Palliative Care for Populations Who Experience Homelessness
May 12, 2017 | Review Brief

Review Highlights

The current methods in which palliative care is provided does not fit the unique need of homeless and marginally housed populations.

Some of the main barriers individuals face in accessing palliative care is holding a distrust of institutions, lack of harm reduction approaches to care, and lack of services available in places they are comfortable in.

Many promising practices emphasize the need for stable housing as a key component of providing palliative care. In some practices this meant developing a centre specifically designed for homeless palliative patients, and in others in meant getting the funding to house them in the community.

Providing palliative services in shelters and transitional housing was identified as a promising practice, and has been done in many other jurisdictions with success.

The research was consistent in identifying the need for any services targeting the homeless population needing to take a harm reduction approach.

Street outreach via a van was identified as a key access point for homeless populations who are not connected to other supports, and could include palliative supports.

A group of people with lived experience were consulted and identifying that it is an issue in the community, and that "we are all human and deserve to die with dignity."

Waterloo Wellington Overview

Across Waterloo Wellington, there are 14 shelters with a capacity of approximately 340 beds. There is currently an estimated 611 people experiencing homelessness in Waterloo Wellington, [1][2] though many more precariously housed and vulnerable to the risk of homelessness. There is limited (if any) data on the number of individuals who are homeless/at risk of homelessness and who also are in need of palliative care.   The closest data are the priority requests for social housing. In the last few years, have been approximately 4200 households on housing waitlists across Waterloo Wellington. Of these, a small number (< 1%) have priority requests for housing due to terminal illness or due to hospital discharge. However, because of the significant waitlist in both regions, even these few individuals are unlikely to get housing. Despite the lack of data, it is well documented that individuals who experience homelessness experience higher rates of illness and chronic medical conditions (e.g. tuberculosis, HIV infection, traumatic injuries) which lead to higher than average mortality rates.[3]

From the Homelessness Hub[4]

Waterloo Region, ON

Population: 426,000 (July 2016)
Unemployment Rate: 5.9% (as of July 2016)
Minimum Wage: $11.40/hr (as of October 1, 2016)
Total Number of Shelters: 7 (2017)
Total Number of Beds: 245 (2017)

POPULATION FACTS

HOMELESSNESS
Annual number of individuals estimated to have stayed in emergency shelters: 2,726 (2017)
Point-in-Time number of individuals identified as experiencing homelessness: 316 (2014)

HOUSING
Number of community housing units: 10,410 (2017)
Number of households on housing waitlist: 3,432 (2017)
Rental Vacancy Rate: 2.2% (2017)
Average Cost of Rent (1 bdrm): $872/mo. (2017)
Households in core housing need: 10.3% (2011)

SOCIAL ASSISTANCE
Number of heads of households receiving Ontario Works assistance at December 2016: 8,782 (2016)
Ontario Works Assistance (single person/month): $706 (2016)

Guelph-Wellington, ON

Wellington Population: 222,726 (2016)
Guelph Population: 131,794 (2016)
Unemployment Rate: 5.3% (July 2016)
Minimum Wage: $11.40/hr (as of October 1, 2016)
Total Number of Shelters: 3 (2016)
Total Number of Beds: 54 (2016)

POPULATION FACTS

HOMELESSNESS
Annual number of individuals estimated to have stayed in emergency shelters: 586 (2016)
Point-in-Time number of individuals identified as experiencing homelessness: 295 (2016)

HOUSING
Number of community housing units: 2,673 (2016)
Number of households on housing waitlist: 1,455 (2016)
Rental Vacancy Rate: 1% (2016)
Average Cost of Rent (1 bdrm): $952/mo. (2016)
Households in core housing need: 12.2% (2012)

SOCIAL ASSISTANCE
Average monthly number of households receiving Ontario Works assistance: 2,102 (2015)
Ontario Works Assistance (single person/month): $706 (2016)

Literature Review

This document presents preliminary highlights from our literature review on best practices in delivering palliative care to populations who are homeless or vulnerably house.

