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Cross Cultural End of Life Beliefs & Practices of Immigrants in Guelph and Wellington County

A Research Study in Partnership with Hospice Wellington

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MARCH, 2024

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Introduction

The experiences of providing and receiving palliative care can offer insights into the development of useful interventions to improve end of life care. This report explores the cross-cultural beliefs and practices surrounding terminal illness, dying, palliative care, grieving, and caregiving within various immigrant ethnocultural groups in Guelph and Wellington County. The focus is on the awareness and experiences of palliative care, with the aim of identifying commonalities and differences across diverse populations. The goal is to build understanding that can inform Hospice Wellington's policies, practices, and programs, ensuring that they are inclusive, culturally sensitive, and responsive to the needs of individuals from different ethnocultural backgrounds. Semi-structured interviews were conducted with staff members of Hospice Wellington and key members from ethnocultural communities, and the data collected was analyzed thematically using Nvivo software. The findings reveal that immigrant perspectives are influenced by various cultural preferences, and that personalized care in hospice settings is valued. The report suggests recommendations, such as targeted awareness campaigns, a multi-layered approach to deducing immigrant needs, modifications of Hospice Wellington's services, and the integration of multilingual staff, to enhance cultural sensitivity and accessibility.

Overview

Approach to Hospice and Palliative Care

Individuals in advanced stages of an incurable illness usually require palliative care (Tatum & Mills, 2020). Palliative medicine provides specialized care and seeks to improve the quality of life of patients and their family by addressing their needs, managing symptoms, and reducing the use of healthcare services (Tatum & Mills, 2020; Wajid et al, 2021; Holdoway, 2022). Hospice is a form of palliative care provided to patients with the aim of reducing pain and minimizing hospitalization in the end-of-life stages (Canadian Hospice Palliative Care Association, 2019; Tatum & Mills, 2020; Ling et al., 2023). This service is provided by trained professionals, such as doctors, nurses, counselors, and volunteers, who are specially dedicated to attending to the medical, spiritual, and psychological needs of patients and their families (Ling et al., 2023).

The National Hospice and Palliative Care Organization 2022 identifies four levels of hospice care. Routine Home Care (RHC) is the most common level of hospice care and is provided to individuals who have elected to receive hospice care at their residence. Continuous Home Care (CHC) is primarily administered through nursing and care services and requires the management of pain and medical symptoms. Inpatient Respite Care (IRC) provides short-term relief to the patient's primary caregiver. General Inpatient Care (GIP) commences when all other approaches to managing symptoms have proven insufficient and cannot be addressed elsewhere. This type of care can be provided in

certified facilities including hospice inpatient facilities. Hospice care typically adopts a comprehensive approach that brings together various professionals to deliver extensive care for individuals who are approaching the end of their lives (Wajid et al, 2021). When approaching the end of one's life, it is important to maintain the right state of mind, and hospice care plays an essential part in stimulating this attitude (Wajid et al, 2021).

Literature Review

Historical Background, Development and Perspectives of Hospice and Palliative Care

Palliative care is recognized globally within the broader context of global health discussions, usually for older individuals and those living with dementia and cancer (Tatum & Mills, 2020; Clark et al., 2020). The demand for palliative care is high, particularly in low-income countries where the number of people experiencing serious health-related suffering is projected to double by 2060 (Clark et al., 2020). In response, the World Health Organization urged governments to incorporate the delivery of palliative care services into their healthcare strategies through various policy interventions (Clark et al., 2020).

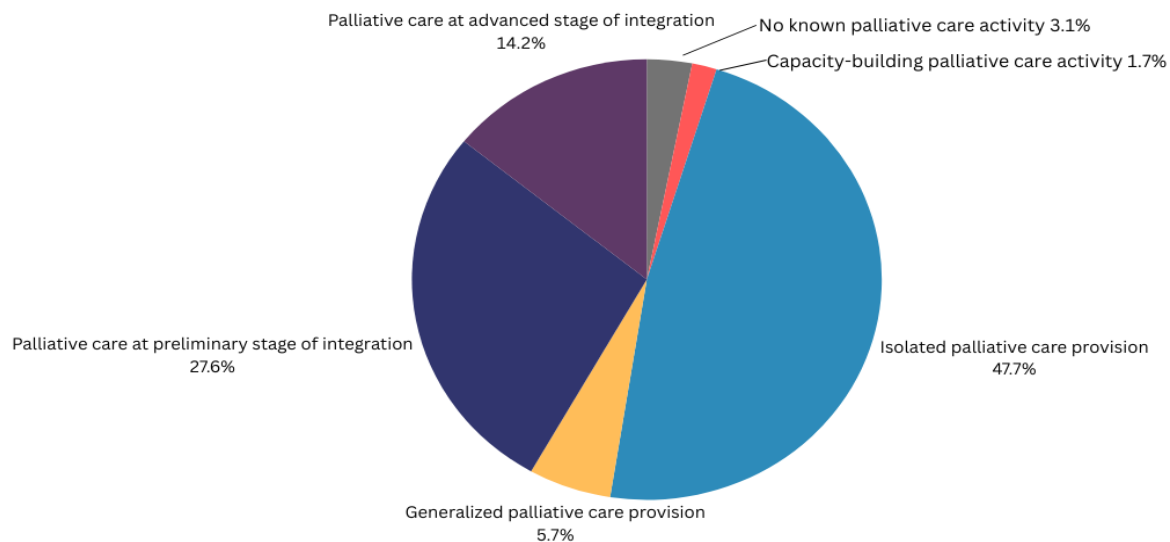


Figure 1: Level of Palliative Care Development in 2017 as a Percentage of the World Population. Adapted from: Clark et al, (2020).

Table 1: Description of Palliative Care Development with Country Level Examples. Adapted from: Clark et al, (2020).

S/N	Country Classification	Description of Palliative Care Development	Country Examples
1	No known palliative care activity	No known evidence of palliative care activity	Mali, Somalia, Cuba, North Korea, Syria
2	Capacity-building palliative care activity	Existing efforts aimed at establishing the workforce, and policy capabilities for advancing palliative care services.	Eritrea, Haiti, Angola, Uzbekistan
3	Isolated palliative care	Characterized by the lack of clear palliative services.	Cameroun, Nigeria, Ecuador, Peru, Lebanon, Greece, Turkey
4	Generalized palliative care provision	Development of palliative care activism in various locations with the presence of local support	Gambia, Zambia, Colombia, Jordan, Oman, Belarus, Bulgaria, Cyprus, Finland, Luxembourg, Macedonia, Malta, Serbia, Slovenia
5	Palliative care at preliminary stage of integration	Preliminary stage of integration into mainstream health care services	Zimbabwe, Mexico, Russia, China, Ukraine
6	Palliative care at advanced stage of integration	Advanced stage of integration to mainstream health care services	Malawi, Canada, United States of America, United Kingdom, France

Figure 1 and Table 1 show that the adoption of hospice care lags in several developing nations in the global south compared to countries in the global north with advanced palliative care such as Canada, USA, and United Kingdom (Clark et al, 2020). In India, there is a considerable number of terminal cancer patients without sufficient palliative care during their final stages of life (Wajid et al, 2021). The Chinese government recognize the rise in elderly population and cancer cases and have commenced the setup of pilot facilities to improve the development of hospice care (Ling et al, 2023). Palliative care remains poorly integrated into the African healthcare systems (Agom et al, 2021). Although some African countries, such as Malawi and Swaziland, have made considerable progress in improving the quality of services for users, more efforts are needed to address the situation in other African countries (Agom et al, 2021). Globally, governments continue to establish legislative frameworks, organizations, medical associations, and volunteer initiatives aimed at helping palliative patients address the associated challenges (Kasimovskaya, et al., 2023).

