



# Social disparities and symptom burden in populations with advanced cancer: specialist palliative care providers' perspectives

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## Abstract

Disparities in access to palliative care services for populations with social disparities have been reported in Western countries. Studies indicate that these populations tend to report higher symptom distress than other population groups. We need to further investigate how social disparities influence symptom burden to improve symptom relief in these populations.

**Purpose** To examine the perspectives of specialist palliative care providers concerning the relationship between social disparities and symptom burden in populations with advanced cancer.

**Methods** Two sequential qualitative studies that followed a combination of interpretive and critical methodologies. The interpretive approach was outlined by van Manen's hermeneutic phenomenology while the critical component was informed by the works of Paulo Freire. Participants involved two specialist palliative care teams from a large acute care hospital and a large cancer center in Western Canada. Participants included 11 palliative care providers including registered nurses, nurse practitioners, physicians, and pharmacists.

**Results** Participants perceived that social conditions that might aggravate symptom burden included low income, low education, lack of social support, language barriers, and rurality. The relationship between income and symptom burden reflected diverse views. Participants identified populations prone to complex symptom burden including homeless individuals, Indigenous people, people with a history of addictions, and people with mental health or psychosocial issues.

**Conclusion** Participants perceived that social disparities may increase symptom complexity in populations with advanced cancer. Participants did not identify ethnicity and gender as influencing symptom burden. Further research is needed to examine the interactions of social disparities, patient individuality, and symptom burden.

**Keywords** Palliative care · Symptom assessment · Symptom burden · Health status disparities · Qualitative research · Social determinants of health

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Socioeconomic inequalities worldwide constitute one of the most salient global challenges [1]. In 2017, the richest 1% of the world owned 50.1% of all household wealth in the world while the bottom-half owned less than 1% [2]. Health implications of these inequalities are significant. Research shows that socioeconomically vulnerable groups have worse health outcomes than their counterparts [3, 4]. In Canada, where cancer is the leading cause of death [3], cancer disparities have been reported for low income, rural, and immigrant groups [5].

The World Health Organization has declared palliative care as an essential component of cancer control programs because of the impact early symptom control can have on populations with advanced cancer [6]. Recent evidence suggests that palliative care integrated early with cancer care can improve quality of life, symptoms, and possibly survival [7]. There is a lack of research regarding the impact of early palliative care in populations with social disparities [7]. How social disparities affect symptom burden needs to be better understood.

We report findings from two sequential qualitative research studies where we explored the perspectives of specialist palliative care providers concerning social disparities and symptom burden in populations with advanced cancer. The second study sought to further verify and expand findings from the first study. A qualitative approach was appropriate to investigate clinical practitioners' perspectives [8].

## Social disparities and health

This study was informed by the Social Determinants of Health (SDOH) framework [9]. This framework recognizes how complex interactions between individual, economic, social, and environmental conditions can generate avoidable health differences. Social disparities refer to the differences in income, housing, employment, education, social support, gender, or ethnicity, among others. Social disparities can lead to lower acceptability and utilization of health care resources.

## Social disparities and symptom burden

Studies reveal inequities in access to palliative care services associated with the SDOH [10]. Populations from ethnic minorities [11], with low educational levels [12] and low income [13], access palliative care less often than their counterparts. There is growing evidence of symptom burden variation according to SDOH, for groups receiving palliative care [14, 15] although some studies report no significant association [16–18]. Discrepancies in research findings pose the need to continue to investigate this phenomenon to further advance knowledge. Knowledge of palliative care providers and patients and families' perspectives of how SDOH affect symptom burden are also limited.

## Research purpose

We sought to investigate palliative care practitioners' perspectives on how the SDOH affect the symptom experience of populations with advanced cancer. A related aim was to outline practice strategies with populations with social disparities to enhance symptom relief. Research questions included (1) What are palliative care providers' perspectives on how the SDOH affect the symptom experience and symptom burden in populations with advanced cancer? And (2) What strategies do they employ with populations with social disparities to enhance symptom relief? Given space limitations, we report findings for only our first research question.

