



# Palliative Care Services for People Experiencing Homelessness in Toronto

## A preliminary needs assessment

Centre for Urban Health Solutions  
Survey Research Unit,  
St. Michael's Hospital  
May 12, 2017

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This evaluation was conducted by the Centre for Urban Health Solutions (C-UHS) Survey Research Unit (SRU) at the request of the Toronto Central Palliative Care Network.

### **LEAD CONTRIBUTORS**

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### **ABOUT THE CENTRE FOR URBAN HEALTH SOLUTIONS SURVEY RESEARCH UNIT**

The Centre for Urban Health Solutions (founded in 1998 as the Centre for Research on Inner City Health), is an interdisciplinary research centre within St. Michael's Hospital in Toronto. The Centre seeks to improve health in cities, especially for those experiencing marginalization, and to reduce barriers to accessing factors essential to health, such as appropriate health care and quality housing. The Centre's Survey Research Unit (SRU) was created in July 2009 to consolidate, mobilize and expand the Centre for Urban Health Solutions' survey research capabilities and expertise. The Unit has the capacity to undertake large-scale qualitative and quantitative research in multiple languages and using a range of techniques.

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## TABLE OF CONTENTS

### Executive Summary

### Introduction

### Chapter I – Literature Review

1.1 Homelessness in Toronto	5
1.2 Barriers to access and gaps in services for people who are homeless	9
1.3 Description of known palliative care approaches, models and principles for people experiencing homelessness	12

### Chapter II – Key Informant Consultations

2.1 Palliative care needs of people who are homeless	19
2.2 Areas of success	29
2.3 Facilitators	31
2.4 Palliative care services	33
2.5 Integrating and optimizing palliative care service delivery in Toronto	36

### References

## EXECUTIVE SUMMARY

Recognizing the complex social and health care circumstances of people experiencing homelessness in Toronto, this report aims to identify the state of the palliative care services available to this population. This preliminary needs assessment brings together a literature review alongside key informant consultations to understand the current needs, barriers and areas of success in palliative care services for people who are homeless in Toronto. The main findings from this needs assessment follows:

- **There is a need for a strong palliative care approach that recognizes the rights and complex health and social care circumstances of people who are homeless.** In Toronto, this population experiences higher risk of illness, barriers to accessing mainstream health services (including access to a family doctor), significantly higher mortality rates, experiences of trauma, discrimination, social isolation, mental health challenges and substance use and related feelings of distrust of the health and social work systems.
- **Mobility of palliative care services to reach clients beyond the hospital setting is necessary.** Going to clients, following them between services (e.g. when a client moves from a shelter into a palliative care unit) and meeting outside of health care environments, are strategies that have been successful in not only initially engaging people who are homeless but also keeping them in a care plan.
- **Criteria for admitting people into care environments are often too rigid** for people who are homeless and experiencing multiple comorbidities, an unclear prognosis and/or nonlinear disease trajectories. Clients often 'fall in the middle' of being too ill to be on their own, but also not quite ready for palliative care units or hospice. More flexible admission criteria and length of stay for palliative care units and hospices are needed.
- **Abstinence-based approaches were considered to be one of the largest barriers to accessing palliative units and hospice care** for people who are homeless, as it can be unrealistic to their needs and history with substance use. There is a need to adopt harm reduction approaches that recognize and respond to the substance use history of clients.
- **Better engagement with social service providers and programs in the community is important.** Developing relationships with case workers, other service providers, and people in the community that the client knows, can assist with the initial introduction into palliative care and also while a client is receiving care. Including someone they trust and have a developed relationship with can often ease this transition for both the client and health care provider, and also be helpful during follow-up.
- **Maintaining the continuity of care across settings is needed.** As people move from different health and social service providers, it is important that communication and involvement is maintained, to ensure a more effective palliative care plan that involves people of whom the client already has a developed relationship.
- **Further work must be done to evaluate and document available palliative care models for people who are homeless.** The literature available on palliative care models for people who are homeless is sparse. Additional work to publish and report interventions, strategies and models could benefit care.

## INTRODUCTION

In 2014, the Toronto Central Local Health Integration Network (TC LHIN) released the report: *Dignity. Compassion. Choice: TC LHIN Palliative Care Strategy*<sup>1</sup> and in early 2016, the Ministry of Health released the *Palliative and End-Of-Life Care Provincial Roundtable Report*<sup>2</sup>. Both reports outline strategies for the provision of equitable palliative care services and highlight the importance of constructing an effective palliative plan that adapts to meet the needs of special groups, such as the homeless population.

In December 2016, the Toronto Central Palliative Network approached the Centre for Urban Health Solutions (C-UHS) to conduct a preliminary needs assessment on the state of the palliative care services available to people who are homeless in Toronto. This report outlines the results of this assessment, which includes a literature review and key informant consultations with representatives of organizations strongly connected with palliative care services for people experiencing homelessness in Toronto.

A literature review was conducted for the years 1985 to 2017 of literature that discusses palliative care services and the homeless population. Medline, PsycINFO, Web of Science (including Social Sciences Citation Index), CINAHL and Social Works Abs., were all searched. Additionally, a hand search was done to snowball additional sources from the literature and to also identify more grey literature reports. During the key informant consultations, additional sources were sent in by participants. The literature was reviewed by two team members to identify literature that mentioned street homelessness or shelter homeless populations. In the end, 78 publications were reviewed for this report.

In addition, we conducted a consultation with eight key informants involved in a variety of palliative care service models that serve people who are homeless. The consultation was not exhaustive of the services available, but represents palliative care health services frequently used by this population group. We spoke with leadership and frontline staff at the following organizations:

- Inner City Health Associates (ICHA)
  - Palliative Education and Care for the Homeless (PEACH)
- Inner City Family Health Team (ICFHT)
- Toronto Central Community Care Access Centre (Toronto Central CCAC)
- The Kensington Hospice
- The Temmy Latner Centre for Palliative Care
- St. Michael's Hospital Palliative Care Unit

All key informants were invited to review the draft of this report. This process of validation was used to clarify any information that was missing or misinterpreted. All suggestions were reviewed and considered when finalizing this report.

This assessment has important limitations, including: (1) lack of direct consultation with people experiencing homelessness, (2) the key informant interview sample was not built to achieve saturation nor represent the variability of staff engaged with palliative care for people experiencing homelessness in Toronto, including shelter workers, primary care physicians and allied health professionals, (3) the findings are not generalizable (i.e. not a representative sample), (4) the report does not cover the many vulnerably housed people in Toronto, and (5) it does not include models not published in academic and

grey literature. Despite these limitations, this assessment shows a picture of the state of the palliative care services for people who are homeless in Toronto, and provides important insights into areas where improvement and further evaluation are needed.

The World Health Organization defines Palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” For the purpose of this report we are considering *life-threatening illness* to include non-linear disease trajectories and uncertain prognosis.

Additionally, we defined homeless as people living on the streets or in shelters. We did not include in the definition of homeless, people who are living in unsafe, crowded and/or precarious housing, an important group for further research. The report outlines the challenging scenario for delivering palliative care services for people experiencing homelessness in Toronto. These challenges are closely related to organizational and societal barriers that impact the experience of being homeless and palliative. The report also presents models of care described in the literature and best practices put forward by the network of providers committed to palliative care services and to the rights of individuals experiencing homelessness in this city.

