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Original qualitative research

Improving access to palliative care for people experiencing socioeconomic inequities: findings from a community-based pilot research study

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Abstract

Introduction: In Canada, people experiencing socioeconomic inequities have higher rates of late diagnosis and lower survival rates than the general population. Palliative care services focussed on this population are scarce. We developed a community-based nursing intervention to improve access to palliative care for people experiencing socioeconomic inequities and living with life-limiting illnesses in an urban Canadian setting.

Methods: This community-based, qualitative research study combined critical and participatory research methodologies. The study was conducted in partnership with the Palliative Care Outreach Advocacy Team (PCOAT) based in Edmonton, Alberta, a team dedicated to serving populations experiencing socioeconomic inequities who require palliative care. Following an exploratory phase that served to delineate the intervention, we undertook a one-year pilot implementation during which a part-time registered nurse (RN) joined PCOAT. The RN engaged in trust building, resolution of health and practical needs and complex care coordination. Twenty-five patients participated in the intervention. Participants were interviewed at least once to explore their experiences with the intervention. Data were analyzed through thematic analysis.

Results: Most participants were men, were Indigenous and had advanced cancer. Participants had significant financial concerns, lived or had lived in precarious housing situations and had previously faced serious challenges accessing health care. Participants reported social and health needs including housing, finances, transportation, symptom control, harm reduction and end-of-life care. Participants reported improved access to health and social services and expressed satisfaction with the study intervention.

Conclusion: Study findings suggest the study intervention may have contributed to improved access to palliative care, improved experiences for participants and increased equity in the delivery of care.

Highlights

- Improved access to community-based palliative care for people experiencing socioeconomic inequities with life-limiting illnesses is urgently needed.
- A community-based registered nurse can improve access to palliative care and the experiences of people facing serious socioeconomic inequities.
- People experiencing socioeconomic inequities require palliative care services tailored to their context.
- Addressing the health challenges of people experiencing socioeconomic inequities is more effective when done concurrently with practical actions such as addressing precarious housing conditions and lack of income.
- Paying attention to the intersections of people's multiple social domains with their lived experiences can improve equity in palliative care.

Keywords: *palliative care, health equity, health services, socioeconomic disparities in health, social determinants of health, Canada, cancer, Indigenous*

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Introduction

Socioeconomic inequities in Canada are a growing public health concern.[1,2] These inequities are influenced by income, education, occupation, gender, ethnicity and other factors.[3] They reflect an unjust social hierarchy that results from people's social and economic positioning.[4] People with lower socioeconomic status may experience earlier onset of illness, delayed access to health care, higher risk of complications, prolonged hospital stays and reduced life expectancy.[5,6] The negative health impacts of socioeconomic inequities are pressing for individuals with life-limiting illnesses.[7]

Palliative care promotes quality of life and the relief of suffering of those with life-limiting illnesses and their families.[7] Although Canada is an international leader in palliative care, disparities in access to palliative care exist,[8] with those experiencing socioeconomic inequities being most affected.[9] They experience a higher symptom burden,[10] poorer health outcomes toward the end of life,[11] barriers in access to specialist palliative care,[11] fewer palliative home visits[9] and poorer palliative care outcomes, such as a lower likelihood of a home death.[11] They also experience marginalization and discrimination within the health care and other social systems.[12]

Few palliative care services exist for people experiencing socioeconomic inequities in Canada.[13] A program in western Canada dedicated to serving people experiencing houselessness reported improved patient satisfaction and health system navigation and better access to health and social services.[14] A Toronto-based program described changes in resuscitation status that reflected patients' care preferences, and decreased acute health services utilization.[15] Services designed to improve access to palliative care in people experiencing socioeconomic inequities in other countries have shown positive outcomes at the end of life.[16,17] The purpose of this study was to explore how a community-based nursing intervention could contribute to improving access to palliative care for people experiencing socioeconomic inequities living with life-limiting illnesses in an urban Canadian setting. This article presents the qualitative findings, with a specific focus on participants' experiences with the study intervention.

