizations. Still, the content needed to be more appropriate for the population being served by the development of an ACP program. The environmental scan provided multiple resources that spoke of capacity and advanced directives. Both are outside the scope of practice as a nurse with the PCCT; therefore, they will be mentioned but not promoted. The content provided on the Advance Care Planning Ontario and Canada websites will be used as the primary source of information on ACP. The printed copy of the Advance Care Planning Ontario was a guideline for the information's format and design. The environmental scan found information that was not included in the resource and is not appropriate for the population: speaking of capacity and advance directives.

Consultation Results

The survey had a response rate of 19.44% among all three participant groups. The topics the physicians found essential to include in the development are why a DNR is okay, services available in the community, organ donation, and identifying POAs, wills and POAs. The physicians also identified the need for human resources in the community for personal care. Still, developing the resource will not assist with the human resource problem in the community and can be improved through the increased acceptance of PC and ACP in the community. The members of the PCCT offered that there are no topics that should be avoided when developing an ACP resource and that the resource should be a printed resource. The respondents identified that multiple versions should be included and may be considered in the future, but only one version will be used for the practicum project. Only one clinical staff member responded, and they identified the importance of ensuring that caregivers are supported through ACP and EOL. The topics the clinical staff identified as necessary were simplifying how to navigate the system, the importance of the documents for families, and simplifying the wants and needs of people at the end of life. The content identified as necessary in the consultations will be used to guide the content to be included in the resource guide.

The information obtained through the consultations influenced what was to be included. All participants identified that an ACP guide should be in printed form and ensure the guide is provided early in the disease trajectory. The consultations identified the following topics that should be included- Do Not Resuscitate, identifying SDMs, completion of wills, services available at home, and the importance of communicating important information on finances and tasks to family. 100% of the participants said no topics should be avoided when developing the resource. The palliative physicians and PCCT members voiced that an ACP resource should be

provided early in the disease trajectory and should be introduced before the palliative care physicians are even involved in care. The PCCT members mentioned digital guides and workbooks available at major book retailers but are just guides on writing down wishes and do not explore values and provide accurate information on ACP discussions. Although the response rate was low, the information obtained from the consultations reveals what other palliative care professionals view as important.

Summary of the Resource Developed

The information obtained through the literature review, environmental scan and consultations guided the development of an ACP resource for patients diagnosed with advanced cancer in Northumberland County, Ontario. A copy of the resource guide is found in Appendix C.

Overview of the Resource

The developed resource contains a disclaimer that the information is intended as a general reference and is not considered legal, medical, or financial advice. It is also noted that the reader should consult a lawyer, physician or legal advice center if needed. An overview of the PCCT was included to ensure clients understand the different supports available through the PCCT. The definition of ACP was included, and its importance was discussed. The importance of SDMs and how they are identified was discussed. The consultations identified several topics that were important to be discussed, including resuscitation, Medical Assistance in Dying, EOL locations, organ donation, and a list of tasks that may be required to be completed after death by the family. The resource included a section on contact information and passwords so the patient can start to work on providing critical information to the family.

The developed resource is in a PDF format that can easily be printed to give to patients and families. The ability to easily access and distribute the guide aligns with the PCCT's roles

and the support provided to patients and families. The resource is 17 pages long and can be printed double-sided on paper to reduce the resource to 9 pages. A shorter resource is most appropriate for the patients the PCCT supports. The font and font size of the resource allow patients to read and meet compliance with accessibility standards.

Discussion of Advanced Nursing Practice (ANP) Competencies

The proposed practicum project assisted me in fulfilling the advanced nursing practice competencies identified by the Canadian Nurses Association [CNA] (2019). I have met the following CNA competencies: optimizing the health system, education, research, and leadership (CNA, 2019).

Optimizing Health System

The development of the ACP resource met the CNA optimizing health system competencies (CNA, 2019). Advanced practice nurses meet this competency by advocating, promoting client care and facilitating equitable, client-centred health care (CNA, 2019). The competency was met by identifying a need in the community and developing a resource that will support patients in receiving client-centred healthcare and promote the patients to advocate for themselves. The access to appropriate ACP discussions will be improved through the identified gap in the health system and improved delivery of ACP in Northumberland County.

Educational

The competency of education was met by committing to professional growth and contributing to the continuous learning of healthcare providers and opportunities to learn from other healthcare providers to optimize client care (CNA, 2019). The competency was met by creating a resource for healthcare providers to provide to patients and advance their ability to have ACP discussions with patients before EOL. Through the improvement of ACP discussions

in the community, healthcare providers will become more comfortable having conversations prior to a diagnosis of a life-limiting illness.

Research

The research competency is met when nurses generate, synthesize, critique, and apply research evidence (CNA, 2019). The development of the ACP resource met the criteria of competency. The ability to synthesize and critique research improved through the literature review and grew through the development of the ACP resource. The research was conducted to improve healthcare delivery to patients with advanced cancer and to support healthcare team members in having ACP discussions.

Leadership

The leadership competency is met through being agents of change, consistently seeking new ways to practice and improve care (CNA, 2019). The vision for the project was effectively articulated and will improve the care that the PCCT can provide. A gap in the care being provided was identified, and a solution to improve care to patients and the care provided by healthcare providers was created.

Next Steps

After completing the practicum project, the ACP resource can be distributed to patients, families, and healthcare providers. The resource can easily be printed to provide to patients as needed. Additionally, future research opportunities do exist for the ACP guide. Feedback from patients, caregivers, and healthcare providers can be obtained to determine the effectiveness and benefit of the guide. The guide can be reviewed and assessed by surveying clients, caregivers, and healthcare providers. The survey can include a section allowing open-ended answers for the participant to write comments, describe the importance of the guide, and provide feedback.

The resource can be used to assess whether there is an increase in ACP using the guide through an educational intervention study. In a study where some clients receive the resource, and others do not, both groups are surveyed to understand and assess whether knowledge of ACP has increased.

Conclusion

The development of an ACP resource ensures that patients diagnosed with advanced cancer can help their families prepare for their death and ensure QOL is maintained from diagnosis through EOL. Through the literature review, environmental scan, and consultations, an ACP guide was developed for use by the PCCT. The guide is easily accessible and user-friendly for patients, and the PCCT supports it. Further research is needed to evaluate the effectiveness of the developed ACP resource on ACP discussions with patients diagnosed with advanced cancer. The practicum project demonstrates a commitment to meeting the advanced nursing practice competencies of optimizing health systems, education, research, and leadership. Future opportunities exist to implement and use an ACP guide for patients with advanced cancer. The use of an ACP guide will improve the support provided to the patients supported by the PCCT.

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Appendix A
Literature Review

Abstract

Advance care planning [ACP] is essential to providing quality EOL care and promoting the wishes, values and goals of patients diagnosed with advanced cancer. The lack of a resource for patients diagnosed with advanced cancer was identified by the Palliative Care Community Team [PCCT] in Northumberland County, Ontario. A literature review was completed to determine the benefits, impacts, and implications of ACP resources on patients. Fourteen qualitative, nine quantitative, and one mixed-method research study were reviewed and included in the literature. The literature review findings support the need for an ACP resource for patients, and the information obtained will help guide the future development of an ACP resource. Ensuring family involvement, adequate time for discussions, promoting early engagement, and providing culturally safe resources are essential factors in developing an ACP resource.

Introduction

The diagnosis of a life-limiting illness, such as cancer, is devastating and life-altering for the patient and their family due to the changes in roles and the impact of disease and treatment on the body (Canadian Cancer Society, 2024). When patients initially present to an oncology clinic or medical setting, the focus is placed on establishing diagnosis staging and developing a treatment plan. Still, at times, patients often experience emotional and spiritual distress that may impair their quality of life [QOL] (Greer et al., 2013). Palliative care [PC] emphasizes the well-being of patients and families coping with severe medical conditions at any point in their disease trajectory (Greer et al., 2013). PC providers assist in helping patients understand their diagnosis and treatment goals and facilitate informed decisions about their care throughout the illness trajectory, not just at the end of life [EOL] (Temel et al., 2017). The early integration of PC into oncology care improves QOL, reduces depression symptoms, and enhances coping with prognosis and communication of EOL care preferences (Temel et al., 2017). Advance care planning [ACP] is a process that supports anyone at any age or stage of health to understand and share their personal values, goals, and preferences for when they lose the capacity to make decisions for themselves (Howard et al., 2022). It is an essential aspect of PC (Advance Care Planning Canada, 2016). Healthcare providers must first introduce ACP when the client is relatively stable and not experiencing significant symptoms or disease burden (Zadeh et al., 2015). ACP is a shared decision-making concept as the patient provides insight into their goals, values, and preferences. At the same time, the clinician offers support and outlines the benefits, risks, and uncertainties of the treatment options based on experience and scientific evidence (Plaisance et al., 2022). Unfortunately, most SDMs are unprepared to face difficult decisions and feel ill-prepared to make decisions that align with the patient's goals, values, and preferences

(Plaisance et al., 2022). ACP aims to prepare caregivers to ensure that care follows the patient's wishes. The question is not if ACP should be provided to patients with advanced cancer but when and how it should be delivered to ensure optimal patient outcomes and improved QOL (Hui & Bruera, 2016).

An ACP resource guide that assists patients in speaking with their families about their advance care planning wishes, goals, and preferences, planning and communicating wishes have been identified as a priority for a Palliative Care Community Team [PCCT] who supports patients diagnosed with end-stage cancer in Northumberland County, Ontario, Canada. The objective of the literature review is to discuss the importance of ACP, the contributing factors for ACP, the impact of ACP on patients and families, the interventions that impact ACP, and the gaps identified in the research. A resource guide for ACP has been identified as necessary for PCCT since it ensures that all patients receive ACP information and are guided through their disease trajectory.

Literature Search Methods

The review initially used the Memorial University of Newfoundland Library One Search option and narrowed it to appropriate databases: CINAHL Plus, PubMed, and Cochrane Library. Search terms included *palliative resources*, *end-of-life guide*, *preparing for end-of-life*, *cancer end-of-life guide*, and *guiding families through end-of-life*, *after-death resources*, *end-of-life cancer*, *advanced care planning guide cancer*, *palliative care in Canada*, *palliative care with cancer*, and *early engagement of palliative care*. Initially, no filters were applied; then the following filters were applied: Primary English language, within the last ten years, within North America or the Western World. Google Scholar was reviewed, but all relevant articles were found in the academic search through the Library One Search option. After reviewing the

articles' abstracts and identifying the appropriate articles, fourteen qualitative, nine quantitative, and one mixed-methods study were included in the literature review. The quantitative articles were critically appraised using the Public Health Agency of Canada's [PHAC] Critical Appraisal Toolkit (PHAC, 2014). The qualitative studies were appraised using the Joanna Briggs Institute [JBI] Critical Appraisal Checklist for Qualitative Research (Lockwood et al., 2015) and Lincoln and Guba's Evaluation Criteria for determining trustworthiness (Lincoln & Guba, 1985; Schwandt et al., 2007). The appraisal of the studies can be found in the literature summary tables (see Appendix A).

In this review, I will discuss the occurrence of ACP, the contributing factors for the implementation of ACP, and the impact of ACP on patients and families. I will then identify research studies on ACP interventions, identify the gaps in the literature, and make suggestions for future research and projects related to ACP.

Background

The Canadian Institute for Health Information reported that 58% of Canadians who died in 2021-2022 received some form of PC, an increase from 52% in 2016-2017 (Health Canada, 2023). Among those who received PC, 61% had PC in the hospital only, and 36% received PC home care (Health Canada, 2023). In 2021-2022, 13% of Canadians died at home with PC support, reflecting improved PC at home and meeting wishes of remaining at home for EOL, as only 7% received PC in 2016-2017 (Health Canada, 2023). ACP discussions are essential for ensuring QOL is maintained, values are identified, and integral to providing effective PC. The increase in the number of patients receiving PC in Canada requires more ACP resources. The benefit of early ACP discussions is well explored in the literature, but more research is needed on the occurrence of ACP programs.

The actual occurrence of ACP discussions is challenging to study due to the subjective nature of the discussions and the fact that ACP discussions are usually only done near EOL. Privacy laws also restrict research on patient charts. A Convergent mixed-methods design was conducted to evaluate timing and factors affecting ACP discussions (Miyashita et al., 2020). Over 60% of respondents believe ACP discussions were necessary, while less than 20%, in contrast, thought that ACP should only be discussed once EOL is approaching. While more than 60% state ACP is important and should be completed, almost 20% do not want to initiate conversation until EOL is nearby. Forner et al. (2021) completed a retrospective, cross-sectional study of patients undergoing surgery for head and neck cancers and the discussion and documentation of ACP. Of the 301 patients, only 31 (10.3%) had ACP discussions documented (Forner et al., 2021). Patients with advanced disease were almost twice as likely to have an ACP discussion documented compared to patients early in their disease trajectory (1.97, 95% [0.98, 3.97]) (Forner et al., 2021). ACP is difficult to standardize due to the various options available and the differences in provincial regulations. The benefits of ACP discussions and PC early in the disease trajectory are explored, but there is limited research on the occurrence of ACP discussions. While patients know the importance of ACP discussions, the discussions are not occurring.

Contributing Factors

The contributing factors to the poor implementation of ACP vary depending on patient needs and service providers. The literature review identified two primary contributing factors to the barriers to ACP: cultural and intrapersonal factors and a lack of education and time.

Cultural and Intrapersonal Factors

The literature search yielded limited research studies that have been conducted on cultural and intrapersonal factors as contributing factors to implementing ACP into practice (Kelly et al., 2021; Vashisht et al., 2023). However, two studies identified the impact of culture and intrapersonal factors on ACP discussions and how they impact the ability of ACP to be implemented into practice (Vashisht et al., 2023; Kelly et al., 2021). One study utilized a qualitative, grounded theory approach using content and thematic analysis of moderate strength and trustworthiness (Vashisht et al., 2023), while the other used a retrospective, cohort methodology of moderate quantitative design (Kelly et al., 2021), and both obtained moderate strength results. Vashisht et al. (2023) explored Canadian physician experiences with ACP discussions with Canadian-South Asian patients with 22 physicians. Meanwhile, Kelly et al. (2021) assessed intrapersonal factors' influence on ACP in 3,463 patient charts. Although the study methods differed, the results were similar, and the goals aimed to identify the role of culture and intrapersonal factors on ACP. The increasing number of immigrants in Canada must be considered when discussing ACP. The findings of Kelly et al. (2021) apply to Canada as the study was conducted with the South Asian Canadian population, and culture should be considered when interacting with patients.