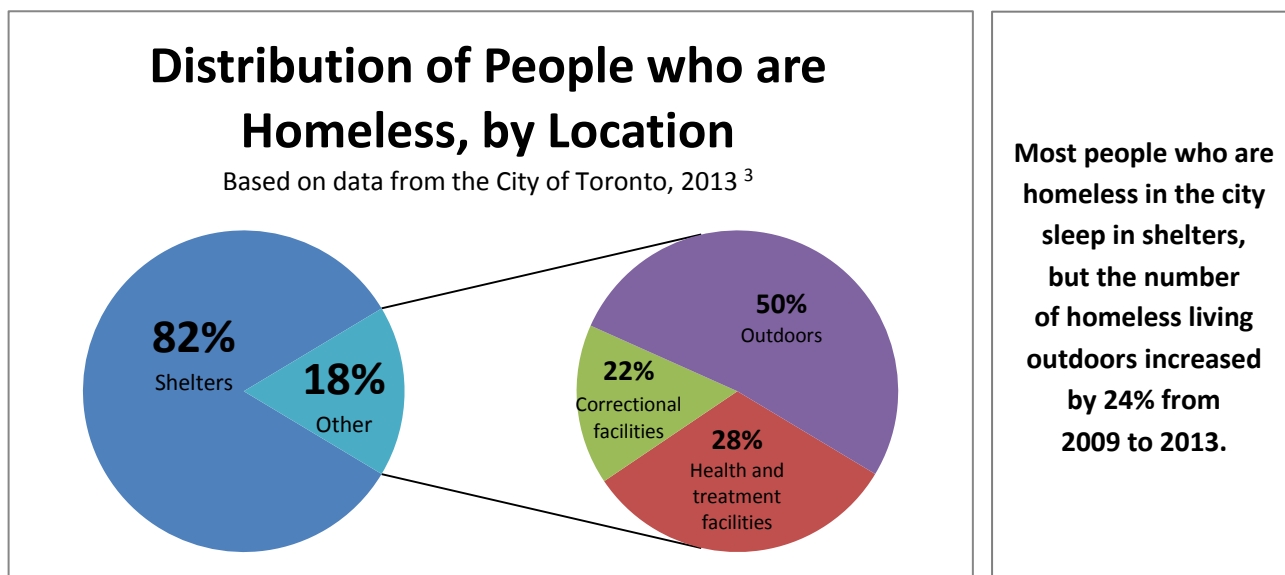
## CHAPTER I – LITERATURE REVIEW

### 1.1 HOMELESSNESS IN TORONTO

Statistics about homelessness in Toronto are very limited. Currently, the major sources of these vital statistics are the Street Needs Assessment (undertaken by the City of Toronto in 2006, 2009 and 2013) and the Street Health Report (undertaken by Street Health in 1992 and 1997). More current information is needed.

#### *Demographics*

On any given night, about 5,250 people in Toronto are homeless. The chart below shows the distribution of the homeless population estimated by a point-in-time count assessment undertaken on April 17, 2013. This estimation excludes the so-called “hidden” homeless (e.g. couch surfers) and the large proportion of Toronto residents in unstable living arrangements, such as rooming houses and subsidized housing, who move in and out of homelessness.<sup>3</sup> It is estimated that 31,985 people stayed in Toronto shelters in 2002.<sup>4</sup> In 2013 there were 3,836 shelter beds available in the city with a 96% occupancy rate.<sup>5</sup>



There is a diverse homeless population in Toronto with a disproportionate representation of particular groups.<sup>6</sup> According to the 2013 Street Needs Assessment:<sup>3</sup>

- Men represent 65% of the overall homeless population. Men also represent 93% of homeless individuals who are in correctional facilities and 85% of the homeless population that sleep outdoors.
- Women represent 33% of the overall homeless population, a proportion that has increased roughly 7% since 2006.
- People identifying as LGBTQ represent 9% of the overall homeless population and 21% of youth living in shelters.
- Indigenous people represent 16% of the homeless population and 33% of the homeless population sleeping outdoors.

- New residents to Toronto (one year or less) represent 18% of the homeless population: 6% from outside of Canada, 9% coming from other parts of Ontario and 3% from other parts of Canada.
- Most residents of Toronto who are homeless are adults between 21 and 60 years of age (83%). Youth (under 21) represent 7% of the population and adults over 61 represent 10%. The percentage of homeless seniors in Toronto doubled between 2009 and 2013.

### *Vulnerability to violence*

According to the Street Health Report 2007, the Toronto homeless population is at a much greater risk of violence than the general population:<sup>7</sup>

- One-third of all people who were homeless in Toronto were physically assaulted or beaten in the previous year.
- Sixty-eight percent of those assaulted were assaulted more than once, averaging 6 times in a year.
- Women are particularly at risk of sexual assault. The 2007 report found that one in every five women who are homeless were sexually assaulted or raped in the previous year.

### *Mental health, learning disabilities and isolation*

People who are homeless in Toronto report significantly higher rates of mental health problems in comparison to the general population. A difference of 14% for learning disabilities, 10% for anxiety, 9% for depression, 7% for bipolar disorder and 4% for schizophrenia was reported.<sup>7</sup>

- 37% of people who are homeless in Toronto reported that they have no one to help them in an emotional crisis.
- It is estimated that 50 percent of people who are homeless in Toronto use at least one illicit drug regularly (59%).
- The rate of smokers (87%) is significantly higher than the general population (18%).
- For those who consume alcohol, 72% are heavy drinkers in comparison to 44% in the general population.

### *Health and health care use*

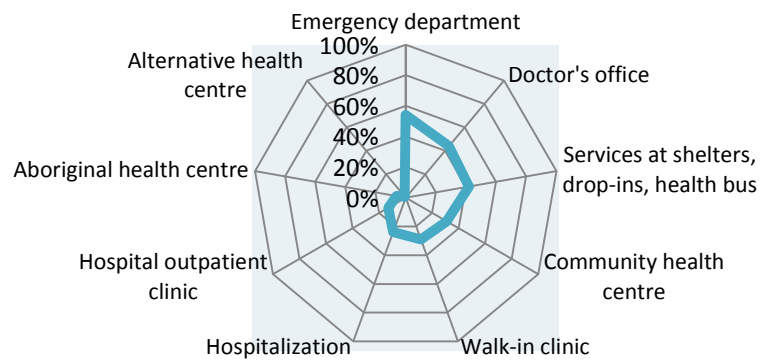
Toronto homeless are at higher risk for illness, with 74% reporting at least one serious health condition:<sup>7</sup>

- Homeless Torontonians are 300 times more likely to have HIV, 29 times more likely to have Hepatitis C, 20 times more likely to have epilepsy, 5 times more likely to have heart disease and 4 times more likely to have cancer.
- Most of the population does not have a family doctor and access health care through emergency departments.
- Those using the emergency departments (54%) are frequent users with an average of 5 visits in a year. The chart below shows the distribution of health care services utilization.



## Where do people who are homeless go for care?

Based on data from Street Health Report, 2007



In addition, due to lack of medication insurance coverage, a portion of the Toronto homeless population faces barriers obtaining medications that are prescribed to them.<sup>8</sup>

### *Mortality rates*

Mortality rates are significantly higher in the Toronto homeless population in comparison to the general population. Based on a cohort of homeless Torontonians using the shelter system during 1995-1997 (table 1), both homeless women and men from all identified age groups were more likely to die in comparison to the general population. Rates were particularly alarming in the younger age groups, with homeless men aged 18-24 being 8 times more likely to die and homeless women aged 18-44 being 10 times more likely to die in comparison to the general population.<sup>9,10</sup>

**Table 1 – Mortality rates of men and women using shelters in Toronto and rate ratios comparing mortality rates among homeless men and women with those of men and women in the general population\***

	<b>Mortality rate</b> Deaths per 1000,000 person-years	<b>Rate ratios</b> Mortality rate comparison with their gender counterpart in the general population
<b>Men 18-24</b>	421	8.3
<b>Men 25-44</b>	669	3.7
<b>Men 45-64</b>	1680	2.3
<b>Women 18-44</b>	515	10.1
<b>Women 45-64</b>	438	1.2

\*Based on data from Hwang, 2000<sup>9</sup> and Cheung & Hwang, 2004<sup>10</sup>, utilizing data from 1995-1997

The social conditions, health status, morbidity and mortality indicators of the homeless population in Toronto call for a strong palliative care approach. The next chapters of this report will outline what approaches have been used elsewhere for the provision of palliative care for the homeless, as well as, what services are currently offered in Toronto and what services gaps and challenges were identified by services providers.

