

RESEARCH ARTICLE



Nonphysical Suffering: An Under-Resourced and Key Role for Hospice and Palliative Care Social Workers

Maxxine Rattner and Cheryl-Anne Cait

Faculty of Social Work, Wilfrid Laurier University, Waterloo, Canada

ABSTRACT

This article highlights recent research findings that have significance for hospice and palliative care social work in Canada, and for the field of hospice and palliative care more broadly. A 2020 discourse analysis study examined the experiences of 24 interdisciplinary palliative care clinicians across Canada in their work with patients' nonphysical suffering. Nonphysical suffering is suffering that may be emotional, psychological, social, spiritual and/or existential in nature. The study found an absence of specialist social workers on hospice and palliative care teams or limited time for specialist social workers to address patients' nonphysical suffering due to high caseloads and complex practical needs. While the study recognizes social workers have expertise in supporting patients' nonphysical suffering, a competency and skill that has not been sufficiently captured in the existing literature, the systemic barriers they face in providing care may leave patients' needs unmet. The study also highlights the unique pressure social workers may feel to relieve patients' nonphysical suffering due to the psychosocial focus of their role. The need for specialist social workers to be included and adequately resourced on hospice and palliative care teams across diverse settings in Canada is evident.

KEYWORDS

Canada; palliative care; social work; suffering; psychosocial

Introduction

A primary aim of palliative care is the relief of patients' suffering, both physical and nonphysical (WHO, 2022). Nonphysical suffering is suffering that may be emotional, psychological, social, spiritual and/or existential in nature (Rattner, 2022). Despite the centrality of relieving suffering to palliative care philosophy and practice, very little research exists on front-line clinicians' experiences with patients' nonphysical suffering. Existing research focuses on the experiences of palliative care nurses with patients' nonphysical suffering (White, Wilkes, Cooper, & Barbato, 2004). Interdisciplinary clinicians' experiences with both physical and nonphysical

suffering (Hegarty, Breden, Swetenham, & Grbich, 2010; Vachon & Guité-Verret, 2020), nonphysical suffering alone (Rattner, 2020), or the experiences of interdisciplinary clinicians, family members and patients with existential suffering, specifically (Bruce, Schreiber, Petrovskaya, & Boston, 2011) are also captured in the existing literature. The latter study on existential suffering includes the voices of 10 clinicians, including a couple of social workers (specific number of social workers not included).

The discourse analysis study was conducted with 24 palliative care clinicians and includes the voices of 6 social workers. The purpose was to expand understanding of front-line clinicians' 'realities' working with patients' nonphysical suffering. The focus of this paper is on study results specific to the experiences of the hospice/palliative care social workers that participated in the study. This paper begins by providing brief overviews of hospice and palliative care in Canada, and more specifically hospice and palliative care social work in Canada. It then provides an overview of study findings specific to social workers' experiences, before detailing their implications for both hospice and palliative care social work, and the field of hospice and palliative care more broadly.

A historical snapshot of hospice and palliative care in Canada

Dr. Balfour Mount introduced the concept of hospice care in Canada in the 1970s. At the time, he faced resistance to the concept due to the association of the term 'hospice' with death and religious organizations. To make the concept more acceptable to bilingual Canadians (French and English), he coined the term 'palliative care'. This term closely aligned with the principles of hospice care advanced by Dame Cicely Saunders as a form of holistic care near the end of life and gained widespread acceptance both in Canada and internationally (Allen, Chapman, O'Connor, & Francis, 2008, p. 351).

Canada had its first national *Strategy on Palliative and End-of-Life Care* from 2002–2007, championed by Senator Sharon Carstairs. While no national strategy has existed since that time, the Canadian federal government initiated the development of the *Framework on Palliative Care in Canada* in 2018 after broad consultation with health care providers, people living with life-limiting illness, caregivers, and subject matter experts (Health Canada, 2018). The Framework's intention is to help mitigate the "considerable variation and disparity in palliative care services provided across Canada" and to ensure "Canadians are able to access high quality palliative care" (Health Canada, 2018, p. 12).

In Canada, adult and pediatric palliative care is practiced in a variety of settings, including consult teams within acute care settings, hospital-based

palliative care units, outpatient clinics, home/community care settings, long term care homes, and residential, day, and community hospice programs. Interdisciplinary team make-up within these settings can vary; for example, a social worker and spiritual care provider may not be consistently government-funded positions in residential hospice settings, and therefore may not exist at all or may be staffed only through fundraising efforts. Also, palliative care consult teams in acute-care settings may be physician-centric and not utilize specialist interdisciplinary professionals. Post-death bereavement care, an essential part of palliative care, is largely under-funded and under-delivered in Canada outside of residential/community hospice programs. At present, only 30% of Canadians have access to specialist palliative or end-of-life care services (Canadian Society of Palliative Care Physicians, 2016). Research has shown that people living in wealthier and urban neighborhoods, people living with cancer, and people accessing care in acute care hospitals have the greatest access to palliative care in Canada (Tanuseputro, Budhwani, Bai, & Wodchis, 2017). Access to home/community-based palliative care is more limited (CIHI, 2023).

Canada has a long and ongoing history of colonialism (Absolon, 2022), and this continues to have a significant effect within health care systems where palliative care is provided (Lavallee & Harding, 2022). Black, Indigenous and communities of color experience barriers to accessing palliative care due to racism, social and structural inequities, and historical and ongoing mistrust of health care systems that have harmed, and continue to harm them (Algu, 2021; Prince, Kortes-Miller, Stajduhar, & Marshall, 2022; Shahid et al., 2018). As Canadian palliative care physician and researcher Dr. Kavita Algu (2021) writes, “Racialized individuals have less utilization of palliative care services, experience worse symptom control, and are less likely to have their end of life wishes documented or respected” (p. 1). Skepticism and lack of confidence 2SLGBTQ+ communities have toward healthcare systems and anticipated discrimination, homophobia and transphobia also pose barriers to accessing palliative care for these communities (Grassau, Stinchcombe, Thomas, & Wright, 2021; Kortes-Miller, Boulé, Wilson, & Stinchcombe, 2018; Prince et al., 2022). ‘2S’ stands for “Two-spirited,” which is the culturally specific term used by some Indigenous Peoples to describe their gender, sexual and/or spiritual identity; it is placed first in ‘2SLGBTQ+’ as a sign of respect and honor to Indigenous Peoples (Native Women’s Association of Canada, n.d.). Individuals who are living in poverty, unstably housed, and/or homeless may have even less access (Prince et al., 2022; Reimer-Kirkham et al., 2016). Publicly-funded health care in Canada, while at risk for increasing privatization in some settings (Pesut et al., 2022), works to mitigate some of the financial stressors, or financial suffering (Delgado-Guay et al., 2015; Rattner, 2020), that may accompany a life-limiting diagnosis and illness.