Vashisht et al. (2023) analyzed physician interviews to examine the impact of South Asian culture on ACP, while Kelly et al. (2021) examined the influence of intrapersonal factors, including race and religion, on ACP, documented in patients' charts. ACP is not as common for South Asian individuals as Caucasians (Vashisht et al., 2023). Still, Vashisht et al. (2023) did not provide statistics on the differences in different cultures, while Kelly et al. (2021) found that Caucasian patients had higher odds of having a substitute decision-maker [SDM] (OR 1.57, 95% CI: 1.16-2.13) and preferences for ACP (OR: 1.61, 95% CI: 1.21-2.15). However, Vashisht et al.

(2023) did include in the findings that approximately 2/3 of physicians experienced differences in family and patient beliefs, as the adult child is not as open to ACP discussion as the patient. Kelly et al. (2021) further examined intrapersonal factors, while Vashisht et al. (2023) only examined culture as a factor. Patients who identified as religious had 61% higher odds (95% CI: 1.08-2.40) of having a DNR and approximately 30% higher odds of having an SDM (95% CI: 1.08-1.62) (Kelly et al., 2021) recognizing that intrapersonal factors positively influence the presence of ACP. A physician mentioned that different cultures may not participate in ACP discussions as readily, not out of fear or mistrust but due to the community's lack of knowledge of ACP (Vashisht et al., 2023).

The findings of both studies suggest that culture influences the presence of ACP discussions. Both studies recognized that culture impacts the presence of ACP. The results of the two studies show that culture and intrapersonal factors will affect how ACP is perceived and completed. Cultural considerations will be made in the development of the ACP resource. Both studies (Kelly et al., 2021; Vashisht et al., 2023) results suggest that culture should be considered when having ACP discussions with patients and recognize when ACP discussions are not beneficial to the patient as their culture may impact the ability to be beneficial. There are limited studies on the impact culture has on ACP discussions; therefore, it should be recognized that more research is needed on the impact of culture on ACP discussions.

Education and Time

The lack of education and understanding of the importance of ACP and the limited time healthcare providers must spend with patients impact the ability of healthcare providers to have ACP discussions with patients (Biondo et al., 2019; Taneja et al., 2019). A study utilizing grounded theory methodology of moderate strength with semi-structured interviews (Taneja et

al., 2019) and another used focus groups with a phenomenological, moderate, strength design (Biondo et al., 2019) to examine how ACP discussions occur and the concerns noted by healthcare providers. Both utilized semi-structured interviews and purposive sampling (Biondo et al., 2019; Taneja et al., 2019), and the results were deemed trustworthy. Taneja et al. (2019) completed 20 interviews with the public, while Biondo et al. (2019) interviewed 67 participants from 47 community organizations to identify themes. Both studies conducted focus groups and analyzed the results to identify common themes. Common findings were identified in the two studies that lead to poor ACP discussions- public understanding of ACP, access to the healthcare system, confidence in the SDM's ability to make decisions, and the limited time healthcare providers spend with patients (Biondo et al., 2019; Taneja et al., 2019). Despite the increased acknowledgement of the benefits of ACP, the low levels of engagement remain a problem (Biondo et al., 2019), and the lack of knowledge on life-sustaining interventions is a cause (Taneja et al., 2019). The healthcare system in Canada requires patients to make decisions on complex life-sustaining measures without the benefit of having prior ACP discussions, suggesting that engagement in ACP should be done before becoming sick (Taneja et al., 2019). However, to respond to the increase in ACP discussions needed in the community, healthcare providers and organizations require support to be able to provide skilled facilitative conversations with patients to elicit values, wishes, and priorities, sharing prognosis, illness trajectory and outcomes, and the ability to re-approach the conversation as needed (Biondo et al., 2019). Outreach efforts to increase public awareness and education for patients and healthcare providers are required to ensure active conversation on ACP and that the conversation is normalized (Biondo et al., 2019; Taneja et al., 2019). Both studies identified the difficulties of

the conversations and how each patient's ACP discussion is unique (Biondo et al., 2019; Taneja et al., 2019).

Improved education for patients and integration of ACP into life events was identified as necessary to improve the perception and integration of ACP into practice (Biondo et al., 2019; Taneja et al., 2019). The impact of the lack of time healthcare professionals must spend on ACP discussions is evident as patients and healthcare providers have identified it as a concern. The lack of understanding of ACP from patients impacts the ability of ACP to be fully integrated into care. Ensuring patients are educated and that healthcare providers provide enough time to discuss ACP with patients will improve the rates of ACP discussions. The limited research on the lack of education and time available for patients and healthcare providers is recognized, and additional research is required to improve the amount of time healthcare providers must spend with patients to have ACP discussions. Education on the benefits of ACP to the public is also an identified limitation of the studies, and public education is required.

Impacts

There are two beneficial impacts of ACP on patients identified in the literature. The first is the impact on QOL, and the second is the impact that ACP discussions have on the medical care and interventions received by patients at EOL.

Quality of Life

Four studies show that the QOL of patients is positively impacted by improving ACP discussions while receiving PC (Bakitas et al., 2009; Temel et al., 2017; Temel et al., 2010; Vanbutsele et al., 2018). Four randomized trials of moderate strength and robust design examined the benefit of early integration of PC and ACP discussions into standard oncology

care. The studies were of moderate strength and strong design support that early PC integration improves QOL (Bakitas et al., 2009; Temel et al., 2017; Temel et al., 2010; Vanbutsele et al., 2018). Randomized control trials assigned newly diagnosed patients with advanced cancer into two groups, an interventional and a control group, to receive either early PC integrated with standard or standard oncology care only (Bakitas et al., 2009; Temel et al., 2017; Temel et al., 2010; Vanbutsele et al., 2018). One study assigned 186 patients to the early and systematic PC group at a hospital in Belgium (Vanbutsele et al., 2018), while the second studied 322 patients at a comprehensive cancer center in New Hampshire, United States of America (Bakitas et al., 2009). The other two studies randomly assigned 350 patients and 151 patients, respectfully, to standard care or intervention groups at a hospital in Massachusetts, United States of America (Temel et al., 2017; Temel et al., 2010). Vanbutsele et al. (2018) assessed QOL by utilizing the European Organization for Research and Treatment of Cancer Quality-Of-Life Questionnaire Core 30 Items [EORTC QLQ C30] and the McGill Quality of Life Questionnaire [MQOL]. Patients in the intervention group were more likely to discuss their wishes for advance care planning ($p=0.004$) and have a better reported QOL ($p=0.005$) (Temel et al., 2010). The results were statistically significant. The reported QOL was higher in the early PC group compared to the intervention group, 61.98 (95% CI 57.02-66.95) versus 54.39 (49.23-59-56) respectively, ($p=0.03$) using the EORTC QLQ C30 (Vanbutsele et al., 2018). The mean QOL assessed using the MQOL was 7.05 (6.59-7.50) for early and systemic PC versus 5.94 (95% CI 5.50-6.39) in the standard oncological care group ($p=0.0006$) (Vanbutsele et al., 2018). Patients who received the intervention had a significantly better QOL, $p=0.02$, and determined they had lower symptom intensity, $p=0.06$ (Bakitas et al., 2009). After analysis of the data and control of baseline variables, patients who received the PC intervention had significantly higher QOL and lower

depression symptoms at two and four months before death (Temel et al., 2017). The patients in all four studies improved their reported QOL after receiving an education session on ACP (Bakitas et al., 2009; Temel et al., 2017; Temel et al., 2010; Vanbutsele et al., 2018). The findings of the studies apply to the Canadian population as the study populations are like the Canadians. The Belgian healthcare system is like Canada's, and although there are differences between the American and Canadian healthcare systems, the data obtained applies to the Canadian population. Cancer diagnosis and its impact on QOL is the same regardless of the country; therefore, measures to reduce the impact are generalizable. The methods to assess QOL must ensure the questions are appropriate to the Canadian healthcare system and the treatments offered. Temel et al. (2017) additionally identified that QOL may be impacted differently depending on the type of cancer diagnosis the patient has. There is limited research on how the type of cancer diagnosis impacts QOL.

The research evidence supports that the involvement of early PC and ACP discussions positively impacts QOL. Although QOL is perceived differently by each patient, ensuring that ACP discussions are held early allows each patient to benefit.

Reduced Medical Care and Interventions

Two further studies examined the association between ACP and the number of healthcare treatments patients may receive at EOL (Ahluwalia et al., 2015; Aller et al., 2024). Cohort studies of moderate strength and design examined the association of ACP discussions with patients with advanced cancer (Ahluwalia et al., 2015; Aller et al., 2024). Both studies reviewed the number of medical treatments received by patients diagnosed with advanced cancer (Ahluwalia et al., 2015; Aller et al., 2024). Approximately 31% of patients received some acute medical care, 9.3% received intensive intervention, 6.5% initiated a new chemotherapy regime in

the last month of life, and 46.8% had documentation of a care planning discussion within the first month after diagnosis (Ahluwalia et al., 2015). Goals of care conversations were documented in 86% of the deceased patients (Aller et al., 2024). Integrating ACP into traditional care has demonstrated an increase in advanced care planning completion and goals of care documentation (Ahluwalia et al., 2018; Aller et al., 2024). Both studies identified the difficulty of ACP discussions as the content and context of the conversations are limited in the charts and cannot be fully explored (Ahluwalia et al., 2018; Aller et al., 2024).

The involvement of ACP discussions in care improves the reported QOL of individuals and the number of medical treatments patients experience after being diagnosed with cancer. The involvement of ACP discussions reduces the number of medical treatments and ensures that goals of care conversations are documented in the chart, reducing the number of unnecessary medical treatments experienced by patients diagnosed with advanced cancer.

Interventional Studies

ACP programs are available to encourage conversations between patients, families, and caregivers. The impact of ACP programs on ACP discussions in patient records and the content and themes required in ACP discussions is supported in the research.

Impact on Inclusion of Advance Care Planning in Patient Records

Three studies explored the impact of ACP discussions on the inclusion of ACP discussions in patient records (Howard et al., 2022; Howard et al., 2021; Korfage et al., 2020). Two randomized control trials (Howard et al., 2022; Korfage et al., 2020) of moderate strength and strong design and one cohort study of moderate strength (Howard et al., 2021) of moderate strength and trustworthiness examined how ACP intervention impacts the inclusion of ACP

discussion in the patient records. Howard et al. (2021) had 177 patients in a prospective pre-post study of moderate strength and design, Korfage et al. (2020) randomly assigned 1,117 patients, and Howard et al. (2021) randomly assigned 45 patients to the intervention. Howard et al. (2022) identified that patients who received ACP education were more ready to discuss ACP and include it in charting. Howard et al. (2022) overall mean score on the patient ACP Engagement Survey at baseline was 3.9 in the immediate intervention group and 3.7 in the delayed intervention group. Howard et al. (2021) determined that records and readiness of patients to implement change in their records increased by a mean of 0.5 on a five-point scale. Patients who received ACP education were more likely to involve specialty PC resources (37% versus 27%, $p=0.002$) and include ACP discussions in their medication records (10% versus 3%, $p<0.001$) than those who did not (Korfage et al., 2020). All studies identified that more strategies were needed to improve the availability of low-literacy ACP forms and the amount of clinical time to implement discussions (Howard et al., 2022; Howard et al., 2021; Korfage et al., 2020). These studies identified the importance of recognizing the limited time healthcare professionals must spend with patients and improving the accessibility and readability of resources.

Content to be Included in Future Resource Development

The required content of ACP programs will vary between organizations and patient needs. The research has identified important themes, such as the inclusion of family in conversations and how to ensure inclusivity.

Themes that Should be Included

Three qualitative studies identified the themes that should be included in ACP programs (Carlozzi et al., 2018; DeCoursey et al., 2021; Fritz et al., 2020). Two studies had a

phenomenological approach using focus groups and interviews (DeCoursey et al., 2021) and a phenomenological qualitative study using focus groups (Carlozzi et al., 2018), while the third used a grounded theory approach to guide the focus group (Fritz et al., 2020). The three studies utilized a moderate-strength design with trustworthy results applicable to the Canadian population (Carlozzi et al., 2018; DeCoursey et al., 2021; Fritz et al., 2020). Two studies were conducted in the United States of America with 508 and 50 participants, respectfully (Carlozzi et al., 2018; DeCoursey et al., 2021), while the third was conducted in the Netherlands with ten physicians and 13 patient-SDM dyads (Fritz et al., 2020). Two studies found that reviewing the current health situation, ensuring fears are identified, establishing a preferred place of death, identifying SDM, conversations on finances, estate planning, and funeral arrangements as necessary to include in ACP programs (Carlozzi et al., 2018; Fritz et al., 2020). Some questions to consider to be included in an ACP resource are: “‘How I would like to be supported so I do not feel alone,’ ‘How I want to be comforted,’ ‘Whom I want to make my medical care decisions if I cannot make them on my own,’ ‘The types of life-support treatments I want, or do not want,’ ‘What I would like my friends and family to know about me?’, ‘Spiritual thoughts and wishes,’ ‘How I wish to be remembered,’ and ‘my voice’” (Zadeh et al., 2015). The studies provided four primary themes that are important to delivering effective PC and ACP: introducing ACP early in the disease trajectory, adequate preparation of patients and families for ACP discussion, ensuring flexible conversation timing, and documentation of ACP discussions (Carlozzi et al., 2018; DeCoursey et al., 2021; Fritz et al., 2020). These identified themes should be considered in developing ACP programs and assist in ensuring wishes, values, and goals.

Inclusion of Family in Conversations

One study utilized a phenomenological qualitative approach using individual interviews with 11 participants to examine how to increase ACP discussion with patients (Pritchett et al., 2021), while a second study utilized a grounded theory approach by interviewing 67 patients to identify constructs critical to ACP implementation (Lynch et al., 2022). Through the thematic analysis, 54.5% of participants wanted to discuss ACP but were unsure how to speak to the family about their wishes (Pritchett et al., 2021). Lynch et al. (2022) identified that early ACP discussions promote conversations with family, and the preference for open communication allows the patient to maintain control of an uncertain future. Lynch et al. (2022) also was the only study to recognize the strength patients receive from their families and that patients obtained their strength and hope from family members. While there is limited statistical data on including families in ACP discussions, the identified themes and the importance of families are recognized (Lynch et al., 2022; Pritchett et al., 2021).