In Canada, the development of hospice palliative care can be traced back to the 1970s, when cancer treatment programs expanded, leading to the establishment of palliative care units within hospital settings. Winnipeg and Montreal were home to the first two units, as noted by the Canadian Hospice Palliative Care Association (2019).

The global population is rapidly aging (Xiong et al., 2019), and this trend is evident in Canada, where it is projected that there will be nine million seniors by 2041, representing 25% of the total population (Health Canada, 2001). The fastest- growing segment of the population will be individuals aged eighty-five and older (Health Canada, 2001). As the population ages, there will be an increasing need to care for elderly individuals (Jutan, 2006). A 2019 survey conducted by the Canadian Hospice Palliative Care Association found that 96% of Canadians believed that hospice palliative care has a positive impact on end-of-life care, indicating that it is a common concern among the public.

Hospice Care and Relevant Statistics in Canada

To be eligible for the hospice care program in Canada, an individual must have a life-limiting illness with a prognosis of six months or less, and treatment will focus on comfort rather than curing the illness. Additionally, resuscitation measures may not be utilized in the event of a natural death resulting from the illness (Xiong et al., 2019). Home care is an important aspect of the Canadian health care system (Romanow, 2002) and prioritizing individuals with mental health conditions, recent hospital releases, and those in need of palliative services is recommended due to potential cost implications. (Jutan, 2006).

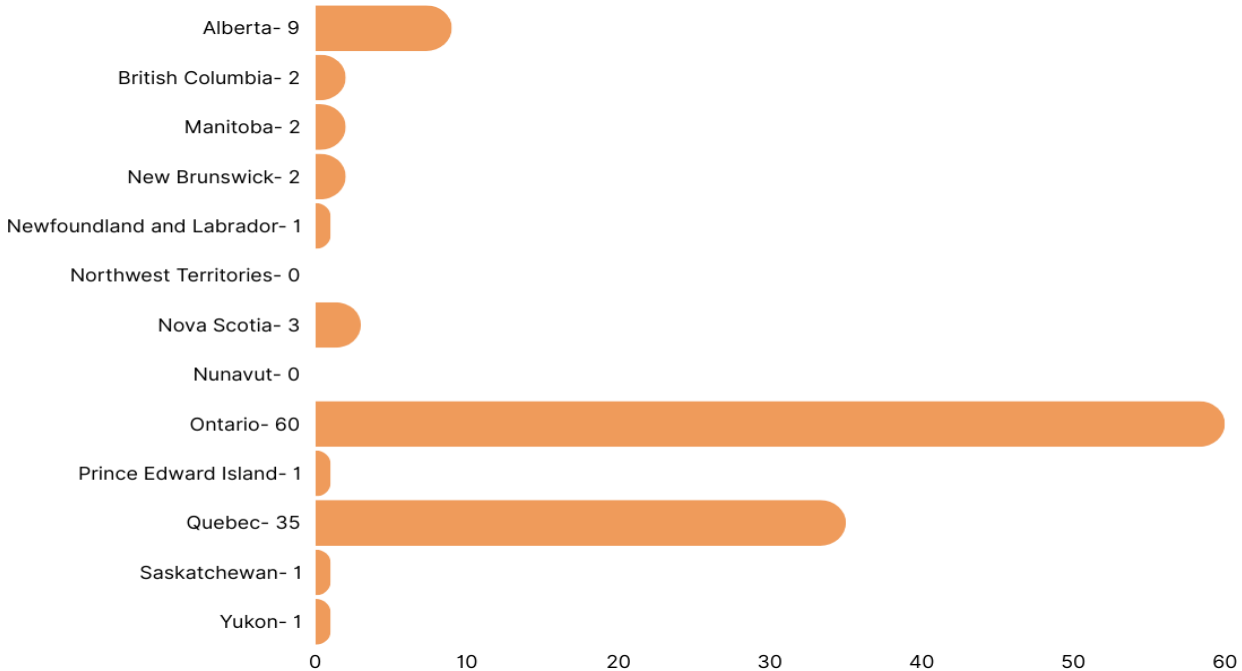


Figure 2: Number of hospices per Canadian province /Territory. Adapted from Canadian Hospice Palliative Care, 2023

Figure 2 shows that the province of Ontario has the highest number of hospice facilities in Canada. These facilities are distributed across at least thirty-eight cities, including Toronto, Mississauga, Newmarket, and Guelph (Canadian Hospice Palliative Care Association 2023). Since the 1990s, significant resources, including time, expertise, and energy, have been devoted to training hospice volunteers in Canada. In Ontario, a unified training program ensures that the care provided by volunteers across the province meets high standards. Currently, there are over 16,000 trained volunteers in these hospices, all working together to support individuals in need (Hospice Palliative Care Ontario, 2023).

Dynamics of care, perceptions, and experiences

Individuals facing end-of-life illnesses share common desires and wishes, like others. They want to feel a sense of dignity, privacy, control, and respect, and they often wish to avoid being a burden to others (Hospice Palliative Care Ontario, 2023). This shows the importance of incorporating the emotional and spiritual aspects of care while applying the hospice model (Bainbridge and Seow, 2018). A caregiver's responsibility is to honor these priorities by doing their best to take a problem-solving approach to provide the best possible care (Hospice Palliative Care Ontario 2023).

Caregivers are individuals who may or may not be family members. They assume a supportive role by performing essential care work, managing emotions, and sharing patients' experiences of illness (Mertens et al., 2023). Caregivers who are family members may occasionally lack understanding of the roles of healthcare professionals. This could lead to friction in communication, duplication, conflict, and a lack of clarity regarding certain needs and expectations (Remawi et al., 2021). For instance, nutritional support and interventions in end-of-life care are critical and can create opportunities to improve patient care when provided at the appropriate stage (Holdoway, 2022). Improving the integration of such support can result in better coordination and collaboration between healthcare services provided by professionals and assistance offered by family caregivers (Remawi et al., 2021).

Ethnocultural Factors in Hospice and Palliative Care.

Cultural and ethnic factors play a significant role in how patients access care and how palliative care is delivered and accepted (Busolo & Woodgate, 2015). For instance, a study conducted in North America found that the needs of Muslim patients at the end of life, as well as the needs of their families, are unmet because the care provided falls short of culturally competent care (Gustafson & Lazenby, 2019). Additionally, the Chinese consider open discussions around death a strong taboo, this suggests that discussions about death are highly discouraged or socially unacceptable in Chinese culture (Seto Nielsen et al., 2019).