## 1.2 BARRIERS TO ACCESS AND GAPS IN SERVICES FOR PEOPLE WHO ARE HOMELESS

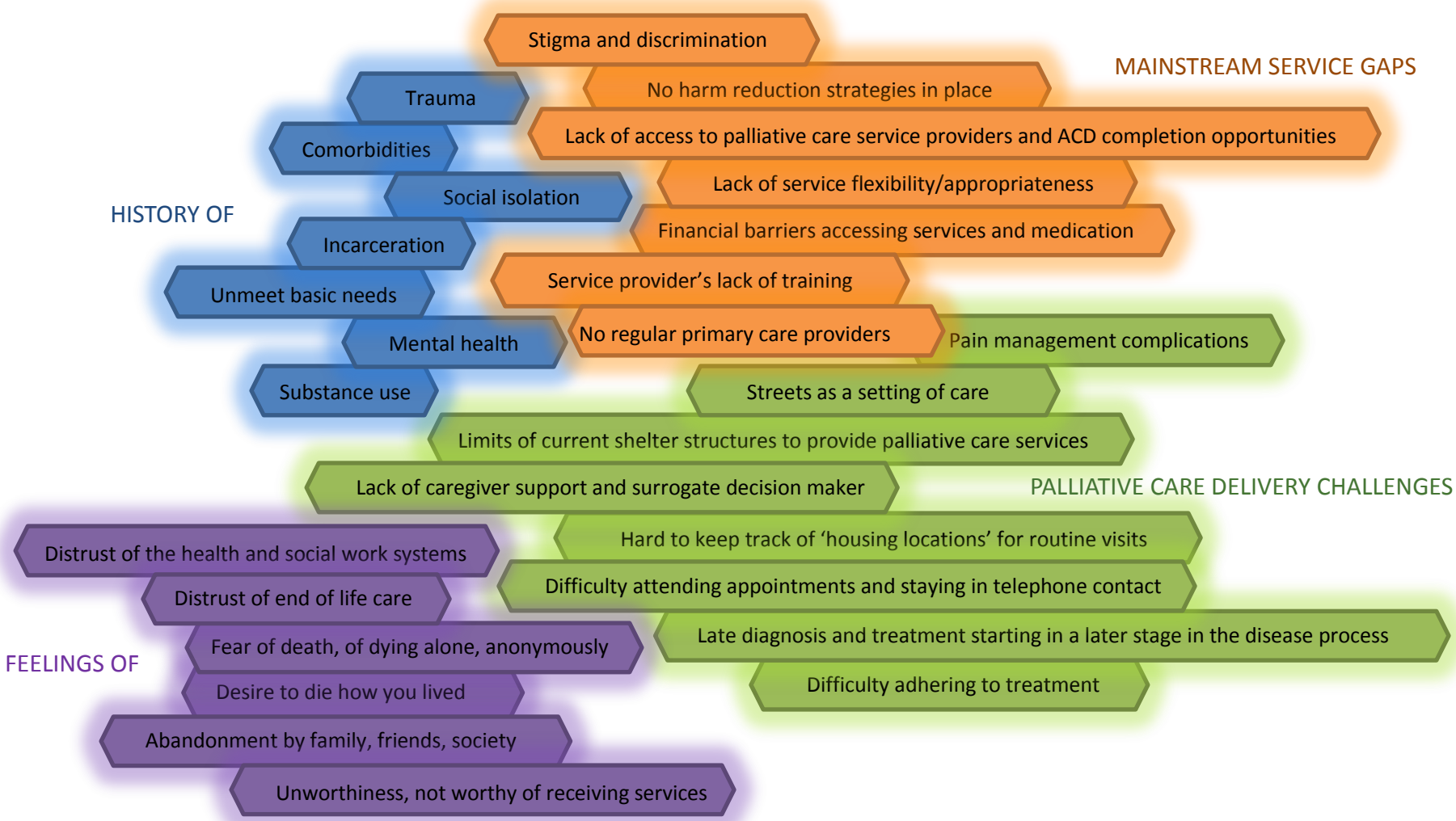
The literature presents many barriers for people experiencing homelessness to access high quality palliative care. The experience of homelessness, feelings of distrust and fear, access to mainstream services and palliative care delivery challenges are discussed as interconnected components.

- *Personal History* – Experiencing homelessness encompasses a variety of circumstances and histories that impact people’s experiences with the health care system and palliative care services. Common trajectories include: (a) history of trauma including abuse, neglect, discrimination, assault and traumatic experiences with death; (b) higher rates of illness and frequent comorbidity; (c) social isolation due to mental illness, disconnection with family members and poverty; (d) history of incarceration and conflicts with the law; (e) unmet basic needs, such as shelter, food, utilities and transportation; and (f) mental health challenges, including significant substance use<sup>11-13</sup>.
- *Mainstream services* – Mainstream services are ill-equipped to meet the needs of people who are homeless. Besides financial barriers to accessing services and medications, people who are homeless suffer stigma and discrimination when engaging with care.<sup>11, 13, 14</sup> Service systems, including shelters and mainstream palliative services, are not well equipped to deal with this population’s palliative needs, lacking necessary training and flexibility.<sup>14-17</sup> It has been suggested that training is needed in the areas of addictions, mental health and principles of palliative care.<sup>14,18</sup> Service providers also need to learn to talk comfortably about death.<sup>16</sup> In addition, evidence-based practices, such as harm reduction are still not accepted and/or not understood by the majority of service providers, creating large barriers for service delivery.<sup>16,19,20,21</sup> Finally, the provision of palliative care services for people who are homeless is severely limited by the availability of professionals offering services to this population or even offering the opportunity to complete an advance care directive.<sup>12,22</sup>
- *Feelings of people experiencing homelessness* – The very limited literature available on the palliative services perspectives of people experiencing homelessness suggests that this population can have feelings of distrust of health and social services, including palliative care and end of life services. Previous poor experiences with the system, mental illness, substance use, among other factors associated with the experience of being homeless, contributes to the development of relationship barriers with health care and social service providers.<sup>12- 16,22</sup> Previous experiences with death were negatively associated with interactions with the health care system.<sup>23</sup> Some people experiencing homelessness fear services will be withheld from them at end of life<sup>12</sup> and others internalize discrimination and feel unworthy of receiving services.<sup>14</sup> People experiencing homelessness, like most people, want to die how they lived, even if this means living on the streets or in shelters.<sup>9,12</sup> Still, they fear dying alone or anonymously, and worry about what will happen to their physical body after death.<sup>13, 15</sup> They can feel abandoned by their family, friends, and society.<sup>13,23</sup>
- *Palliative care delivery challenges* – Regular challenges for the provision of palliative care become accentuated when dealing with the homeless population. Known palliative wishes such as ‘dying at home’ and ‘dying how you lived’ might mean dying on the streets. Palliative care strategies need to adapt to this reality and provide services where needed.<sup>12,15</sup> Shelters are also where many people stay long-term, but they are ill-equipped to deal with palliative care needs, lacking training, dedicated resources, and an overall palliative care plan.<sup>16,19</sup> Histories of substance use and lives that

make it difficult to establish routines can also get in the way of pain management. Doctors fear prescribing pain relief medicine due to high opioid tolerance and fear of overdose.<sup>12,14</sup> In addition, disconnect with family members, social isolation, unreliable social/personal connections and lack of social supports makes it difficult for someone who is homeless to have appropriate care giver support for their palliative needs as well as surrogate decision makers.<sup>11,17,19,47</sup> Sometimes it is also difficult for the palliative care professionals to keep track of where their clients are when they do not have a fixed address. People might also have a difficult time attending appointments and staying connected with service providers either in-person or by telephone.<sup>20</sup> Management of the treatment is also a challenge, since many people who are homeless might have a hard time adhering to treatment<sup>12</sup> and some start treatment in a later stage in their disease trajectory.<sup>24</sup>

Each of these circumstances demands special consideration for the provision of palliative care services. It is, however, the combination of these circumstances that highlights the unique inter-related barriers that individuals experiencing homelessness face in order to have their palliative needs appropriately addressed.<sup>16,17</sup> These multidimensional barriers require multidimensional solutions. The next chapter presents what models of care are available in the literature today, as well as principles of palliative care that can guide implementation practices.

# BARRIERS TO ACCESS AND GAPS IN SERVICES FOR PEOPLE WHO ARE HOMELESS\*



\*Based on literature review

### 1.3 DESCRIPTION OF KNOWN PALLIATIVE CARE APPROACHES, MODELS AND PRINCIPLES FOR PEOPLE EXPERIENCING HOMELESSNESS

A literature search on palliative care models for the homeless population was conducted. The literature available on the topic is sparse. The majority of sources lack information on formal palliative care models. We have included a summary of selected palliative care models for the homeless population as well as approaches and principles for offering palliative care services to people who are homeless.

#### SELECTED APPROACHES

- *Shelter-Based Palliative Care Services* – Offering palliative care services in shelters or providing shelter-based hospice care has generated higher levels of satisfaction and lower costs than hospital-based care.<sup>14</sup> Having beds available for homeless patients within palliative care sites has been suggested;<sup>25</sup> however, the necessary types of services are rarely offered since the funding is not intended or adequate for this purpose<sup>12</sup>. Shelter-based low barrier services using harm reduction strategies have been reported as an effective model for delivering palliative care services to this population. It has also been demonstrated that it is beneficial to offer end of life care at Emergency Shelters, Drop-in Shelters, and Harm Reduction sites<sup>14,19</sup>. Some people working in the social services feel that existing services including shelters, drop-in meal programs and harm reduction sites should partner with palliative care services.<sup>19</sup> The relationships developed with the care providers and service workers could facilitate the transition to end of life services.<sup>19,26</sup> Dr. Jeffrey Turnbull from the Ottawa Inner City Health Project feels that, “homeless people have lived outside the mainstream health system their entire lives and to make them live their last days in that system would only add to their suffering.”<sup>22</sup> When describing the shelter-based hospice in Ottawa, Dr. Turnbull explains, “Our hospice is right in the shelter. That’s their home. Most people want to die at home. Why would they think any differently? They want to be among their friends.”<sup>22</sup> An evaluation of the Ottawa hospice during its pilot phase revealed that it was a cost effective model for delivering palliative care to people experiencing homelessness.<sup>27</sup> Indeed, the researchers estimate that using the shelter-based hospice model saved close to \$50,000 per patient on average when compared with the costs of traditional palliative care.<sup>27</sup>
- *Harm Reduction* - The necessity of including harm reduction strategies in palliative care services for people who are homeless is often mentioned.<sup>11,14,15,18,19,27,28</sup> Research has shown that harm reduction protocols improve care for homeless populations during end of life.<sup>19</sup> One strategy for managing alcohol use includes dispensing alcohol to patients on an hourly basis to promote comfort while preventing withdrawal symptoms.<sup>19</sup> Other strategies involve provision of sterile syringes to patients and allowing illicit drug use outside of the institution.<sup>14,19</sup> Offering low barrier harm reduction approaches are felt to lower risks and improve the quality of care as providers have acknowledged that changes during the end of life phase may not be realistic or comfortable for patients.<sup>19</sup> Moreover, harm reduction services have been shown to improve

access to and satisfaction with palliative care for populations that may not find traditional models of care including abstinence and zero tolerance policies suitable.<sup>18,27</sup> Finally, harm reduction services have been the point-of-entry and sole source of care for some homeless individuals to access end of life supports, including pain management and emotional and personal support.<sup>19</sup>