Ensuring Inclusivity in Advance Care Planning Discussions

Only one study examined an existing ACP resource to ensure it is culturally sensitive. (Beddard-Huber et al., 2021). The study utilized a mixed methods approach of moderate strength and design to determine if the program was culturally safe for the Canadian population (Beddard-Huber et al., 2021). Sixty-one nurses and 35 community members provided feedback on the guide (Beddard-Huber et al., 2021). Most of the 35 community participants and over 80% of the nurses stated that the conversation was appropriate, but the language of some of the questions needed to be more direct and plain to be more culturally safe (Beddard-Huber et al., 2021). Participants said that using the term “we” while being an inclusive term does not validate the individual's journey, and the community members preferred using “I” or “you” instead

(Beddard-Huber et al., 2021). The cultural safety of resources must be considered when developing ACP resources.

The studies that have looked at the implementation of ACP programs have found that ACP discussions are essential for patients to include in patient records, and the content should promote values, wishes and goals (Advance Care Planning Canada, 2016). Beddard-Huber et al. (2021) was the only study to identify that a guide or script might distract from having an empathic conversation and may exacerbate a power imbalance. Programs should guide patients in determining the most beneficial content for patients diagnosed with advanced cancer. They should guide patients in ACP discussions that benefit their lives and journeys.

Gaps in the Research

Through searching the literature on ACP, gaps were identified that prevent ACP's successful integration into care. While Forner et al. (2021) identified the importance of ACP with patients with cancer utilizing a retrospective, cross-sectional of moderate strength and design, they also identified the gaps in practice. Despite patients recognizing the importance of ACP, patients with cancer frequently do not have documented ACP discussions with providers (Forner et al., 2021) due to the common misconception that PC is associated with death and dying (Hui & Bruera, 2016). This is commonly experienced in the health care system in Canada. More research is needed on the number of ACP discussions in the community. DeMiglio and Williams (2012) identified that community-based PC programs vary across Canada and have difficulties supporting patients at home. The qualitative study by DeMiglio and Williams (2012) used a longitudinal case study methodology to examine the barriers and facilitators involved in implementing community-based PC teams. Financial barriers and geographical location were

identified as the primary barriers to service delivery and the misperceptions of shared care (DeMiglio & Williams, 2012).

However, with the vast array of documentation systems and the fluid nature of community EOL supports, the frequency of ACP discussions takes time to study. No studies were found on the differences in ACP discussions between hospital and community settings. All studies only looked at physician-to-patient ACP discussions but did not examine the impact of visiting nursing conversations. The significant differences between Canadian provinces in legislation and available resources also make it difficult to assess the impact of a newly developed ACP resource. Although most of the research critiqued in this literature review applies to the Canadian population, caution must be taken to ensure appropriateness to patient and situation as most of the studies are from the United States, where the healthcare system is different. Only one study (Temel et al., 2017) examined different cancers' impact on ACP discussions. More research is required to determine the impact of the type of diagnosis on the impact and inclusion of ACP discussions. Additional research is also needed on the impact of culture on ACP programs. As cultural diversity increases in Canada, more research is required to support ACP discussions with different populations and how to practice culturally safe EOL care.

Implications of Research

ACP discussions are essential to ensure that care aligns with the patient's wishes. Many healthcare providers use the surprise question "Would you be surprised if this patient dies in the next six months?" to determine when end-of-life discussions should occur (Lewis et al., 2020), typically when ACP discussions are initiated. Two qualitative studies of moderate strength and design using semi-structured interviews examined the importance of including caregiver needs in

ACP discussions (Durieux et al., 2022; Prater et al., 2023). The caregivers described the importance of clear communication with healthcare providers and ensuring adequate prognostic communication was done, which assists in minimizing the gaps that undermined the caregiver's confidence in the decision-making process (Durieux et al., 2022; Prater et al., 2023). Patient-clinician relationships and ACP discussions were considered higher quality when felt to be humanistic (Durieux et al., 2022). Caregivers want to ensure that the whole person is supported. Ensuring the caregivers are supported is essential to ensure the patient feels the care is person-centred. The caregivers are left when the patient dies; therefore, to ensure optimal support, early integration of difficult conversations and caregiver support is required.

In Detroit, the Hospice of Michigan created a complete tool kit that empowers individuals and families to take control of their end-of-life decision-making and planning (NewsRX LLC, 2011). The 'Have You Had the Talk' website provides a checklist of steps and things to do, suggests resources, and provides a guide to clarify wishes, organize paperwork, and write wishes (NewsRX LLC, 2011). The guide also includes six questions:

“‘What tasks do I want to complete before I die?’, ‘What does quality of life mean to me?’, ‘When faced with death, what does a ‘good death’ mean to me?’, ‘What role do I want do I want my loved ones to have should I be facing death?’, ‘What kind of help and support do I want my loved ones to get if I should die?’ and ‘Who is the person I want to advocate for me in an emergency?’” (NewsRX LLC, 2011).

Hospice of Michigan developed the toolkit but needed to have research attached to support the inclusion of the data in the review. These questions are essential to consider as they are critical to identifying goals, wishes, and values, which are integral components of ACP.

The implications of the research show the benefit of ACP discussions with patients diagnosed with advanced cancer. Although structured ACP discussions are difficult to have and the barriers to implementation are difficult to overcome, the benefits of ACP discussions are evident, and all efforts should be made to ensure that ACP discussions are held with every patient. The evidence found in the literature review will be used to implement my ACP resource guide for patients diagnosed with advanced cancer.

Conclusion

The benefit of ACP is well explored in the literature and should be included early in the disease trajectory. The positive impact on QOL and ensuring care for EOL is a priority for patients, as well as ensuring ACP is completed, ensures patients and caregivers feel supported. There is limited data on the conversations, but research has shown the information and themes that should be identified in future ACP resources. The information collected through the literature review will assist me in developing my own ACP resource for clients that I support with advanced cancer. The goal of the practicum project is to uphold the patient's dignity by allowing them to focus on completing tasks typically completed closer to death, early in the trajectory, to enable them to focus on what is important to them.

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Appendix i

Literature Summary Table

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Ahluwalia et al (2015)</p> <p><u>Design:</u> A retrospective cohort quantitative design</p> <p><u>Purpose:</u> To evaluate the association of between medical record documentation of patient-physician ACP discussions and intensity of EOL care among veterans with advanced CA.</p>	<p><u>N:</u> 665 patients diagnosed with stage IV colorectal, lung, and pancreatic CA</p> <p><u>Country/setting:</u> National sample of veterans identified through the VA Central Cancer Registry in the USA.</p> <p><u>Data collection and outcomes:</u> Data was drawn from the VA National Cancer Quality ASSIST study Detailed medical record abstraction from date of diagnosis until death or 3 years after diagnosis</p> <p><u>Analysis:</u> Descriptive statistics summarizing characteristics. Bivariate associations between patient characteristics and receipt of aggressive care in last month of life using Pearson-chi-square tests or Students t-tests where appropriate. Additional regression model testing. All tests were performed using statistical software SAS</p>	<p>Findings:</p> <p>1. Early care planning discussion</p> <ul style="list-style-type: none"> - 46.8% of veteran decedents had ACP discussions within a month of diagnosis - More veterans with pancreatic and lung CA had ACP discussions than those with colorectal CA (55% and 46.8%, respectively, versus 39%, p=0.004) <p>2. Intensity of care received at EOL</p> <ul style="list-style-type: none"> - 30.8% of decedents had some form of acute care in the last month of life - 9.3% had intensive intervention - 64.2% received chemotherapy - Almost 41% were admitted to hospice less than 3 days before death or received no hospice <p>3. Early ACP and intensity of EOL care received</p> <ul style="list-style-type: none"> - after controlling for other factors, veterans who had early ACP discussion were significantly less like to receive acute care at EOL (p=0.025) 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p><u>Issues:</u></p> <ul style="list-style-type: none"> - No information available on type of ACP discussions - Reliance of chart documentation of ACP - Chance of bias in the chart documentation

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Aller et al. (2024)</p> <p><u>Design:</u> An retrospective, descriptive cohort quantitative design</p> <p><u>Purpose:</u> To characterize the clinical context of ACP for patients with advanced CA</p>	<p><u>N:</u> 82 patients diagnosed with stage IV cancer</p> <p><u>Country/setting:</u> Kaiser Permanente San Francisco Cancer Centre, USA</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> • Patient demographics, tumour characteristics, initial workup, treatment practices, PC consultations, hospital admissions, GOC conversations • Information extracted from electronic health records and chart reviews by independent reviewers <p><u>Analysis:</u> Descriptive statistics were utilized to analyze data</p>	<p>Findings:</p> <p>1. Clinical Course</p> <ul style="list-style-type: none"> - 82% (n=62) patients receiving chemo, radiation, systemic therapy or combination of each - Only 22% of patients had no additional hospital admission after diagnosis <p>2. ACP Events</p> <ul style="list-style-type: none"> - 73% of patients received PC supports - GOC conversations documented fully in 56% of patients - Only 16% of deceased patients had a GOC conversation documented by an oncologist. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Study design limits the number of patients and may impact appropriateness of patients - Diagnosis was all stage IV CA but each CA is different - Bias was attempted to be limited but could have occurred - Limited to only one site and difficult to generalize to other facilities

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Bakitas et al. (2009)</p> <p><u>Design:</u> Randomized control trial quantitative design</p> <p><u>Purpose:</u> To determine the effect of a nursing-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer</p>	<p><u>N:</u> 322 patients with advanced cancer</p> <p><u>Country/setting:</u> Cancer center in New Hampshire, USA and VA medical center in Vermont, USA</p> <p><u>Group 1:</u> n=161 received 4 weekly multicomponent, psychoeducational intervention and monthly follow up sessions until death or study completion</p> <p><u>Group 2:</u> n=161 in usual care group</p> <p><u>Data collection and outcomes:</u> QOL measured using Functional Assessment of Chronic Illness Therapy for Palliative Care. Symptom intensity measured by ESAS. Mood measured by CED-S. Measured at baseline, 1 month and q3 months until death or study completion</p> <p><u>Analysis:</u> Longitudinal, intention-to-treat analysis, repeated measures of ANCOVA, mixed-effects model, exploratory post hoc analysis of survival, log-rank test, Kaplan-Meier survival curves</p>	<p>Key results:</p> <p>1. QOL, Symptom Intensity, and Mood</p> <ul style="list-style-type: none"> - no statistical differences between the groups - lower symptom intensity (mean[SE]. -27.8[15]; P=.06) and lower depressed mood (mean [SE], -1.8 [0.81]; P=.02] in intervention group <p>2. Resource Use</p> <ul style="list-style-type: none"> - No statistical differences between groups <p>3. Survival</p> <ul style="list-style-type: none"> - Post-hoc exploratory analyses showed no statistically significant differences in groups - Median survival was 14 months (95% CI, 10.6-18.4months) in intervention group and 8.5 months (95% CI, 7.0-11.1 months) for usual care group 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Did not reach full data saturation - Data was collected through questions and self-reported assessments that could skew results - Participants were notified of in which group they were placed after baseline questionnaire completed - Referring clinicians were not formally blinded or informed to patient assignment

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Beddard-Huber et al. (2021)</p> <p><u>Design:</u> Quantitative phenomenological design</p> <p><u>Purpose:</u> To assess the cultural safety of the Serious Illness Conversation Guide (SICG)</p>	<p><u>N:</u> 34 nurses, 35 community members in two focus groups</p> <p><u>Country/setting:</u> Nurses who provide PC to patients who identify as Indigenous, or one of the Indigenous community members, in British Columbia, Canada</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> • Data was collected from the nurses through emailed surveys and focus groups • Community members provided data during two community sharing circles <p><u>Analysis:</u> Done in three phases: authors reviewed the collection of data, each independently reviewed transcripts and findings, and finally shared themes each had identified</p>	<p>Themes:</p> <p>1. Themes identified from the nurses transcripts</p> <ul style="list-style-type: none"> - <i>Preparing the patients for the conversation</i> (ensure patient is ready to have the discussion and must be done with a clinician with an established relationship) - <i>Asking permission</i> (ensure patient consents to conversation throughout process) - <i>Word adjustment in accordance with health literacy</i> (ensure use of plain language in an informal approach) - <i>Inclusion of a question about desire for specific cultural practices</i> (culture is respected and patient comfortable identifying needs) <p>2. Themes identified by community members</p> <ul style="list-style-type: none"> - <i>Being direct when asking questions</i> - <i>Including family in the conversation</i> - <i>Establishing a trusting relationship with the patient</i> - <i>Asking for permission</i> - <i>Scheduling time for storytelling of previous experiences</i> - <i>Include patient in preparation of discussion</i> - <i>Using “I” or “you” in questions, not “we”</i> 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Data obtained through focus groups which could lead to bias - Only discussed with two small Indigenous communities which may lead to bias of their experiences - High nurse drop out after before post-focus group survey was sent

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Biondo et al. (2019)</p> <p><u>Design:</u> A qualitative design using phenomenological approach</p> <p><u>Purpose:</u> To elicit community group perspectives on how to help people learn about and participate in ACP</p>	<p><u>N:</u> 67 participants from 47 community organizations in focus in two focus groups</p> <p><u>Country/setting:</u> World Café style focus group in Edmonton and Calgary, Alberta, Canada</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> - Written comments from focus groups were independently coded and themed into categories by two of the authors <p><u>Analysis:</u> Themes were coded and grouped together using thematic analysis</p>	<p>Findings:</p> <p>Themes identified through thematic analysis</p> <ul style="list-style-type: none"> - <i>Prior learnings on ACP</i> (many participants had previous experience either personally or professionally) - <i>Concerns about promoting ACP via community groups</i> (concerns with public understanding of ACP, legal and emotional issues, ACP necessity, documentation) - <i>Suggestions for normalizing ACP in Alberta</i> - <i>What community organizations can do to share ACP</i> <p>Recommendation to improve ACP</p> <ul style="list-style-type: none"> - Make ACP resources easily accessible to community groups - Provide education and facilitation opportunities for community groups - Simplify healthcare system processes and increase support for conversations - Use stories/make use of personal experiences - Increase marketing of ACP to the public - Capitalize on opportunities to integrate ACP into major life events - Include business partners in ACP - Standardize ACP terminology across the country 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Weak</p> <p>Issues:</p> <ul style="list-style-type: none"> - Bias as participants who attended focus group are actually interested in topic - Only conducted in English