Methods

Ethics approval

The study received ethics approval from the Health Research Ethics Board of Alberta Cancer Committee (HREBA.CC-17-0255).

Study design

We employed a critical theory research design and incorporated principles of community-based participatory research. The critical theory approach, informed by Paulo Freire's works,[18-20] pays attention to socioeconomic inequalities and systemic barriers that create oppressive conditions. Freire's work with groups experiencing oppression has inspired community-based participatory research. The participatory approach is a transformative opportunity to incorporate the voice of communities in research.[21] We achieved this by first initiating an exploratory phase to learn about our study population's experiences with life-limiting illnesses, and their needs and priorities. The study was also undertaken in partnership with the Palliative Care Outreach and Advocacy Team (PCOAT) based in Edmonton, Alberta, a team dedicated to serving populations experiencing socioeconomic inequities who require palliative care. PCOAT's medical director (one of the authors and study co-principal investigator, CB) was involved in the planning, design and implementation of the study. We sought input from palliative care and community providers working with individuals with life-limiting illness and socioeconomic inequities.

Description of the study

The study included two interrelated phases. In phase one, we explored the experiences, needs and preferences of people with life-limiting conditions living in precarious housing conditions. This entailed semistructured interviews with patients and relatives, and focus groups with community and palliative care providers. Phase one of the study took place between August 2018 and January 2019. Seven patients with advanced illnesses and three relatives participated in this phase. In addition, two focus groups were held with eight palliative care, nongovernmental health care and community agency personnel serving the study population ("providers"). The interviews revealed issues with continuity of care, symptom assessment and management, and family and community support. Participants described a need to access appropriate medical equipment and community services. Focus group findings echoed the need for improved care coordination. These findings provided the basis for delineating the community-based nursing intervention before phase two. Following development of the intervention, we secured ethics approval for phase two on 14 November 2018.

Phase two, the pilot implementation of the intervention, began in January 2019 and lasted one year (until January 2020). The intervention consisted of a part-time registered nurse (RN) who engaged in care coordination with health and social agencies, patient care and intersectoral collaboration. The RN documented care and extracted data from participants' health records. Table 1 provides an overview of the intervention.

The RN (one of the authors, HM) had previously worked with the Indigenous Wellness Clinic in which PCOAT is located. The RN had over 20 years of experience working with people with life-limiting conditions in diverse settings and had experience in Indigenous health and underserved populations and a master's degree in nursing; however, the RN had limited palliative care experience. Before the pilot implementation, the RN had a three-month orientation that included an introductory two-day palliative care training course, weekly mentoring by an expert palliative care nurse in oncology hired by the study, visits to community agencies, time with PCOAT and qualitative research training. The RN was hired by the principal investigator's home faculty and placed with PCOAT for the duration of the intervention.

Settings and sample

PCOAT is a new palliative care service that supports individuals experiencing socioeconomic inequities with life-limiting illnesses, whose director (CB) is a family physician with a palliative care specialization. PCOAT is located within the Indigenous Wellness Clinic in a tertiary hospital serving the northern half of Alberta, a western Canadian province. This clinic serves First Nations, Métis and Inuit people and promotes accessible, culturally safe and equitable health care.[22] The study took place in Edmonton, a city served by a comprehensive integrated palliative care program.[23]

TABLE 1
Overview of pilot palliative care intervention for people experiencing socioeconomic inequity, Edmonton, Alberta, January 2019 to January 2020

Specific intervention	• A part-time registered nurse was placed with the Palliative Care Outreach and Advocacy Team[a] between January 2019 and January 2020. • Efforts were focussed on improving access to community-based palliative care. • The intervention was directed at people with advanced, life-limiting illnesses and socioeconomic inequities.
Development of intervention	The development of the intervention was informed by • qualitative interviews and focus groups with study population and health care and social care providers • research and clinical work to date by study investigators • evidence from the literature
Content of intervention	The content focussed on • supporting participants' palliative care experiences • coordinating patient care • building trust and relationships • improving access to services • monitoring patient health status and follow-up care • providing culturally safe care • improving wellness • supporting end-of-life decision-making
Co-interventions and additional relevant information	• Palliative care services were provided by the Alberta Health Services (Edmonton Zone) palliative care program. • Palliative care treatments were provided as needed. • Comorbidities were also treated.