Healthcare providers may sometimes struggle to address various palliative care needs of patients, possibly because of cultural and religious considerations (Busolo & Woodgate,

2015). As a result, certain cultural needs may remain unaddressed, raising concerns about the inclusivity and effectiveness of current practices (Doorenbos 2003; Statistics Canada 2010). It is also inappropriate to assume that all members of a particular culture share the same beliefs and behaviors, as people's beliefs and customs can be complex and subject to change, especially in the context of providing end-of-life care (Seto Nielsen et al., 2019). Training programs that take this into account are more effective and avoid relying on generalized notions about cultural norms (Seto Nielsen et al., 2019).

A study showed that ethnocultural beliefs and practices have a greater influence on end-of-life care decision-making processes than formal healthcare regulations (Weerasinghe & Maddalena, 2016). Often, the process by which end of life care decisions are made is based on cultural influences although slight variations could exist (Weerasinghe & Maddalena, 2016). For instance, a study conducted on immigrant elderly Chinese individuals found that their decisions were guided by their beliefs and family ties, even though this pattern of decision-making may have some limitations (Bowman and Singer, 2001). Recognizing the cultural values of patients is important for healthcare professionals, as these values influence various assumptions, beliefs, and practices regarding end- of-life care, death, and grief (Clements et al., 2003; Harris, 2010; Hospice Palliative Care Ontario, 2023).

Expectations of how individuals should grieve may differ across cultural backgrounds (Harris 2010). Recent investigations into the psychology of grief have shown that grief is a multidimensional yet personal experience. It involves emotions, norms, and relationships between the living and dead, most of which are related to culture (Silverman et al., 2021; Hospice Palliative Care Ontario, 2023). Bereaved individuals require empathy and acknowledgement of their loss. However, certain cultural and religious beliefs influence perceptions and interpretations around the dead, as well as the responsibilities of the bereaved towards the dead (Silverman et al., 2021). This has several implications for professionals who work with terminally ill or bereaved individuals, as they need to be open to learning and understanding how to deliver individualized care (Harris, 2010; Clements et al., 2003). Healthcare providers who have a deeper understanding of the perspectives and experiences of palliative care patients from diverse ethnocultural backgrounds are more likely to identify and deliver such care (Busolo & Woodgate, 2015).

Hospice Wellington

Hospice Wellington is a registered charity that has been providing excellent palliative and bereavement support in the Guelph and Wellington County communities for over 40 years. Services include care provided in the residential facility and community programs

such as bereavement support, complementary therapies, education, respite care, spiritual/pastoral support, volunteer coordinators, community care, emotional support, and practical assistance to people of all ages and their families facing a life-limiting illness (Hospice Wellington, 2019).

Hospice Wellington understands that providing care to a loved one can be tough on the mind and body. Therefore, services that cater to family caregivers of patients are available as they empower the caregiver to excel in their role while attending to their loved ones. These services provide comfort by assuring them that they are not alone in their journey (Hospice Wellington, 2019).

Research Objectives

The purpose of this report is to identify and understand various cross-cultural beliefs and practices about terminal illness and dying of people from different immigrant ethnocultural groups in Guelph and Wellington County who have experience with palliative care, grieving and caregiving. The objective is to increase understanding of these diverse perspectives so that Hospice Wellington can ensure that their policies, practices, and programming are appropriate, respectful and include individuals and their families from various ethnocultural groups.

Research Questions

- What beliefs, practices and supports around dying, caregiving and grieving are common to specific ethnocultural groups in Guelph and Wellington County?
- Which of these beliefs, practices and supports around dying, caregiving and grieving are less accessible/not accessible in Guelph and Wellington County?
- How can we as a community (your cultural community and Hospice Wellington) better support people in your ethnocultural group who are palliative, caregiving and grieving?
- What reasons may deter members of a specific ethnocultural group from either volunteering, working, or partnering with Hospice Wellington?
- What acts of remembrance do specific ethnocultural groups practice and relate to? (e.g., lighting candles, feasts, or death anniversaries)

Methodology

This study adopted a qualitative methodology using primary and secondary data. The literature review was based on various credible and reliable materials, including peer-reviewed articles, academic reports, and valid hospice organizations' websites, to ensure a proper examination and understanding of hospice care globally and in Canada. The environmental scan was integrated into this process to gather, assess, and present information and to offer deeper insights into areas such as country categories of hospice

care, hospice in Canada as well as innovative practices within the field. Furthermore, the service mapping provided an overview of the support services offered by Hospice Wellington. This explored the support services and approach to end of life at Hospice Wellington, key roles, and involvement of staff and volunteers as well as the Equity, Diversity, Inclusion and Justice (EDI-J) centered approach in delivering hospice care.

Participants were selected using purposeful sampling based on accessibility and identification of individuals who were knowledgeable about or experienced in hospice care (Palinkas et al., 2015). The interviewees occupied key positions that enabled them to contribute to and provide more insights into the research. Overall, the study focused on participants who were readily available, willing to participate, and capable of articulating their thoughts and feelings through clear, reflective communication.

Semi-structured online interviews were conducted. Four organizational-level interviews were conducted with staff, and five interviews were conducted with key members of selected ethnocultural groups in Guelph and Wellington County. These groups were chosen because they were the most representative of the immigrant/ethnocultural population in Guelph and Wellington County as identified in the 2021 census report published by Statistics Canada (2021). Assessing a participant in the Hindu group was challenging because the group was unable to provide a participant. As a result, the evidence presented for this group relies solely on previously published literature.

All interviews were audio-recorded and transcribed verbatim, and the Nvivo software was used to organize and analyze the data. Using inductive and deductive approaches, the data was grouped into codes, categories, and themes. Overall, six themes emerged from the service mapping and the various perspectives of ethnocultural groups.

Study Significance

Policy interventions by the World Health Organization emphasize the importance of integrating palliative care into global healthcare strategies (World Health Organization, 2020; Clark et al., 2020). Each year, more than 20.4 million people worldwide require palliative care, suggesting a need for appropriate services (Busolo & Woodgate, 2015; Jutan, 2006). This study acknowledges common priorities among individuals facing end-of-life illnesses, such as dignity, privacy, control, and respect, yet it acknowledges the role of culture by exploring diverse ethnocultural perspectives and beliefs around caregiving, dying, and grieving.

The motivation is based on the increasing number of diverse, aging cultural populations in Canada and the research-based knowledge gaps on their end-of-life care (Jutan, 2006), especially as it is documented that patients of racial and ethnic minority have reduced access to culturally sensitive palliative care services (Siriwardena & Clark, 2004; Weerasinghe & Maddalena, 2016). Given the increasing demand for palliative care and the significance of ethnocultural factors, it is important to understand the experiences of

patients with various backgrounds (Busolo & Woodgate, 2015; Remawi et al., 2021).