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Carlozzi et al. (2018)</p> <p><u>Design:</u> A phenomenology, qualitative approach design</p> <p><u>Purpose:</u> To develop a measure to evaluate EOL planning</p>	<p><u>N:</u> 508 patients with pre-manifest or manifest Huntington Disease</p> <p><u>Country/setting:</u> Multiple Huntington Disease treatment centers in the USA</p> <p><u>Data collection and outcomes:</u> Qualitative focus groups explored factors that influence EOL</p> <p><u>Analysis:</u> Used Item Response Theory analysis on QOL tool and exploratory factor analysis</p>	<p>Findings: 4 factors were identified</p> <p>Factor 1: Legal planning for EOL</p> <ul style="list-style-type: none"> -advance directives - healthcare power of attorney - Living will <p>Factor 2: Preferences for EOL Care</p> <ul style="list-style-type: none"> - Nursing home care - Location of death preference - Hospice care <p>Factor 3: Preferences about death and dying</p> <ul style="list-style-type: none"> - Conversations about death and dying - Palliative care - Support to make decisions - Resuscitation preference - Funeral arrangements <p>Factor 4: Financial planning</p> <ul style="list-style-type: none"> - life insurance -finances -child care planning -estate planning 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Reliability and validity were preliminary - differences in state legality of EOL choices - recruitment was biased - reliability of self-report data

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> DeCoursey et al. (2021)</p> <p><u>Design:</u> Qualitative, phenomenology design</p> <p><u>Purpose:</u> To develop a generalizable ACP intervention for children and AYAs with serious illness using a multistage, stakeholder-driven approach</p>	<p><u>N:</u> 50 stakeholders in total (34 healthcare providers, 9 parents, 7 seriously ill AYAs)</p> <p><u>Country/setting:</u> Boston Massachusetts- healthcare providers from the Boston Children’s Hospital and Dana-Farber Cancer Institute, parents from the Courageous Parents Network or Boston Children’s Hospital, and the AYAs from Boston Children’s Hospital.</p> <p><u>Data collection and outcomes:</u> Thematic analysis on transcripts from 7 focus groups and 17 interviews</p> <p><u>Analysis:</u> 3 coding structures used, Data analysis assisted by NVivo12</p>	<p>Recommendations for Resource:</p> <ol style="list-style-type: none"> 1. Enhance provider knowledge and learning <ul style="list-style-type: none"> - Reported minimal formal instruction on ACP communication - Recommended provision of feedback, online training, use of role play or simulation 2. Make conversation timing flexible <ul style="list-style-type: none"> - 3 recommendations: at the end of a prolonged admission, at the “beginning” of admission or diagnosis, and in the outpatient setting 3. ACP conversations should occur with a trusted provider <ul style="list-style-type: none"> - Families should identify SDMs 4. ACP conversations should be easy to document and locate <ul style="list-style-type: none"> - Ensure conversations are in EMR 5. Prepare patients and families for ACP <ul style="list-style-type: none"> - AYAs want to prepare, reflect on present situation, and consider what is important to QOL 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Mild</p> <p>Issues:</p> <ul style="list-style-type: none"> - Difficult to generalize due to focus groups only done at two academic hospitals and did not include nonacademic general pediatricians. - Can only be applied to patients at tertiary hospitals - Recruitment was not random due to high care needs and consent for participation

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> DeMiglio et al. (2012)</p> <p><u>Design:</u> Longitudinal, qualitative design</p> <p><u>Purpose:</u> To explore the views and experiences of community-based palliative care team members and key informants about the barriers involved using a shared care model to provide care in the community</p>	<p><u>N:</u> 33 team members from 5 CBPCTs and 8 key-informants participated in interviews participated in focus group</p> <p><u>Country/setting:</u> Ontario, Canada</p> <p><u>Data collection and outcomes:</u> Focus groups and one-to-one interviews, with semi-structured interviews</p> <p><u>Analysis:</u> Thematic analysis and coding, and transcripts analyzed with 3-I framework exploring role of institutions, interests, and ideas</p>	<p>Findings:</p> <p>1. Institutional barriers</p> <ul style="list-style-type: none"> - Funding - Geographical organization of service delivery <p>2. Interest-related barriers</p> <ul style="list-style-type: none"> - Autonomy and time <p>3. Idea-related barriers</p> <ul style="list-style-type: none"> - Misperceptions about shared care - Lack of information/evidence 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Weak</p> <p>Issues:</p> <ul style="list-style-type: none"> - Results are not generalizable as only studied specific CBPCTs - Used purposive sampling.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Durieux et al. (2022)</p> <p><u>Design:</u> Qualitative design</p> <p><u>Purpose:</u> To understand caregivers' perceptions about patients' care experiences, the extent to which care was perceived a goal-concordant, and the factors that contextualized the EOL care experience</p>	<p><u>N:</u> 19 bereaved caregivers</p> <p><u>Country/setting:</u> 2 academic medical centers in Northeastern United States</p> <p><u>Data collection and outcomes:</u> Used semi-structured interviews to explore how much care was goal-concordant</p> <p><u>Analysis:</u> Thematic analysis using inductive and deductive approaches to coding</p>	<p>Three themes identified:</p> <p>1. Communication</p> <ul style="list-style-type: none"> - Communication clarity and accessibility - Importance of prognostic communication - Gaps in information <p>2. Relationships and humanistic care</p> <ul style="list-style-type: none"> - Ensuring relationships are fostered and whole-person care is provided. <p>3. Care transitions</p> <ul style="list-style-type: none"> - No continuity of care between institutions, inadequate sharing of information 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> weak</p> <p><u>Issues:</u></p> <ul style="list-style-type: none"> - inability to assess if care was goal-concordant with patient as they were deceased - could introduce bias with families responding - Small sample size from two closely affiliated institutions

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Forner et al. (2021)</p> <p><u>Design:</u> Retrospective, cross-sectional qualitative design</p> <p><u>Purpose:</u> To describe ACP documentation in adults who underwent surgery for oral cancer</p>	<p><u>N:</u> 301 patient charts reviewed; adult patients diagnosed with oral cancer</p> <p><u>Country/setting:</u> 2 academic hospitals in Ontario and Nova Scotia, Canada</p> <p><u>Data collection and outcomes:</u> Used chart reviews and descriptive statistics</p> <p><u>Analysis:</u> Statistical analyses performed with Chi-Square analysis for categorical variables, Student's <i>t</i>-tests for continuous variables</p>	<p>Key findings:</p> <ul style="list-style-type: none"> • Only 10.3% had ACP documented • Age, sex, and religion did not differ between those with or without ACP documentation • Patients with locally advanced disease were almost twice as likely to have ACP documentation (RR 1.97, 95%CI[0.98, 3.97]) • Complications during admission were associated with ACP documentation in unadjusted analysis (RR1.83, 95%CI[1.5, 2.4]) 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Moderate</p> <p>Issues:</p> <ul style="list-style-type: none"> - Only examined one type of cancer limiting generalizability - Misclassification bias may have been present - Exploratory nature of the design therefore unable to determine the precise cause of poor ACP - Statistical power was limited due to low ACP discussions and large sample size.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Fritz et al. (2020)</p> <p><u>Design:</u> Grounded theory, qualitative design</p> <p><u>Purpose:</u> To assess preferred content, best time to introduce ACP in the disease trajectory, and possible barriers and facilitators for participation and implementation</p>	<p><u>N:</u> 10 healthcare providers in focus group, 13 patient-SDM dyads and 6 SDMs of deceased patients partook in interviews (must have been diagnosed with glioblastoma)</p> <p><u>Country/setting:</u> Tertiary hospital in The Netherlands</p> <p><u>Data collection and outcomes:</u> -Semi-structured interviews done with patient-SDM dyads, patients, and SDMs of deceased patients -focus group of healthcare providers</p> <p><u>Analysis:</u> Descriptive statistics using SPSS software for participant characteristics, thematic analysis for semi-structured interviews and focus groups</p>	<p>Themes-</p> <p>Content of ACP program</p> <ul style="list-style-type: none"> • Current situation - overview of health issues, future perspective, available resources (psychological), relationship with family/friends • Worries and fears - Anxiety, Household, work, worries of proxies and patients • Supportive treatment - Preference and goals form, SDM, Palliative sedation, Euthanasia, withdrawal and withholding of treatment, supportive treatment EOL <p>Timing of ACP program</p> <ul style="list-style-type: none"> - Best after chemoradiation to ensure competency (identified by healthcare providers) - Families identified as early in disease course <p>Barriers and Facilitators</p> <ul style="list-style-type: none"> - Encourages conversations about ACP - Not wanting to think of EOL at beginning of trajectory 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Study is not generalizable due to setting (especially certain topics) - Purposive sampling

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Howard et al. (2022)</p> <p><u>Design:</u> Randomized control trial, quantitative design</p> <p><u>Purpose:</u> To evaluate the feasibility and efficacy of a serious illness decision aid in increasing the engagement of SDMs in ACP</p>	<p><u>N:</u> 45 patient-SDM dyads were randomly assigned the intervention immediately or to wait 3 months</p> <p><u>Country/setting:</u> Outpatient settings in Ontario, Canada</p> <p><u>Group1 :</u> receive ACP education immediately</p> <p><u>Group 2:</u> ACP education after 3 months</p> <p><u>Data collection and outcomes:</u> Outcomes measured were measuring changes in 17-item SDM ACP Engagement Survey and 15-item patient ACP Engagement Survey</p> <p><u>Analysis:</u> Statistical analysis of results of the studies, tests were two-sided at the significance level of 0.05</p>	<p>Key results:</p> <p>Intervention group</p> <ul style="list-style-type: none"> - Mean score on SDM ACP Engagement survey at baseline was 3.7 (SD=0.8) - Increased by a mean of 0.1 after intervention <p>Delayed intervention</p> <ul style="list-style-type: none"> - Mean score on SDM ACP Engagement Survey was 3.6 (SD=0.8), increased by 0.1 after intervention received after 3 months 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Weak</p> <p>Issues:</p> <ul style="list-style-type: none"> - Difficulties with retention and recruitment. Did not meet target sample size - Inability to blind participants - Study was statistically underpowered

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Howard et al. (2021)</p> <p><u>Design:</u> Prospective, cohort quantitative design</p> <p><u>Purpose:</u> To evaluate the effect of the Canadian Speak Up Campaign tools on engagement in ACP, with patients attending outpatient clinics</p>	<p><u>N:</u> 177 patients completed study</p> <p><u>Country/setting:</u> Outpatient primary care and cancer clinics in Ontario, Albert and British Columbia</p> <p><u>Data collection and outcomes:</u> All patients received Speak Up material. Baseline data obtained prior to patient receiving materials. Assessed the 55-item ACP engagement Survey</p> <p><u>Analysis:</u> Met statistical power for sample size, mean pre-post differences, confidence interval, and Cohen's d effect size coefficient calculated</p>	<p>Key results:</p> <ul style="list-style-type: none"> - Mean overall Behavioural Change Process Score was 2.9 (SD 1.8) at baseline and 3.5 (SD 0.7) at follow-up. Mean change of 0.5 (95%CO 0.5-0.7) with large effect size (Cohen's d 0.8) - Mean number of actions reported at baseline was 3.7 (SD 4.8) and 4.8 (SD 5.1) at follow up (mean change = 1.2 95% CH 0.6-1.6) 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - No control group - Results on generalizable to Caucasian English speaking population

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Kelly et al. (2021)</p> <p><u>Design:</u> Retrospective, quantitative design</p> <p><u>Purpose:</u> To assess the influence of patient intrapersonal factors including race, religion, level of depression, and cancer stage on overall preferences for ACP (presence of DNR, POA, and advance directives)</p>	<p><u>N:</u> 3,463 patient records reviewed, must have been diagnosed with cancer</p> <p><u>Country/setting:</u> Records from the Ohio State University James Comprehensive Cancer Center, United States of America</p> <p><u>Data collection and outcomes:</u> Variables extracted: race/ethnicity, birth year, year of diagnosis, marital status, gender, religion. Depression assessed by the Patient Health Questionnaire screening tool Outcomes- presence of DNR (any DNR, full code/assumed full code), POA (yes vs no), and advance directive (yes vs no)</p> <p><u>Analysis:</u> Descriptive statistics, multivariable logistic regression</p>	<p>Key results:</p> <ul style="list-style-type: none"> - 46.3% identified a specific religious affiliation or practice - 16.0% of participants had clinically relevant depression. - 51.6% had stage I or II cancer - 12.0% had an advance directive, 17.7% had a designated POA, 4.1% had a DNR - Caucasians had higher odds for: presence of advance directive (OR 3.10, 95%CI: 1.95-4.93), presence of POA (OR 1.57, 95%CI: 1.16-2.13) - Patients with clinical depression had higher odds: of a DNR (OR: 2.08, 95%CI 1.40-3.10; p<0.001), of a POA (OR 1.35, 95%CI 1.07-1.70; p=0.012) - Patients who identified with a religion had higher odds for DNR, POA and advance directive 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Moderate</p> <p>Issues:</p> <ul style="list-style-type: none"> - Study sample relied heavily on breast cancer - skewing data towards patients who are still alive receiving treatment - Information bias may be present

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Korfage et al. (2020)</p> <p><u>Design:</u> Cluster-randomized, quantitative design</p> <p><u>Purpose:</u> To test the implementation of ACP in patients with advanced cancer on perceived QOL</p>	<p><u>N:</u> 442 in intervention, 675 in control</p> <p><u>Country/setting:</u> Cluster trials in 23 hospitals in Belgium, Denmark, Italy, Netherlands, Slovenia, and United Kingdom</p> <p><u>Intervention group:</u> Provided scripted ACP educational materials to patients and families</p> <p><u>Control group:</u> received PC as usual</p> <p><u>Data collection and outcomes:</u> QOL assessed by the 10-item European Organisation for Research and Treatment of Cancer emotion functioning form Descriptive statistics were pulled from medical charts to assess for advance directives and use of medical care</p> <p><u>Analysis:</u> Statistical analyses were by intention-to-treat and multiple imputation procedure</p>	<p>Key results:</p> <ul style="list-style-type: none"> - Patients had an average of 1.3 ACP conversations with a mean length of 93 minutes in the intervention group - The education did not influence survival (P=0.57 and p=0.41 on follow up assessments 1 and 2, respectfully) - No statistically significant differences between intervention and control group in emotional functioning score - At 12 months post-inclusion, 10% of patients in intervention group had advance directives versus 3% in control group (p<0.001). - 67% of participants in intervention group found the ACP resources helpful while 16% found them stressful 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Fewer eligible patients in intervention group than control group - PC barriers identified in study: patients not interested in intervention, burden of illness, and gatekeeping by healthcare workers - Control group also had some ACP discussions skewing the data as it is a normal aspect of PC - Attrition of patients was high