Context

- People with low socio-economic standing, including who experience homelessness have poorer access to health care overall, and even poorer access to palliative health care.[5]

- Homeless populations experience higher levels of morbidity and mortality, having a much lower life expectancy than the general population, living to about 42-53.[6]

- As well, homeless individuals experience more health issues, with those over 50 years of age being 3.6 times more likely to have chronic health issues than those under 50, meaning a higher need for health supports.[7]

- Individuals who experience homelessness commonly go without any sort of end-of-life care.[8]

- The number of elderly homeless is growing, and for those who are elderly it is often their first experience with homelessness (from job loss or an eviction).[9]

Barriers to accessing palliative care

Access to palliative care for individuals who experience homelessness, including:

- **Anti-drug policies**: Behavioural codes or policies that prohibit drug use in palliative care programs is one of the most significant barriers to end-of-life care.[10] Homeless populations experience substance use and problematic substance at a higher rate than the general population, and as such are excluded from accessing any facility that had a zero-tolerance or compliance policy.[11]

- **Availability of care:** The current structure for delivering palliative care does not fit the uniqueness of the homeless population.[12] For example, palliative resources rely often on a family member or close friend as a caregiver; those within the social network of homeless individuals may not be in a position to be a caregiver.[13]

- **Lack of stability:** Lack of residential stability (where services provide care in homes) and lack of financial stability (where services are not fully covered) are barriers to this population.[14]

- **Trust of health care professionals:** A lifetime of disenfranchisement from institutional settings, can result in low trust in and disconnection from hospitals and health care professionals.[15]

- **Lack of training for health and social care professionals:** Palliative health care professionals are often ill-equipped to provide services to the homeless population: and shelter staff or other social care staff who commonly work with the population are ill-equipped support quality palliative care.[16]

- **Transience:** Palliative workers can find it difficult to know where the individual is currently residing as there can be a lot of relocation between transitional housing, shelters, and sleeping rough. Eligibility requirements of different homeless resources can limit the length of time an individual can stay in one location.[17]

- **Mental health and drug use:** Palliative care workers have identified that patients with substance use and/or mental health challenges can complicate the delivery of care. Planning for and managing pain can be especially difficult when working with people who use substances, as palliative care workers have a lot of concern over misuse of prescribed medication.[18]

Best practices for providing palliative care to the homeless population

- **Residential hospices designed for homeless:** In denser populations where there are higher numbers of homeless individuals, developing a hospice especially designed for homeless people has been shown to be effective.[19] Residential hospices for homeless people were found to cost $125 per night whereas traditional palliative was $684 and tertiary hospital was $633.[20]
    - **Ex. Hospitality House.** A six-bed shelter for marginally housed individuals with health or palliative needs. 24-hour support is provided.

- **Case-by-case palliative accommodation:** In settings where there is a smaller homeless population, providing accommodation where palliative care can be provided is more effective on a case-by-case basis.[21,22]

    - **'Outside the box' approach.** Workers often tap into many resources to get a client housed, even on short-term basis such as hotels.[23]

    - **Funding for homeless palliative patient housing.** Apply for funding specific to this need.[24]

- **Shelter-based palliative care:** Homeless individuals, especially those over 50, are much more likely to access shelter-based or outreach services for health issues than the hospital.[25] Best practices for effective shelter-based palliative care include:
    - Train shelter staff. Specifically, training on how to talk about death and dying.[26,27]
    - **Hire palliative staff.** In one case of a shelter shifting to provide palliative care, one full-time registered nurse was hired, one overnight practical nurse, and a 24/7 client care worker. Physicians saw clients on in-shelter rounds, and any specialists needed were brought in through partnerships.[28]
    - Introduce services slowly.[29]
    - Build family-like relationships.[30,31,32]
    - Communicate effectively. [33]
    - Practice person-centred care.[34]

- **Training for palliative care providers:** Palliative care providers are not typically knowledgeable about the unique issues homeless people face.[35] Training palliative staff to deal with unique issues confronting the homeless, especially on issues like mental health and substance use will better prepare care providers to practice quality care to homeless patients. [36,37,38] Training for palliative care workers should include:

    - Palliative staff to be sensitive to street issues.

    - Understand and respect harm reduction strategies.