## Research design and methods

We employed a qualitative research approach that combined tenets from both critical and interpretive research methodologies. The interpretive approach was informed by hermeneutic phenomenology as delineated by van Manen [19] and the critical approach followed Freire's works [20]. Hermeneutic phenomenology seeks the elucidation of human experience in light of individuals' perceptions in the context of their everyday world [19]. Through practitioners' experiences with socially vulnerable patients and those reporting a high symptom burden, we sought to generate an understanding that could foster reflection in practice [19]. Critical theory places its emphasis on critique of the social conditions that shape human experience [20]; in this case, we examined how SDOH affected patients' symptom experiences. Both the hermeneutic phenomenology and critical theory were intertwined. While the critical theory was predominant given the emphasis on the SDOH, the interpretive approach also permeated the study through dialog and reflective questioning with participants, and later during data analysis and interpretation. In the analysis, we problematized experience [21] in light of the SDOH. The interplay of interpretive and critical approaches served to focus on both experiences and social conditions surrounding them. We followed several strategies to ensure the qualitative rigor of the study based on Lincoln and Guba's criteria (please see Table 1) [22].

## Settings

Participants were drawn from two specialist palliative care teams. One team worked in an acute care hospital located in the inner city; the other worked in a tertiary cancer center serving the population of the northern half of the province, both in Western Canada. These teams provide palliative care within the Edmonton Zone Palliative Care Program, a well-established program that offers comprehensive palliative care services. These teams have an extensive clinical load with

**Table 1** Qualitative rigor strategies

Criteria	Strategies
Credibility: degree to which study findings are considered to be true or credible	<ul style="list-style-type: none"> <li>• Purposive sampling and in-depth interviews of expert palliative care providers.</li> <li>• Data collection continued until an in-depth understanding was obtained.</li> <li>• Research team with combined expertise in oncology, palliative care, health equity, and qualitative research.</li> <li>• Prolonged data analysis that followed a systematic approach to synthesize data and generate themes.</li> <li>• Well-established theoretical and methodological frameworks.</li> </ul>
Dependability: degree to which similar study findings can be generated in similar settings	<ul style="list-style-type: none"> <li>• Study 2 assisted us to generate similar findings in another clinical setting.</li> <li>• Records kept of study and data analysis processes to establish an audit trail.</li> <li>• Same investigator conducted all interviews decreasing variability in data collection procedures.</li> </ul>
Confirmability: degree to which study findings can be verified by others including researchers and participants	<ul style="list-style-type: none"> <li>• Data analysis by at least 2 team members. Consensus reached through dialog.</li> <li>• Data interpretation and discussion by both palliative care clinicians and researchers.</li> <li>• Review of findings and interpretation by 2 study participants and other members of participating clinical teams.</li> </ul>
Transferability: degree to which findings can be applicable to other contexts	<ul style="list-style-type: none"> <li>• Two sequential qualitative studies in 2 clinical contexts.</li> <li>• Thick descriptions to allow readers for exploration of potential application in their own contexts.</li> <li>• Study presentations with clinical oncology and palliative care audiences to enhance transferability.</li> </ul>

approximately 700 to 800 palliative care consults per year and treat populations from various ethnic and socioeconomic backgrounds.

## Sample

A purposive sample of 11 participants including registered nurses, nurse practitioners, physicians, and pharmacists was accrued. Interested participants contacted the researcher via phone or email. This sample size was considered sufficient to accomplish the research objectives [22]. Participants shared rich stories that generated solid data. Most participants worked part-time with a few being full time; they had worked in palliative care for over 15 or 20 years, and the majority had over 20 years of health care professional experience. Sociodemographic characteristics were not collected. No participants dropped out.

## Data collection

Participants took part in one digitally recorded in-depth individual conversation of approximately 30–45 min with the first author. Interviews were conducted in a private room in their workplace. Participants were encouraged to tell their own stories and to choose a particular aspect that may, in their view, have influenced the severity of patients' symptom(s). Participants shared their views with regard to how social disparities may affect patients' symptom experiences. They were also invited to talk about strategies that they employ to

enhance symptom relief in these populations. Data collection for study 1 took place between September 2013 and January 2015 and from January to May 2015 for study 2.