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Lynch et al. (2022)</p> <p><u>Design:</u> Grounded theory, qualitative design</p> <p><u>Purpose:</u> To assess content of patient-verified summaries of health-related values among newly diagnosed cancer outpatients</p>	<p><u>N:</u> 67 patients completed patient values summary documents. Patients were diagnosed with either gastrointestinal cancer and myelodysplastic syndrome</p> <p><u>Country/setting:</u> Memorial Sloan Kettering Cancer Center, New York, USA</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> - Patients provided answers to semi-structured questions during meetings at the cancer center <p><u>Analysis:</u></p> <ul style="list-style-type: none"> - data extracted from medical record uploaded into Atlas.ti v 7.5. - themes coded by multiple authors 	<p>5 thematic constructs found-</p> <ol style="list-style-type: none"> 1. Cancer as threat/disruption <ul style="list-style-type: none"> - Physical impact - Treatment - Disease trajectory and death 2. Character <ul style="list-style-type: none"> - Functional independence - Maintaining identify & autonomy - EOL preferences/preferences in a crisis 3. Communication <ul style="list-style-type: none"> - Communication with loved ones - Communication with the medical team 4. Connection <ul style="list-style-type: none"> - Connection to loved ones - Connection to medical team 5. Sources of meaning and fulfillment <ul style="list-style-type: none"> - Maintain normalcy - Meaning & fulfillment 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Minimal patient variability as only one cancer center studied - Details in values provided to nurses was limited - Information bias as nurses interpreted patients wording

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Miyashita et al. (2020)</p> <p><u>Design:</u> Mixed-methods design</p> <p><u>Purpose:</u> To evaluate timing and factors affecting initiation of ACP discussions</p>	<p><u>N:</u> responses from 700 patients</p> <p><u>Country/setting:</u> 6 hospital outpatient departments (4 in Japan and 2 in Taiwan)</p> <p><u>Groups:</u></p> <p><u>Data collection and outcomes:</u> Survey provided to all patients to complete. Explored ACP discussions initiation and self-reported frailty scores in different case scenarios. Also elicited qualitative descriptions of underlying choice of early ACP discussions. Descriptive variables also were identified</p> <p><u>Analysis:</u> -Quantitative data used multiple imputation procedure and STATA/IC 15 for statistical analysis -Qualitative responses utilized content analysis</p>	<p>Key results:</p> <p>Quantitative Findings</p> <ul style="list-style-type: none"> - Older Japanese patients had a lower tendency compared to younger Japanese patients to select early ACP discussions (age: 66-75 vs 40-55, PR:0.76, 95% CI: 0.64-0.90) - Older Taiwanese patients had a higher tendency compared to young Taiwanese patients to select early ACP discussions (age:66-75 vs 40-55, PR: 1.15, 95% CI: 1.00-1.32) <p>Qualitative themes</p> <ol style="list-style-type: none"> 1. Wise precaution (preparing for future) <ul style="list-style-type: none"> - Forewarned is forearmed - Desire for autonomy - Desire to avoid troubling others 2. Postponed of ACP (discussions should only be done at EOL, less than 20% identified this) <ul style="list-style-type: none"> - Impossibility while health of knowing needs at EOL - Uneasiness at too-early talk of ACP 3. Universal inevitability at EOL (need to accept that discussions need to occur) 4. ACP discussions at healthcare providers' initiative (most patients welcome ACP discussions when providers initiate it) 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Results not generalizable to other populations - Despite scenario validation during development, unable to control attitudinal factors - Potential for non-responder bias

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Prater et al. (2023)</p> <p><u>Design:</u> A qualitative design</p> <p><u>Purpose:</u> To explore caregivers experiences and perceptions on the transition of their loved one to hospice, and develop a preliminary checklist of considerations for a successful transition</p>	<p><u>N:</u> 19 adult caregivers</p> <p><u>Country/setting:</u> Caregivers of patients who died in hospice in USA</p> <p><u>Data collection and outcomes:</u> Semi-structured interviews with caregivers</p> <p><u>Analysis:</u> Descriptive inductive and deductive thematic analysis</p>	<p>Key themes:</p> <ol style="list-style-type: none"> 1. Hospice intake <ul style="list-style-type: none"> - The education provided to families about hospice and the transition from active to comfort care - Identified ensuring updated advanced directives and POA 2. Preparedness <ul style="list-style-type: none"> - Hospice caregiver preparedness, pre-hospice preparation by medical providers, medical/societal attitudes on death, prior experience with hospice, caregiver with prior experiences as a clinician, false hope/denial, empathetic communication were all identified as sub-themes 3. Burden of care <ul style="list-style-type: none"> - Increased care families have to provide at EOL - Ensuring a teamwork dynamic with family and healthcare providers 4. Hospice resources <ul style="list-style-type: none"> - Early involvement of hospice - Ensuring religious and spiritual needs are met pre-hospice <ul style="list-style-type: none"> - Improved symptom management 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Not generalizable to other countries as hospice is unique to each country - Limited study participants - Information bias as only caregivers examined

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Pritchett et al. (2021)</p> <p><u>Design:</u> A phenomenology, qualitative design</p> <p><u>Purpose:</u> To assess the initiation of ACP discussions with patients in long term care</p>	<p><u>N:</u> 11 long term care residents</p> <p><u>Country/setting:</u> Missouri, USA</p> <p><u>Data collection and outcomes:</u> Semi-structured interviews using the developed ACP discussion guide</p> <p><u>Analysis:</u> Descriptive statistics and summative content analysis. Data analysis used Microsoft Excel and Nvivo 12 software</p>	<p>Key results:</p> <ul style="list-style-type: none"> • 54.5% of patients had no issues talking with family about ACP • Only 36.36% had an identified POA, and 36.36% had family identified as SDM with no formal paperwork • 54.5% of patients perceive their family would honour their wishes, 27.3% perceived their family would not offer support 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Weak</p> <p>Issues:</p> <ul style="list-style-type: none"> - Small sample size - Only recruited from one center - Not able to generalize due to sample

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Taneja et al. (2019)</p> <p><u>Design:</u> Grounded theory, qualitative design</p> <p><u>Purpose:</u> To describe how laypeople understand and make decisions for life-sustaining interventions when engaging in ACP</p>	<p><u>N:</u> 20 health participants over 55 years old</p> <p><u>Country/setting:</u> Ontario, Canada through public recruitment at community centers</p> <p><u>Data collection and outcomes:</u> Multiple semi-structured interviews with each participant</p> <p><u>Analysis:</u> Theoretical sampling used to explore results after first interviews. Data collection and analysis were iterative and ongoing.</p>	<p>4 major themes identified from interviews:</p> <ol style="list-style-type: none"> 1. Lack of knowledge of life-sustaining interventions towards EOL <ul style="list-style-type: none"> - Lacked knowledge in modern life-saving measures - Participants recognized the terms but not the meaning of them - Misconceptions about DNR and POA - Misconceptions about outcomes of life-sustaining treatments 2. Confidence in SDMs ability to make the right decision <ul style="list-style-type: none"> - All participants had an identified POA - Participants voiced that POAs would follow their wishes but do not remember explicit ACP discussions 3. Expression of preferences in terms of unacceptable functional outcomes <ul style="list-style-type: none"> - Preferences revolved around values based on ‘unacceptable’ outcomes - Wishes based on QOL 4. Decisional conflicts while articulating preferences <ul style="list-style-type: none"> - Unable to make decisions once options presented 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Participants were members of general public and did not explore ACP discussions when unwell. - Convenience sampling (homogenous sample) - Did not evaluate whether ACP discussions were had after study

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Temel et al. (2017)</p> <p><u>Design:</u> Randomized control, quantitative design</p> <p><u>Purpose:</u> To evaluate impact of early integrated PC in patients with newly diagnosed cancer</p>	<p><u>N:</u>350 patients with new lung or noncolorectal GI cancer. Two groups</p> <p><u>Country/setting:</u> patients newly diagnosed at Massachusetts General Hospital, USA</p> <p><u>Early PC group:</u> Randomly assigned 175 patients received early integrated PC</p> <p><u>Regular care group:</u> Randomly assigned 175 received normal oncological care</p> <p><u>Data collection and outcomes:</u> Intervention group met with a PC clinician monthly until death, and control group only met PC when requested. Assessed change in QOL</p> <p><u>Analysis:</u> Statistical analysis done with STATA software and R software. Independent t-tests and ANCOVA also used</p>	<p>Key results:</p> <ol style="list-style-type: none"> 1. PC visits <ul style="list-style-type: none"> - Mean number of visits by week 24 for early PC group was 6.54 (range, 1-14) and 0/89 (range, 0-7) in regular care group 2. QOL and mood <ul style="list-style-type: none"> - Early PC patients reported a mean 1.59-point increase in QOL from baseline compared to a 3.40-point decrease in usual care group 3. Prognostic understanding and communication <ul style="list-style-type: none"> - Early PC group were more likely to report knowing their prognosis was helpful with choosing treatment compared to usual care (96.5% v 89.8%, p<.289) and coping with disease (97.3% v 83.6%; p<.001) - At 24 weeks, early PC group reported EOL discussions with oncologist compared to usual care group (30.2% v 14.5%, p=.004) 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Moderate</p> <p>Issues:</p> <ul style="list-style-type: none"> - Nonblinded study - Sample size limited ability to assess outcomes by cancer type - Study was done at a single institution, limiting generalizability

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Temel et al. (2010)</p> <p><u>Design:</u> Randomized control, quantitative design</p> <p><u>Purpose:</u> To examine the effect of early PC on patient reported outcomes and EOL care newly diagnosed with lung cancer</p>	<p><u>N:</u> 151 patients randomly assigned to early PC group or usual care group</p> <p><u>Country/setting:</u> Patients newly diagnosed with lung cancer at Massachusetts General Hospital</p> <p><u>Early PC group:</u> 77 patients enrolled</p> <p><u>Usual care group:</u> 74 patients randomly assigned</p> <p><u>Data collection and outcomes:</u> Patients in early PC group met with palliative physician within 3 weeks of diagnosis and monthly afterwards until death. Assed for QOL and mood</p> <p><u>Analysis:</u> Statistical analysis was performed using SPSS software, with descriptive statistics using two-sided Fisher's exact tests and chi-square tests, and independent-samples Student's t-tests for continuous variables. Multivariate linear regression analyses also used.</p>	<p>Key results:</p> <ol style="list-style-type: none"> 1. PC visits <ul style="list-style-type: none"> - Average number of PC visits in early PC group was 4 (range, 0-8). Only 10 patients in usual care group had a PC consult within 12 weeks 2. QOL and mood outcomes <ul style="list-style-type: none"> - Patients in early PC group had higher QOL measurements at 12 weeks with a 2.3 in in mean score, and 2.3 decrease in scores in usual care group 3. EOL care <ul style="list-style-type: none"> - 70% of patients died at analysis of EOL care - Within this subsample, more from the usual care group were deceased than early PC group (54% vs. 33%, p<0.05) - Less patients had ACP decisions in medical records (28% vs. 53%, p=0.05). 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Participants are from only one site - Sample lacked diversity in population therefore difficult to generalize - Participants and clinicians were nonblinded

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Vanbutsele et al. (2018)</p> <p><u>Design:</u> Randomized control, quantitative design</p> <p><u>Purpose:</u> To examine whether early and systematic integration of PC alongside usual psychosocial oncological care provides added benefit compared to usual care.</p>	<p><u>N:</u> 186 patients randomly assigned to usual care group or early PC integration</p> <p><u>Country/setting:</u> Patients with advanced cancer at Ghent University Hospital in Flanders, Belgium</p> <p><u>Usual care group:</u> 94 randomly assigned</p> <p><u>Early PC integration:</u> 92 randomly assigned</p> <p><u>Data collection and outcomes:</u> Patients in early PC integration group received PC and ACP education to measure for changes in QOL</p> <p><u>Analysis:</u> Multivariate regression analyses were adjusted for baseline scores, Mann-Whitney U tests examine differences, a Kaplan-Meier plot and log-rank test used in SPSS software</p>	<p>Key results:</p> <ul style="list-style-type: none"> - Significant improvement of QOL when receiving early PC. QOL scores of early intervention group was 61.98 (95%CI 57.02-66.95) versus usual care score of 54.39 (49.23-59.56) - No differences in mean survival times between the two groups 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - Only one sample site used, homogeneity in sample - Cross-over effect could have been introduced - Study was nonblinded - Selection bias was potentially introduced - Adherence to study was low

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Vashisht et al. (2023)</p> <p><u>Design:</u> Mixed methods design</p> <p><u>Purpose:</u> To explore physicians' experience with ACP including barriers/facilitating factors encountered when initiating/conducting ACP discussions with South Asians</p>	<p><u>N:</u> 11 primary care physicians and 11 hospitalists</p> <p><u>Country/setting:</u> British Columbia, Canada with physicians who provide care to South Asians</p> <p><u>Data collection and outcomes:</u> Interviews done with each physician</p> <p><u>Analysis:</u> Content and thematic analysis to analyze physician responses. SPSS softer was implemented for quantitative analysis using Fisher's exact tests and Mann-Whitney <i>U</i> tests</p>	<p>Key results/themes:</p> <ul style="list-style-type: none"> - Fostering ACP discussions - Forms and content of ACP discussion - Tools and resources - Physicians evaluation of ACP discussion - Culture - Family dynamics - COVID-19 - Comparisons - suggestions 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> - selection bias as physicians had to want to participate - impact of COVID-19

Appendix B

Environmental and Consultation Report

The diagnosis of a life-limiting illness is life-altering to the patient and their family, resulting in the need for difficult conversations and decisions to be made before the patient was planning. Palliative care [PC] emphasizes the well-being of patients and families coping with serious medical conditions at any point in their disease trajectory (Greer et al., 2013). PC providers assist in helping patients understand their diagnosis and treatment goals and facilitate informed decisions about their care throughout the illness trajectory, not just at the end of life [EOL] (Temel et al., 2017). Advance care planning [ACP] is a process that supports anyone at any age or stage of health to understand and share their personal values, goals, and preferences for when they lose the capacity to make decisions for themselves (Howard et al., 2022), and is essential to PC. ACP is a shared decision-making concept as the patient provides insight into their goals, values, and preferences. At the same time, the clinician supports them and outlines the benefits, risks and uncertainties of the treatment options based on experience and scientific evidence (Plaisance et al., 2022).