[a] A cross-functional medical outreach team working among people experiencing socioeconomic inequity in Edmonton, Alberta.

We followed purposive sampling in the accrual of participants. Each participant received thirty dollars as a thank you gesture. Inclusion criteria were: living or having lived in precarious housing with a life-limiting illness, age of 18 or older and ability to provide consent and to communicate in English. Following admission to PCOAT, potential participants received a letter of initial contact. Patients who lacked capacity were not eligible. A clinic staff member not involved in the study approached patients and explained the study. With patients' consent, the staff member provided their contact information to a study team member who contacted the patient, explained the study and obtained written consent. Participants were enrolled in the intervention immediately after signing the consent.

Data collection

We undertook individual, semistructured interviews on admission or after admission, depending on participants' preferences. We focussed on participants' experiences to determine how the intervention helped them throughout their illness. The interviews varied in length from 10 to 45 minutes. We undertook a few follow-up interviews due to patient frailty and personal preferences. The RN conducted the interviews because placing another team member was impractical due to trust issues. Although this could potentially have influenced participants' responses, since the RN was the intervention provider, it was important to develop the relationship with participants over time, and create a space for participant autonomy. In the interviews, participants shared challenging past experiences to contrast with their experiences with PCOAT during the intervention. In our view, this increased the trustworthiness of the data, as they provided a comparison point to understand potential impacts of the intervention. The RN also kept a journal to foster reflexivity. We extracted demographic and clinical data to develop a profile of the study sample. We employed REDCap software version 13.4.10 (Vanderbilt University, Nashville, TN, US) for clinical data extraction. A clinical profile of patient study participants will be reported elsewhere.

Data analysis

Manual qualitative data analysis started shortly after data collection. We employed a thematic analysis approach.[24] Two research assistants (RAs) were initially engaged in data analysis, followed by advanced data analysis by the principal investigator and one RA. The study RN participated in data analysis by adding contextual information and deepening data interpretation. We moved back and forth between reading the transcripts as a whole and a focussed reading in search of rich descriptions. We examined how living and social conditions shaped participants' experiences. Preliminary themes were generated and further developed or discarded until we achieved a thorough description of the theme. The analysis generated a rendering of participants' experiences and perceptions of the intervention that integrated theirs and the study RN's perspectives.

To ensure trustworthiness, we safeguarded the credibility, confirmability, dependability and transferability of the study.[25] Credibility was enhanced by incorporating the voices of people experiencing socioeconomic inequities and providers from health care and social agencies; the RN's reflexive diary recorded context, biases and misconceptions. We kept an audit trail with study documentation. Confirmability was supported by discussing interpretations with selected participants. Dependability was promoted through an audit trail and by spending a prolonged time in the clinical setting. Data collection was completed by one study team member, ensuring consistency in the interviewing process. Transferability was fostered by rich descriptions to allow health care providers to incorporate study findings in other settings.

Positionality statement

The study team included Indigenous and non-Indigenous scholars. One of the study's co-principal investigators (CB) is an Indigenous physician and scholar. LV is a Métis scholar who engaged in data interpretation and writing. The nominated principal investigator (AS) has had Indigenous cultural training and research experience with Indigenous Peoples in Alberta. We integrated cultural safety throughout data collection, analysis and interpretation to honour the tradition of Indigenous Peoples in Canada. We were cautious with data interpretation to avoid out-of-context interpretations of Indigenous participants' experiences.

Results

All participants partook in at least one interview. We conducted 12 follow-up interviews. No family members took part in the intervention phase. Participants remained in the intervention phase until they died or until the end of the study, whichever came first. Table 2 provides a summary of participant characteristics.