Medical Assistance in Dying (MAiD), Canada's term for euthanasia, was legally introduced in 2016, changing the country's landscape of dying and death. Proponents of MAiD generally acknowledge that there may be suffering associated with a life-limiting illness that cannot be relieved, even with exceptional clinical care. Generally, those in opposition strongly believe that MAiD can be avoided with proper interdisciplinary care and/or clinical interventions (Karsoho, Fishman, Wright, & Macdonald, 2016). There is acknowledgement that MAiD should not be more readily accessible than quality palliative care and that better access to palliative care is required Canada-wide (Booker & Bruce, 2020).

Hospice and palliative care social work in Canada: a brief overview

There is little if any research focusing specifically on social workers working in hospice and palliative care settings in Canada. Searching the terms 'palliative' OR 'hospice' AND 'social work*' AND 'Canada*' within peer-reviewed article abstracts in PubMed, APA PsycInfo and CINAHL revealed only one article specific to hospice and palliative care social work in Canada, which captures clinical competencies for practice (Bosma et al., 2010). These competencies include advocacy, assessment, care delivery and care planning, and self-reflective practice, among others (Bosma et al., 2010). They were first articulated in a 2008 document titled, *Canadian social work competencies for hospice palliative care: A framework to guide education and practice at the generalist and specialist levels* (Bosma et al., 2008; Cadell & Bosma, 2022). The development of these competencies was supported by Health Canada's Secretariat of Palliative and End-of-Life Care (Cadell, Johnston, Bosma, & Wainwright, 2010), part of Canada's former *Strategy on Palliative and End-of-Life Care* (Health Canada, 2018).

While there is little research on social workers' experiences providing hospice and palliative care in Canada, social workers and social work researchers in Canada are involved in wide-ranging research and scholarship on topics of significance to the field of hospice and palliative care. For example, they have advanced discourse, practice and understanding around social work leadership within hospice and palliative care (Blacker, Head, Jones, Remke, & Supiano, 2016), post-traumatic growth within pediatric palliative care (Cadell et al., 2014), hospice volunteering and community engagement (Cait, Lafrenière, Coakley, & Godin, 2019), the experiences of 2SLGBTQ+ older adults receiving palliative and end-of-life care (Grassau et al., 2021; Kortes-Miller et al., 2018), and building palliative care capacity in First Nations communities (Prince et al., 2019). They have also developed psychosocial practice guidance along the trajectory of serious illness (Thompson & Wainwright, 2016), and grown palliative care's

understanding of end-of-life care needs for persons living with schizophrenia (Relyea, MacDonald, Cattaruzza, & Marshall, 2019), and of suffering (Rattner, 2022).

Hospice and palliative care social workers play a pivotal role on interdisciplinary hospice and palliative care teams, responding to diverse and complex psychosocial and practical support needs. Specialist palliative care social workers; however, are not a standard part of hospice and palliative care teams in Canada (Henderson et al., 2019).

Methodology

Study rationale

Dame Cicely Saunders' concept of 'total pain' denotes that suffering can be multi-dimensional, embodying both physical and nonphysical aspects (Clark, 2016). A recent scoping review, however, confirmed that palliative care clinicians struggle in working with patients' nonphysical suffering more and differently than physical suffering. The same scoping review found that patients with life-limiting illnesses also distinguish between their physical and nonphysical sources of suffering. This provides an alternative understanding of 'suffering' or 'total pain' (Rattner, 2022). These important distinctions between physical and nonphysical suffering, in addition to clinicians' experiences specific to working with patients' nonphysical suffering being minimally explored in the palliative care literature (Bruce et al., 2011; Hegarty et al., 2010; Rattner, 2020; Vachon & Guité-Verret, 2020; White et al., 2004), provided a rationale for this study (Rattner, 2023).

Methods

Using a poststructural discourse analysis as the methodology, the larger study aimed to: (i) identify what discourses exist within how palliative care clinicians talk about their experiences with patients' nonphysical suffering; and to (ii) identify whether and how these discourses may affect palliative care clinicians and impact clinical care. 'Discourse,' itself a poststructural concept, has been defined as "the language practices through which knowledge, truth, our sense of selves and social relations are constructed ... [it] refers to the language practices through which we understand 'reality' and act on it" (Healy, 2005, p. 211–12). Discourses are "systems of thought and systematic ways of carving out reality. They are structures of knowledge that influence systems of practices" (John, 1994, p. 57). Discourse analysis, poststructuralism and palliative care have previously converged within existing literature and research (e.g., Allen et al., 2008; Borgstrom & Walter, 2015; Campbell & Amin, 2012; Clark, 1999; Dahlborg-Lyckhage &

Liden, 2010; Nagington, Walshe, & Luker, 2016a, 2016b; O'Connor, Mellar, & Abernethy, 2010) and the goal of this study was to build upon this work.