## Data analysis

All interviews were recorded and transcribed verbatim. The data analysis team involved one researcher, one postdoctoral researcher for each study, and one graduate student. All team members read the transcripts individually. Emerging themes were generated individually and consensus reached during meetings. van Manen's thematic approach assisted with data analysis [19]: Firstly, transcripts were read as a whole to obtain a sense of the core story; secondly, particularly revealing statements were highlighted; and thirdly, transcripts were read line by line to inform emerging themes. Preliminary themes were generated and then further developed or discarded until data allowed for thick and thoughtful descriptions, a criterion of rigor in phenomenological research. The interpretive approach was enacted through a back and forth dialog with the text that assisted the team to elucidate meanings and unravel concealed ones. This task of unraveling meaning is interpretive and influenced by our own backgrounds. Our focus on the SDOH also influenced the interpretation of meaning. We recognize that other plausible interpretations are possible. Freire's [20] work illuminated the analysis. Participants were prompted in the consent form to consider the SDOH (please see [supplementary file](#)). This facilitated the *problematizing* of patients' experiences in light of social conditions, and *conscientization*, a work of personal transformation through a critical analysis of reality [21]. Conscientization is

always a personal task and its impact is difficult to grasp. The elucidation of participants' critical understanding of patients' symptom experiences in light of the SDOH was perhaps one of the primary study accomplishments.

## Ethical considerations

Ethics approval was obtained separately for each study through the University of Alberta Health Ethics Research Board (study 1 Pro00037064 approved on April 22, 2013, and study 2 Pro00051080 approved on September 17, 2014). Informed consent was obtained from all participants. Participants were informed of risks and benefits and their right to withdraw from the study. Steps were taken to ensure confidentiality and anonymity. Data was securely stored in a Health Research Data Repository at the first author's home institution.

## Research findings

Participants engaged deeply with the topic of the study. Their responses pointed predominantly to social conditions although many issues associated with symptom burden were recognized. Participants identified specific populations prone to experience complex symptom issues and several clinical strategies. We outline two main themes to portray the close relationship between SDOH and symptom burden. The first theme reveals the impact of the SDOH on patients' symptom experiences and the second, the vulnerability of particular populations to present with complex symptom experiences. Excerpts from participants' stories are presented below to illustrate these and four stories to further depict the themes (Figs. 1, 2, 3, and 4). The arrows indicate that no single issue takes precedence over the others. Please read the [electronic supplementary material](#) for expanded and additional quotations to support findings. Each participant (P) is identified by a number and the site (H) of the study.

### The impact of the social determinants of health on symptom experiences

The impact of the SDOH on patients' symptom experiences was a predominant theme. Participants' stories revealed the complex interactions of the SDOH affecting patients' ability to deal with their symptoms due to a lack of financial resources, lack of education, lack of social support, vulnerable housing, rurality, psychosocial issues, addictions, or other personal circumstances. Figure 1 portrays a couple from a rural community dealing with a diagnosis of advanced disease, severe symptoms, isolation, lack of support, and health care access issues. The story reveals the at

times chaotic situations, providers deal with that can be further complicated by patients' social circumstances.

Below, we describe specific SDOH that participants perceived made symptom relief challenging. We recognize that in real life, these SDOHs are difficult to take apart from one another. Our approach serves mostly to highlight the impact of specific SDOH.

## Income

The impact of income on patient experiences was acknowledged by participants. They recalled situations were both low and high income affected patients' ability to deal with their illness. Low income and financial constraints were commonly perceived as barriers.

Oh, yeah, income... certainly our younger patients... those who are under 65 and don't have a steady income and they are the breadwinner—the stress surrounding how they're going to support a family and pay for their rent, feed their family, things like that can cause incredible, I think, stress, but increase the symptoms that they may be having. H1-P3

On the other side, the view that high income could affect symptom burden was also expressed. A few participants stressed that symptom challenges were not always associated with social disparities:

I'm just thinking of an individual that I had 2 weeks ago who was very well educated and in a very professional position and lived quite well, but still the chaos existed in terms of very difficult family dynamics, a lot of stress, that chemical coping. H2-P4

## Education

Participants perceived that both educational level and intellectual issues might affect the patient's ability to understand symptom control. While the degree to which education affects symptom complexity cannot be determined, limited education emerged as a contributing factor.

I don't know if it would be intelligence or education, but people who have a hard time understanding the actual mechanism of their pain or symptoms or their medical problems, sometimes they have harder-to-control symptoms because they don't understand why it's happening. H1-P4



**Fig. 1** Story of a couple from a rural community dealing with a diagnosis of advanced disease, severe symptoms, isolation, lack of support, and health care access issues

### Social support

Participants also recognized the role social support plays in symptom relief. Participants perceived that those who had few social supports had a difficult time dealing with their symptom experience.

When people come in with this very supportive family... and they’re all willing to help in a variety of directions... whereas people who don’t have that, they’re dealing with that, emotional struggles and the psychological struggles

of being maybe isolated or alone, which will influence their symptom burden as well. H2-P2

### Language barriers

Participants stated that language barriers affected their ability to establish good communication with patients and thus limited patient capacity to comprehend symptom issues and treatment. Language barriers seemed more significant than cultural background.