    - Have a method to evaluate outcomes of training and improve it over time. [39]

- **Care is relationship-based.** Providing palliative care comes after developing and maintaining trust and respect, sometimes taking years to build this relationship.[40]

- **Harm reduction strategies.** Palliative services that aim to be accessible to this population must use a harm reduction approach. Trust must also be built between the patient and care providers to have care discussions about substance use.[41,42]

    - **Point of entry.** Accessing harm reduction services, which in one case was a needle exchange program, can be a way to initiate relationship with clients.[43]

    - **Build relationship over time.** Since clients who use drugs access harm reduction services frequently, the workers could develop trust over time by frequent contact.

- o **Actively seek partnerships.** Harm reduction workers should actively seek out partnerships with palliative care services and vice versa to best provide care services for this population.

- o **Drug treatment.** In cases where drug use was prohibited in the end-of-life care location, harm reduction practices were used. For example, clients who depended on drugs to manage pain were provided opioids by patch or pump, and those that depended on drugs for anxiety were provided benzodiazepine or antidepressants.

- **Strong partnerships between health care and community agencies**. Strong relationships can be fostered between community agencies and health care/palliative services, for example by increasing communication on how to make and manage referrals, and how to manage care tasks.[44,45]

  - o **Harm reduction partnerships.** Palliative services should partner with harm reduction services, as this can be a pint-of-entry for homeless populations seeking services.

  - o **Shelter partnerships.**

  - o **Establish roundtables to build relationships.** For example, in Toronto there is a Working Group on Homelessness and Palliative Care. This is a group of nurses, physicians, social workers, and shelter/program workers that meets monthly to discuss issue, share ideas, set goals and discuss progress.[46]

- **Flexible and low threshold strategies.** Strategies that aim to engage homeless populations should be flexible and have low-thresholds. People who have faced homelessness and are needing palliative care often have complex and competing issues. It is unrealistic to try to address all issues at once, and workers have had more success in addressing the most pressing or threatening issue first.[47,48,49]

  - o **Flexibility**. Dying at home should follow clients wishes, even if unorthodox and requires flexibility on the part of the palliative team. Examples were provided of clients choosing what to watch on television and choosing where they want to die, even if it might be places unsuitable to care workers like the street, shelters, or hostels. In some cases this also included being open to diverse visitors who make up the person's social network.[50]

  - o **Indigenous populations**. In some cases it may be appropriate to provide traditional healing practices and 'smudging' for indigenous populations, requiring partnership with indigenous agencies.[51]

- **Multiple avenues to access palliative care.** Approaches that work for some patients may not work for all patients, therefore there should be as many avenues as possible for homeless individuals to access palliative care.

  - o Avenues should include shelter-based, street-based mobile units and hospital-based. [52]

The Local Experience

Four key informant interviews were held with local organizations as well as one focus group with 5 individuals with lived experience of homelessness. Participants were asked about the current needs of the homeless population in the region, the available supports in their communities, and the kinds of supports or initiatives that are needed to increase access to palliative care.

The population

- After being excluded from these settings for most of their life, often people are distrustful of 'institutional' settings and of formal supports like hospitals.
- Often health issues are complex and chronic, and there is a high comorbidity rate often with mental health issues, substance use and sometimes cognitive impairment.
- People with lived experience identified that fear of overdose (of themselves or members of their support network dying of overdose) is a high priority right now.
- People will not move into somewhere they cannot use drugs or that does not use a harm reduction approach.
- People with lived experience identified that physical health is not a high priority and *"in the scope of your life, if you don't have a roof over your head, and you don't know where your next meal is coming from your plan for death is the last thing on your mind."*
- Marginally housed populations are often disconnected from formal supports, services and from the 'system' and have been disconnected for a very long time.
- Sometimes they move into long-term care to die, but often they prefer to stay in places they are comfortable such as shelters or transitional housing.
- The population has strong community ties, and a social network, but this network is often not made up of family members.
- People with lived experience identified that outreach workers are in a good position to connect the marginally housed to supports, especially those that are not already connected to services.