In the summer and fall 2020, 24 palliative care clinicians (6 social workers, 6 physicians, 8 nurses, 3 music therapists, and an occupational therapist) from across Canada (Yukon, British Columbia, Alberta, Manitoba, Ontario, Quebec and Nova Scotia) participated in a qualitative study specifically exploring their experiences working with patients' nonphysical suffering. Participants took part in 45–60 minute long, semi-structured phone interviews and completed a written informed consent form before the interview. Interviews were transcribed verbatim, and interview transcripts were the 'texts' that were analyzed for the presence of discourses (Abell & Myers, 2008; Albertín Carbó, Vázquez Ahumada, Dorado Caballero, & Lezama Argüelles, 2016; Cheek, 2000, 2004; Lupton, 1992; Talja, 1999; Taylor, 2013). Grounding the study's methodology in the discourse analysis literature, data analysis involved asking key questions of the data (Cheek, 2000; O'Connor & Payne, 2006; Talja, 1999; Taylor, 2013), including: What patterns of themes and topics exist within and across the interview texts? What variations/tensions/contradictions exist within and across these themes/topics? And, What reality is being constructed within the interview texts? What does this constructed reality 'do'? That is, what are its effects? (Albertín Carbó et al., 2016; Cheek, 2004; Hall, 2001; Healy, 2005; Jorgensen & Phillips, 2002; Livholts & Tamboukou, 2015; Lupton, 1992; O'Connor & Payne, 2006; Park & Bhuyan, 2012; Talja, 1999; Taylor, 2013)? The authors of this paper collaborated on this study which was approved by Wilfrid Laurier University Research Ethics Board (REB Approval #6546). Most study participants identified as white, female, and spiritual, practiced full-time in a combination of palliative care practice settings (e.g., inpatient hospital, outpatient clinic, home/community-based care, residential hospice), and had between 10–19 years of palliative care practice experience. All participants worked with adult patients. While the substantive results from the larger study (Rattner, 2023) are not included in this analysis, results specific to social workers' experiences working with patients' nonphysical suffering are highlighted within the Canadian context, and within the field of palliative care more generally.

Highlighted findings

A discourse is visible within the larger study about the numerous barriers clinicians encounter when supporting patients' nonphysical suffering. These barriers appear as tensions in the data between clinicians wanting to support patients with their nonphysical suffering, and not necessarily being

able to do so. One barrier consistently noted by participants was the lack of specialist hospice/palliative care social workers on hospice/palliative care teams.

Lack of specialist hospice and palliative care social workers on teams

This study revealed that a lack of access across settings to specialist palliative care social workers poses a barrier to supporting patients with their nonphysical suffering. This was consistently noted by social workers and by other interdisciplinary team members throughout the interviews.

Participants consistently noted that community/home-based palliative care settings lack access to social workers with specialist training in hospice and palliative care. For example, in the following excerpt, a nurse in an urban home/community care setting describes a patient's death anxiety and how they feel ill-equipped to address it on their team due to limited spiritual care and social work support:

He just was anxious about dying and having to think that he's got an expiration date now. It seemed to be more like that he was trying to rely on his faith in a way but yeah, it's a tricky thing when you know, we're told "Oh, you'll be resurrected, or—but it's another thing to you know recognize that you're the one that actually has to go through that... [And] there's no go-to really for like, we're on our own for—we don't even have a spiritual care person on our team, there's one social worker for 4 or 500 palliative patients, like, we just are not equipped or trained to—other than sort of on our own team—to be able to help people deal with [death] anxiety. (Nurse, Home/Community Care)

In the above excerpt, the participant speaks to how the palliative home/community care caseload is significant (400–500 patients), with only one social worker and no spiritual care provider; contributing to patients' nonphysical suffering being less supported.

Another nurse in an urban home/community care setting expressed similar sentiments, noting one of their main challenges was the delay in accessing resources such as social work and spiritual care. In response to the interview question, "When you encounter patients' nonphysical suffering in your work now, what do you have challenges with? They shared the following:

Uh, well, being in the community, it's probably the [lack of access to] resources... and just kind of an inability, like, when you work in the hospital and you call up spiritual care and you call up the doctor and you call up the social worker, and you see them face to face, and you're chit chatting within the hour, right? kind of thing, um, in community [care] it's a lot different; things move a lot slower um because of being in the community, right? (Nurse, Home/Community Care)

Here, the nurse participant speaks to how it takes more time to involve social workers and spiritual care providers in home/community care settings versus hospital inpatient settings; these are the care team members who the nurse identifies as commonly supporting patients' non-physical suffering. In hospital settings, such team members are more readily available and can work together to more quickly respond to and support patients' non-physical suffering. In home/community care settings, patients must wait longer to meet with social workers or spiritual care providers if a need is identified during another team member's visit.

Study participants consistently noted that palliative home/community care settings, in particular, lacked access to specialist psychosocial care, including social workers. The following interview excerpt reveals how even inpatient palliative care unit social workers can lack sufficient time to support patients' nonphysical suffering. For example, a palliative care physician who works in both urban inpatient and home/community care settings noted:

I just think it would be nice to be resourced with clinicians who—whose main objective is to be able to sit and spend time and go through some of the non-physical suffering that patients are having. And, I just don't think we're—we don't have that resource. I feel like the social workers that we have are excellent, especially the ones in the community, but they're stretched extremely thin. And on the [palliative care] unit the social workers are, I would say, more primarily involved in um logistics around paperwork and housing and things like that rather than being able to sit at the bedside and do some of the counselling pieces. (Physician, In-Patient Palliative Care & Home/Community Care)

This participant speaks to how social workers in both home/community care and inpatient palliative care unit settings lack the necessary time to focus on patients' nonphysical suffering; there are either too few social workers available, such as in home/community care settings, or on inpatient units, they can end up needing to focus on practical aspects of support rather than one-on-one counseling. These barriers can lead to patients' nonphysical suffering being less supported.

The lack of time available to sufficiently explore and attend to patients' nonphysical suffering is specifically named by a social worker participant who shared the following:

It's more about putting in the time to create the comfort, the safety, and build the connection and that's where the healing comes. There's nothing you can say or do as a one shot intervention that fixes it and that's what's frustrating. 'Cause we have such big case loads we don't have time to put the time in to help. (Social Worker, Home/Community Care & Residential Hospice).