- *Advance Care Planning* - Arguably, advance care planning is the most commonly suggested strategy for care of palliative patients.<sup>11,16,19,29,30</sup> Advance directives are completed less often within people experiencing homelessness,<sup>31</sup> although research has shown that members of the homeless population are willing to participate in advance care planning.<sup>19,32</sup> This is of interest given the distrust that members of the homeless population often feel towards documentation; however, it was felt that being asked about personal preferences is different than completing typical documentation.<sup>32</sup> It has been shown to promote feelings of empowerment and autonomy, and lower feelings of uncertainty, especially in individuals who have been marginalized.<sup>11,31</sup> A study conducted in Toronto, Canada<sup>21</sup>, offered chronically homeless persons participating in programs at a shelter the opportunity to complete an advance directive with a trained counselor. Over 50% of participants in the study completed an advance directive highlighting the willingness of this population to participate. This particular study emphasizes the benefits of using non-health care specialists to engage with this population.<sup>21</sup> Another study in Toronto assessed the value of having a one-on-one counselor session to facilitate completion of the advance directives.<sup>33</sup> The researchers found that offering one-on-one services significantly improved the rate of completion of advance directives when compared with self-administered completion without support.<sup>33</sup> It should also be stated people who are homeless have expressed concerns that their lives are less valued, and so, as a result, health care providers might not go as far to save their lives as they would with others, thus, proper training surrounding advance care planning for homeless individuals has been recommended.<sup>32</sup>
- *Designated Coordinator* - The importance of advocating for people who are homeless was underscored.<sup>15</sup> Having a coordinator within palliative care services who is knowledgeable about engaging with patients who are homeless has been cited as an important aspect in the provision of care for this population.<sup>16,19</sup> An advocate can help patients to navigate the system and access care while respecting their individual needs and mitigating marginalization. Health and social service workers in Canada felt having a third-party patient navigator could bridge the gap in communication with palliative care workers and people who do not have a place to live.<sup>19</sup> It has also been suggested, "Usually, people don't want a system. They want a person that they can call..."<sup>19</sup> The coordinator should offer a patient-centred model of care that focuses on their unique individual needs including cultural sensitivity without judgment.<sup>14</sup> The coordinator would be able to act as a liaison between different sites and services to provide support and training as needed.<sup>25</sup> Many individuals with no place to live lack social support networks. A designated coordinator could act as a substitute decision maker and support.<sup>11</sup> Workers at a hostel for the homeless in the UK felt that the staff at the hostel would be the most suitable people to advocate for people when they require palliative care and also most likely to identify when

palliative care is needed.<sup>34</sup> Also, in the UK, there is a system called Pathway that operates under this model of care.<sup>16</sup> Pathway provides teams of experts (both professionals and by experience) in the care of people who are homeless within hospitals and other organizations to aid in the provision and continuity of care. Although not focused solely on palliative care, the model could be adopted for many types of services, and has been used in palliative care.<sup>16</sup>

- *Tailored Pain Management* - Pain management may need to be approached differently depending on the substance use history of patients.<sup>12,35</sup> Patients who have developed a high tolerance to medications may need higher doses of medications to manage pain effectively. Pain agreements have been recommended.<sup>12</sup> The agreements are agreed upon and signed by the provider and the patient and may include the following components: (a) prescription details including dose, frequency, and when required; (b) refill frequency restrictions; (c) maximum to dispense per term; (d) required follow-up care and check-in details; (e) consequences for missing, lost or stolen medications including; (f) required drug testing; and (g) consequences for breaking the agreement.<sup>12</sup>
- *Tool Kits for Providers* - It may be helpful to offer providers a questionnaire to deliver to patients to inform their practice. The questionnaire would ask questions related to current housing experiences, nutrition needs, how to communicate with the patient (e.g., phone, friends), and financial situation. The results of the questionnaire would inform the providers about the needs and wishes of the patients and how to best offer support.<sup>12</sup> In a UK initiative, a resource pack was created to help hostel staff members identify and address palliative care needs of their clients.<sup>16</sup> Furthermore, Sick Kids Hospital in Toronto has developed a social determinant of health screening tool for palliative care patients.<sup>28</sup>
- *Service Provider Training* - Providing training on the unique needs of homeless patients accessing palliative care is recommended.<sup>15,28</sup> Suggestions for training elements include: (a) complex end of life care needs; (b) harm reduction strategies; (c) how to discuss death and dying appropriately; (d) developing trust between provider and patient; (e) addiction and mental health concerns;<sup>14-16</sup> (f) how to discuss and acknowledge patients' concerns about dying;<sup>12</sup> (g) pain and symptom management;<sup>19</sup> and (h) substance use.<sup>19</sup>

## **PROGRAM EXAMPLES**

### ***Mobile Programs***

- *Palliative Education and Care for the Homeless (PEACH)* - Stakeholders have acknowledged the need for outreach programs to service people who are homeless who require palliative care.<sup>36</sup> The PEACH program in Toronto was developed by the Inner City Health Associates to provide effective mobile palliative care support and education for the homeless population.<sup>37</sup> The PEACH program's objective is to provide a collaborative shared care model among primary care and palliative care. Most referrals come from primary care practitioners and PEACH works closely



with providers and patients to appropriately refer patients to palliative care. PEACH also provides support to palliative care teams to promote and educate about the unique care needs related to the homeless population. This is achieved by providing educational sessions at relevant organizations that deal with end of life care. In addition, PEACH provides educational sessions regarding end of life issues to community agencies that service people who are homeless. The mobile services aim to reach patients in their preferred location, by bringing health care to the community including on the street, or in a shelter.<sup>16,37</sup> They have developed key messages for providers that can be used to facilitate advocacy. A harm reduction approach is utilized, when appropriate. Formal advanced care planning tools are not used, but advanced care planning, including DNR orders and designation of substitute decision makers is often accomplished. The PEACH program attributes its effectiveness in part to many partnerships in the community including the CCAC, Hospice Toronto, shelters and palliative care organizations.<sup>35</sup>

- *The Calgary Allied Mobile Palliative Program (CAMPP)* – The CAMPP program started in October 2016 and modeled their services after Toronto’s PEACH program. The services are delivered by a two-person team consisting of a physician and a registered nurse. The patients are met in shelters, drop-in centres, on the streets, or wherever the patients prefer. They operate with a harm reduction approach while helping patients manage pain and understand the health care system and services available. In their first few months, the program served more than 30 patients; however, the program needs to find additional funding to be sustainable.<sup>38</sup>

### **Hospice**

- *Ottawa Inner City Health Hospice* - The Ottawa Inner City Health Project set out to conduct a pilot program starting in 2001 to provide palliative care services in a shelter-based setting.<sup>27,30</sup> The hospice was situated within an existing shelter in an area separated from the regular shelter beds. The hospice operates with a shelter-based medical model of care where shelter operators addressed the needs of the patients.<sup>27</sup> Medical care was performed by physicians, nurses, and a client care worker and was available 24 hours per day, 7 days per week. The client care worker’s role involved that of a substitute family member including facilitating continuity of care, escorting to and/or attending medical appointments, helping with daily activities, and accessing services.<sup>27</sup> A harm reduction approach was implemented. Pain and symptom management consults were performed at the hospice by an affiliated specialist physician. Availability and disposal of clean needles was offered, an outdoor smoking area was provided, and measured alcoholic drinks (14 g) were dispensed as requested. Eligibility criteria for the program included chronic homelessness, lack of available caregivers, absence of financial resources, and diagnosis with a life-limiting illness. At the end of the pilot program (in 2003) the researchers concluded that the shelter-based model with harm reduction approach was an effective, and likely cost saving, model for delivering palliative care services to the homeless population.<sup>22,27</sup> Located and operated by the Ottawa Mission, the hospice offers the full spectrum of palliative care services to the homeless population. Volunteers, families, and friends facilitate delivery of care, as needed.