The need for a resource guide for patients diagnosed with advanced cancer has been identified as the number of patients diagnosed with advanced cancer is increasing, requiring an increase in the number of resources. A resource guide that assists patients in speaking with their families about their advance care planning wishes, goals, and preferences, planning and communicating wishes have been identified as a priority for a Palliative Care Community Team [PCCT] that supports patients diagnosed with end-stage cancer in Northumberland County, Ontario, Canada. In my role as a Hospice Clinical Navigator with the PCCT, I have seen a lack of resources for patients newly diagnosed with cancer in support of their EOL planning. The information in the available resources is only sometimes beneficial or required. Through my role, I often obtain additional information from various sources to present to patients which is not

contained in one document. I am usually the first to initiate difficult conversations with them and their family, and it would be beneficial to provide them with a printed resource to review on their own time and guide them through the difficult conversations with their families. Patients and families often ask for resources to support them in having discussions. However, the only resource I have available is the information, which is only partially relevant as it is focused on supporting people while still healthy. My colleagues often ask for resources for their patients, and collectively, we have decided that a resource developed with our patient's needs and the gaps we have identified is important.

A literature review was completed, and an environmental scan and consultations were conducted to review available resources and determine what the community would find necessary for inclusion. Environmental scans aim to find available information to inform decision-making (Canada School of Public Service, 2022). Environmental scans are relevant to decision-making and planning in the healthcare sector to inform program development (Charlton et al., 2019). Environmental scans have been used to gather information for identifying service gaps, evaluating community and patient needs, and supporting quality improvement initiatives (Charlton et al., 2019). An environmental scan has been conducted on available resource guides for patients on EOL planning and ACP discussions.

The Canadian Nurses Association [CNA] has identified that advanced practice nurses are expected to be able to consult and collaborate with colleagues to develop quality improvement strategies (2019). It is important for nurses to consult with other healthcare providers to ensure quality programs are being developed, and it is a requirement for the practicum project to meet advanced practice competencies. Consultations with other healthcare providers were done with key stakeholders of PC information in PC to determine what information should be included in a

resource guide for patients.

I will review the environmental scans' objectives, consultations, and data collection methods. I will identify how the data was managed and analyzed. The environmental scan findings and consultations will be presented, and the implications will be reviewed. The barriers and gaps identified will also be discussed.

Ethical Considerations

I completed the Health Research Ethics Authority [HREA] Screening Tool before the environmental scan and consultations. The completed HREA screening tool for my proposed practicum project is found in Appendix A. After completing the HREA screening tool, I determined I did not need research ethics approval based on the exemption list of the HREA tool. The research exclusively relies on publicly available information that is legally accessible. The proposed project is a quality improvement project for my workplace; therefore, no specific research question is being proposed either, as the data will be used exclusively for improvement. Before conducting the consultations, I described the purpose of the survey, and they obtained implied consent by completing the survey. No identifying information was included in the consultation survey. The data obtained from the consultations were kept on my password-protected computer. Once themes were identified and data was entered into the Word document, the original paper copies of the surveys were placed in a confidential shredding bin, and the Word document will be deleted once the practicum project is completed.

Methods

An environmental scan and consultations were conducted concurrently with the literature review. I created a consultation and environmental scan plan with objectives, settings, samples,

data collection, data management, and analysis in consultation with my practicum supervisor before initiating the consultations and environmental scans.

Environmental Scan Objectives

The objective of the environmental scan was to review the available resources for patients used by healthcare providers for patients diagnosed with advanced cancer. The goal was to find resources online and those utilized by organizations that support similar patients. I spoke with other PCCTs to determine the resources they used and reviewed available documents to determine what may be essential to include in the proposed practicum project. I did a Google search on the Intranet for specific resource guides utilized by similar organizations that provide the same support as the Palliative Care Community Team or support patients diagnosed with advanced cancer. Any resources that were found during my literature review were also examined. The resources found were in written form and online. The environmental scan allowed me to review the available resources and understand what information is beneficial for health providers who support patients with advanced cancer. The environmental scan will show me what is available and what information is being provided to the public by those who support patients similarly to those I support.

Data Collection

The data was collected by reviewing the websites of identified organizations by reviewing the sections of their website for patients and the resources available online. Websites searched include Hospice Palliative Care Ontario, Princess Margaret Cancer Centre, Hospice Toronto, Government of British Columbia, Advance Care Planning Ontario, and Advance Care Planning Canada. After reviewing each website, further sources were reviewed as the resources

they use were found through other organizations. These include Plan Well Guide, the Ontario Caregiver Organization, the College of Family Physicians of Canada, and Canadian Virtual Hospice. Many of the organizations utilize the same resources. I reviewed all documents available to clients on the website.

Information will be sourced from organizations such as the other PCCTs and the primary cancer clinic, Durham Regional Cancer Centre [DRCC], where my patients receive treatment. I reviewed the information from the DRCC and will look at the websites of the other five PCCTs offering palliative care support. I contacted the other Hospice Clinical Navigators with the other five PCCTs to ask what resources they use and have available for their clients. A copy of the email inquiry is included in Appendix B.

The resources found were printed and reviewed. A chart was used to organize important information from each resource and for all resources identified for review to ensure consistency and quality of resource review. I looked for information relevant to my target population that is used in my role as a hospice clinical navigator. Information received by the providers (i.e., other hospice clinical navigators, palliative navigators, and hospitals) was also added to the chart. The completed chart is found in Appendix C.

Consultation Objectives

The objective of the consultations was to determine what information should be included in the proposed practicum project and what they feel is missing in the community. I asked three physician colleagues, clinical staff working in the residence, and other members of the PCCT what they think is missing in the community and what would be necessary to provide care. Clinical staff support patients at the end of their lives and have ideas on how to support patients

earlier in their journey before being at the end of life. The clinical staff comprises Registered Nurses, Registered Practical Nurses, and Personal Support Workers. The other members of the PCCT were surveyed. They include a bereavement counsellor, hospice services coordinator, supportive care counsellor, clinical manager, intake lead, and another hospice clinical navigator, and all have various professional backgrounds. The community manager was also consulted as she was previously the bereavement coordinator before the bereavement counsellor started. Each has different roles in supporting patients, their families, and the community, which has resulted in a broader understanding of what has been identified as important to the community. The three primary palliative physicians were consulted to determine what they feel is important to include and what is missing in the community. The three physicians provide palliative support to clients in the community and refer their clients to the community team that I support. The survey questions are found in Appendix D.

Data Collection

The consultations included a survey provided to participants that assessed what they felt was essential to include in the proposed project. The survey was emailed via Survey Monkey and provided to all participants. Initially, the survey would be provided in person and on paper. Still, with most of the intended participants working shift work, it was easier to collect data by sending an online version. The survey allowed ample space for my colleagues to complete questions and provide their ideas and concerns about the project and what to include.

The surveys were collected, and the answers to each question were placed in a chart. Shared ideas and suggestions were grouped in each section. The completed chart is found in Appendix E. Ideas repeated by multiple individuals were only reported once.

Data Analysis

Content analysis was used to analyze the resources and complete the environmental scan. Each resource was reviewed, and terms such as Advance Care Planning, End of Life, Caregivers, and Quality of Life will be identified. Common themes were identified and analyzed to determine the relevancy and importance of the information. The information deemed necessary in the reviewed resources was identified and included in the proposed practicum project. The relevant information is presented in Appendix C.

Descriptive statistics were not used in the data analysis, but content analysis was on completed surveys during the consultations. The data was entered into a table in Microsoft Word, and common responses were presented to each question. The content was reviewed to identify themes and the information that most participants would find beneficial, such as different topics or subsections. The percentages of the identified themes and key information are presented in the consultation findings.

Findings

The environmental scan findings will be presented by discussing each resource and website. The data is presented in a chart in Appendix C. The findings of the consultations will be presented by type of participant: physician, clinical staff, and PCCT staff member. All survey responses are found in Appendix E.

Environmental Scan

The environmental scan reviewed several websites for the guides and resources they provide to patients diagnosed with advanced cancer.

Resources from other PCCTs

I sent an email inquiry to the other six PCCTs that provide similar support. The email inquiry is found in Appendix B. No responses were received to my email inquiry from the other organizations. This may suggest that limited resources are available to the public or that they are developing their own.

Plan Well Guide

The Plan Well Guide was found through an online search for ACP resource guides and is Canadian. There are multiple guidebooks available, and each has its topic that it focuses on. All books are standalone and do not combine more than one topic. The purpose of the resource is to learn what serious illness is, how to prepare for serious illness decision-making, identify values, an in-depth understanding of what cardio-pulmonary resuscitation and Intensive Care Unit support are available, and create a letter for the healthcare team to communicate values and treatment preferences (Plan Well, n.d.). The guides were developed in consultation with other organizations. The guides are only available in electronic format; only one is complimentary, while the others have a significant associated cost. To view the free guide, an online account must be made. Due to the limited ability to look at the guides, the costs, and the inability to have a physical copy of the resource, I will not recommend this resource to my patients. I will not be using it to guide the development of my resource.

Advance Care Planning Canada

Advance Care Planning Canada is the primary support resource for all reviewed websites. It is an online resource for patients, families, and healthcare providers on ACP. An online workbook for patients on ACP allows them to download it to a PDF for printing. Their Quick

Booklet is designed to assist patients in understanding the five steps of ACP and helping patients think about their values and wishes for the future (Advance Care Planning Canada, 2024b). They also have a podcast that invites guest speakers to talk about life planning, ACP, and other topics. All resources are available free of charge and can be printed for easy provision. The benefit of this website is that multiple printable options are patient-orientated and have resources for healthcare providers. Advance Care Planning Canada was created as an initiative for the Canadian Hospice and Palliative Care Association [CHPCA] to develop a national strategy to implement ACP in Canada, raise the awareness of Canadians on the importance of ACP, and provide tools to engage in the ACP process effectively (Advance Care Planning Canada, 2024a). While the goal of the resource and program was to develop a national framework on ACP, Ontario and Prince Edward Island have province-specific guidebooks available.

Advance Care Planning Ontario

Advance Care Planning Ontario is a derivative of Advance Care Planning Canada. It prioritizes information specific to Ontario developed by the governing body of hospice and palliative care in Ontario, Hospice Palliative Care Ontario [HPCO]. The website explains what ACP is and the ACP process. Previously, this website and program were named Speak Up Ontario, which is how some healthcare providers still refer to the ACP workbook. An online workbook is available that allows you to print the completed online workbook. The benefit of Advance Care Planning Ontario is the ability to purchase and order physical copies of the workbook. The PCCT uses the printed copy and provides it to patients as requested. The benefit of this program is the ability to provide a physical copy to patients, but the information included is limited to identifying values and substitute decision-makers [SDM]. Advance Care Planning Ontario's online guide allows patients to follow six fictional patients with different medical

conditions and how they follow the ACP process. The website is difficult to navigate, but the printed workbook is easy to follow; not all information included is used by the PCCT. Therefore, I will utilize some of the information in the resource to develop my practicum project.

Dying With Dignity Canada

Dying with Dignity Canada is a national human-rights charity committed to improving quality of life, protecting EOL rights, educating on patients legal EOL options, including their right to medical assistance in dying [MAID], and the importance of ACP (Dying with Dignity Canada, 2021). An ACP kit is available online and can be printed. The information that is beneficial and appropriate for developing my proposed practicum project is ensuring patients think of their values and wishes, consider medical scenarios, determine EOL preferences, and appoint an SDM. The workbook encourages patients to document their directions in an advance directive that is not legally binding for healthcare professionals. It is often a topic brought up during my assessments; therefore, I will include a section on advance directives and living wills in my resource to ensure patients are educated.

Hospice Toronto

Hospice Toronto utilizes an outdated ACP guide developed by the Government of Ontario. It is a PDF copy of the guide that reviews various important aspects of ACP. I tried to find the original copy from the Ontario Government but failed to find it. I followed the link in the PDF to the appropriate government site, but it is no longer available to read except on the hospice website. Therefore, I will not use this guide to influence the proposed one.

Government of British Columbia

The government of British Columbia has created its own ACP guide for patients to review and assist with their ACP process. The resource was found by conducting an online search for ACP guides. Initially developed in 2020, it has multiple online language options for patients and families to review. The guide is a PDF to print and can be ordered for a fee for organizations requiring a physical copy. The guide is very similar to the available guide through Advance Care Planning Ontario; therefore, it will guide the proposed project's development. The document also talks about advance directives, which will not be included similarly to the Dying with Dignity guide.

In the next section, the results of the consultations will be presented, and common themes will be explored.

Consultations

Surveys were sent to various professionals to complete the consultations. The survey was sent to three palliative physicians, seven PCCT members and twenty-six clinical staff. The complete responses to the survey are found in Appendix E.

Palliative Physicians

Two of the three palliative physicians responded to the survey, a 66.66% response rate. 100% of the respondents knew of any available ACP resource, and 100% stated that no topics should be avoided. Both thought the guide would be helpful and should be provided before they are involved in care. The topics the physicians identified as important to include are why a DNR is okay, services available in the community, organ donation, and identifying POAs, wills, and POAs. Both identified that personal support needs to be added to the community, but that support cannot be improved with the development of the guide. The physicians provided

information and topics that will be included in the development of the guide.

Palliative Care Community Team

Four members of the PCCT responded with a response rate of 57.1%. 50% of the respondents were unaware of resources, and 100% stated no topics to avoid. 100% of the participants agree that a resource would be beneficial. The guide should be distributed to all healthcare providers in the county and to the patients in the community. The respondents offered that the resource should be printed but have small and large versions of the information distributed depending on the patient's disease trajectory. All participants voiced a need for a guide in the community.

Clinical Staff

The survey was sent to twenty-six clinical staff with only one person responding, a response rate of 3.85%. The respondent was unaware of any resource guides besides the Cancer Care Ontario website and that end-of-life and ACP are not publicized to support the caregivers. The topics identified as important to include in the resource were simplifying how to navigate the system, the importance of the documents for families, and simplifying the wants and needs of people at the end of life.

Implication of Findings

The information obtained from the consultations and environmental scan will guide the development of the proposed resource. The important topics the consultants identified will include wills, substitute decision-makers, ACP, and resources in the community. The environmental scan showed that some resources are available online from various organizations but are not all appropriate for the population I serve. I will not mention capacity in my resource

as it is not part of my scope of practice. I will also not be speaking too much on advanced directives, which are identified in many ACP resources. Information provided on the Advance Care Planning Ontario and Canada websites will be used as the primary source of information on ACP.