Here, the social worker describes how high case loads prevent them from having the necessary time to build that therapeutic connection and therefore fully attend to patients' nonphysical suffering. The social worker

importantly notes, too, that supporting patients' nonphysical suffering takes time and does not have any quick fixes; they express their frustration with how large case loads mean that they do not have the requisite time to help patients with the full extent of their suffering.

Within the data above, it becomes clear that both interdisciplinary team members and social workers themselves identify supporting patients' nonphysical suffering as something that is significant to social workers' scope of practice within palliative care. The study also reveals that palliative care settings are differently resourced when it comes to specialist psychosocial palliative care, and how this impacts care provision, in particular, a team's ability to support patients' nonphysical suffering. While some settings do not have specialist social workers on their palliative care teams, such as in home/community care settings, in other settings like inpatient palliative care units, social workers may be consumed with practical needs (e.g., paperwork, housing), leaving little time for in-depth counseling and support. In terms of the effects of this discourse, participants consistently noted that being unable to adequately support patients with their nonphysical suffering can result in feelings of helplessness and inadequacy.

A unique pressure to relieve patients' nonphysical suffering

A discourse was identified in the larger study about the pressure palliative care clinicians feel to relieve patients' nonphysical suffering. While the larger study found that this is a pressure that is felt across all interdisciplinary team members, findings revealed that social workers in the study may uniquely experience aspects of this. For example, in referencing the pressure they feel to relieve patients' nonphysical suffering, one social worker working in inpatient and home/community settings shared:

I do feel the pressure just because, I don't know, I think because my job is strictly the psychosocial, so I have to fix that piece. But it's not—I know that, in my logic brain I certainly know that I can't, but I think that whenever I'm triggered emotionally it's easier to me to spiral into "Oh, but I should be able to," you know, but if I'm calm and just relaxed I can, I know that I can't possibly do that. (Social Worker, Home/Community Care & Residential Hospice)

This participant noted that they feel a unique source of pressure from the "strictly psychosocial" focus of the role as a social worker; that is, because they and others perceive nonphysical suffering to fall within their scope of practice, they can feel a particular pressure to relieve it. The participant shared logically knowing within themselves the limits of what's possible, based on their practice experience: that not all nonphysical suffering can be 'fixed,' coupled with still feeling pressure to relieve patients' nonphysical suffering.

In the following interview excerpt, a social worker working in a hospice setting, also articulated some of the conflicting feelings they hold around the pressure to relieve patients' non- physical suffering:

I mean, I think there's a certain amount of pressure, but it was never overwhelming for me to sort of—I don't know if that was ever my goal, sort of, to make them feel better, like, I think it was. Yes, you want to ease suffering, yes, you want to make them feel better, but I know that I'm not going to take the pain away. I guess that's the difference. Like, yes, you want to ease, but you can't change the situation, so helping them feel a little bit better, but I don't know if it's pressure that I felt. (Social Worker, Residential Hospice)

Here, the social worker appeared to appreciate the limits of what's possible in terms of relieving patients' nonphysical suffering; they clearly express wanting to ease patients' nonphysical suffering and to make them feel better, while simultaneously noting that they know they cannot change the situation. The social worker initially states that they do experience this as a pressure to relieve patients' nonphysical suffering, though also state they do not. This social worker expresses feeling resigned to accept this contradiction, and tension, that is inherent to, and shapes, their practice: wanting to relieve patients' nonphysical suffering while knowing that they can't "change the situation"—the fact that the patient will die.

And in the following interview excerpt, another social worker in a hospice setting speaks to how it feels when they cannot help a patient with their nonphysical suffering:

I will encounter [patients] like that, who aren't able to name what's going on for them and

maybe they won't ever be able to do that and they're, and that's just the way it is and, and being able to navigate that more, maybe with less judgment and less um, being less hard on myself that I didn't give him a good death. (Social Worker, Residential Hospice)

In this instance, the social worker speaks about feeling as though they did not do their job and/or help as much as they feel they could have, when patients are not able to name or identify their nonphysical suffering. This social worker hints at the pressure they feel when they describe being hard on themselves for not being able to help a patient with their nonphysical suffering. This leads them to feeling as though they did not give that patient a "good death." Here, too, the effects of this discourse include feelings of clinician helplessness and inadequacy.

Discussion

Working with patients' nonphysical suffering is a necessary trans-disciplinary skill. Still, the study results pinpoint how interdisciplinary team

members identify supporting patients' nonphysical suffering as something that is very much within hospice and palliative care social workers' scope of practice. Social workers in the study, too, recognized nonphysical suffering as comprising a central aspect of their role. Time constraints related to untenable case loads and insufficient staffing impede social workers' and therefore teams' capacities to adequately support patients' nonphysical suffering. Current literature discusses the importance of social workers having knowledge of and "maintaining appropriate boundaries in the face of" suffering (Bosma et al., 2008, p. 8; 2010; Gwyther et al., 2005). That social workers are key team members that support patients' nonphysical suffering has not before been identified within hospice/palliative care social worker competencies (Bosma et al., 2008, p. 8; 2010; Gwyther et al., 2005).

Study results also highlighted the pressure social workers can feel to relieve patients' non-physical suffering. This may be uniquely experienced due to the psychosocial focus of their role and the significance of nonphysical suffering to their scope of practice. The 'pressure' clinicians may feel to relieve nonphysical suffering that may be difficult to relieve has been minimally articulated in the palliative care literature (Rattner, 2019, 2020; Rattner & Berzoff, 2016). This pressure is more so alluded to within the existing literature, with several studies finding clinicians experience helplessness and inadequacy when they cannot relieve patients' suffering (Arbore, Katz, & Johnson, 2016; Back, Rushton, Kaszniak, & Halifax, 2015; Bruce et al., 2011; Clark, 2011; Rattner, 2020; Rushton & Ballard, 2011; Sacks & Volker, 2015; Vachon & Guité-Verret, 2020; White et al., 2004). Feelings of clinician helplessness and inadequacy are mirrored in the present study's results, as noted above. How social workers on hospice and palliative care teams may experience this pressure to relieve nonphysical suffering in unique ways, as this study found, has also not yet been articulated in the existing literature. Social workers in this study also expressed knowing, within themselves, the limits of what is possible: that not all nonphysical suffering can necessarily be relieved. That not all suffering can be relieved, despite clinicians' best efforts, is an idea that is less acknowledged in palliative care's discourse (e.g., Bruce et al., 2011; Currow & Hegarty, 2006; Gregory & English, 1994; Hegarty et al., 2010; White et al., 2004). A previous study by Breaden, Hegarty, Swetenham, and Grbich (2012) is the only one found that comes close to this idea. They found that "living the paradoxes" was a central theme for palliative care clinicians working with patients' refractory physical and nonphysical suffering (p. 898). 'Living the paradoxes' describes how "clinicians had to accept realistic limits, yet also do everything possible" in their work with patients' suffering (Breaden et al., 2012, p. 898). This still differs from the study results described above, wherein the social workers shared knowing that nonphysical suffering's