- *Kensington Hospice* – Kensington Hospice operates under a traditional hospice model. They offer a full spectrum of services: pain control, symptom relief, nursing care, social work, therapies, spiritual support and nutritious meals. When Perram House closed in Toronto, Kensington Hospice was re-allocated funds from the Ministry of Health and Long-Term Care.
- *The Inn Between* – The Inn Between opened as a “surrogate home” in Utah in 2015 to provide palliative services to the homeless population. The home has 15 beds and offers refuge to the most vulnerable who have nowhere else to go. A broad range of palliative care services is offered as well as additional supports such as massage, acupuncture, Reiki, and pet and music therapy. The Inn is primarily funded by donations.
- *Joseph’s House* – Located in Washington, Joseph’s House offers hospice services to homeless individuals who have late- or end-stage AIDS or terminal cancer.
- *The Alpha Project* – The Alpha Project Hospice for the Homeless in San Diego provides housing and case management support to people requiring palliative care. The medical and hospice services are provided by a local hospice service.

## **HOSPICE MODELS**

One unpublished source described models of hospices, which are described below.<sup>39</sup> The Inner City Health Associates along with an Advisory Committee comprising key stakeholders from the palliative care and homeless sectors conducted a study to explore the feasibility of implementing a hospice for homeless and vulnerably housed people in the city of Toronto.<sup>39</sup> The hospice models proposed include a stand alone hospice designated for this population; dedicated hospice beds located in a partner hospice; dedicated hospice beds located in a partner facility; a mission; interdependent structural partnership; a network of dedicated hospice beds across the city; and a boarding house. The research team conducted interviews with operating palliative care/hospice providers for insight into existing models. The models described included a community health centre providing palliative services; a surrogate home; a boarding home; stand alone hospice; a mission hospice; a medical respite facility; and rent low-cost apartments. A description of each of the models follows.

- *Stand Alone* – A hospice serving people who are homeless, located in a stand alone building (the whole building is the hospice) that is both managed and operated by one organization.
- *Dedicated Hospice Beds in a Partner Hospice* – An existing stand alone hospice that designates one or more beds for the homeless population, managed and operated by the existing hospice.
- *Dedicated Hospice Beds in a Partner Agency* – An existing partner agency (e.g., shelter, supportive living, long-term care, complex continuing care) that designates one or more beds to providing hospice services for the homeless population. The management is provided by the partner agency or a third party.

- *Mission* – This is similar to the *Dedicated Hospice Beds in a Partner Agency*. The model is based on a mission-based hospice in Ottawa where the mission is managed by a lead agency with multiple partners. It is located in a shelter funded by the City and an Inner City Health team provides health care services. Volunteers, families, and friends facilitate delivery of care, as needed.
- *Interdependent Structural Partnership* – One or more designated hospice beds are located within a partner agency that provides a service. The management is provided by a third party while the operation is provided by a structured partnership between two or more parties.
- *Satellite or Network of Dedicated Beds* – Designated beds are located within a group of facilities across a geographical area. The shared health services are coordinated centrally and independently while travelling to each of the facilities.
- *Boarding House* – A home with beds that can be used as a hospice. Services are provided by home care.
- *Community Health Centre* – Palliative care is provided during clinic visits or home care visits.
- *Surrogate Home* – A designated hospice for the homeless. Basic personal and medical needs are provided by the home as well as home care service providers. The facility operates as a home, for example, meals are served around a dining room table for all to enjoy together.
- *Medical Respite Facility* – Offers respite care for short stays. Does not focus on palliative care.
- *Rent Low-Cost Apartments* – Offers resources to help pay for housing and necessities. Hospice services are offered by home care visits.

A hospice model serving people who are homeless should include chronic disease management models and palliative care models combined. In addition to standard palliative care services, it was recommended that a hospice dedicated to people who are homeless would require a harm reduction approach (and training of staff members to support this), low barrier services, case management, partners to facilitate referrals, and an understanding of the needs of people who experience mental illness and are homeless. The research also gave much consideration to the need for sustainable funding.

## PRINCIPLES

The following principles have been cited as important for inclusion in the palliative model of care.

- Provide **flexibility** in the delivery of the care model, services and sites of care provision.<sup>16,26</sup>
- Incorporate **low barrier services**, including harm reduction strategies. Relinquishing abstinence and zero-tolerance models during end of life care have been shown to be effective for the homeless population.<sup>14,19,26,28</sup>
- **Patient-centred care** geared towards the specialized needs of the homeless: Be flexible and open to the unique needs of this population including what ‘dying the way you live’ might mean to someone who is homeless rather than ‘dying at home’.<sup>15</sup>
- The **setting** of palliative care service delivery should be adaptable depending on the wishes of the individual. These should include hospital-based, shelter-based, and street-based care.<sup>15,35</sup> The offer of these services should also be iterative as an individual’s preferences change.

- It is important to nurture a **trusting relationship between the provider and patient**.<sup>16</sup> This would entail respecting the distinctive and diverse needs of this population. It is especially important to understand that many patients who have been homeless may have had previous negative encounters with health care and may need additional support to develop trusting relationships with health care workers.<sup>12,15,28</sup>
- The homeless population may have less social support than other members of society. When possible, it is important to honour the **relationships with family and friends** that each individual values.<sup>15</sup> Where possible and requested, reuniting patients with family and family should be attempted.<sup>37</sup>

## CHAPTER II - KEY INFORMANT CONSULTATIONS

### 2.1 PALLIATIVE CARE NEEDS OF PEOPLE WHO ARE HOMELESS

Similar to the literature, overall, participants seemed to agree that, in addition to specific needs, the palliative care needs of people who are homeless mirror on a much larger scale many of the same needs of the general population, resulting in a complex challenge that requires multilayered interventions.

*“Whatever we deliver, it needs to be on steroids compared to the mainstream population because at baseline the homeless, their needs are much, much, more.”*

We spoke with leadership and frontline staff at select organizations providing palliative care services to people who are experiencing homelessness. Further work should include perspectives of community service providers and people who are homeless.

#### **Harm Reduction**

- *Harm reduction approaches to care* – harm reduction approaches were one of the most talked about needs for patients who are homeless. As opposed to abstinence-based care, harm reduction approaches were discussed as more realistic and conducive to more successfully engaging and keeping a person in care. Interviewees noted the lack of harm reduction programs across the city and many instances where patients were resistant to care at facilities that did not understand or implement a harm reduction approach. In some examples, patients would be admitted to care but often leave during the day without informing staff. Some interviewees highlighted the need for harm reduction advocacy. Participants discussed the barriers that are created when palliative care services use abstinence based approach. These approaches can easily become inappropriate for people using substances, making the services inaccessible and people less likely to engage. One participant talked about the inability to provide high level palliative care because of addictions and symptom control in more mainstream environments that do not use a harm reduction approach. Another participant discussed the experience of having patients not admitted to palliative care if they were inhaling or injecting illicit drugs.

#### **Engagement with family**

- *Engagement with family and assistance to reconnect* – the desire to reconnect and get in contact with family and friends was expressed by some interviewees as a much greater need in the homeless population compared to other patients. During palliation, patients often need assistance reconnecting with family members and friends that they have not been in contact with for quite some time. This need for assistance can range from having someone inform a loved one about where they are, to actually tracking down someone for them. This work is often done by social workers but can also be taken on by other members within the care team. Additionally, when a patient’s desire is to palliate in a shelter, the shelter tries to accommodate family and friends visiting. In hospices, there are often guest rooms for visitors to stay overnight. In a shelter, it can be difficult to find this space.

## Providers

- *Trust of providers* – distrust of health care providers and the health care system was brought up by many of the interviewees. Past experiences with primary and acute health care can cause people to become distrustful of the health care system. These experiences can impact their engagement with palliative care services. When patients are referred to palliative care – from a primary care provider, allied health professional or even someone in the community – they move from a relationship with someone they trust to a relationship with someone they do not know. This can often be where past negative experiences translate into resistance to care. One interviewee mentioned the need to make many visits and appointments with patients to gain this trust. Once providers earn this trust from patients, it is important that it remain by including those trusted individuals in their care, i.e., ensuring continuity of care when the relationship is working from the perspective of the patient. When patients are referred into palliative care or a hospice, sometimes trusted medical staff are not included in care plans, and the trust is broken.
- *Maintaining relationships with non-palliative care providers when entering care and moving around* – key informants discussed the many social and health service providers often involved in palliative care with people who are homeless. These can be providers that were a part of their lives prior to becoming palliative and also providers involved in their care once they are in a program of palliative care. Interviewees highlighted that in some cases, shelter workers or case managers can be the closest people in the lives of people who are homeless, making them one of the most trusted individuals to a patient. Interviewees stressed how important it was to include providers and staff from social services and primary care, to make sure all those involved in their lives are well informed and aware of the course of care someone is in. Some even pointed out that maintaining such relationships can be quite beneficial to not only engaging patients, but to have them continue in care. When relationships are lost with these individuals once someone is admitted to a hospice or palliative care unit, it can become very confusing for patients and set them back. In addition, it can disrupt a course of treatment when a patient's regular physician is replaced by one at a palliative care facility.