Findings

Hospice Wellington Service Mapping

Hospice Wellington Services, and End-of-Life Approach

The services offered by Hospice Wellington include providing residential care, community services, and various programs for palliative care, caregivers, and bereavement. Various in-person, virtual, and hybrid programs also can cater to unique needs. The emphasis is on emotional and spiritual support and the provision of collaborative care through workshops, one-to-one support, and support groups with additional services such as art and music, yoga, and in-home companionship. Hospice Wellington is committed to patient-centered care, flexible support, and outreach to bereaved families, even if the person did not die in their care. Digital tools are used to support translation services, and the need for interpreters is met as they arise. Furthermore, Hospice Wellington collaborates with individuals to understand obstacles to receiving service.

Accessing care in Hospice Wellington

Patients access Hospice Wellington services through various referral pathways, including self-referrals, healthcare professionals, and community agencies. A professional makes the referral, but a resident or their families may initiate this process with their healthcare provider upon learning about available services. Healthcare providers, such as doctors and nurse practitioners, also refer clients who express interest in the service. Written materials such as pamphlets and brochures also play a role in informing the community.

Staff and Volunteer Roles in Service Provision

Key roles in Hospice Wellington lay emphasis on cultural sensitivity, communication, and personalized services in providing end-of-life care. By creating a supportive environment that encourages residents to express their needs, staff can incorporate a client-centered approach that involves patients and their families in decision-making. Staff emphasize the importance of holding conversations and listening to various perspectives related to end-of-life, which involves accommodating diverse cultural and religious beliefs, for example, linking residents with representatives from Christian faith communities to provide support when needed. Additionally, various acts of remembrance, and other culturally rich events, contribute to the acts of remembrance and grieving experiences of patients and their families.

Staff members recognize the powerful role of storytelling, shared experiences, and human connections in the context of end-of-life care. This is in line with Yu (2021) who discovered positive outcomes in this psychotherapeutic approach. Similarly, the participants noted that the significance of allowing individuals to share their stories provides a sense of dignity and contributes to reduced fear and increased comfort for

all involved. This offers the potential for incorporating such stories into acts of remembrance.

While describing the emotions experienced by the patients during this process, a participant said,

“They still maybe want that opportunity to share their memories.”

Volunteers in Hospice Wellington assume a range of responsibilities and roles, including acting as friendly visitors and providing support such as Reiki and therapeutic touch. Volunteers address the needs of patients and their families by providing companionship and support. There is also a broader scope of volunteer activities, such as advanced care planning, companionship for palliative caregivers, front desk and kitchen assistance, and fundraising event support. Volunteers undergo a 33-hour training program where they develop core competencies in understanding professional boundaries, cultural considerations, ethics, and communication.

The Advance Care Planning (ACP) education program engages Guelph Wellington residents in conversations about advance care planning and health care consent in Ontario. Volunteers are trained to be ambassadors and to give presentations in the community to increase awareness and understanding of advance care planning (Hospice Wellington, 2019). The following table highlights innovative strategies culled from other Hospice facilities throughout Canada.

Table 2: Some Innovative Practices among Hospices in Canada

S/N	Category	Description	Where in Canada?	Benefit to Hospice Wellington
1	Accessing care	Website has an inbuilt translation software from English to 100 different languages including Chinese, Arabic and Hindi	Hospice Niagara, Ontario	Automatic translation of website content to a diverse audience
		The website includes a comprehensive handbook and brochure which is translated into three different languages.	Hospice Halifax, Nova Scotia.	Key information could address initial inquiries from diverse ethnocultural groups.
		Website provides a list of what to bring along to residence (similar information could be included in an FAQ)	Hospice Greater Saint John, New Brunswick	
2	News/Media	Spotlight newsletter or information sheets	Yee Hong Peter K. Kwok Hospice Toronto	Opportunity to distribute special stories and newsletters more widely.
3	Coping with Grief	The Wind Phone initiative is an unconnected phone booth designed for those who have lost someone special. It serves as a place to express feelings, share memories, and say goodbyes, providing a therapeutic opportunity for individuals in grief to talk to their departed loved ones and release their emotions to the wind.	Hospice Niagara (Originated in Japan and now used globally).	Added initiative for bereavement support.

Table 3: Some Innovative Practices among Hospices in Canada

		Bereavement Camp	Hospice Mississauga, The Toronto Commandery Hospice, Ontario Hos	For ongoing bereavement and grief journey
4	Community & Residence support	A small choir which could also include bereaved individuals as members.	Bulkley Valley Hospice Society, Milton, Ontario, Peace Arch Hospice Society, British Columbia	Existing music therapy program could be expanded or complemented with a choir to bring the community together, raise awareness and funds for the hospice as well as provide essential social and peer support for hospice staff and volunteers.
5	Acts of remembrance	Remembrance workshops	The Toronto Commandery Hospice	Could take place around specific and faith-based holidays or ethnocultural festivals as an opportunity to honor the deceased through art activities etc.
7	Story telling as a tool	Highlights of stories shared by the residents before passing could be captured, documented as text or audio and passed on to the family for reference.	Victoria Hospice, British Columbia	Building highlights of patients' life as an act of remembrance

Incorporating additional services or initiatives could be beneficial provided they are feasible and align with the organization's available resources. Hospice Wellington has demonstrated openness to such initiatives as staff recounted instances where patients were connected to other service providers or offered services on a case- by-case basis. An interviewee noted,

“The team will usually bend over backwards to try and make people feel as at home as possible.”

Equity, Diversity, Inclusion and Justice (EDI-J), in Hospice Wellington

The findings show a homogeneous demography among both staff and clients, with clients typically being Canadians or first to second generation immigrants from Western or Eastern European backgrounds. However, staff acknowledge the importance of diversity and inclusivity and express the desire to support all populations while recognizing the need for specific initiatives to address unique cultural or religious aspects of care. While facing some language diversity limitations, the organization remains responsive by leveraging volunteers and digital tools for interpretation when needed. Ongoing commitment to learning and improvement is important to provide informed and supportive culturally appropriate end-of-life care.

Equipping Staff for Service

Hospice Wellington adopts a proactive approach to staff education and training. The organization's commitment to continuous improvement is evident through structured performance reviews, educational reimbursements, workshops, leadership sessions, and regular staff meetings featuring EDI-J presentations. However, additional efforts should focus on equipping staff to engage with diverse communities. A participant said,

“From a diversity standpoint...I haven't received much in the way of training on that.”

Another participant added,

“I'm gonna say not a lot. I don't have a lot of experience with that.”

This learning experience can also be achieved by strengthening partnerships with the various ethnocultural groups in Guelph. A participant stated,

“I think community connections are really important. No one agency or one person can do it.”

Staff collaborative learning experiences are important for effective communication. Staff noted that during meetings, there is a practice of conducting rounds and team check-ins

to discuss and address any challenges or concerns related to clients who may be experiencing difficulties or requiring additional support. A participant also shared how she would usually access information outside of a meeting setting.

“If I needed more, I would ask... Do you have any tools? Do you have any resources?”

This approach may be effective, but there is room for improvement in facilitating information flow within the team outside the meeting environment. Digital tools like Slack and WhatsApp can enable smooth and quick information sharing within large and small teams, as well as between individuals. Utilizing these tools and platforms that enhance group learning will prevent staff learning in silos thus prevent the duplication of queries and making the most of a shared learning opportunity. This could translate into better service delivery overall. In addition, Hospice Wellington staff anticipate a more integrated approach with external healthcare organizations to support patients with regard to general medical services in Guelph and Wellington County. A participant said,

“There’s no good communication system so that we’re all on the same page, or that we’re all not duplicating.”