TABLE 2
Overview of study sample for study pilot palliative care intervention for people experiencing homelessness, Edmonton, Alberta, 2019 to 2020

Descriptor	n
Sample size	25
Age, average (range), in years	57.3 (39–84)
Ethnicity	
Indigenous[a]	15
Non-Indigenous	10
Sex	
Male	16
Female	9
Diagnosis	
Advanced cancer	15
Other advanced condition:	10
Liver failure (2)	
Advanced lung disease (6)	
Advanced kidney disease (1)	
Other (1)	
Income	
No income	1
< CAD 20 000	9
CAD 20 000–CAD 40 000[b]	15
Housing status	
Stable housing	12
Precarious housing	11
No housing	2
Study intervention	
Length of stay in the study, average (range), in months	5.5 (0.25–12)
Study RN interactions per participant, average (range)	9 (3–32)

Abbreviations: CAD, Canadian dollars; RN, registered nurse.

[a] Refers to First Nations, Métis or Inuit people in Canada.

[b] Most had an annual income slightly above CAD 20 000.

Four themes were identified based on participants' experiences, including "living with unmet social care needs," "health and wellness concerns," "experiences of victimization and discrimination in health care" and "transformative experiences with PCOAT and the palliative care intervention."

Theme 1: Living with unmet social care needs

Participants faced several challenges related to unmet social care needs. Participants faced financial and health-related barriers in using transportation, affording basic needs, securing stable housing, and social isolation.

Living in insecure housing conditions

Several participants experienced precarious housing. This included pests or infestation, unsafe housing or mobility challenges due to housing layout. Some expressed a need to move to an assisted living facility while others described limited services in their place of residence. Following relocation to safe housing, one participant expressed:

> I wanted to die like, last week, I wanted to die. 'Cause there was nothing, I just felt like there was nothing to live for. And today I don't feel like that, I feel like, you know, to look forward tomorrow turn to be better than yesterday. (P18)

Struggling with financial support

Most participants were on income assistance and had major financial constraints. They described insufficient funds, difficulty balancing health expenses and bills, inability to work due to illness and challenges accessing social support programs. The following exchange portrays some of these struggles.

> P13: Oh, I have a money problem.
>
> RN: Money problem, okay. And what are we doing about the money problem?
>
> P13: Well, you're helping me right now, which is great.
>
> RN: Yeah, yeah. And we're gonna get started on [income assistance].
>
> P13: Which is really great—if that comes through, it'll really be a blessing for me. Because … I can't pay my rent and my cable. I don't make enough to pay my rent. I get five hundred and two dollars a month.

Limited transportation

Participants experienced transportation problems. They reported financial burden when they had to purchase bus passes or pay for parking, had to rely on others for transportation, were unable to drive or had mobility issues. They expressed a desire for independence and funding for transportation. Their symptoms and health status also interacted with their transportation needs.

> I'm getting by but it's getting difficult … just going to the store is hard right now…. For example, go to this store

> over here … it's only a block away and I have to take a cab. And just carrying a jug of milk back into this place and up here it's hard for me…. It's cost me an extra ten bucks a shot, just every time I wanna go buy a six-dollar jug of milk. (P19)

Social isolation and reconnecting

Participants desired social support though some were estranged from family, socially isolated or receiving limited social support. Some talked about having family or partners' support, while others struggled to reconnect with family.

> My brother won't talk to me, my sisters won't talk to me or have anything to do with me. They live in the town. So like I'm slowly, I got a couple of more that came on board with me, family members, 'cause they got cancer and realize how hard it was, and they're married. And all of a sudden, the lights came on and say, 'Jesus, you know, we're not doing anything to help him.' And … they realized how difficult life was for me, doing this by myself. (P6)

Theme 2: Health and wellness concerns

Participants reported concerns related to health and wellness such as symptom experiences, access to auxiliary health supports and harm reduction.

Symptom experiences

Participants reported diverse symptom experiences including shortness of breath, pain, mobility problems, fatigue, dysphagia and neurological issues, among others. These symptoms interfered with their wellness. Complex health status at times resulted in unbearable suffering.