**Fig. 2** Situation of a homeless individual in need of cancer treatment and palliative care

I see that is not really necessary, the culture, because you could be all [background A], but your aspect or your thoughts about how to deal with a terminal illness could be so different... I actually highlight here that sometimes culture is not just about culture, but language barrier. H2-P6

multiple readmissions due to lack of stable housing and acknowledged how this can affect the comfort patients can achieve.

**Housing**

Precarious housing conditions were another issue that affected symptom management. Participants recalled stories of

I had a fellow with a wound that was homeless. So again, if you don't have a comfortable bed to sleep on, your pain will be worse. So something as simple as the comfort of your home, and then being well-fed to heal a wound is compromised in these patients. H1-P4



Fig. 3 Story of an indigenous woman with advanced esophageal cancer

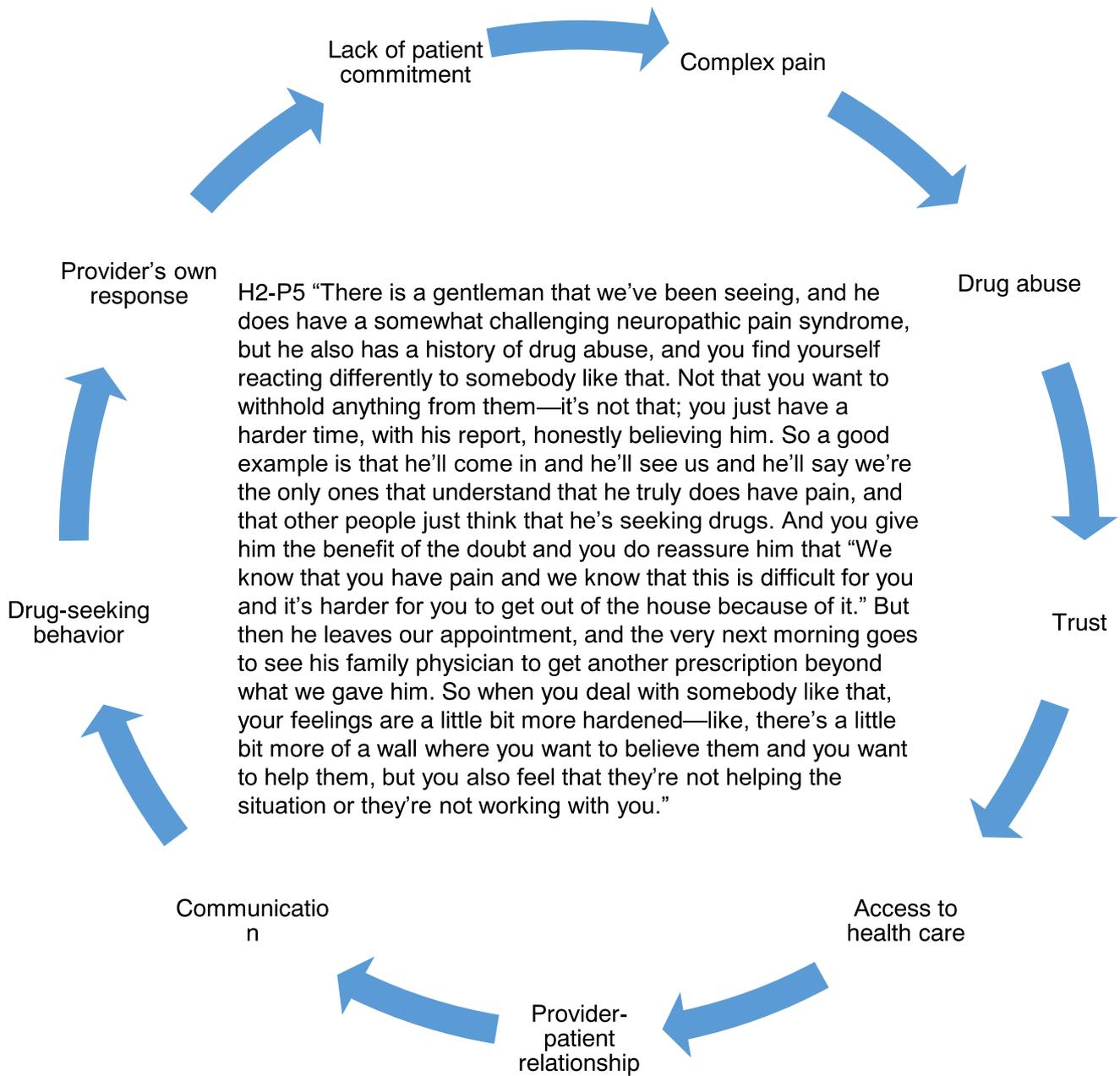
**Recognizing the vulnerability of particular population groups**

