

Palliative Care and Opioid Prescribing for Marginalized People with Opioid Use Disorder and Advanced Illness: A Multi-setting Qualitative Study

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Introduction

- Due to a rising prevalence of opioid use disorder (OUD), there is an urgent need to understand people’s palliative care needs
- People with OUD face difficulty accessing palliative care and opioid prescriptions, which are essential for management of pain and shortness of breath at end of life
- This study is the first to explore qualitatively the current state of palliative care, opioid prescribing and end-of-life outcomes for people with OUD

Objective

To understand the end-of-life experiences of people with OUD, including how stigma influences their access and experiences surrounding palliative care and opioid prescriptions.

Methodology

STUDY PARTICIPANTS:

- Patients with life-limiting illness and OUD, who had or had not received palliative care
- Current or bereaved caregivers
- Healthcare providers offering palliative care to this patient population across diverse settings

DATA COLLECTION AND ANALYSIS:

- Semi-structured interviews or focus groups with patients, caregivers, and providers
- Virtual recruitment across Canada, in-person in cities of Ottawa and Toronto
- Applied thematic analysis

Results – Demographics

62 participants, including 18 patients/caregivers and 44 healthcare providers

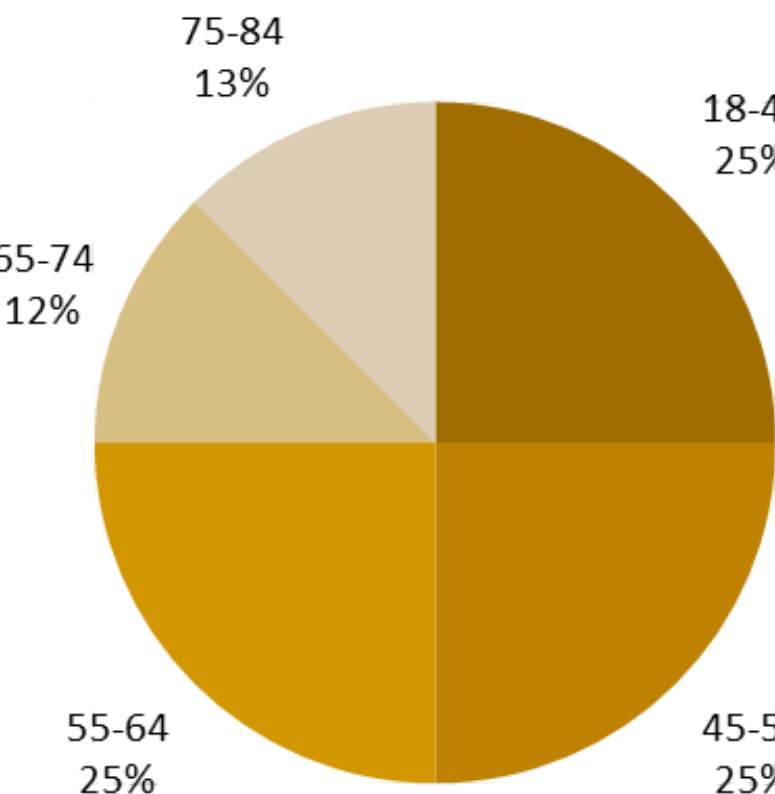
PATIENT DEMOGRAPHICS

Gender	63% men
Race/ethnicity	75% white
Urban residence	100%
Received palliative care	25%

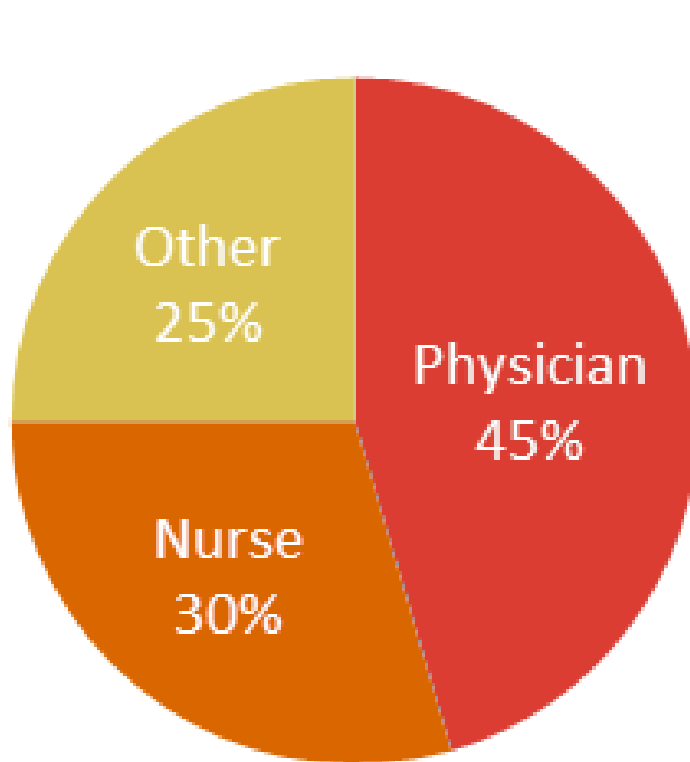
HEALTHCARE PROVIDER DEMOGRAPHICS

Gender	67% women
Urban practice	98%
Palliative care training	82%
Patients in practice with OUD	36%