Benefits of Partnerships to Patients and the Organization

Hospice Wellington is committed to promoting partnerships and community outreach to strengthen the delivery of palliative care services. The organization seeks to collaborate with diverse cultural and religious groups by building connections and a network of support. The benefits of such partnerships extend to hospice patients, providing them with a sense of dignity and comfort, and potential benefits also exist for the organization to address the diverse needs of individuals facing end-of-life care and bereavement. Seeking feedback from the community is also essential for obtaining external perspectives to improve existing practices. Hospice Wellington staff emphasize the importance of shared knowledge, trust, and partnerships in the community and advocate for genuine engagement in demystifying end-of-life care through continuous dialogue and collaboration.

Highlights from Hospice Wellington Staff Service Mapping

Three major themes emerged from the service mapping.

Comprehensive and Compassionate End-of-Life Care

Hospice Wellington is a provider of a broad range of end-of-life care services. Staff members, including volunteers, play significant roles in providing culturally sensitive care, accommodating diverse requests related to end-of-life rituals, and recognizing

the therapeutic value of storytelling. The organization also employs various programs, workshops and support groups, demonstrating commitment to patient-centered care and flexible support. However, opportunities also exist to incorporate additional services or initiatives that could be beneficial to diverse ethnocultural groups, especially in care, bereavement support, and acts of remembrance.

Inclusivity, Diversity, and Continuous Improvement

Hospice Wellington prioritizes staff education and training but acknowledges the need for continuous learning and improvement, particularly in addressing cultural diversity and religious aspects of care.

Communication and Collaboration

The importance of effective communication and collaboration among staff members is emphasized. The organization could benefit from a unified technology platform or database sharing and maintenance of updated information on various cultural or religious groups.

Cross Cultural Beliefs and Practices of Ethnocultural Groups

The top three countries of origin for immigrants residing in Guelph in 2021 were India, the United Kingdom, and the Philippines. For recent immigrants in Guelph, the top three countries of origin were India, Eritrea, and the Philippines (Statistics Canada, 2021).

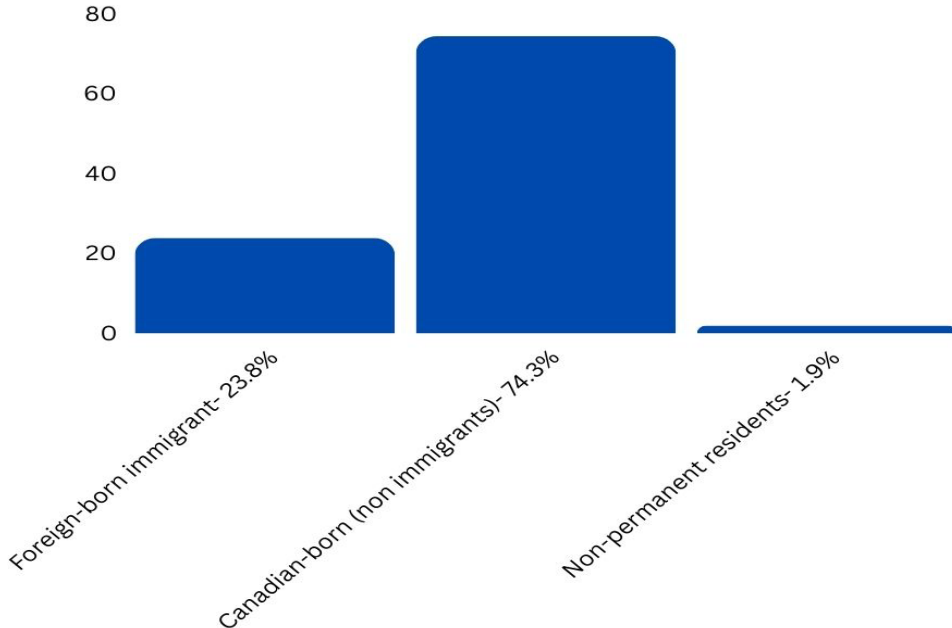


Figure 3: Immigrant Status in Guelph. Source, Statistics Canada, 2021

According to the 2021 census reflected in Figure 3, 23.8% of the population in Guelph were foreign-born immigrants, 74.3% were Canadian born (non-immigrants) and 1.9% were non-permanent residents (Statistics Canada, 2021). Among these immigrants those who entered Canada between 2016 and 2021 make up 17.3% of the population.

Immigrant perspectives to End-of-life Care and Access

Leaders within the ethnocultural groups in Guelph assume distinct roles. Their responsibilities range from organizing communal activities to officiating lifecycle events, such as weddings and funerals, and facilitating various educational seminars and programs. They also provide spiritual and emotional support for the sick, such as administering communion and words of encouragement. Various ethnocultural groups view hospice care differently. In Muslim tradition, it is advisable for direct family members to care for individuals in need of hospice or palliative care. This is rooted in the duties and respect that Muslims hold for their elderly. Similarly, within the Sikh community, there is a longstanding tradition that supports the family's responsibility in caring for the elderly and the terminally ill. These perspectives demonstrate the cultural and family dimensions that influence attitudes toward hospice care in these communities. For some, hospice care is only considered an option when family support is insufficient or unavailable. However, members of a group who decide to take their loved ones into hospice care are not criticized. An interviewee clearly stated,

“If any member of your group decides to go into hospice care, it doesn't mean that you will look at that person differently or in a negative way.”

The findings revealed that members within ethnic groups seek information on hospice care from various sources. One participant acknowledged that people facing terminal conditions typically seek medical attention directly rather than approaching a community or religious leader. The remaining four participants were unsure of how their members received information about hospice care. They speculated that the information came from different municipal resources, close family, or the internet, particularly Google searches. Participants expressed support for hospice care and shared positive experiences of visiting patients and providing spiritual care, with no reported dissatisfaction by community members. Participants were mostly familiar with Hospice Wellington's end-of-life care but lacked awareness of other services. They also noted a general lack of knowledge among community members and expressed the need for more information to enhance understanding. A participant said,

“So, we don't have many like, messages of this. Yeah, I guarantee most of my friends don't know...we don't know a lot of things about hospice”.

“I feel like we definitely need some education or sources too.”

A participant revealed.

“I don’t even know what will happen if my parents die, what to do next...what hospitals? What about the cemetery? I have no idea.”

This limited awareness could be because some immigrant groups in this study originate from countries lacking advanced palliative care services (see Table 1). Although participants also noted that the immigrant population is not yet elderly. In terms of the appropriate time to hold conversations about end-of-life care, the participants acknowledged the discomfort associated with discussing death. A participant noted.

“It’s uncomfortable so people might avoid it”.

Reflecting on cultural differences, a participant noted that these discussions often happen within family groups and emphasized continuous conversations throughout one’s life, rather than waiting for specific milestones.