Issues and barriers homeless population faces in accessing palliative care:

- Concerns for safety for palliative workers with people with mental health and substance use.
- The current palliative system is not built with the homeless population in mind. It is built to be delivered in a home, and built based on routine. Both characteristics are not effective for homeless populations.
- Difficulty in diagnosing a patient as 'palliative' because lack of patient history, current living situation like access to warmth and food.
- Palliative workers do not have the skill set to help people who use drugs and have mental health issues.
- People with lived experience said that there would be stigma from other residents at long-term health care facilities toward people formerly homeless, preventing the marginally housed from being comfortable in these types of centres.

- There is a lack of affordable housing in the region, creating an inequity for access to palliative care.
- People with lived experience identified that they have trouble being prescribed appropriate drugs for pain management because they use other drugs, the feeling of not being trusted by physicians.

Strategies that have had success in encouraging access to current palliative services:

- **Trust in individual worker**. A lot of work needs to be put into gaining the trust of clients/patients, and this trust develops slowly over time.
- **Trust in agency**. If agencies become known and trusted in the community and word spreads by word-of-mouth and those agencies are then become leaders for homeless and marginally housed to access other resources. People with lived experience supported this, saying specific agencies and workers became major supports once they trusted them.
- **Slow introduction to supports**. Supports need to be built up one at a time.
- **Police as an access point**. Police officers are frequently working on the street and knowledgeable about the homeless population and could be tapped into to connect to non-emergency health services.
- **Reduce stigma from health care professionals**. Palliative workers need to be comfortable meeting the wishes of palliative patients, even if unorthodox.
- **Physicians who can effectively work with drug users**.
- **Increasing collaboration**. Creating partnerships, collaboration and training opportunities to provide coordinated care.
- **Train palliative workers**. It was suggested by people with lived experience that palliative workers get training in mental health, addictions, anti-oppressive practice and have mandatory shadowing or experience with this population. The interviewees with lived experience stated that "We are people and they need to understand that we are people and that their job is to serve people." It was also identified that people who are not homeless have mental health issues and addictions as well.

Ideas to change the way palliative care is provided to increase access:

- **Providing palliative care in known spaces**. This suggestion was provided by most interviewees and discussed at length by the interviewees with lived experience. Some places that were suggested were drop-in centres, community health centres, transitional housing and shelters. Shelters were discussed most in-depth, and were spoken about as the persons only support and feeling like a home and community. It was also identified that shelters already have a lot of partnerships with health services that could be relied upon and expanded further if palliative services were to be provided at shelters. Some suggestions for how to implement palliative care into shelters were:
  - A position to administer health services;
  - A clinic room to connect patients to the help they need;
  - Training for staff to be able to deliver some palliative services;
  - Partnerships with services to come provide grief support when a significant loss is felt by the shelter or transitional housing unit.

- **Medical street outreach**. Street outreach team that has capacity to provide some medical care on the street, a medical bus was used as an example. It was also suggested by people with lived experience that palliative services be provided with outreach services that are already in the community like Sanguen.
- **Buddy-up palliative workers.** People with lived experience suggested palliative workers work in pairs of two if the workers are concerned for their safety when working with the homeless population.
- **Centre for homeless palliative patients**. Many sited Hospitality House as a great example of palliative supports built to serve the marginally housed. People with lived experience had not heard of Hospitality House but descried something similar, a unit, centre or house, designed specifically for homeless palliative people as an ideal place for this population. Some of the reasons interviewees said the Hospitality House works so well is:
    - It is a local resource, and was started by a large street outreach program, so they have ties and trust in the community.
    - All of the services residents need are located in one place, including CCAC.
    - Their workers were trained in palliative care.
    - There is no time limit on the length of time residents can stay there.
    - There are the staffing levels needed to effectively meet the needs of the residents.

General comments about supporting the population:
- The more doors that are open for people to access healthcare the better, one avenue will not work for everyone so we need to increase the avenues.
- The question is not about how to fit the marginally housed into the current system, because they don't fit. The question is about how to best serve everyone and meet this populations end-of-life wishes.
- The community needs to be looking upstream at this issues, the real issue is housing. If this community addressed the housing issue this would not be a problem.
- "Can we please be equal when we die?" – Person with lived experience.

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[26] Krakowsky, et al., 2012

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[28] Podymow, Turnbull & Coyle, 2006

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[30] Cagle, 2009

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[32] Håkanson, et al., 2016

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