relief is not necessarily possible, while still feeling pressure to relieve it. In each of the ways noted above, study results help to make more visible aspects of front-line care with patients' nonphysical suffering that are less visible within palliative care literature and discourse. These findings have significance to hospice and palliative care social work and the field of hospice and palliative care more broadly.

Study findings also importantly highlight that specialist palliative care social workers may either be absent in certain Canadian settings, like home and community care and/or they may have insufficient time to address non-practical patient needs. In addition to the under-utilization of specialist palliative care social workers in Canadian settings, the under-utilization of their clinical skills in supporting patients' nonphysical suffering due to high case loads and complex practical needs also becomes evident. These findings add an urgency to existing calls for the inclusion of specialist palliative care social workers across diverse settings in Canada (Henderson et al., 2019).

Implications for hospice and palliative care social work in Canada

More research into social workers' experiences practicing hospice and palliative care in Canada is needed. This is an area of research that has been minimally explored previously. More advocacy and funding is needed, too, to support specialist palliative care social workers becoming a standard part of hospice and palliative care teams in Canada across diverse settings (Henderson et al., 2019). In settings that have a social worker on the team, study results demonstrated that patient loads may be too high to have the time to engage in the type of work supporting patients' nonphysical suffering requires. Therefore, social worker/patient ratios also need to be re-considered and adequately funded in relation to the capacity required to truly support patients' and families' nonphysical suffering across diverse settings. For example, palliative care consult teams in acute care settings often do not have a specialist palliative care social worker on the team and the ratio of social workers to residents in long term care homes can commonly be one social worker to more than 300 or 400 residents. These ratios systemically do not allow for social workers' clinical skills and competencies to be fully utilized, nor for complex patient and family psychosocial needs to be adequately addressed. Ongoing calls for the expansion of palliative care services in Canada must continue to include calls for the consistent funding of specialist psychosocial care. Beyond social workers, the consistent funding of spiritual care providers and music therapists must also be included in these calls, as they are key team members integral to supporting patients' and families' nonphysical suffering (Rattner, 2023).

Within Canada, the need for more education and training for social workers who wish to specialize in hospice and palliative care must also be considered. It is all too rare in Canada to have palliative care or even grief-related content integrated into social work education at both the bachelors' and masters' levels (Berkman & Stein, 2018; Stein, Berkman, & Pollak, 2019). As Bosma et al. (2010) and colleagues note, "Most social work practitioners will encounter adults, children, and families who are facing progressive life limiting illness, dying, death, or bereavement. Such social work interactions occur not only in health care settings, but in all locations where social workers practice" (p. 79), denoting the importance of these areas of focus in generalist social work education. Additionally, post-MSW specialized training specific to working in hospice and palliative care (e.g., Berzoff, Dane, & Cait, 2005; Gardner, Gerbino, Warner Walls, Chachkes, & Doherty, 2015) does not currently exist in Canada, and is an area requiring further exploration and funding.

Conclusion

This study identified systemic barriers that can prevent social workers from supporting patients' nonphysical suffering in diverse palliative care settings (e.g., in-patient palliative care unit, home care, etc.). Working with and supporting patients' nonphysical suffering is a key skill and competency of the hospice and palliative care social worker role that has, before now, been largely under-acknowledged in palliative care literature, practice and research. These findings have significance for hospice and palliative care social work and the field of hospice and palliative care more broadly. Study findings also provide evidence for the vital role that social workers play in hospice and palliative care across diverse settings in Canada, while also identifying the under-funding and under-utilization of specialist palliative care social workers in these settings.

Funding

This research was supported by a Social Sciences and Humanities Research Council Doctoral Fellowship.

References

- Abell, J., & Myers, G. (2008). Analyzing research interviews. In R. Wodak & M. Krzyzanowski (Eds.), *Qualitative discourse analysis in the social sciences* (pp. 145–161). Palgrave MacMillan. doi:[10.1007/978-1-137-04798-4_7](https://doi.org/10.1007/978-1-137-04798-4_7)
- Absolon, K. (2022). Colonialism: A commentary. In S. Shaikh, B. LeFrançois & T. Macías (Eds.), *Critical Social Work Praxis* (pp. 363–368). Fernwood Publishing.