> 'Cause there's nothing can be done anymore … I don't … wanna suffer anymore, and I'm suffering as it is right now. And I'm glad to get it over with, because … I hate being like this, you know. Always hurting [pause]. Always throwing up and, it's no good for anybody. I don't wish this on anybody. (P13)

The need for auxiliary health supports

Participants described concerns related to health care procedures, prescription coverage and auxiliary supports such as hospital beds, assistive breathing devices or hearing aids. Some expressed the need for medical cannabis. They were unable to access these resources due to cost.

> One of the items that I use which has helped me greatly to deal with pain, nausea, lack of sleep—is marijuana. Well, it's expensive. And now that it is legal, you would assume that sooner or later, the people in the medical profession in this province would go, 'He's using it to deal with his cancer. Maybe we can help him out.' And whether it's reimbursed partially or something, that would definitely help out. (P3)

Accessing harm reduction services

Some participants had a history of substance use disorder and expressed the importance of accessing harm reduction services. PCOAT facilitated access to these services.

> Well, no. I'm unfit, for nothing. I get tired now … going down to get my methadone and stuff like that … But I still do it. 'Cause it keeps me going, I gotta do it … it gives me some purpose. (P12)

Theme 3: Experiences of victimization and discrimination in health care

Several circumstances affected participants' ability to access care. Poor prior experiences with health care providers were described. One participant recounted having been a victim of sexual and physical abuse in the hospital. Some recalled experiences of discrimination due to their Indigenous status. They shared experiences of shame, prejudice and systemic racism.

> Before you see my skin, [voice breaking] if I could just go into a place where people couldn't see my skin colour before they treated me I would do that. And because I don't want anyone to see me cry, 'cause they mock us. I get mad at first … [weeping]. Even as I leave this world I'll leave it knowing that they didn't like us, that they didn't like me because of how I was born [sniffling]. It's embarrassing, being Native. I feel ashamed. I just don't even want you guys to see me. (P20)

Theme 4: Transformative experiences with PCOAT and the palliative care intervention

Phase two was a qualitative exploration of the impact of the study intervention. The RN dedicated time to care coordination to resolve the health and practical needs of patients. Participants emphasized the difference between their prior health care experiences and those after admission to PCOAT and the study intervention. Participants described improvements in access to health and social services and wellness. Below, we describe prominent features of the nursing intervention.

Building trust

The RN created opportunities for participants to regain trust in health care providers. Building trust was a critical component of the intervention because of participants' past experiences with the health care system. Patients highlighted the understanding and supportive nature of PCOAT providers and the RN.

> You're just angels of mercy, you're godsends, you know? You guys are so much better than any other doctors I've ever been to. You got a lotta heart, put it that way. A lot of empathy, empathy is a good word. But no … I look forward to coming here when I come here. (P6)

Complex care coordination

The RN spent most of the time doing complex care coordination to support participants' health and wellness. This entailed communicating on a regular basis with community and health care providers to ensure patient concerns were addressed. The RN facilitated access to health care through regular monitoring of patients' health, home visits, phone calls and outpatient care. Complex care coordination served to lessen the impact of unequal living and working conditions and improve patient well-being.

> We visited P1 today and as we were leaving the director of the building let us know that he is very close to eviction…. We know that [supportive housing] place is very harm reduction focussed … and willing to work with patients in almost any condition…. One of my tasks for next week will be for planning a case conference meeting with the whole team … to problem solve and work together to assist

> both P1 but support the functioning of [supportive housing]. (RN note—P1)

End-of-life decision making

The RN engaged in end-of-life conversations with participants, offering assistance to reconnect with families, and doing referrals to social services to manage personal affairs. The RN helped in exploring participants' end-of-life preferences. For instance, the RN helped with requests for medical assistance in dying (MAID) by processing the referrals to the MAID team. She accompanied one participant undergoing MAID. The exchange below took place shortly before the participant died.

> RN: Was there anything that the nurse or the team has been able to help you with, to assist with your needs?
>
> P9: Yeah, they helped me get into the MAID program.
>
> RN: Do you wanna talk about that a little bit?
>
> P9: I like it because I have suffered my abuse physically and mentally … mostly towards the ending of my years … suffering through my, ah, can't breathe … And I just having problems with just, ah, even when I am walking.… I can't even walk no more. That's how bad it is.