*“They have their own physicians there and we don’t have privileges there so we do not continue to follow them when they go into PCU...that relationship is lost and they have to start all over again. (...) One guy kept calling me, thinking I was going to be able to adjust his medications. And I said ‘I cannot. I don’t have any control anymore over your medications’ and he was really upset. Until he got so sick, we had a plan in place to start him on say methadone or something for his pain and the doctors over there didn’t agree. I don’t know the conversations over there but he thought this plan was in place prior to being accepted into the PCU, so I think that’s very confusing for patients. The plan – what they thought was going to control their pain has now changed. So the continuity is lost for sure. It’s like you’re starting back at square one. Even when we send all our notes, the history and everything that we’ve tried.”*

- *Peer support* – some interviewees mentioned the need for peer support in palliative care for people who are homeless. It was argued that peer support along with case workers, could be more suitable

than volunteers from more mainstream networks. Additionally, one participant talked about the effect of a client's death in a shelter on other clients living there. It was suggested that peer support networks could help with bereavement.

- *More people who are trained and passionate to work with people who are homeless* – along with education on complex needs, many interviewees thought the passion to work with people who are homeless is often needed. One interviewee used examples of losing staff or finding it difficult to assign nurses to people's care when patients appear unappreciative and resistant to care.

*“The client could be verbally abusive or belligerent or just not, sometimes they're not the easiest clients to service. And so keeping staff can be difficult. I think it takes a special kind of person to be able to support clients that are living in poor conditions, and especially when some clients aren't appreciative. And then there are clients that are just not really compliant as well. You make an appointment and then they leave.”*

Many interviewees noted the challenges of following up with patients and staying connected, and argued how this could be very difficult for people who are not used to working with such a mobile population. In some cases, interviewees named individuals who work really well amongst this population and can connect and build those trusting relationships with patients. They spoke about their success with reaching out to patients and engaging them in palliative care. It often seems, however, like there are not enough of these passionate people to work with the population.

- *Provider-provider relationship* – Some participants that refer patients to palliative care environments also discussed the tensions that could occur between primary care providers, palliative care providers and staff in palliative care spaces. At times, there seems to be more of a takeover approach as opposed to a shared-care model where providers can stay involved. Participants cited the negative impact this can have on a patient's experience – including confusion, feeling like they are starting over and losing past progress – but also the tense relationship that can occur when a service or health care provider wants to stay involved but the new palliative care provider takes over.
- *Attitudinal barriers* – during the interviews it was also discussed that some participants have had the experience of encountering providers that 'do not want to deal with this population.' While some providers in the community make efforts to educate health care and service providers about the needs of people who are homeless, there still remains some resistance and lack of acceptance within palliative care services.

*“There are attitudinal barriers and that is one of the challenges with this. On the provider's side and not the social services side. It is challenging population to work with and you need to work differently and the standard kind of model...isn't possible for all of our patients.”*

## Basic supports and health insurance coverage

- *Basic supports and housing for last days of life* – many interviewees noted that palliative care is challenging for people who are homeless because basic supports such as friends and family, as well as housing, are missing. While other patients may choose to palliate at home with the assistance of loved ones and people brought in by the CCAC, those who are homeless often do not have this as an option. For many, their home is the shelter in which they live and it is challenging to provide someone with the care they need in that environment, as often there is not enough staff or private space.
- *OHIP and drug coverage* – having a valid OHIP card, as well as coverage for medication can be a challenge for providing palliative care to people who are homeless. One interviewee spoke about how difficult it is to refer a patient somewhere when they do not have a valid health card or if they are unable to apply for a health card. While some practices have comfort funds to assist people with some of these costs, it was argued that sometimes it feels like they are having to find ‘band aid solutions’ each time this comes up, instead of something more reliable and put in place.

*“We have clients that do not have health insurance. They’re non-status. Some have interim federal health. And those all pose lots of challenges for sure, depending on what their health needs are. We have one client who had, he had an Ostomy and we couldn’t, we had to scrounge for supplies because he couldn’t afford it himself...sometimes it’s just like you have to, or the medications not covered so you have to find somebody who will cover the medication ... It’s always like you’re scrounging to solve – it’s like little band aid solutions.”*

- It has left some providers feeling as though they are constantly using time and resources just to navigate and advocate for more resources.

## Admission criteria

- *Flexible admission criteria* – many interviewees brought up the need for flexible admission criteria when providing palliative care services to people who are homeless. When considering the illnesses and comorbidities often diagnosed amongst people who are homeless, interviewees argued that prognosis is often unclear and disease trajectories are nonlinear. This can prevent people from getting admitted to palliative care services, as well as end of life/hospice care. Often guidelines are too rigid for this population even when their high symptom burden would benefit from a palliative care approach. Additionally, sometimes it is difficult to have a diagnosis for the patients. One participant talked about how people with chronic diseases are not being accepted at palliative care units because their prognosis is not quite as clear but it is also too unsafe for them to be on their own. Some participants argued that people can often ‘fall in the middle’ where they are not quite ready for end of life care (e.g. prognosis of more than three to six months) but too ill to stay in the shelter and receive the care they need. When patients become bed bound it is difficult for them to stay in a shelter, as the shelter may not be able to provide a private space or requires clients to



leave during the day. Furthermore, once admitted, when patients are admitted and make improvements, they may be considered inappropriate for palliative care units or hospice care and thus discharged.

*“[It is] very challenging because a lot of these clients do not have a clear diagnosis. A lot of them are not diagnosed, do not want to go to hospital, do not want to do scans. So you have nothing on paper to say they’re palliative and you base it on their functional decline. So [there are] a lot of the barriers for clients to get into general stream, because you need the diagnosis, you need all the tests to support it and without it they don’t get accepted in places.”*

In this population, a discharge could mean back to the street or to a shelter where they can become disengaged with health care services and their health worsens. What is needed, are more palliative care spaces that can accept patients that seem to fall between being able to stay in the shelter and having a prognosis to be admitted to a palliative care unit. Additionally, accommodations of longer stays once admitted should be incorporated into policies.

## **Shelter**

- *Palliating in shelters* – participants also discussed that shelters often end up being places where people spend end of life. Some *choose* to palliate there because that is the environment they feel most comfortable, others stay there while waiting for admittance into hospice or palliative care unit, and when people refuse admittance elsewhere they may sometimes stay at the shelter and receive care only from their primary care provider. Interviewees seemed to agree that often shelters are neither an appropriate place to palliate nor are they set up for end of life care. One issue discussed was the lack of space to allow patients more privacy. When patients choose to spend end of life in a shelter, it is not always possible to move them to a private space – either because one does not exist or one is not available – so sometimes they have to palliate with others. Unlike health care spaces, it is not possible to have a private washroom or areas for family to visit. As most shelters operate at capacity or close to capacity, this can often pose challenges for the patient, staff and other clients as well. During end of life, people are often bed bound and for some shelters where clients have to leave during the day, this does not appear to work. Additionally, it was discussed that it is a lot to ask of a shelter to accept a planned death and there are few that will.

*“As soon as someone couldn’t get up and get out of their room for the day, they weren’t appropriate for the shelter anymore. (...) They were uncomfortable with patients being there during the day and so they would want them to go into somewhere sooner and they may not be eligible for palliative care units at that point. And a lot of the time, patients do not want to go yet. They want to remain a bit independent. But they were kind of on that cusp.”*

Overall, what seemed to be the most agreed upon point about shelters is that they are not set up – by way of staff and space – to provide palliative care. There needs to be places to lock up medication, and there also needs to be on-site nurses and medical staff that are comfortable to

administer the medication 24 hours a day. Some participants discussed the challenge of sending in medical staff to shelters, especially during the night where shelters are usually located in 'no go zones'. If a shelter has nursing staff, they are usually only there until 10pm. This means during the night there is no one available to dispense medication, and it is a safety risk to ask patients to hold onto it themselves. Aside from medical needs, there is also an increased demand on staff to provide more services and to do so more frequently. Participants spoke about the added strain on shelter staff to either operate in roles outside of their responsibilities or to increase their tasks (e.g. cleaning beds) during an already full schedule. Moreover, not all staff have been trained in mental health, addictions and harm reduction policies.