- Albertín Carbó, P., Vázquez Ahumada, M. A., Dorado Caballero, A., & Lezama Argüelles, G. A. (2016). "How do I do discourse analysis?" Teaching discourse analysis to novice researchers through a study of intimate partner gender violence among migrant women. *Qualitative Social Work*, 15(3), 363–379. doi:[10.1177/1473325015617233](https://doi.org/10.1177/1473325015617233)
- Algu, K. (2021). Denied the right to comfort: Racial inequities in palliative care provision. *EClinical Medicine*, 34(100833), 1–2. doi:[10.1016/j.eclinm.2021.100833](https://doi.org/10.1016/j.eclinm.2021.100833)
- Allen, S., Chapman, Y., O'Connor, M., & Francis, K. (2008). Discourses associated with nursing aged people who are dying in the Australian context: A review of the literature. *International Nursing Review*, 55(3), 349–354. doi:[10.1111/j.1466-7657.2008.00628](https://doi.org/10.1111/j.1466-7657.2008.00628)
- Arbore, P., Katz, R. S., & Johnson, T. A. (2016). Suffering and the caring professional. In R. S. Katz & T. A. Johnson (Eds.), *When professionals weep: Emotional and countertransference responses in end-of-life care* (pp. 13–26). Taylor & Francis Group. doi:[10.4324/9781315716022-3](https://doi.org/10.4324/9781315716022-3)
- Back, A., Rushton, C., Kaszniak, A., & Halifax, J. (2015). "Why are we doing this?": Clinician helplessness in the face of suffering. *Journal of Palliative Medicine*, 18(1), 26–30. doi:[10.1089/jpm.2014.0115](https://doi.org/10.1089/jpm.2014.0115)
- Berkman, C., & Stein, G. L. (2018). Palliative and end-of-life care in the masters of social work curriculum. *Palliative & Supportive Care*, 16(2), 180–188. doi:[10.1017/S147895151700013X](https://doi.org/10.1017/S147895151700013X)
- Berzoff, J., Dane, B., & Cait, C. (2005). Innovative models for developing post-masters curriculum in end-of-life care. *Journal of Teaching in Social Work*, 25(3-4), 63–88. doi:[10.1300/J067v25n03_05](https://doi.org/10.1300/J067v25n03_05)
- Blacker, S., Head, B., Jones, B., Remke, S., & Supiano, K. (2016). Advancing hospice and palliative care social work leadership in interprofessional education and practice. *Journal of Social Work in End-of-Life & Palliative Care*, 12(4), 316–330. doi:[10.1080/15524256.2016.1247771](https://doi.org/10.1080/15524256.2016.1247771)
- Booker, R., & Bruce, A. (2020). Palliative sedation and medical assistance in dying: Distinctly different or simply semantics? *Nursing Inquiry*, 27(1), e12321. doi:[10.1111/nin.12321](https://doi.org/10.1111/nin.12321)
- Borgstrom, E., & Walter, T. (2015). Choice and compassion at the end of life: A critical analysis of recent English policy discourse. *Social Science & Medicine* (1982), 136–137, 99–105. doi:[10.1016/j.socscimed.2015.05.013](https://doi.org/10.1016/j.socscimed.2015.05.013)
- Bosma, H., Johnston, M., Cadell, S., Wainwright, W., Abernethy, N., Feron, A., ... Nelson, F. (2010). Creating social work competencies for practice in hospice palliative care. *Palliative Medicine*, 24(1), 79–87. doi:[10.1177/0269216309346596](https://doi.org/10.1177/0269216309346596)
- Bosma, H., Johnston, M., Cadell, S., Wainwright, W., Abernathy, N., Feron, A., ... Nelson, F. (2008). Canadian Social Work Competencies for Hospice Palliative Care: A Framework to Guide Education and Practice at the Generalist and Specialist Levels. http://cms.virtualhospice.ca/Web/CVH/Assets/Social_Work_Competencies_July_2009_20150708134353.pdf.
- Breaden, K., Hegarty, M., Swetenham, K., & Grbich, C. (2012). Negotiating uncertain terrain: A qualitative analysis of clinicians' experience of refractory suffering. *Journal of Palliative Medicine*, 15(8), 896–901. doi:[10.1089/jpm.2011.0442](https://doi.org/10.1089/jpm.2011.0442)
- Bruce, A., Schreiber, R., Petrovskaya, O., & Boston, P. (2011). Longing for ground in a ground(less) world: A qualitative inquiry of existential suffering. *BMC Nursing*, 10(1), 2. doi:[10.1186/1472-6955-10-2](https://doi.org/10.1186/1472-6955-10-2)
- Cadell, S., & Bosma, H. (2022). Palliative social work in Canada. In T. Altilio, S. Otis-Green & J. Cagle (Eds.), *Oxford textbook of palliative social work* (pp. 482–484). Oxford University Press. doi:[10.1093/med/9780197537855.003.0047](https://doi.org/10.1093/med/9780197537855.003.0047)

- Cadell, S., Johnston, M., Bosma, H., & Wainright, W. (2010). An overview of contemporary social work practice in palliative care. *Progress in Palliative Care*, 18(4), 205–211. doi:10.1179/096992610X12775428636700
- Cadell, S., Hemsworth, D., Smit Quosai, T., Steele, R., Davies, E., Liben, S., ... Siden, H. (2014). Posttraumatic growth in parents caring for a child with a life-limiting illness: A structural equation model. *The American Journal of Orthopsychiatry*, 84(2), 123–133. doi:10.1037/h0099384
- Cait, C., Lafrenière, G., Coakley, L., & Godin, M. (2019). *Re-imagining hospice volunteering and thinking about community engagement*. Vancouver, BC: Congress of the Humanities and Social Services, CASWE.
- Campbell, L., & Amin, N. (2012). A poststructural glimpse at the World Health Organization's palliative care discourse in rural South Africa. *Rural and Remote Health*, 12, 2059. doi:10.22605/RRH2059
- Canadian Institute for Health Information. (2023). Access to palliative care in Canada 2023. <https://www.cihi.ca/sites/default/files/document/access-to-palliative-care-in-canada-2023-report-en.pdf>.
- Canadian Society of Palliative Care Physicians. (2016). How to improve Palliative Care in Canada. <https://archive.cspcp.ca/wp-content/uploads/2016/11/Full-Report-How-to-Improve-Palliative-Care-in-Canada-FINAL-Nov-2016.pdf>.
- Cheek, J. (2000). *Postmodern and poststructural approaches to nursing research*. SAGE. doi:10.4135/9781452204895
- Cheek, J. (2004). At the margins? Discourse analysis and qualitative research. *Qualitative Health Research*, 14(8), 1140–1150. doi:10.1177/1049732304266820
- Clark, D. (1999). 'Total pain,' disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Social Science & Medicine*, 49(6), 727–736. doi:10.1016/S0277-9536(99)00098-2
- Clark, D. (2016). *To comfort always: A history of palliative medicine since the nineteenth century*. Oxford University Press. doi:10.1093/med/9780199674282.001.0001
- Clark, E. J. (2011). Self care as best practice in palliative care. In T. Altilio & S. Otis-Green (Eds.), *Oxford Textbook of Palliative Social Work* (pp. 771–777). Oxford University Press. doi:10.1093/med/9780199739110.003.0083
- Currow, D., & Hegarty, M. (2006). Suffering—At the bedside of the dying. *Journal of Religion, Spirituality & Aging*, 18(2-3), 123–136. doi:10.1300/J496v18n02_10
- Dahlborg-Lyckhage, E., & Liden, E. (2010). Competing discourses in palliative care. *Supportive Care in Cancer*, 18(5), 573–582. doi:10.1007/s00520-009-0691-6
- Delgado-Guay, M., Ferrer, J., Rieber, A., Rhondali, W., Tayjasanant, S., Ochoa, ... Bruera, E. (2015). Financial distress and its associations with physical and emotional symptoms and quality of life among advanced cancer patients. *Oncologist*, 20(9), 1092–1098.
- Gardner, D., Gerbino, S., Warner Walls, J., Chachkes, E., & Doherty, M. (2015). Mentoring the next generation of social workers in palliative and end-of-life care: The Zelda Foster studies program. *Journal of Social Work in End-of-Life & Palliative Care*, 11(2), 107–131. doi:10.1080/15524256.2015.1074142
- Grassau, P., Stinchcombe, A., Thomas, R., & Wright, D. K. (2021). Centering sexual and gender diversity within Compassionate Communities: Insights from a community network of LGBTQ2S+ older adults. *Palliative Care and Social Practice*, 15, 26323524211042630. doi:10.1177/26323524211042630
- Gregory, D., & English, J. (1994). The myth of control: Suffering in palliative care. *Journal of Palliative Care*, 10(2), 18–22. doi:10.1177/082585979401000204