Varying Beliefs around Caring, Dying, Grieving and Acts of Remembrance

The following section captures the individual beliefs and customs reported by cultural group leaders, particularly in the context of end-of-life care. It is important to recognize that a wide range of beliefs exists within and across ethnocultural groups, highlighting the need for cultural sensitivity in this area

Table 4: Varying Beliefs around Caring, Dying, Grieving and Acts of Remembrance

S/ N	Culture/religion	Group Objective	Beliefs Around			Variations	Acts of Remembrance	Perception of Hospice Care	Barriers	Preference	Opportunities for Partnership
			Caring	Dying	Grieving						
1	Chinese	Promotion of cultural engagement and intergroup active ties.	Preference for family-based end-of-life care.	<p>People want to be around their kids at the end of life.</p> <p>Children want to do their best to show their love at the end of life.</p> <p>Not open to discussing death because it's a bad sign and extremely sensitive subject.</p> <p>Family do not mind a Hospice staff facilitating end-of-life discussions.</p>	<p>Private grieving, minimal questioning.</p> <p>Emphasis on preserving the memory of the deceased.</p> <p>Meals could be served in communal settings. However, in Canada, some people tend to keep to themselves during this period.</p>	Variations exist around religious practices e.g. Christians, Buddhist	Use of digital photo, album and a 3-4 mins videos to share the memories of the deceased with others.	Open to hospice care Limited knowledge but desire more information, resources, and awareness programs on hospice so that members are better prepared.	Language barrier especially for the elderly is a major concern. Dislike cold water and food. Especially when served in hospital settings. Music would be a luxury - <i>"Oh, that's really a luxury dream come true for people"</i> . Would be comfortable with being asked questions to facilitate smooth communication during end of life. Would appreciate recognition of cultural festivals	Open and willing to help connect Hospice Wellington with the wider community.	

Table 3: Varying Beliefs around Caring, Dying, Grieving and Acts of Remembrance

S/ N	Culture/Religion	Group Objective	Beliefs Around			Variations	Acts of Remembrance	Perception of Hospice Care	Barriers	Preference	Opportunities for Partnership
			Caring	Dying	Grieving						
2	Muslim	Complete religious support from birth to death and beyond.	Prioritize caring for their elderly, by themselves to external care	<p>God has ultimate control over life and death and not humans</p> <p>Maintain positivity and avoid negative statements around the dying.</p> <p>Caring for the dying is a rewarding responsibility, and those capable should undertake it personally.</p>	Offer prayers, give comfort and assistance to the family services and vigils.	Variations exist along cultural lines	<p>In some cultures, mourning takes place on the 1st. and 3rd days after passing.</p> <p>There is recitation of the Quran and sharing of meals. on the 40th day after passing.</p>	<p>The family have first right and responsibility over care Hospice should be seen as an alternative.</p>	<p>Receiving hospice care from a staff of different gender can be regarded as demeaning to the patient.</p> <p>Inappropriate dressing around the dying is a major concern.</p> <p>May hesitate to communicate their needs.</p> <p><i>"People usually don't whine and complain"</i></p>	<p>Playing music around a dying person could be regarded as demonic and destructive.</p> <p>Provision of a designated praying area for visiting family members</p> <p>Inappropriate dressing and putting on high heels around a patient could be regarded as offensive.</p> <p>More disposed to receiving Hospice care in the home</p> <p>Dietary concerns exist e.g Halal</p>	Open and willing to help connect Hospice Wellington reach the wider community.

Table 3: Varying Beliefs around Caring, Dying, Grieving and Acts of Remembrance

S/ N	Culture/Religion	Group Objective	Beliefs Around			Variations	Acts of Remembrance	Perception of Hospice Care	Barriers	Preference	Opportunities for Partnership
			Caring	Dying	Grieving						
3	Eritrean Eastern Orthodox.	To ensure attendance on Sundays and Saturdays weekly church meetings, organize events, and collect funds for church expenses.	Home care is preferred to Hospice unless immediate family is unable to provide it. The primary provider of care at end or life should be the children. Priest provides economic support and care for the sick, visiting and offering prayers and encouragement to individuals in need.	The act of confession is necessary for patients at the end of life. Priest embalms the body privately; no relatives should witness this process.	Priest offers prayers immediately after the person passes.	In most cases, practices are the same religious wise.	Special prayers held in church on days 12 and 40. Another special prayers are held after 6 months. Sharing of food takes place during such times.	Open to Hospice care as an alternative to care from family members.		Friendly and polite service	Open and willing to help connect Hospice Wellington with the wider community.

Table 5: Varying Beliefs around Caring, Dying, Grieving and Acts of Remembrance

S/ N	Culture/Religion	Group Objective	Beliefs Around			Variations	Acts of Remembrance	Perception of Hospice Care	Barriers	Preference	Opportunities for Partnership
			Caring	Dying	Grieving						
4	Sikh	Catering to the needs of the North Indian Sikh community, primarily Punjabi-speaking.	Preference for family-based end-of-life care.	Cremation is performed for adults only.	Most people come together to grieve with the bereaved for 10 days. Recitation of the Gurbani for 2-3 days is necessary for closure.	Practices are common throughout Sikh, religion,	Recitation of the Gurbani can be done every year (Scriptures are sung during this time) People may also gather to share memories about the departed as an act of remembrance	Open to Hospice care	Concerns about the possibility of misreading the culture of food sharing.	Cultural consideration of food sharing for visitors in Hospice Recognition of festivals such as Diwali Music is powerful, especially the musical poetry of Gurbani.	Open and willing to help connect Hospice Wellington with the wider community.

Table 3: Varying Beliefs around Caring, Dying, Grieving and Acts of Remembrance

5	Culture/Religion	Group Objective	Beliefs Around			Variations	Acts of Remembrance	Perception of Hospice Care	Barriers	Preference	Opportunities for Partnership
			Caring	Dying	Grieving						
	Chabad Jewish	To serve the Jewish community from birth to death and promoting unity.	End-of-life care should prioritize comfort	<p>Assisted suicide or activities to hasten the natural course of death is forbidden.</p> <p>Special preparation of the body and ritual purification takes place before burial.</p> <p>Designated funeral home for the Jews is in Toronto and burial takes place in a Jewish cemetery.</p> <p>Cremating and Embalment are forbidden.</p> <p>A practicing Jewish individual (Honor guard) should be around the body until burial</p>	<p>When someone passes away a candle is lit immediately. Next to the individual as soon as possible</p> <p>Immediately after the burial, Jews sit in Shiva (7-day mourning period)</p> <p>Then 30 days after, up till eleven</p> <p>To twelve -month period. The mirrors are covered in the home and no beautification.</p> <p>Donation of food to the bereaved</p> <p>Special Hebrew prayer conducted three times a day</p>	<p>Kosher dietary preferences may differ across the culture as well as adherence to some practices</p>	<p>Takes place every year on the Hebrew date of passing, Could be observed at the temple or at home.</p>	Open to Hospice care	<p>Concern about meeting dietary needs and restrictions e.g., Pork, Shellfish as sourcing Kosher certified foods for a resident may be challenging in Guelph.</p> <p>Lighting of candles as observe din Jewish tradition during Sabbath may be inappropriate in hospital settings.</p> <p>Concerns about limited knowledge on Jewish perspectives</p>	<p>Provision of Kosher diet that conform with Jewish laws.</p> <p>Would appreciate recognition of festivals e.g., Passover, Jewish new year etc.</p>	<p>Open and willing to help connect Hospice Wellington with the wider community.</p> <p>Also willing to assist in sourcing external support and services for Jewish patients.</p>