## **Hospice**

- *Hospice Environments* –hospice environments can sometimes be inappropriate spaces for people who are homeless. As already presented, hospice environments are not always able to care for pain management needs alongside substance use, or to even use a harm reduction approach instead of abstinence based policies. In other experiences, the aesthetic of the environment can make people uncomfortable. In the interviews, participants also mentioned that some patients who are homeless may feel 'unworthy' of the attention they are now receiving during end of life. The rules of hospices may also not be in line with what a patient wants (e.g. substance use, entry policies) and this can lead to resistance. Participants also recognized that diagnoses among people that they are trying to get into hospices are different from what these places are used to and it can often take a lot of advocating to convince them to accept the patients. These are diseases that are nonlinear where patients may be admitted, get better and then leave. Hospices, at times, do not seem to have the flexibility to accept these cases. Participants also talked about the low awareness of palliative care services and hospices within the community. Organizations and service providers are often able to connect people with palliative care services. When people who are homeless are not regularly connected to services or community centres, they have a decreased awareness of palliative care services and are less likely to engage. Interviewees talked about the need for more awareness of these services among people who are homeless, so people are more familiar with what is available when they move closer to that stage in their health. It was suggested that when a person who is homeless becomes palliative, it is often their first direct experience with palliative care and/or the hospice environment, making that initial introduction to care that much more challenging. Introductions to palliative care and the hospice environment prior to patients becoming palliative or in crisis can have some benefit to easing the transition.

## **Preparation for palliative care**

- *Individual preparedness for end of life planning and care* – key informants discussed the variation in their experiences of how prepared people are for accepting and thinking about end of life care. Some suggested that they are more prepared than one would expect. It was discussed that some people who are homeless appear to be more realistic around end of life because of choices they have made in the past, that they know what they want and that they have even thought about it

before. In certain cases, this can lead to a better transition into end of life care. For the most part, however, participants felt that people who are homeless are often not prepared for end of life care and planning. One participant argued that so many people are used to living with chronic health conditions and comorbidities, that they are often in and out of the hospital for episodic care. When people go to a hospital and are told they can no longer be treated and are introduced to palliative care, it can be very difficult for them to accept.

*“Because this population has so many comorbidities and is quite ill. It may not be a chronic thing sometimes...but they’re used to going to the hospital very sick and getting better and coming home. So they don’t really understand, they’re not really accepting that they’re not going to get better this time. There was one guy I was following, he wouldn’t even go to the ICU because he was so hopeful that he would get better. So it was difficult to perhaps plan for him.”*

*“Perhaps it’s a coping mechanism to never come to the realization that they’re dying. There’s such a survivorship mode that people who are living life on the streets engage in, that in reality, the realization that they’re dying is equated to giving up. It’s a coping mechanism.”*

Another participant argued that often patients lack basic information about their disease and its trajectory. With COPD and heart failure, patients experience many episodes and plateaus in their disease, that when it comes to being told they are palliative, it is difficult to accept. People who are homeless are often already living in a survivorship mode, to accept end of life care can be seen as giving up.

- *Awareness of palliative care approach* – it was discussed amongst participants that there is some lack of awareness around the palliative care approach and therefore misconceptions about what palliative care provides. Coupled with poor knowledge of their illnesses, this can lead people who are homeless to not explore or engage with palliative care as they do not understand what is available to them or how they can benefit from end of life care. One participant discussed that there is some stigma around palliative care amongst social services and the homeless population. Furthermore, how the palliative care approach fits with other medical approaches was seen as a barrier to successful care relationships between providers. One participant highlighted the need for additional psychiatric services in palliative care for people who are homeless. When these services are paired together, however, some conflict can arise between patients and providers, as well as between the providers themselves. The participant explained that by contrast, a psychiatric approach involves more tests, while palliative care can focus more on pain management. This can create disagreement amongst the providers, but also resistance from the patient who is now moving into a different form of care. During the interviews participants also brought up the need for more education around illnesses and palliative care. Some found that people who are homeless often lack a basic understanding of their illness and what palliative care provides. It was argued that more targeted education could clarify misconceptions about palliative care and disease trajectories.

- *Coming to palliative care late in the disease trajectory* – many participants believed one of the largest barriers to people not receiving high quality palliative care was that they were not coming to care early enough. One participant discussed that in her experience some people come within days or even hours of passing. Even with palliative care units having prognosis criteria of three months, some people are identified quite late in their disease trajectory and could have benefited from palliative care a lot earlier. Participants discussed how often people do not have a regular primary care provider and that they can go quite a while without being engaged in palliative care. Some participants highlighted that the average age for someone who is homeless and entering palliative care is a lot younger than the general population. As a result, palliation can be hard to accept amongst this population and can also be less commonly identified.
- *Advance Care Directives* – advance care directives (ACDs) are not in widespread use in the general population, and additional barriers to their completion exist amongst people who are homeless. One interviewee explained that it is difficult to complete these with the resources that are available to them and that earlier engagement with patients (i.e. before they become palliative) are most successful but this is a challenge to do within a population that already does not have good access to health care. In some cases, patients may have already filled out ACDs with health care providers in the community but then the challenge becomes connecting with them and tracking the ACDs down when a patient becomes palliative. In some cases, people do not want to talk about their ACD. While it remains uncommon for people to have these completed, some participants did agree that when they are completed, the care experience is much more pleasant for the patient and less stressful for staff.

## **Communications**

- *Communication and follow-up with patients* – clear and effective communication from diagnosis was discussed by participants as important for this population. Some participants discussed poor communication around disease, treatment and care can lead to a more difficult experience during palliation. Communicating with patients and staying in contact can also be challenging as often they do not have access to a personal phone or ways to be contacted. One participant highlighted that a lot of resources go into following up with patients and trying to reconnect, and the ways in which this can impact appointment attendance and connection to care. There are patients who do not have a power of attorney or someone who can act in that role for them, so shelter staff or case managers who they are close to may act in this role. As a result, keeping in communication with trusted providers becomes important.
- *Coordinating communication among providers* – as important as it is to keep in communication with different health care and service care providers who are involved in someone's life, one participant pointed out that in such provider networks it is not always clear who will take the lead or even who *should* take the lead in keeping everyone informed. This can often lead to breakdowns in communication.

## **Pain management and safety**

- *Pain management plans that recognize alcohol or drug dependence* – pain management plans need to consider any current or past substance use. Past substance use can impact a patient’s pain threshold, requiring a higher dose of pain medication. Pain medication could also compromise recovery or interact with other substances in use. It was expressed that palliative care providers must consider and understand the substances patients have taken in the past or are currently using. This was expressed as essential to both the patient’s safety and their success with care.
- *Safety while on the streets or in shelters and needing narcotics* – the potential risks associated with using of narcotics while living on the street or in community settings was expressed as a reality that should be recognized when implementing a plan for care. Monitoring the intake of medications as well as the high street value of some of them is a reality that care providers should consider when designing a plan for care that is both beneficial to the patient and that takes into consideration the environment in which they live. Interviewees described the challenge of providing such medication to people who really needed it, but knowing they could be taking them in areas that would make them vulnerable to unsafe situations (e.g., have medications stolen from them).

## **Continued support across settings**

- *Consistent and continuous case management* – during interviews, participants also noted the need for more shared care models when caring for people who are homeless. When illnesses have non-linear trajectories or care plans are unsuccessful in engaging patients, people will often need services for when they are, for example, discharged from palliative care units. It is important to know where they are going and to inform other people they are engaged with in social and health services, that they have been discharged.

*“They’re bouncing back and forth between their home and the hospital and for us it’s almost like – of course our goal is to reduce emerge visits - but being able to support them when they’re having these emerge visits, like connecting with physicians in the hospital, building the relationships, so when they do go to hospital the team at the hospital knows that they can call and build that relationship there but it’s definitely very time consuming.”*

- *Assistance to navigate the system and know what is available* – disengagement with health care services and lack of experience often means people who are homeless need assistance to navigate the health care system and to know what health and social services are available for them. Additionally, planning for end of life – a role that others may have their loved ones assist them with – is often taken on by a member of their care team. Some key informants spoke about how often people who are homeless need one-on-one help to navigate the system of health and social services. One participant discussed setting patients up with a social worker to navigate ODSP, make funeral arrangements and help identify a person that can make decisions on their behalf. Many believed with the amount of services and their geographic spread, it can be difficult for people to navigate on their own.

- *Intersection between social services and health services* – a well-recognized area of need was the intersection between social services and health care, when providing palliative care to people who are homeless. While participants discussed examples of where this worked well, they still had the experience of instances where the complexity and range of services was challenging. One participant described how much of a learning curve the whole range of social services can be for health care providers and the need for a better understanding of the social determinants of health, for providers to effectively and appropriately engage with patients.