- Gwyther, L., Altilio, T., Blacker, S., Christ, G., Csikai, E., Hooyman, N., ... Howe, J. (2005). Social work competencies in palliative and end-of-life care. *Journal of Social Work in End-of-Life & Palliative Care*, 1(1), 87–120. doi:10.1300/J457v01n01_06
- Hall, S. (2001). Foucault: Power, knowledge and discourse. In M. Whetherell, S. Taylor, & S. Yates (Eds.), *Discourse theory and practice: A reader* (pp. 72–81). SAGE.
- Health Canada. (2018). Framework on Palliative Care in Canada. <https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada/framework-palliative-care-canada.pdf>
- Healy, K. (2005). *Social work theories in context: Creating frameworks for practice*. Palgrave.
- Hegarty, M., Breaden, K., Swetenham, C., & Grbich, C. (2010). Learning to work with the “unsolvable”: Building capacity for working with refractory suffering. *Journal of Palliative Care*, 26(4), 287–294. doi:10.1177/082585971002600405
- Henderson, D., Boyle, A., Herx, L., Alexiadis, A., Barwich, D., Connidis, S., ... Sinnarajah, A. (2019). Staffing a specialist palliative care service, a team-based approach: Expert consensus white paper. *Journal of Palliative Medicine*, 22(11), 1318–1323. doi:10.1089/jpm.2019.0314
- John, L. (1994). Borrowed knowledge in social work: An introduction to post-structuralism and post-modernity. In A. Chambon & A. Irving (Eds.), *Postmodernism and social work* (pp. 47–60). Canadian Scholars’ Press.
- Jorgensen, M., & Phillips, L. (2002). *Discourse analysis as theory and method*. SAGE. doi:10.4135/9781849208871
- Karsoho, H., Fishman, J., Wright, D., & Macdonald, M. (2016). Suffering and medicalization at the end of life: The case of physician-assisted dying. *Social Science & Medicine*, 170, 188–196. doi:10.1016/j.socscimed.2016.10.010
- Kortes-Miller, K., Boulé, J., Wilson, K., & Stinchcombe, A. (2018). Dying in long-term care: Perspectives from sexual and gender minority older adults about their fears and hopes for end of life. *Journal of Social Work in End-of-Life & Palliative Care*, 14(2-3), 209–224. doi:10.1080/15524256.2018.1487364
- Lavallee, B., & Harding, L. (2022). How Indigenous-specific racism is coached into health systems. In A. Gebhard, S. Mclean & V. St. Denis (Eds.), *White benevolence: Racism and colonial violence in the helping professions* (pp. 51–68). Fernwood Publishing.
- Livholts, M., & Tamboukou, M. (2015). *Discourse and narrative methods*. SAGE.
- Lupton, D. (1992). Discourse analysis: A new methodology for understanding the ideologies of health and illness. *Australian Journal of Public Health*, 16(2), 145–150. doi:10.1111/j.1753-6405.1992.tb00043.x
- Nagington, M., Walshe, C., & Luker, K. (2016a). Quality care as ethical care: A poststructural analysis of palliative and supportive district nursing care., *Nursing Inquiry*23(1), 12–23. doi:10.1111/nin.12109
- Nagington, M., Walshe, C., & Luker, K. (2016b). A poststructural rethinking of the ethics of technology in relation to the provision of palliative home care by district nurses. *Nursing Philosophy : An International Journal for Healthcare Professionals*, 17(1), 59–70. doi:10.1111/nup.12099
- Native Women’s Association of Canada (n.d). Sex and gender inclusive terminology. <https://nwac.ca/assets-knowledge-centre/NWAC-2SLGBTQ-Factsheet-EN.pdf>.
- O’Connor, M., & Payne, S. (2006). Discourse analysis: Examining the potential for research in palliative care. *Palliative Medicine*, 20(8), 829–834. doi:10.1177/0269216306072348
- O’Connor, M., Mellar, D., & Abernethy, A. (2010). Language, discourse and meaning in palliative medicine. *Progress in Palliative Care*, 18(2), 66–71. doi:10.1179/096992610X12624290276421