Improved accessibility to services

Participants described how things had improved for them in terms of access to health and social services. They spoke of how these changes supported their wellness.

> Yeah, so I've got—I've got [income assistance program] now.… You guys hooked me up with [transportation].… I also got a [recreational pass] … so that I can go to the gym, go to the sauna or the steam room. That's really a big one for me. 'Cause I think that'll work towards my recovery. (P4)

Provision of culturally safe care

Recognizing participants' preferences and needs regarding access to Indigenous care practices and traditions was important. This was made possible thanks to the support of the Indigenous Wellness Clinic and the guidance of Indigenous providers.

> The background voices are the four ladies from the [Indigenous services] program that [P13] accessed before we met him. They came part way through our visit. They were preparing for a smudge in the background. After the tape stopped, we formed a circle. It was [P13], his four housing workers, his good friend, [family physician], myself and [medical student]. We smudged together and then held hands to pray. We all took turns praying aloud in our support, feelings, gratitude and honour of [P13]. Not a dry eye in the house I tell you! What a powerful and amazing experience. Everyone hugged one another even though some of us had just met. It was a powerful experience that I won't soon forget. (RN notes)

Improved wellness

Participants described that the actions of the study RN and PCOAT increased their wellness and helped them to have peace of mind. One participant stated, "I just need to know, like I wanna be able to talk to you guys and tell you what my worries are and, hopefully I'll have help. You guys will give me that" (P15). Another one expressed:

> Clothing, medication, you've made me feel secure. Ah, you know, you brought my spirits up, like I got to rest finally you know when no one bothered me and I just feel, I wake up [and] feel better. I don't feel like you're a prisoner … of someone that doesn't care. (P18)

Building hope over time

In describing their experiences with the study intervention, participants recalled contrasting episodes with the health care system before their admission to the study. They recounted encounters with providers that made them feel worthless, whereas their experiences with the study RN and PCOAT were remarkably different. These descriptions demonstrated how both PCOAT and the study intervention improved their experiences and helped them regain their sense of worth. Table 3 contains excerpts from P18, a participant with end-stage kidney disease requiring dialysis three times a week. She was living in a shelter and was relocated into stable housing. Her story recounts her transition from feelings of hopelessness, neglect and abandonment to greater security and independence in stable housing.

Discussion

In this study, we sought to leverage the voices of people with lived experiences of socioeconomic inequities and life-limiting illnesses. Study findings revealed that participants struggled with their health and social needs, lack of access to health care and fear of discrimination. Findings suggest the need to support the unique end-of-life experiences of individuals facing socioeconomic inequities. Support should include expanding access to community-based palliative care, building transformative care practices, eliminating systemic discrimination in health care and promoting community engagement in clinical practice and research.

Expanding access to community-based palliative care

Study participants had a history of living with life-limiting illnesses, and multiple health and wellness concerns. People experiencing social disparity encounter greater challenges in access to palliative care compared to other Canadians.[26] Access to community-based palliative care is a pressing issue in Canada, with few Canadians accessing this service.[27] A recent national survey showed that only 15% of Canadians who died in 2016/17 received palliative home care in Alberta and Ontario.[27] Studies show that community-based palliative care increases access to palliative care and patient and provider satisfaction, reduces acute care utilization, supports a home death and may lower health care costs.[28] Research is needed to determine how community-based palliative care improves outcomes in groups experiencing socioeconomic inequities.[28] Our findings suggest registered nurses can contribute to increased access to palliative care in the community. There is a need to study the role of nurses in addressing inequities in access to palliative care in Canada. Increasing providers' access to palliative care education is another important step.[7]

Building transformative care practices

Study findings suggest participants' experiences as well as their perceived health and wellness improved with PCOAT and the study intervention. Our findings also suggest that participants' journeys were often hindered by a combination of pressing

TABLE 3
Building hope over time: one participant's experience with the study intervention