Table 6: Varying Beliefs around Caring, Dying, Grieving and Acts of Remembrance

S/N	Culture/Religion	Group Objective	Beliefs Around			Variations	Acts of Remembrance	Perception of Hospice Care	Barriers	Preference	Opportunities for Partnership
			Caring	Dying	Grieving						
6	Hindu	Individualized religious group	<p>Family members are responsible for making end of life decisions. Caregivers should be modest i.e., be mindful of religious and cultural beliefs that prioritize privacy and purity, especially during physical examinations and personal care activities.</p> <p>The pandit (the Brahmin priest) may be called upon to conduct spiritual care</p>	<p>Cremation is performed within 24 hours after death.</p> <p>Someone remains with the body until cremation</p>	<p>A 13-day mourning period is observed, during which the bereaved avoid activities like reading the holy scriptures and visiting family/friends.</p> <p>This is followed by a one-year mourning period.</p> <p>Post-funeral rituals include ceremonial bathing and house cleansing which is performed by the priest.</p> <p>Refrain from life changing decisions during the mourning period eg, weddings, moving house, changing jobs.</p>	<p>Beliefs around diet and post ritual practices are not universal and vary across sects and castes</p>	<p>A memorial service on the one-year anniversary is conducted by the priest.</p>	<p>Open to Hospice care</p>	<p>Language barriers between healthcare professionals and patients could hinder effective communication</p>	<p>Preference for culturally competent care</p> <p>A dedicated space for prayers is preferred.</p>	<p>May seek informal bereavement support from relatives and friends than from Hospice service.</p> <p>Hindus are vegetarians</p>

* Findings on the Hindu community were derived from the literature, as no individuals from this community could participate in the research.

* Cultural perspectives and practices regarding end-of-life are diverse may vary within and across the ethnocultural communities stated above.

Chinese

The Chinese have a strong aversion to discussing death openly, especially among older generations. Younger individuals are influenced by evolving trends and may engage in more open conversations regarding death. Variations may also exist between cultural and religious perspectives. However, prominent cultural perspectives reflect Confucian values of respect and love. Preserving the memory of the dead is important, and the Chinese often prefer to gather to commemorate the deceased. The use of WeChat, a popular app, facilitates the sharing of videos and pictures of the deceased with family and friends. Cultural preferences include warm water, warm food, and recognition of festivals in hospice care. However, the findings indicate that adhering to traditional Chinese cultural practices in Canada is perceived as not realistic. A participant noted,

“But it's not very practical now ... In Canada, it's different.”

“We don't expect you have everything the same as in China because it's not practical.”

The need for education and resources regarding hospice care is desired. The Chinese community is also willing to collaborate with Hospice Wellington during seminars and offer support for spreading information about hospice care.

Muslim

The Muslim community emphasizes religious guidance from birth to after death. Life and death are divinely determined, and control over these aspects is forbidden. In terms of palliative care, a participant said,

“Muslims generally don't abandon their dying and leave them to Hospice care.”

“So it's against the Islamic tradition to tell the dying person that you're dying, you're sick and, you know, be negative around them.”

The Muslim community prefer caring for the elderly at home and collaborating with hospice facilities only if required. Muslims also value the care provided by immediate family members and importance of direct family members looking after individuals in hospice or palliative care. An interviewee revealed that music is not encouraged around a patient and some individuals may have dietary preference for Halal food. Gender-sensitive care is also preferred for patients in end-of-life care since services rendered may require touching sensitive areas.

A participant said,

“Fully covered. So basically there would be no nudity or any illusion of nudity which means no tight clothes.”

Muslims pray for hope and healing, avoiding negativity around the dying person. Therefore, negative discussions are discouraged in front of the dying person and serving a dying person is considered a significant duty. A participant said,

“Serving that dying person is a huge reward. It's a huge responsibility. Anybody who can do it should do it. So why pass that on to somebody else as a job?”

Grieving involves prayers and offering comfort to the family. Special prayers or feasts held during acts of remembrance are not part of Islamic religious practices but more of a cultural practice.

Eritrean Orthodox

The Eritrean Orthodox community actively fulfills its responsibilities by organizing church services on Sundays and Saturdays. Cultural and religious expectations are that end-of-life care should be provided by close family following the biblical principle of taking care of parents. A participant said,

“In our culture, parents should be taken care of by their children.” “The Bible says we have to take care of our parents.”

Before a church member passes, the church begins the confession process. After the member passes away, their body remains unseen until the priest performs an embalment. Financial support for the deceased and their families is typically organized by the priests, who also visits their homes to offer prayers, and words of encouragement. Special prayers occur in the church on days 12, 40, and six months following a person's death. The community's approach to hospice care includes values such as mutual respect and kindness, especially towards the elderly, emphasizing the importance of supporting and helping them in a polite manner.

Sikhs

The Sikh community is primarily North Indian and Punjabi speaking. The community in Guelph runs a Punjabi school and music classes, and aids seniors by providing information on global events. Sikhs believe in caring for the elderly at home, but with the changing times, some consider hospice facilities. Sikhs emphasize a welcoming hospice environment and appreciate the provision of free food.

"It's just culturally like that. They really like it. That's traditionally a way that we are."

Upon death, grieving involves the recitation of the Gurbani scriptures for 2-3 days to provide closure for the soul. Grieving lasts for approximately 10 days, and community members are assigned duties to support grieving families. Funeral practices involve a cremation ceremony.

Chabad Jewish

During end-of-life care, the Jewish faith avoids hastening death. Exceptional care is taken when preparing bodies for burial and emphasis is placed on prompt burials. Cremation and embalmment are also forbidden.

Jewish grieving practices occur in several stages. During the initial seven-day period following a funeral, the Jewish custom of Shiva is observed, during which the bereaved receive guests, offer prayers, and reflect on their loss. Recitation of the mourner's kaddish prayer is performed in the memory of the dead. The prayer commences on the day of passing and continues for 11 months. Acts of remembrance also occur during specific mourning periods, such as the 30-day mark after death and the 12-month period.

The findings reveal various challenges that may arise in educating the broader population about Jewish laws during end-of-life care, such as adhering to specific practices and dietary requirements.

Hindu

Hinduism is regarded as an individualized religion that lacks a standardized form of worship, unlike other religions (Shanmugasundaram et al., 2010). Caring for individuals at the end of life and making related decisions is the responsibility of family members, particularly the elderly (Shanmugasundaram et al., 2010). More than one relative may be involved in the care of the patient, some visits may occur in large groups, and family members may all be interested in knowing the clinical details of the patient. (Sharma et al., 2013). This contrasts with Western cultures, where individuals, when mentally capable, provide informed consent and make decisions on their own behalf (Shanmugasundaram et al., 2010).