The information obtained in the consultations is extremely valuable as the participants are key palliative healthcare professionals in Northumberland County. There is a lack of resources in the county. The information obtained through the environmental scan and consultations will be used to develop a relevant guide for patients diagnosed with advanced cancer in Northumberland County.

Barriers and Gaps

The environmental scan and consultations identified barriers and gaps to implementing an ACP program in Northumberland County. The environmental scan showed that limited resources are currently available for use and are not entirely relevant to the community I support. The cost of providing the available resources is increased; therefore, ensuring a cost-reduction option for patients is a priority. The consultations identified more significant gaps in the literature and community that may not be addressed by implementing an ACP resource. Human resources were identified as a barrier to accessing proper end-of-life care. The lack of personal care support, coordinated care, and reliable service were identified by 57% of the consultation participants as currently missing in the community. The implementation of ACP late in the disease trajectory is a barrier to care and is currently the case in Northumberland County. Participants identified that early engagement in ACP and having conversations before a crisis are important but are not being done; therefore, the guide will assist. Although the research has shown gaps, the goal of the resource guide is to reduce the gaps and barriers to accessing

appropriate ACP in Northumberland County.

Conclusion

The environmental scan and consultations are important to ensure appropriate information is included in the proposed practicum project. The environmental scan found minimal available and appropriate resources on ACP. The resources were reviewed, and relevant information will be included in developing a new guide. The consultations were meaningful in reviewing what information stakeholders find essential and what is missing in the community. Although participation was low, the information obtained through the consultations is crucial to developing the ACP resource guide. The need for an ACP resource in Northumberland County has been identified, and the information obtained through the consultations and environmental scan is pertinent to developing a resource for clients I support with advanced cancer.

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Appendix i: Health Research Ethics Authority (HREA) Screening Tool

Student Name: Julene Preece

Title of Practicum Project: Everything I Need to Know to prepare for my End of Life: A Guide for Those Diagnosed with a Life-Limiting Illness

Date Checklist Completed: May 22nd, 2024

This project is exempt from Health Research Ethics Board approval because it matches item number 1,3,4 from the list below.

1. Research that relies exclusively on publicly available information when the information is legally accessible to the public and appropriately protected by law; or the information is publicly accessible and there is no reasonable expectation of privacy.
2. Research involving naturalistic observation in public places (where it does not involve any intervention staged by the researcher, or direct interaction with the individual or groups; individuals or groups targeted for observation have no reasonable expectation of privacy; and any dissemination of research results does not allow identification of specific individuals).
3. Quality assurance and quality improvement studies, program evaluation activities, performance reviews, and testing within normal educational requirements if there is no research question involved (used exclusively for assessment, management or improvement purposes).
4. Research based on review of published/publicly reported literature.
5. Research exclusively involving secondary use of anonymous information or anonymous human biological materials, so long as the process of data linkage or recording or dissemination of results does not generate identifiable information.
6. Research based solely on the researcher's personal reflections and self-observation (e.g. auto-ethnography).
7. Case reports.
8. Creative practice activities (where an artist makes or interprets a work or works of art).

For more information please visit the Health Research Ethics Authority (HREA) at <https://rpresources.mun.ca/triage/is-your-project-exempt-from-review/>

Appendix ii

Copy of Email Inquiry

Hello,

My name is Julene Preece and I am one of the Hospice Clinical Navigators with the Palliative Care Community Team for Northumberland County. I am currently completing my Master of Science in Nursing at the Memorial University of Newfoundland and working on completing my final practicum project. I am creating a resource guide for clients I support who are diagnosed with advanced cancer and am inquiring about the resources you provide to clients. Resources may include Advance Care Planning information, End of Life Planning guides, and What to Expect guides.

I look forward to hearing from you.

Thanks,

Julene Preece, RN, BScN, CHPCN(C)

Hospice Clinical Navigator

Community Care Northumberland

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www.commcare.ca

Appendix iii

Resource Guide Review Table

Name of Resource	Relevancy to Target Population	Advantages of Resource	Disadvantages of Resource	To Be Used to Influence Guide
<p>Plan Well Guide</p> <p>https://planwellguide.com/guides/</p>	<p>Relevant to anyone looking for ACP information</p>	<ul style="list-style-type: none"> • Multiple options are available online • Plain language used 	<ul style="list-style-type: none"> • Must pay for all guides but one • free guide requires a free account • cannot print until completed online 	<p>No</p>
<p>Advance Care Planning Canada</p> <p>https://www.advancecareplanning.ca/individuals-families/</p>	<p>Created to be used by anyone prior to a diagnosis</p>	<ul style="list-style-type: none"> • National Initiative • Patient-orientated • Online program is interactive • Ability to print a copy to complete on paper 	<ul style="list-style-type: none"> • Printed copies not available to order, must be printed • Website can be difficult to navigate 	<p>Yes</p>
<p>Advance Care Planning</p>	<p>Developed for the general public and to be completed prior to</p>	<ul style="list-style-type: none"> • Provincial initiative • Patient-Orientated 	<ul style="list-style-type: none"> • Not all information is appropriate in 	<p>Yes</p>

<p>Ontario</p> <p>https://www.advancecareplanningontario.ca/</p>	<p>diagnosis</p>	<ul style="list-style-type: none"> Printed copied are available to order Used by most programs in Ontario Resources for client and healthcare professionals available 	<p>printed guide</p> <ul style="list-style-type: none"> Website can be difficult to navigate 	
<p>Dying with Dignity Canada</p> <p>https://dyingwithdignity.ca/wp-content/uploads/2023/03/DWDC_2024ACPkit_ENG.pdf</p>	<p>Developed for the general public to guide ACP discussions.</p>	<ul style="list-style-type: none"> Patient-orientated language Provides general overview Interactive and ability to insert personal answers 	<ul style="list-style-type: none"> Talks about clinical frailty which is not for the public to decide Speaks of Advance Directives which are not legally binding in Ontario 	<p>Yes</p>
<p>A Guide to Advance Care Planning</p> <p>Utilized by Hospice Toronto</p>	<ul style="list-style-type: none"> Was originally developed for Ontario’s Strategy for Alzheimer Disease and Related Dementias -Not applicable to 	<ul style="list-style-type: none"> Identifies capacity Identifies the importance of SDM Identifies steps of ACP 	<ul style="list-style-type: none"> list of community resources are out of date Too much information on assessing 	<p>No</p>

<p>https://hospicetoronto.ca/care/wp-content/uploads/2020/07/guidetoadvancecareplanning.pdf</p>	<p>advanced cancer but ACP is important for all diseases</p>		<p>capacity</p> <ul style="list-style-type: none"> • focused on patients with dementia 	
<p>Government of British Columbia</p> <p>https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning</p>	<p>Appropriate for all individuals looking to identify ACP wishes</p>	<ul style="list-style-type: none"> • Multiple languages available • Many resources available that align with provincial legislation 	<ul style="list-style-type: none"> • Must download guide before printing 	<p>Yes</p>

Appendix iv

Copy of Questionnaire for Consultations

This survey is circulating to generate your thoughts on what should be included in an end-of-life planning guide. For the practicum project for my Master of Science in Nursing degree, I am developing a resource guide to provide to clients to assist them in planning for their end of life. The guide will be given to clients in the community who are newly diagnosed to assist them in preparing for the future. To develop the resource and make it relevant to the clients I serve and the community, I need your help and value your input. Please complete the following survey. Your answers will remain anonymous.

Are you aware of any currently available resource guides for End-of-life?

What topics should I include in a resource guide for clients?

What do you think is currently missing in the community for end-of-life?

Are there any topics I should avoid putting in my resource? And Why?

Would a guide be helpful for the clients you service and support? And Why?

What would be most helpful in supporting your clients through the end of life?

What format should I use to develop the guide (i.e., binder, printout)?

How should I distribute the guide?

Comments?

Thank you for completing this questionnaire. Your participation and answers will assist me in developing the resource guide to support our community.

Appendix v

Survey Results

Palliative Physicians -Sent to three; two replied

Questions	Responses
Are you aware of any currently available resource guides for End-of-Life?	No (100%)
What topics should I include in a resource guide for clients?	<ul style="list-style-type: none"> ● “Where When With who Why a dnr is ok” ● “Services available in the community. Organ donation. DNR. Talking to family about advanced directives and who the POA is. Wills and POA”
What do you think is currently missing in the community for end-of-life?	<ul style="list-style-type: none"> ● “Adequate PSW support” ● “Your guide”
Are there any topics I should avoid putting in my resource? And Why?	No (100%)
Would a guide be helpful for the clients you serve and support? and Why?	<ul style="list-style-type: none"> ● “Yes” ● “Better suited to before we are involved. Once we are involved we all tell them what’s available and what they should do. This needs to be in FD offices or given electronically on people’s 65th birthday!”
What would be most helpful in supporting your clients through the end of life?	<ul style="list-style-type: none"> ● “More psw support” ● “Coordinated care, coordinated communication”
What format should I used to develop the guide? (i.e. binder, printout, etc?)	<ul style="list-style-type: none"> ● Printout ● Electronic
How should I distribute the guide?	<ul style="list-style-type: none"> ● “I would or PCCT” ● “As above. With notice from the govt.

	“Hey you’re old. Applying for CPP? BTW look at this””
Comments:	“This is a great idea and needed”

Palliative Care Community Team - Sent to seven, four replied

Questions	Responses
Are you aware of any currently available resource guides for End-of-Life?	<ul style="list-style-type: none"> ● No (50%) ● Yes (50%) <ul style="list-style-type: none"> ○ “I have seen some workbooks at chapters and digital guides online” ○ “See all caregiver support programs”
What topics should I include in a resource guide for clients?	<ul style="list-style-type: none"> ● “Will; POA (important people names and numbers) copies & where to find details; Financial institutions list and contact people; Funeral wishes and ceremony details; hopes and wishes to your family for the future; physical, emotional, spiritual and practical education for the dying and the caregivers” ● “See above for list of topics.” ● “What to expect ACP Different Supports available in community Caregiver supports Importance of supporting the whole person, not just pain and symptom management Info on death at home and what that entails Options for Eol” ● “An explanation of choice in care and how to understand all options including comfort only and what that means. Community services/ local resource list. Maid who does it Support groups throughout county Equipment borrowing resources Ducks in a row ACP Funeral options including home. (So people are educated on ideas that can be more affordable)”
What do you think is currently missing in	<ul style="list-style-type: none"> ● “People brave enough to have these discussions; people for those who have no family;”

<p>the community for end-of-life?</p>	<ul style="list-style-type: none"> ● “Define end-of-life. Missing resources in Northumberland County?” ● “Early engagement education” ● “Reliable services at minimal costs”
<p>Are there any topics I should avoid putting in my resource? And Why?</p>	<ul style="list-style-type: none"> ● “It’s better to have too much; more choice” ● No (75%)
<p>Would a guide be helpful for the clients you serve and support? and Why?</p>	<ul style="list-style-type: none"> ● “Yes; another conversation before the crisis” ● “Yes. To help build confidence, open up spaces for conversation and get the business’ of planning for end-of-life, however it’s defined out if the way and make room for living.” ● “Yes, clients and caregivers can be overwhelmed and having a guide they can pull out at anytime to help answer questions or what to do would be helpful. Also to know what to expect can help prepare individuals and their caregiver.” ● “Yes. Understanding all the options, services and things that are often not known to the general public until they discover them”.
<p>What would be most helpful in supporting your clients through the end of life?</p>	<ul style="list-style-type: none"> ● “The crystal ball; more caregivers that look at the whole person” ● “Depends on the person and the context of their lived experience. My best guess would be someone to really listen to them.” ● “Knowing there’s something they can turn to in a moment of desperation that provides them an answer” ● 1 skipped
<p>What format should I used to develop the guide? (i.e. binder, printout, etc?)</p>	<ul style="list-style-type: none"> ● “Depends. Maybe good to check consider the preferences of the demographic.” ● “Small binder for community teams but a print out with quick phone numbers and websites with simple explanation of what each resource is for maybe client families” (50%) ● “Electronic and hard copies meet all needs; the challenge will be keeping it up to date and available”

How should I distribute the guide?	<ul style="list-style-type: none"> • “To the key players; physician offices, family health teams, hospitals, funeral homes, home care and all care provider agencies” • “See above” (50%) • “Start with hospice clients”
Comments:	

Clinical Staff - Twenty-six were invited, and only one responded

Questions	Responses
Are you aware of any currently available resource guides for End-of-Life?	“Just on the cancer care Ontario sight”
What topics should I include in a resource guide for clients?	“Simplifying how to navigate that system The importance of the documents for family and loved ones How it simplifies the persons wants and needs at EOL”
What do you think is currently missing in the community for end-of-life?	“Putting EOL info out in the public, not just in the places where that information is specific to Anywhere, that may give someone who is caring for someone or knows someone who is sick the necessary information on where to and how to find said information”
Are there any topics I should avoid putting in my resource? And Why?	“No, everything needs to be said so people can be able to choose for themselves how they want to be better prepaid or not”
Would a guide be helpful for the clients you serve and support? and Why?	“Yes, even in Hospice we find people don't truly understand the significance. That have been so focused that they don't hear other important info and you then loose pieces of the puzzle”
What would be most helpful in supporting your clients through the end of life?	“Documents, links, person to person follow up over phone email and or in person”
What format should I used to develop the	“Both, on sort of trouble shoot Ling guide and then a more extensive binder. However make

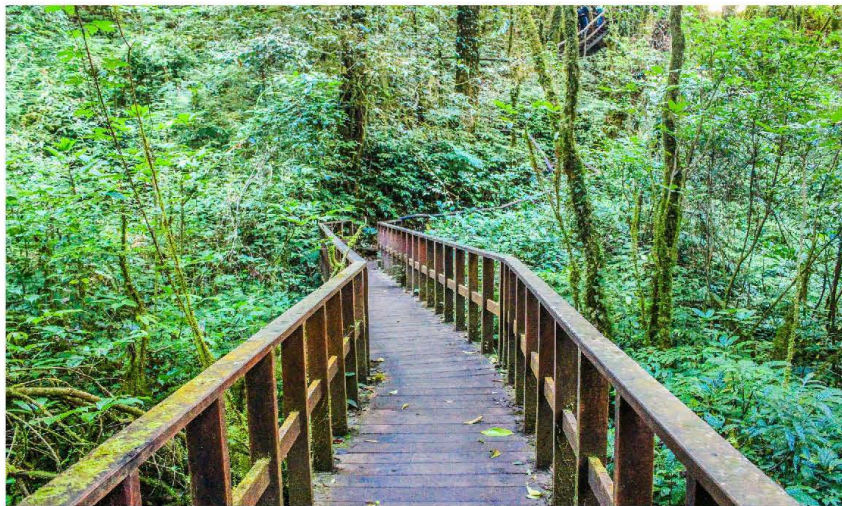
guide? (i.e. binder, printout, etc?)	them both simple for people all people to understand and navigate”
How should I distribute the guide?	“Put this survey Monkey on social media FB Instagram Tiktok Etc”
Comments:	“Keep reaching for the stars and keep making palliative and EOL care visible for all”

Appendix C

Resource Developed

A guide to prepare for the end of life

To assist you in talking about “the elephant in the room”, and help you and your family/caregivers prepare for your death when you are diagnosed with a life-limiting illness



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The information in this guide is intended to be used a general reference only and all efforts have been made to ensure its accuracy. However, the information is not considered legal, medical or financial advice. If you have any questions, please consult a lawyer, physician or legal advice center.