Participants identified populations that in their views faced challenges to achieve symptom relief. Their stories revealed complex issues that contributed to difficult symptom experiences. Figure 2 depicts the situation of a homeless individual in need of cancer treatment and palliative care, very symptomatic and in poor health, who due to health care access issues suffers an avoidable delay in achieving symptom relief. Below, we describe groups identified by participants.

**Homeless individuals**

While acknowledging their ability to cope with tough circumstances, participants identified the homeless population as one group prone to symptom complexity.

The same is true—in my experience, some of the inner city people that we have, it’s so hard to establish a relationship... They’ll usually take pain medication... but trying to get them to take pain medication every 4 hours so they maintain a therapeutic



**Fig. 4** The challenges that a history of drug abuse presented to a participant

drug level is hard, because they want to take it when they have pain. H1-P1

usually a lot more honest, and you can come up with a plan of care that is very upfront. H1-P2

On the other side, some participants found this population better able to deal with illness challenges than those with better socioeconomic status.

**Indigenous people**

I find [the underprivileged population] it's [pause] I hate to say the word "easier," but it is easier, because they're

Participants identified indigenous peoples as one population group at risk of symptom complexity. Figure 3 portrays the story of an indigenous woman with advanced esophageal

cancer who went through multiple hospital readmissions due to a lack of support.

In this case, the study participant emphasized the need to recognize the historical trauma that indigenous peoples in Canada have experienced:

I'm thinking of the Aboriginal population in terms of their Canadian history with the residential schools... the TRC [Truth and Reconciliation], and how we have impacted them in the last... seven generations of residential schools and what we've done to their culture, their spirituality... that all impacts how they're doing today.  
H1-P3

Figure 3 reveals the complex social issues faced by an indigenous woman. This participant emphasized the need to recognize the historical impact of colonization and how a lack of trust, prejudice, and a history of losses contribute to poor health and challenging symptom experiences.

### People with a history of addiction

People with addictions were a commonly identified group. Regardless of their socioeconomic background, this population experiences social marginalization in society. A history of abuse compromised trust and symptom relief. Figure 4 reveals the challenges that a history of drug abuse presented to a participant.

How this population dealt with life in general was perceived by participants to affect their symptom experiences.

Any history of drug abuse, chemical coping... can be quite interfering, because their attitude to coping with life's problems is one of perhaps taking a substance, perhaps taking a breakthrough analgesic... And it, again, skews their ability to perceive how their symptoms are.  
H2-P4

### People with mental health conditions or psychosocial distress

Participants reported symptom challenges associated with mental health conditions or psychosocial distress. While suffering from a medical condition, they are prone to experience social discrimination and marginalization.

I have one individual right now, not that marginalized, but certainly in the lower middle class, that has a psychiatric disorder... it's anxiety and depression, and not

really well diagnosed or treated, and it has become the issue why ongoing recommendations and changes in her meds just don't work. H2-P4

### Rural populations

Rural populations were another group prone to symptom challenges due to the limited availability of palliative care services and a lack of comfort with health technologies to bridge the distance gap. The story presented in Fig. 1 reveals the array of issues that rural populations can face.

Certainly our rural community in remote areas in Canada... their experience regarding symptom management can be negative because of the long distance from—but we have a telehealth pain and symptom control clinic that's very underutilized in the rural areas. H2-P3

### Discussion

Our research findings reveal participants' insights concerning how social disparities may affect symptom burden. Salient social disparities included low income, low education, precarious housing, lack of social support, language barriers, and rurality. Participants perceived the homeless, indigenous people, people with a history of addiction, mental health challenges or psychosocial distress, and rural populations were prone to symptom complexity. Findings suggest that symptom relief may be challenging on both ends of the socioeconomic spectrum. Findings are informed by participants' extensive palliative care experience and the populations they serve. The focus on particular SDOH and specific populations may reveal, in our view, participants' deep concern for their suffering.