Feeling lost and abandoned	Regaining hope
Feeling lost and uncared for in the shelter	***Feeling secure and hopeful after being moved to stable housing***
I was at the [shelter], and, ah, I was in a very, ah, bad state of mind I guess. I wasn't comfortable.… I felt lost there. I felt like I just wanted to give up on life because, I just never felt secure there, and was so, like you know, dirty. (P18) You can't trust nobody, 'cause they'll steal your stuff … you turn your head and it's gone.… I never got asked if I needed help, I never got asked if I needed *anything*, and they didn't care, they just left me laying there. (P18)	I feel way better, I feel secure now.… I wanna … get my stability back, and my independence, and you know get my state of mind off the track I was on which was bad. It was … my depression and my, anxiety, of how people treat you, and how I just hate, I never been in a shelter before in my life, and that was the first time, I hope never to go back, 'cause, that's just not for me, or anybody if you know. I feel better about myself and I'm starting to feel better... (P18)
Feeling dependent on staff due to weakness, but not receiving the necessary help	***Regaining strength and independence***
One time I sat there for an hour begging the staff to help me up, because some of the girls were sick too, they can't even pick me up.… I'm quite a big, I'm tall, and my bones are really skinny, but still I'm tall and that's still lot of bones. And they're like 'Ah, I can't pick you up' … so I sit there and wait and wait, and it's just like they didn't come, it was like they were torturing me. Like I missed breakfast, lunch, dinner … (P18)	P18: I'm starting to walk better.… I am in a hotel.… Study RN: And where are you going tomorrow? P18: I'm going to [assisted living facility]. Umm, it's a house hospital, I guess? Here to help me walk better and maybe, you know give me back to my feet, so then I can look into getting my own independent apartment, and you know, I get back to who I was two months ago.
Study RN notes	
We met her last week after receiving a call from [shelter] saying that they had a sick lady that they weren't really sure what to do with. We went to see her at the shelter. It is a dark, smelly, crowded place. Cots in the low-mobility area on the main floor are close together with a thin partition between the men and women's side.… She couldn't even sit up without assistance. Slowly, with her wheeled walker she made it back to us.… It was a story of such sadness. She said she couldn't believe she was in a shelter and homeless. She has been living out of her truck for a while but as she got sick the last time, her truck was impounded and she lost everything. She can't even find her common-law partner. She is itchy and cold with open sores on her arms and scalp. She has end-stage kidney disease and is on dialysis 3 times/week.… [PCOAT medical provider] made calls, advocated very strongly and got [P18] back in the hotel that night.… Then she battled and advocated for a place at [hospice].… She did get a place and moved in less than a week after we first met her. The most amazing and important thing is that she now has a roof over her head, a secure way to dialysis, meals provided and care aids to assist on those days when she is too weak to get up.	

health and social needs, including lack of social support and food, financial insecurity, precarious housing, limited transportation and social isolation. One participant shared, "I'm getting by, but it's getting difficult." These inequities have implications for palliative care in terms of supporting comfort and quality of life, minimizing symptom burden and ensuring access to services and resources.[10] PCOAT enacted a person-centred, intersectional approach that considered patients' urgent practical concerns concurrently with pressing clinical issues. Our study intervention contributed to transformative care practices by paying attention to intersecting social dimensions of participants' health and wellness and by engaging agencies from health and social sectors. There is a lack of palliative care interventions addressing the multiple intersections of social inequities,[29,30] and a need to address this gap in Canada.

Eliminating systemic discrimination in health care

Study participants reported negative experiences when accessing health care, ranging from racism and discrimination to actual violence against them. Discrimination is any negative action or lack of consideration toward an individual or group that occurs because of a preconceived and unjustified opinion.[12,31] In health care settings, discrimination can manifest as delays in treatment, disrespectful care, verbal and physical abuse and outright denial of care.[32] Individuals who experience discrimination face significant disparities in access to health care and quality of care, and poor health outcomes.[33,34] Discrimination and racism violate people's human rights and affect both health service users and workers.[35] Discrimination in health care deters people from accessing health services, disempowers them and deprives them of their basic human dignity.[35] Discrimination and racism affect multiple aspects of health care delivery, including the timing of palliative care access.[36] Many Canadians experience discrimination based on their ethnicity, socioeconomic status, gender and other social characteristics.[1]