PALLIATIVE CARE COMMUNITY TEAM

The Palliative Care Community Team will help you to live with dignity according to your needs, values, and traditions. We help you to maintain the best quality of life by supporting your physical, emotional, psychological, and spiritual health. We provide ongoing support to clients from diagnosis of a life-limiting illness to bereavement.



Hospice Clinical Navigation

Hospice Clinical Navigators are Registered Nurses who help clients and their caregivers, find their way through the healthcare system from the diagnosis of a life-limiting illness to bereavement. The Hospice Clinical Navigator stays with you for your entire journey to maintain your quality of life.



Supportive Care Counsellor

Our Supportive Care Counsellor provides professional counselling support to you and your family. The support may include understanding the complexities of living with a life-limiting illness as it starts to impact the mental, emotional, and spiritual health of those involved.



Visiting Volunteers

The Hospice Services Coordinator supports you and your family by working with you to carefully match you with a trained visiting volunteer. Hospice volunteers are trusted listeners with a compassionate presence who can focus on what is important to you, and provide respite to your caregiver.

Info obtained from Northumberland Palliative Care Community Team

WHAT IS ADVANCE CARE PLANNING?

Advance care planning is essential to ensure your wishes are respected when you are no longer able to speak and advocate for yourself. After being diagnosed with a life-limiting illness, there are often concerns about what the future may look like. Advance care planning (ACP) allows you to discuss your wishes and goals of care with your caregivers and healthcare team to ensure they understand your wishes.

Advance care planning allows you to learn who would be your substitute decision-maker and reflect on and share your values, beliefs, and wishes for future care. ACP is NOT about making decisions about future treatments.

Why Advance Care Planning matters?

ACP ensures you can think about what is important to you.

- What gives your life meaning? What brings quality to your life?
- Think about how you have made healthcare choices in the past. What factors did you consider?
- Has anything happened in your past or in your medical experience that has shaped your feelings about medical care?
- What worries or fears do you have about your health?
- What does dignity mean to you?

(Advance Care Planning Ontario, 2024a)

SUBSTITUTE DECISION-MAKERS

The first step in ACP is identifying your Substitute Decision-Maker (SDM), whether you have a legally appointed Power of Attorney (POA) or an automatically appointed SDM.

In Ontario, everyone has an automatic SDM, and the Health Care Consent Act tells us who this would be. An SDM must be willing to be your SDM and make decisions on your behalf, be available when decisions need to be made, capable of providing consent, and are 16 years of age or older.

The hierarchy includes people who are appointed through a legal process, family members with the authority to act automatically as SDMs, and a SDM of last resort.

The individuals highest on the list who meet the requirements for SDMs in Ontario is your SDM. Supposed the person automatically appointed to be your SDM differs from who you want to make decisions, in that case, completing a legal POA for Personal Care is essential, allowing you to choose who you want to make decisions. Your ability to make decisions is assessed by your physician and they will decide if you are capable of making decisions. If your mental capabilities prevent you from being able to make decisions, your SDM will be required to.

Did you Know?

It is important to know that SDMs only make decisions for you when you are incapable of making them yourself.

(Advanced Care Planning Ontario, 2024b)

A Power of Attorney for Personal Care does not allow the individual to make decisions about your property or finances. For financial decisions, a POA for Property is required. You can assign different people for both POA for Property and Personal Care.

It is important for you to:

- Confirm who your SDMs are and speak with them now - while you are well.
- Make sure your friends and family know who your SDMs are.
- Tell the people close to you where you keep your important documents.
- Share your wishes, values and beliefs with your family and friends to help support your SDMs when they need to make decisions for you.

Here are a couple of questions to consider

- Can I talk with this person(s) about my wishes, values and beliefs?
- Do I trust this person(s) to make decisions that reflect my wishes, even if they disagree?
- Can they make decisions under stress?
- Can they communicate clearly with my health team in a stressful manner?

Even if you write down your wishes in a 'Living will', it is important to know that consent will still be required before any treatment starts. In Ontario, the law does not allow healthcare providers to follow wishes written on paper and requires either consent from your SDM or you.

More information on the Ontario Power of Attorney for Personal Care can be found at <https://www.ontario.ca/page/make-power-attorney>,

(Advanced Care Planning Ontario, 2024b; Government of Ontario, 2024)

RESUSCITATION

Your wish for resuscitation is your own choice. Some people may already have an idea of what their wishes for resuscitation are. For others, wishes may change as your health changes or deteriorates. Everyone is entitled to receive the resuscitative measures they choose to have.

You may request to have full resuscitation, which may include cardiopulmonary resuscitation, intubation, and advanced medical intervention. Without proper legal documentation, full resuscitation is the default option while at home without a Do Not Resuscitate Confirmation Form, and in the hospital when there is no order for Do Not Resuscitate.

In Ontario, an individual may request a DNR-C form in the home that communicates to paramedics and firefighters that they do not want any advanced resuscitation measures. A physician or nurse can complete a DNR-C form at your request, and it is encouraged to be kept on the fridge for first responders to see. If admitted to the hospital, the physician will still need to speak to you about your resuscitation preferences and order a DNR if that is your wish.

The hospice clinical navigators with the Palliative Care Community Team can complete a DNR-C form for their clients.

If you have any questions, please contact your primary healthcare provider or a member of your healthcare team.

(Dying with Dignity Canada, 2021b)

DYING ON YOUR OWN TERMS

Medical assistance in dying (MAID) is a process that allows an eligible individual to receive assistance from a medical practitioner in ending their life. The federal *Criminal Code* of Canada permits this to occur only under very specific circumstances and rules. MAID was legalized in 2016 through Bill C-14, with changes made to the legislation and criteria in 2021 through Bill C-7. Anyone who requests MAID must meet specific eligibility criteria to receive medical assistance in dying. The determination of eligibility is completed by two physicians or nurse practitioners.

MAID is a personal choice and must be requested by the person. If you have any questions or concerns, please consult a healthcare team member for more information.



For more information on MAID, please visit the Government of Canada website on MAID or Dying with Dignity Canada.

(Dying with Dignity Canada, 2021a)

OTHER THINGS TO CONSIDER

Options for End of Life

There are several options for where to spend your end of life, and each is a personal choice. Your wish for location may change throughout your disease journey as well as the care needs that will be required.

Home

End-of-life is available at home with support from Ontario Health at Home services. Equipment will be ordered such as a hospital bed, commode, and other assistive devices by an occupational therapist. Personal support workers will visit to assist with activities of daily living such as bathing, and nursing will visit to assist with symptom management and treatment plan. A physician or nurse practitioner specializing in pain and symptom management will support you and your family. The nurses will provide you with a number for 24/7 assistance from nursing. The professional supports guide your family in providing care at home.

Hospital

The hospital is available for end-of-life care. Northumberland Hills Hospital has a 6-bed palliative care unit dedicated to patients in their last weeks of life. Nursing and personal support workers provide end-of-life care.

(Northumberland Hills Hospital, 2024; Ontario Health at Home, 2024)

Hospice

Several hospice locations in the area provide care to clients in the last weeks of life. The Bridge Hospice is a 3-bed residential hospice located in the village of Warkworth, and admission is coordinated through the physician or nurse practitioner. Hospice Quinte is a 6-bed residential hospital located in Quinte West, Ontario. Admission is coordinated through Ontario Health at Home. Ed's House Northumberland Hospice Care Centre is a 10-bed residential hospice located in Cobourg and your physician or nurse practitioner coordinates admission. Hospice facilities provide 24/7 care by nurses and personal support workers (The Bridge Hospice, 2024; Hospice Quinte, 2024; Ed's House Northumberland Hospice Care Centre, 2024).

Wills

A will is a legal document that explains your wishes on how your property and possessions are taken care of and distributed once you die. Wills can only be enforced after your death. If you do not have a will, the law determines who is entitled to your belongings, how much they can receive, and who can apply to the court to manage your estate.

To make it easier for your family and friends after your death, it is best if you have an up-to-date will. Some people put their executor of the will on the accounts to ease the transfer after death (i.e. bank accounts, mortgage, house title, insurance, etc).

Please speak with your lawyer to complete this and speak with your family about your wishes. Ensure your family knows where your important documents are.

(Government of Canada, 2023b)

Organ Donation

You may wish to donate your organs after death. Suitability for donation is assessed at the end-of-life to ensure that as many people as possible can be helped.

Suitability to donate is assessed at the end of life to ensure that as many people as possible can be helped through transplant. To be an organ donor for specific organs (heart, lungs, liver, kidneys, pancreas, and small bowel), they must be pronounced deceased under very strict criteria and usually within a hospital setting. Tissue donation can make a profound impact, and donated tissue can be recovered up to 24 hours after death and kept for future use at a tissue bank. Tissue donation can include eyes, heart valves, tendons, bone and ligaments, and skin.



For more information, please visit <https://beadonor.ca/>

What financial supports are available for my family?

As you near the end of life, your primary caregiver may be unable work to care for you. If your caregiver was working, they may be eligible for the compassionate care benefits, which can provide up to 26 weeks of compensation when you are nearing the end of your life.

Your condition must be certified by a physician or nurse practitioner who is providing your end-of-life care. Please consult your healthcare team or the Government of Ontario website for EI Caregiving benefits.

(Government of Canada, 2023a; Ontario Health Trillium Gift of Life Network, 2024)

Funeral Arrangements

A task that you should consider completing to make it easier for your family is to choose and make your funeral arrangements. Funeral homes allow for preplanning. Attached is a list of local funeral homes you may wish to contact for planning if you have not already done so. Completing this allows for your wishes to be followed and guides your family in the immediate days after your death.

Local Funeral Homes

MacCoubrey Funeral Home

30 King St. E.
Cobourg, ON
905-372-5132

Allison Funeral Home

103 Mill St N
Port Hope, ON
905-885-5611

Ross Funeral Chapel

135 Walton St.
Port Hope, ON
905-885-4931

Mill Valley Funeral and Cremation Centre

35 King St. W. PO
Box 327
Millbrook, ON
705-932-5300

Newcastle Funeral Home Ltd

386 Mill St. S
Newcastle, ON
905-987-3964

Quinte Cremation and Burial Services

1-53 Wilson Ave.
Belleville, ON
613-962-7900

Weaver Family Funeral Home - Trenton West

170 Dundas St. W
Trenton, ON
613-392-3579

Weaver Family Funeral Home - Campbellford

77 Second St.,
Campbellford, ON
705-653-1179

Weaver Family Funeral Home - Warkworth

70 Church St.
Warkworth, ON
705-924-2312

AFTER DEATH OCCURS, NEXT STEPS

After you have died, your family will need to complete certain activities. These steps have no specific order, but some cannot be arranged before your death. The first step is for them to contact your funeral home of choice, and they will further guide your family on the next steps.

Additional tasks that your family may be required to complete:

- Ensure your property is secured if no one else lives in the house including watering plants, getting the mail, cleaning out the food in the refrigerator, and installing security cameras.
- Ensure you decide who will be taking your pets.
- Arrange for mail forwarding to a member of your family.
- Obtain the proof of death certificate from the funeral home. The certificate is used for contacting various organizations for closing files and accounts. The funeral home will assist you in obtaining forms that may be required for your estate.
- Meet with an attorney to review your will and estate.
- The executor of your will is required to complete an income tax form. Additional information is available on preparing tax returns for a deceased person through Canada Revenue Agency and tax specialists.
- Cancel any non-essential services (i.e. internet, cable, cellphone, etc).
- Contact your life insurance company, if a policy was in place to notify of your death.
- Contact your banks and financial institution to notify of your death.
- Cancel your driver's license, if there was one.
- Close or update your credit card accounts.
- Delete or memorialize your social media accounts. Ensure you have provided them with your passwords and log in information.
- Close your email and other personal accounts.

(Government of Canada, 2024)

GRIEF SUPPORT

Your family may feel they need additional support after your death. Grief and bereavement support is available for family members through the Bridge Hospice, Hospice Quinte, and Ed's House Northumberland Hospice Care Centre. Each facility provides different supports and programs. Grief and Bereavement staff and trained volunteers are ready to walk alongside you through your grief. They are there to help you understand and cope with grief and bereavement and find meaning after loss. The support can be accessed at any time after your death.

RESOURCES

Government of Ontario – Employment Insurance Benefits and leave

<https://www.canada.ca/en/services/benefits/ei/caregiving.html>

Advance Care Planning Ontario

<https://www.advancecareplanningontario.ca/>

Government of Ontario – Make a Power of Attorney

<https://www.ontario.ca/page/make-power-attorney>

Government of Canada- Medical Assistance in Dying: Overview

<https://www.canada.ca/en/health-canada/services/health-services-benefits/medical-assistance-dying.html>

Dying with Dignity Canada

<https://www.dyingwithdignity.ca/>

Hospices

<https://thebridgehospice.com/>
<https://hospicequinte.ca/>
<https://edshouse.northumberlandhospice.ca/>

(The Bridge Hospice, 2024; Hospice Quinte, 2024; Ed's House Northumberland Hospice Care Centre, 2024)

WORKSHEET FOR CONTACT INFORMATION AND PASSWORDS

The worksheet was developed to assist you in writing down important account information to provide to your family to manage your affairs after death.

<i>Who am I?</i>	
<i>My Substitute decision maker and their contact information</i>	
<i>Banking information (account #'s and passwords)</i>	
<i>Utility companies (account #'s and contact info)</i>	
<i>Vehicle information</i>	
<i>Mortgage and insurance information</i>	
<i>Social Media passwords</i>	
<i>Electronics passwords</i>	

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PHOTO ACKNOWLEDGMENTS

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