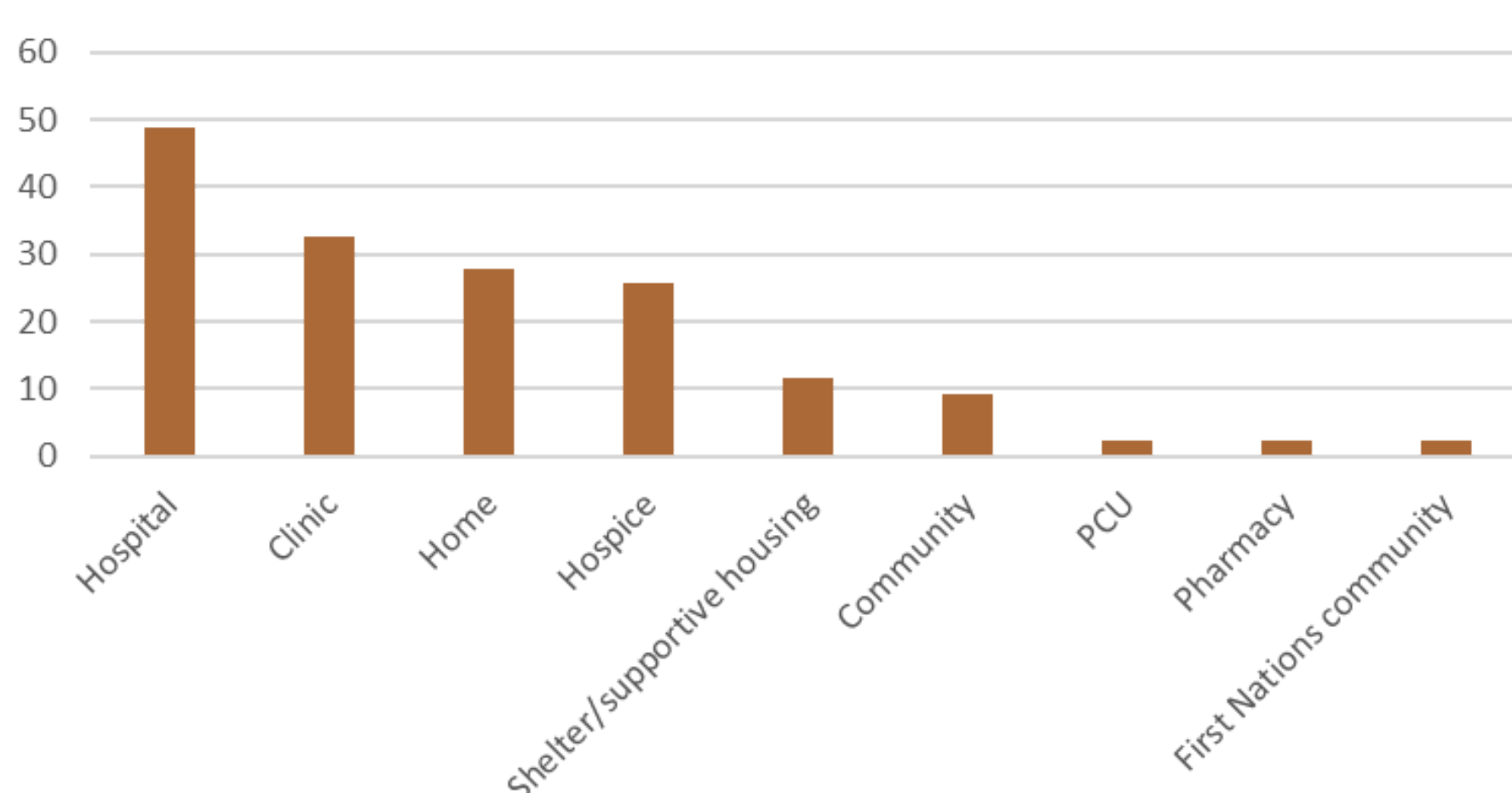
PATIENT AGE



PROVIDER ROLES



PROVIDER LOCATIONS OF PRACTICE



Results – Preliminary Themes

1 BARRIERS TO PALLIATIVE CARE

STIGMA: Structural, interpersonal, and self-stigma reduced patients’ engagement with palliative care.