A patient in end-of-life care may choose to refuse medications to die with a clear mind as pain is viewed as a way of removing sin. The model for good death in Hindu posits that death should be approached positively without any fear or anxiety (Sharma et al., 2013). Upon death, a 13- day mourning period is observed. Hindus tend to prefer cremation, which takes place within 24 hours (Crossroads Hospice, 2024). Post-funeral rituals include ceremonial bathing and purifying the house with incense, prayers, and mantras. These practices are based on the belief that death leaves the home and bereaved in an unclean and impure state. However, these beliefs are not general and may vary across different sects and castes (Econdolence, 2024).

Variations in Beliefs

While similarities exist, differences also occur across and within ethnocultural groups. For instance, the interviews revealed that while some Jews may only consume Kosher meat, others may be lenient and accept non-kosher meat. These variations highlight the diversity even within a particular community, and cannot be stressed enough.

Immigrant Perspectives on Volunteering and Working in Hospice.

Muslim staff and volunteers may have an issue of mixing with the opposite gender while providing care. According to Jewish laws, members of the Kohanim priestly class are restricted from encountering corpses, except for immediate family members.

“And so, they’re not supposed to go into hospitals if there is a corpse under its roof. They’re definitely not going into the morgue. They don’t go into cemeteries unless it’s an immediate family member.”

In contrast, the participants from the Sikh and the Eritrean Orthodox communities expressed a willingness to volunteer or work in hospice care without any issues, especially the Sikh participant who also expressed willingness to support hospice care through donations. In addition, a participant from Eritrean Orthodox acknowledged that several people from his community already work in hospice. The Chinese have registered nurses within their community who may be able to contribute to hospice care; however, there is some hesitancy due to aspects related to death. However, when asked if it would make any difference if a hospice staff member was from their cultural group. An interviewee noted that,

“Oh, definitely. Seeing a staff would feel like, okay, I’m not in a totally strange environment because of some person who probably shares the same background. or... can speak Chinese. So that’s definitely very helpful”.

Collaboration and Partnerships

Leaders play multiple, but significant, roles in their communities. Members may not necessarily go to their leaders for information on locating a hospice, but they play a vital role in providing spiritual and emotional support to members of their groups during end-of-life care, which makes them suitable for helping to spread information about hospice care to their members. It also has implications for organizations that intend to build strong partnerships with these communities.

Participants viewed themselves as instrumental in building relationships between Hospice Wellington and their communities. When asked if they believe their roles can enhance and facilitate members' access to care, a participant said,

“This is a very healthy and good step forward for them to be aware of things and then of course the next step is being in touch.”

Another said:

“But I can definitely be your contact. I can spread out your information to our people.”

“If you have some flyers or you give me the link, maybe email me and then I can just spread out that information to people too.”

One participant acknowledged that, given their numerous responsibilities and commitments, prioritizing community activities related to Hospice Care may not be the primary focus. However, the willingness to offer support when such demands align with other commitments was stated,

“Considering all the hats that I wear and roles that I play. I can't say that this is an enormous priority for me if I'm honest. I can't say I'm gonna be putting up signs to do an event to educate people because I'm already trying to get them to come to things... At the appropriate time. Good to find the appropriate time.”

Highlights from the Ethnocultural Groups

The three major emerging themes are:

Cultural Preferences in Hospice Care

Diverse cultural and religious preferences exist regarding caring, death, grieving, and remembering the dead, and family involvement is a key component in the provision and access to hospice care across all ethnocultural immigrant groups in the study. There is a reluctance to rely completely on hospice care during the end-of-life. However, some would consider hospice care when the family support is insufficient.

Personalized Care and Accommodation of Religious and Cultural Practices in Hospice Settings.

The provision of personalized care to patients and their families is important. The sensitivities and relevance of various beliefs and practices highlight the importance of understanding and respecting cultural norms. However, immigrants may hesitate to communicate their unique needs because of concerns that their requirements may not be accommodated, or that asking for such accommodations may be perceived as burdensome.

Limited knowledge on Various Hospice Services

A knowledge gap exists in terms of how much the communities know about the services available for hospice care. There is a lack of awareness of services beyond end-of-life care, indicating the need for more information and education within immigrant communities. In addition, the participants indicated their readiness to facilitate information sharing and collaboration between Hospice Wellington and the broader community.

Recommendations

- Utilizing a dedicated EDI checklist or questionnaire during the patient and caregiver intake process would serve as a good diversity lens, enabling Hospice Wellington to gather essential cultural information and modify their care accordingly. This approach could also ensure that the provision of inclusive and respectful care is provided to all individuals regardless of their cultural background.
- Hospice Wellington can benefit from implementing a multi-layered approach when engaging and gathering information from patients, caregivers, and their families. It is necessary to consistently inquire about the specific needs of immigrants, as they may not immediately express their requests due to language or cultural barriers.
- Hospice Wellington should emphasize the significant support that their services offer to caregivers and individuals experiencing bereavement. This may be

particularly attractive to certain diverse groups that prefer home-based care for their loved ones.

- Hospice Wellington could undertake a targeted marketing and information campaign, as it appears that some individuals are unaware of the caregiver and bereavement services offered. Awareness within diverse ethnocultural groups could also leverage the role of the community and religious leaders as a valuable resource for end-of-life care. This could address potential misconceptions or reservations regarding hospice care.
- The database in Tables 2 and 3 can be continuously updated with latest ideas and information to boost the current EDI-J drive within the organization. The use of digital chat platforms within the team can also help to disseminate relevant information internally and prompt staff to deliver culturally appropriate services.
- Adjusting the existing services and website information to incorporate touchpoints that are more relevant, accessible, and friendly to various ethnocultural groups would be beneficial.
- Incorporate both multilingual staff and volunteers into the team to ensure a culturally sensitive approach to end-of-life care experiences. This can be accommodated in the recruitment process.

Study Limitations

The limitations of this study include the following: First, the perspectives of patients were not directly assessed because the objectives of the study did not necessitate their participation or that of their caregivers. Accessing Hindu group members was a challenge; however, measures were taken to ensure that the information provided for this group was consistent with the existing published literature.

This study could have benefited from a larger participant pool to increase the generalizability of its findings. Despite this limitation, conducting interviews as a data collection method proved to be practical for a smaller sample size. The results provide a deeper understanding into the complex experiences of immigrant ethnocultural groups in end-of-life.

Conclusion

This study set out to identify and understand various cross-cultural beliefs and practices about terminal illness and dying of people from different immigrant ethnocultural groups in Guelph and Wellington County who have experience with palliative care, grieving and caregiving. The findings from both Hospice Wellington

staff service mapping and perspectives from various ethnocultural groups highlight the importance of a comprehensive approach to delivering hospice care in end-of-life care. Implementing the proposed recommendations could expand cultural competence and improve accessibility to Hospice Wellington's services to better meet the unique needs of individuals and families from diverse ethnocultural backgrounds. This would promote a more inclusive and supportive environment for end-of-life care experiences.

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