- Park, Y., & Bhuyan, R. (2012). Whom should we serve? A discourse analysis of social workers' commentary on undocumented immigrants. *Journal of Progressive Human Services*, 23(1), 18–40. doi:[10.1080/10428232.2011.605745](https://doi.org/10.1080/10428232.2011.605745)
- Pesut, B., Thorne, S., Huisken, A., Wright, D. K., Chambaere, K., Tishelman, C., & Ghosh, S. (2022). Is progress being made on Canada's palliative care framework and action plan? A survey of stakeholder perspectives. *BMC Palliative Care*, 21(1), 182. doi:[10.1186/s12904-022-01074-4](https://doi.org/10.1186/s12904-022-01074-4)
- Prince, H., Kortes-Miller, K., Stajduhar, K., & Marshall, D. (2022). Public health palliative care, equity-oriented care, and structural vulnerability. In J. Abel & A. Kellehear (Eds.), *Oxford textbook of public health palliative care* (pp. 197–208). Oxford University Press. doi:[10.1093/med/9780198862994.003.0021](https://doi.org/10.1093/med/9780198862994.003.0021)
- Prince, H., Nadin, S., Crow, M., Maki, L., Monture, L., Smith, J., & Kelley, M. L. (2019). “If you understand you cope better with it”: The role of education in building palliative care capacity in four First Nations communities in Canada. *BMC Public Health*, 19(1), 768. doi:[10.1186/s12889-019-6983-y](https://doi.org/10.1186/s12889-019-6983-y)
- Rattner, M. (2019). Tellable and untellable stories in suffering and palliative care. *Mortality*, 24(3), 357–368. doi:[10.1080/13576275.2018.1530206](https://doi.org/10.1080/13576275.2018.1530206)
- Rattner, M. (2020). Navigating the intangible: Working with non-physical suffering on the front-lines of palliative care. *OMEGA - Journal of Death and Dying*, 81(4), 670–684. doi:[10.1177/0030222818797171](https://doi.org/10.1177/0030222818797171)
- Rattner, M. (2022). Increasing our understanding of non-physical suffering within palliative care: A scoping review. *Palliative and Supportive Care*, 20(3), 417–432. doi:[10.1017/S1478951521001127](https://doi.org/10.1017/S1478951521001127)
- Rattner, M. (2023). Disrupting and expanding the discourse: Palliative care clinicians' experiences with patients' non-physical suffering. (Doctoral dissertation). Wilfrid Laurier University. <https://scholars.wlu.ca/etd/2530>
- Rattner, M., & Berzoff, J. (2016). Rethinking suffering: Allowing for suffering that is intrinsic at end of life. *Journal of Social Work in End-of-Life & Palliative Care*, 12(3), 240–258. doi:[10.1080/15524256.2016.1200520](https://doi.org/10.1080/15524256.2016.1200520)
- Reimer-Kirkham, S., Stajduhar, K., Pauly, B., Giesbrecht, M., Mollison, A., McNeil, R., & Wallace, B. (2016). Death is a social justice issue: Perspectives on equity-informed palliative care. *ANS. Advances in Nursing Science*, 39(4), 293–307. doi:[10.1097/ANS.0000000000000146](https://doi.org/10.1097/ANS.0000000000000146)
- Relyea, E., MacDonald, B., Cattaruzza, C., & Marshall, D. (2019). On the margins of death: A scoping review of palliative care and schizophrenia. *Journal of Palliative Care*, 34(1), 62–69. doi:[10.1177/0825859718804108](https://doi.org/10.1177/0825859718804108)
- Rushton, C. H., & Ballard, M. K. (2011). The other side of caring: Caregiver suffering. In *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook* (pp. 309–342). The Johns Hopkins University Press.
- Sacks, J., & Volker, D. (2015). For their patients: A study of hospice nurses' responses to patient suffering. *Journal of Hospice & Palliative Nursing*, 17(6), 490–498. doi:[10.1097/NJH.0000000000000197](https://doi.org/10.1097/NJH.0000000000000197)
- Shahid, S., Taylor, E. V., Cheetham, S., Woods, J. A., Aoun, S. M., & Thompson, S. C. (2018). Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: A comprehensive review. *BMC Palliative Care*, 17(1), 72. doi:[10.1186/s12904-018-0325-1](https://doi.org/10.1186/s12904-018-0325-1)
- Stein, G. L., Berkman, C., & Pollak, B. (2019). What are social work students being taught about palliative care? *Palliative & Supportive Care*, 17(5), 536–541. doi:[10.1017/S1478951518001049](https://doi.org/10.1017/S1478951518001049)

- Talja, S. (1999). Analyzing qualitative interview data: The discourse analytic method. *Library & Information Science Research*, 21(4), 459–477. doi:[10.1016/S0740-8188\(99\)00024-9](https://doi.org/10.1016/S0740-8188(99)00024-9)
- Tanuseputro, P., Budhwani, S., Bai, Y. Q., & Wodchis, W. P. (2017). Palliative care delivery across health sectors: A population-level observational study. *Palliative Medicine*, 31(3), 247–257. doi:[10.1177/0269216316653524](https://doi.org/10.1177/0269216316653524)
- Taylor, S. (2013). *What is discourse analysis?* Bloomsbury Academic. doi:[10.5040/9781472545213](https://doi.org/10.5040/9781472545213)
- Thompson, M., & Wainwright, W. (2016). *Transitions in dying and bereavement: A psycho-social guide for hospice and palliative care*. Victoria Hospice Society.
- Vachon, M., & Guité-Verret, A. (2020). From powerlessness to recognition the meaning of palliative care clinicians' experience of suffering. *International Journal of Qualitative Studies on Health and Well-Being*, 15(1), 1852362. doi:[10.1080/17482631.2020.1852362](https://doi.org/10.1080/17482631.2020.1852362)
- White, K., Wilkes, L., Cooper, K., & Barbato, M. (2004). The impact of unrelieved patient suffering on palliative care nurses. *International Journal of Palliative Nursing*, 10(9), 438–444. doi:[10.12968/ijpn.2004.10.9.16049](https://doi.org/10.12968/ijpn.2004.10.9.16049)
- WHO. (2022). Palliative care. <https://www.who.int/health-topics/palliative-care>