“I go to the hospital... The psychiatrist, the doctor, the nurses would kind of slough me off and discharge me early...then the security guards would take me down really, really hard...and hurt me, and then on my way, having them escorting me out of the hospital, mocking me...” – Patient

SOCIAL DETERMINANTS OF HEALTH (SDOH): Homelessness, poverty, and lack of family caregivers interfered with access to traditional palliative care services.*

“Our services are set up for families...even the language is families... I just think that that alone is a barrier—is to assume that you have someone else to help you make decisions, to go home and talk over decisions. And that’s not necessarily the case.” – Nurse

LONG-TERM MARGINALIZATION: Prolonged marginalization contributed to many barriers to care, including a persistent survival mindset, prioritizing independence and control, lacking regular primary care, and having institutional trauma.

“And all of them have—exactly—institutional trauma. And a lot of them have spent time in jail... mental health institutions, long-term care stays in hospitals and things like that. And like we have clients that just—like that is their worst, worst fear. ...and they haven’t had a lot of control over their lives.” – Social worker

“There’s such alignment in palliative care with a harm reduction or trauma-informed approach because our whole point in palliative care is to do what the person wants.”
– Physician

2 COMPLEXITY IN OPIOID PRESCRIBING

DIFFICULTY DOSING: Traditional palliative care providers struggled with prescribing the high doses required for patients with OUD, resulting in inadequate pain management and loss to follow up. Community-based providers were more comfortable with high doses and preferred routes of administration.

"But I also think the pain thing of being open...to doing higher doses. We really have seen other doctors not be willing to do palliative care for our population because of the doses, just not willing to take that risk, but also being open because people are IV drug users. What pain relief looks like for them is using a needle..." – Nurse

SHARED DECISION-MAKING: While traditional palliative care providers were focused more on increased monitoring of patients with OUD, community-based providers used shared-decision making in prescribing opioids – both as an acknowledgement of patients’ lived experiences and as a way to gain the trust of patients who were traumatized by mainstream systems, thus supporting ongoing engagement.

“For me that means trusting absolutely what they say, even if I know that their lived experience may be different than their objective account – which means putting them at risk of...unwarranted dose increase, because I believe so fully that without that trust there will be no tolerance for the discomfort of attempting to safely manage opioid burden.” – Physician

*Traditional palliative care refers to healthcare providers who provide palliative care to the general population within mainstream healthcare settings (e.g., hospitals) or via home care

Preliminary Themes (Cont.)

3 PALLIATIVE CARE ROOTED IN HARM REDUCTION

ALTERNATIVE PALLIATIVE CARE: Community-based providers developed innovative approaches to caring for patients with OUD that included tailored services and a focus on trust-building and holistic, person-centered care.

“Lots of housing, especially supportive housing, doesn’t allow substance use. So our housing is specialized, in that we accept and rejoice in people who use drugs. Our expectation is that you’re using drugs. We don’t really want you if you don’t.” – Nurse

SAFER SUPPLY: Providing pharmaceutical-grade opioids to help patients avoid street drugs supported engaging them in palliative care.

“Without that tool [safer supply], I don’t know that she would probably be here today because she probably wouldn’t have engaged in care... And by us being able to provide her with something that she felt that she wanted and needed, we were able to help her.” – Nurse

ALIGNMENT WITH PREFERENCES: Community-based palliative care aligned better than traditional services with the priorities of patients with OUD, including to control their drug use.

“A lot of people that are using drugs end up in palliative care, but sometimes if it’s in a more conservative healthcare setting, they may be forced to stop using their outside drugs or stop doing things that make them comfortable... If it’s end of their life, why do we care if they’re using drugs, right?” – Patient

NEED FOR RESOURCES: Community-based palliative services were considered essential by all, yet they were limited and required more resources.

"The amount of need versus the amount of service that can be provided here is wildly out of whack. So the nurses and the providers end up doing a lot of the social service stuff, too, because...that’s who the client is able to open up to.” – Social worker

Conclusions

- Marginalized patients with OUD face structural vulnerability and SDOH that impede access to palliative care and opioid prescriptions
- Community-based providers use harm reduction to care for these patients’ life-limiting illnesses

Recommendations

- Palliative care systems should further embrace and integrate harm reduction approaches
- Invest in harm reduction-oriented, community-based supports to:
 - Meet people where they’re at
 - Practice shared decision-making
 - Advocate for patients across care settings
 - Fill gaps in social support for those who are isolated, including via peer support
- Improve training and collaboration for traditional palliative care providers and addiction/harm reduction providers

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