Discrimination can negatively influence people's end-of-life experiences, including the care they receive, how and where they die and whether their preferences are honoured.[37-39] Although we did not study the possible traumas resulting from participants' past experiences, findings suggest participants lived with long-lasting impacts of systemic racism and discrimination. These call for trauma-informed care approaches in the provision of palliative care. Trauma-informed care may increase physical and psychological safety within health care and reduce the risk of retraumatizing patients, promote trusting relationships, promote recognition of people's strengths and resiliency in the face of adverse life events and increase the provision of culturally safe care.[40,41]

Health care stakeholders hold an ethical obligation to "own" the issue and commit to meaningful action to eliminate systemic discrimination.[32] This requires antiracism policies and strategies, as well as antiracism training in the health care system.[39] Collaboration with communities is necessary to inform initiatives that eliminate systemic discrimination and racism in health care.[42] All research, programs and initiatives must be rooted in cultural humility and promote nonpaternalistic, strengths-based, community-clinician partnerships.[39]

Fostering community engagement in clinical practice and research

Implementing palliative care initiatives requires community engagement and community capacity development to collaboratively determine the most appropriate ways of supporting those affected by social disparities.[3,10] Collaborative engagement of individuals and communities with lived experience of inequities can lead to tailored and appropriate care in the context of social disparity, as well as culturally sensitive interventions.[43,44] Community-based research and interventions can improve accessibility and acceptability of health care services by building partnerships and trust within communities.[45] Community-based participatory research (CBPR) explores causes, consequences and solutions for health and health care disparities.[46] As a strengths-based approach, CBPR regards individuals as active agents with a wide range of capacities, talents and resources.[47] Interventions based on strengths affirm the right to self-determination and well-being of individuals and communities.[48] Future palliative and end-of-life care studies could focus on developing programs that address priorities identified by communities using a CBPR strengths-based approach.[49,50]

Strengths and limitations

This was a qualitative exploratory study and thus research findings are confined to the lived experiences of our study participants. The richness of data helped us understand the experiences of people experiencing socioeconomic inequities living with life-limiting illnesses in an urban Canadian setting and the potential impact of a community-based intervention. There is limited evidence of the lived experiences of these populations as well as interventions to improve their access to community-based palliative care in Canada, and this study contributes knowledge that honours their experiences. Throughout the study, the RN was the participants' main nursing provider. It is difficult to disentangle the impact of the study intervention from that of PCOAT, given that participants were part of both. In human science research, it is difficult to isolate parts from the whole, given that the focus is on human experience. This study reflects the principles of human science research and we do not intend to generate a final and conclusive truth. Further, the scope of this study was limited to understanding the experiences of people experiencing socioeconomic inequities living with life-limiting illnesses within the local context; our findings may not be reflective of experiences in other locations.

Conclusion

Study findings revealed key elements of the lived experiences of people experiencing socioeconomic inequities and living with life-limiting illnesses in an urban Canadian setting. The study provides insights into the impact of a community-based palliative care nursing intervention to improve access to palliative care and lessen health and social inequities. Research is needed to advance understanding of inequities in access to palliative care in Canada and practice modalities to tackle these inequities. There is a need to engage members of this population as partners in research to co-design services that recognize who they are at every moment.

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Conflicts of interest

The authors declare there are no conflicts of interest.

Authors' contributions and statement

AS, CB—conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, resources, supervision, validation, visualization, writing—original draft, writing—review and editing. HM—data curation, formal analysis, investigation, project administration, resources, validation, visualization, writing—review and editing. LV—formal analysis, validation, visualization, writing—original draft, writing—review and editing. OB—data curation, formal analysis, investigation, project administration, resources, validation, visualization, writing—original draft, writing—review and editing. JE—data curation, formal analysis, investigation, project administration, resources, writing—review and editing. TW—conceptualization, formal analysis, methodology, resources, validation, writing—review and editing. WD, SW—conceptualization, funding acquisition, methodology, supervision, writing—review and editing. BS—conceptualization, funding acquisition, writing—review and editing.

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