Our findings highlight that palliative care providers face challenges when treating patients with social disparities. Results align with Western studies that suggest a relationship between social disparities and symptom burden. Canadian health data indicate income, housing, and education affect the health of Canadians [3]. Contrasting perspectives concerning income and symptom burden were found though the view that low-income individuals face significant challenges was prominent. Symptom disparities in low-income cancer groups have been reported [23, 24]. Income inequalities in cancer survival [5] and early diagnosis and treatment [25] have been found in Canada. Studies have also reported no

income inequalities [17] or better outcomes for low-income populations [18].

A history of addictions seemed to influence how practitioners interacted with these individuals. Discrimination, homelessness, and mental illness can affect their access to palliative care. Drug dependency and care recipient's perceived lack of respect can be barriers in the care of this population [26]. Participants recognized the need to ensure a balance between providing analgesia and reducing harm. Universal precautions in pain management will promote safe use of these medications [27].

>The lack of significance of ethnicity as a potential contributor was a discrepancy from Western studies [28, 29]. Studies have found no evidence of racial disparities in cancer pain outcomes [16] or better access to palliative care for ethnic minorities [30]. Another study found no significant association between race/ethnicity and access to palliative care yet lower rates of access to primary palliative care services for ethnic minorities [31].

The relationship between ethnicity and symptom burden warrants further investigation. Our findings may reflect participants' experience with ethnically diverse groups, varying symptom expressions, or patient acculturation. Participants recognized that language barriers could increase symptom complexity. These have been associated with lower cancer screening rates [5].

The complexity of issues faced by Canadian indigenous people demands further research. Participants' views coincided with severe cancer disparities reported for this population [32]. Poor outcomes may result from the interaction of late cancer diagnoses, severe health care access issues, compromised SDOH, jurisdictional issues, and a lack of trust along with inter-generational trauma from the loss of their culture and traditions [33].

Housing and homelessness contributed to symptom control challenges. The urgent need for palliative care services for inner city populations has been stated [34, 35]. Unique challenges in the provision of palliative care comprise lifestyles, delivery of end-of-life care in hostels, and those related to the health care system [36]. Disparities in access to palliative care for rural populations have been identified [37, 38] and also require further study.

An unexpected finding was the lack of significance of gender. Participants were not directly prompted to talk about gender, yet gender was mentioned in the consent form. Previous research has shown gender disparities in cancer pain outcomes [39, 40]. Both inequalities in end-of-life care for women [41] and no-gender disparities [42] have been reported. A Canadian study reported higher symptom burden for women and low-income individuals during the first year following cancer diagnosis [43]. Finally, findings point to the palliative care needs of populations with mental health issues who often face additional social barriers. Disparities in access to

palliative care have been identified [44] and specific strategies to support them are needed [45].

## Research and clinical practice implications

Research to examine the multiple interactions of social disparities and cancer care is needed [5]. Canadian low-income groups bear several health and social disparities compared with their counterparts [3]. An intersectoral approach to tackle disparities in symptom control is vital. Increasing community-based palliative care resources is also needed [37].

The lack of significance of ethnicity and gender invites reflection with palliative care providers to explore their views. Studies of how gender and ethnicity could affect symptom experience are needed. Further research to improve care and address providers' and patients' concerns is needed.

## Study limitations

A limitation of the study was a lack of follow-up interviews with participants although two provided feedback. The lack of views from social disciplines is another limitation. Participants' perspectives are informed by the diverse populations they serve and their years of experience. The study focused on the SDOH, participants' backgrounds, and life experiences may have influenced their responses. Finally, though qualitative findings are confined to the context of the studies, we hope findings will assist providers in other settings to explore how these can inform their practice.

## Closing remarks

This study generated a baseline understanding of palliative care practitioners' perspectives and challenges with regard to social disparity and symptom burden. This knowledge is grounded in practitioners' perceptions and own experiences of practice and contributes qualitative evidence to the growing body of knowledge on social disparities and palliative care.

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## Compliance with ethical standards

**Ethical approval** Ethics approval was obtained separately for each study through the University of Alberta Health Ethics Research Board (study 1 Pro00037064 approved on April 22, 2013, and study 2 Pro00051080 approved on September 17, 2014). Informed consent was obtained from all participants. Participants were informed of risks and benefits and their right to withdraw from the study. Steps were taken to ensure confidentiality and anonymity. Data was securely stored in a Health Research Data Repository at the first author's home institution.

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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