*“Prognosticating in the homeless population is a lot different than prognosticating in the mainstream population. Education around the social determinants of health, not being housed, mental illness, addictions [can] impact on people’s prognosis. And also at which point you will refer somebody to a palliative care service. That education piece is really important.”*

Many participants spoke about the lack of collaboration or poor communication across settings. For a population that is in need of different community services in their lives, communication across settings is important to delivering high quality palliative care and a positive care experience.

### **Cultural-based approaches**

- *Cultural-based approaches* – interviewees discussed the need for palliative care services that are cultural and/or spiritually based in their approach. One participant identified the need for services that use best practices to deliver care to Indigenous people in Toronto. Other participants brought up the need to tailor palliative care services to incorporate the diversity and spiritual needs of patients.

## 2.2 AREAS OF SUCCESS

- *Mobile services* – the mobility of services to go to where clients are, was discussed as an area of success within the current network of palliative care services for people who are homeless. PEACH and the services provided by the Toronto Central CCAC were often referred to in discussions of what is working well. PEACH, a client-driven, mobile service that goes to the patient’s bedside whether it be in a hospice or a shelter, was often spoken about as a service that reflects the needs of the homeless population. Additionally, meeting clients in non-conventional spaces such as shelters, coffee shops and on the street was also mentioned.
- *Passionate people* – interviewees often mentioned the success in care and engagement when passionate staff and providers are involved. Many talked about the challenges of providing palliative care to people who are homeless, but one aspect that appeared to really make a difference was when people with a passion to work with this population, were involved. In some cases they could be there to act in a supportive role for the patient and in other cases, they could be doing the outreach to engage people. Hospice Toronto volunteers and personal support workers identified through the Toronto Central CCAC were two main examples. Some participants emphasized that even with training, it takes a ‘special person’ to stay a part of someone’s care and make a genuine effort to engage them despite challenging situations. As an example, a participant spoke about a personal support worker who always gets called into Seaton House because of how well they work with the clients there.
- *Collaboration between health care providers and social services* – maintained partnerships between health care providers and social services was also cited by many participants as an area that is working in palliative care provision. When care plans recognize the role of social services and the many people involved in a patient’s life, it can lead to a more realistic and maintained care plan. Partnerships with volunteer networks, shelters, and organizations using trauma-informed approaches were cited as effective ways to engage people in care that suits their needs. One participant emphasized the importance of involving shelter nurses who are often trusted by patients and know their history. Another participant highlighted how important service providers are for remaining in contact with the patients themselves. People may not have friends and family that can be contacted to get to them, but they do have many service providers that are involved in different aspects of their lives.
- *Early identification and referrals outside of the primary care setting* – early identification of patients that could benefit from a palliative care approach, was also discussed throughout the interviews as something that works well. While it does not happen often enough, when it does happen, it seems to have a positive impact on the care experience. PEACH was cited as a key driver of this. PEACH initiatives include education within the community to identify patients earlier and this has led to more referrals. Additionally, referrals to PEACH do not have to come from primary care providers as social workers and emergency departments can also refer patients. Furthermore, PEACH identifies and connects with clients in shelters that otherwise may be identified for palliative care quite late in their disease trajectory.

- *Shared care models* – palliative care environments that are open to a shared care model were also cited by some interviewees as advantageous to a positive care experience for patients that are homeless. Hospices and palliative care units that are flexible and accommodating for providers to still be a part of a patient’s care once they are admitted somewhere, was discussed as a strategy that works well. The former Perram House was often cited as an example of a place that did this well.

*“What worked really well was when we had Perram House as the palliative care unit for downtown. So I admitted my patients there. They were very flexible and so I would continue to follow people and one of our patients ... he wasn’t coping – he had a really bad disease – he wasn’t mobile...Perram House was so flexible. They were very accepting of drug use and alcohol dependency. The nurses would allow for that, to accommodate in any way they could. It was just a great environment. The patient felt very comfortable there. Perhaps other palliative care units if they want to step up and take that on ... that would be helpful”*

- *Shelters* – when discussing shelters, participants did speak about all the great things that they do to accommodate clients who choose to stay there for palliative care. Participants spoke about shelters providing lock boxes for medication and making nursing rooms available for palliative care providers. Also, when possible, blocking off private rooms for clients.

*“There’s a really good nurse at Fred Victor that really knew the patients and had that trust. And so connecting with him and doing that initial visit at least, with him and the patient, worked really well. He would also tell us the best time to schedule, like after breakfast. He knew their schedule. (...) He also was able to secure meds in kind of a lock box in the shared room, so things like that to make sure it’s safe and that the patients get their medications. We’re always worried about people taking them for their street value.”*



## 2.3 FACILITATORS

Participants also talked about existing strategies and methods that act as facilitators for engaging people who are homeless and providing them with palliative care services that meet their needs.

- *Building capacity and relationships with existing teams* – participants discussed the success of developing relationships with case workers and other service providers that the patient knows. Recognition and engagement with these pre-existing relationships in the community can assist with the initial introduction into palliative care and also while a patient is receiving care. One participant explained how palliative care providers come in so late and a person’s disease has already progressed quite a bit. At this point, it is a challenge for people to be compliant with what is recommended, but including someone they trust and have a developed relationship with can often ease this transition for both the patient and provider. The same participant also highlighted the success of this engagement and its impact on care when it happens earlier on, and recommended involvement before the person becomes palliative. Another participant emphasized the need to work collaboratively with social services and create strategic partnerships that challenge organizations to work in ways they have never worked before. This participant also emphasized the important role this can play with continuity across settings by communicating information, plans for care as well as the patient’s goals.

*“Continuity of care across settings is an enabler to make sure this population gets what they need. Like one of the issues is that we do all this work in the community and then they get hospitalized...if someone doesn’t know, they can undo all the work that we’ve done...and the person ends up in the ICU on a vent. So the continuity of the information, the continuity of goals of care conversations – that’s an enabler to make this work...”*

- *Cultural considerations* – another identified facilitator was cultural considerations informing how to approach palliative care with patients. One participant discussed how important it is to understand and recognize the diversity of people who are homeless, and recognize that when engaging them in palliative care.
- *Mobility of services* – many participants talked about the success of PEACH and other services that are mobile. Going to patients, following them between services and meeting outside of health care environments, are strategies that have been successful in not only initially engaging people in care but also keeping them in a care plan. As previously discussed in both the literature and interview data, there are many reasons why people who are homeless do not seek out care or engage with health care environments – mistrust, poor experiences, misconceptions. Participants stressed the impact of services that are flexible and able to put time and resources into following up with patients in the community. Participants believed that the mobility of people who are homeless must be reflected in health care services that seek to engage them. Many participants cited the work PEACH does at Seaton House and other shelters, as well as the work of the Toronto Central CCAC to meet patients outside of hospitals and follow them as they get admitted to different services. It was believed that services should be set up to support people despite where they are.

- *Early engagement* – some participants discussed the benefits of early introductions and education around palliative care. As one participant emphasized, engaging with patients early in their disease, before the palliative stage, can have a positive impact once patients enter the palliative phase of their disease. Outreach to shelters and other areas of the community can give people an early familiarization about the services available to them. Currently the presence of ICHA in Toronto shelters facilitates many early identifications and referrals to palliative care services as providers already working with these clients can build engagement between the population and palliative care services.

*“A key facilitator for access to palliative care for this population, has been the fact that ICHA is already working in the shelter system. This builds engagement, as an outside group of providers is not coming in, and the providers in the shelter/drop-in network are sources of early referral. Otherwise the palliative care providers would have less access to potential patients.”*

- *Time and resources to follow-up* – having both the time and the staff resources to follow-up with patients in all areas of the community, was also noted as a facilitator for palliative care. Some participants discussed how often follow-up communication and finding patients that have disengaged from services can take up a lot of time and staff. While creating networks and relationships helps a great deal with this, it is important to note that more resources are needed for this population than other groups. One participant discussed that even when patients are compliant and stay connected with care, it is important to schedule follow-up face-to-face visits with the patient in their new care environment to keep them engaged.

*“There’s no way to get a hold of them so a lot of resources go into just tracking people down. There are often times when they don’t have phones or they can’t reach out. ... That’s one of the biggest challenges – it’s very time consuming to keep track of them, to support clients and follow them as they’re moving through the community and having some of these resources to be able to support them.”*

- *Low-barrier and adaptive* – overall participants seemed to agree that one of the most important facilitators are services that are low barrier and adaptive to the needs of people who are homeless. Low barrier can take the form of less rigid admittance criteria, harm reduction approaches, geographic location, and flexibility with length of stay, to name a few. One participant highlighted that services should adopt a more broad definition of palliative care, to be adaptive to the health care needs and disease trajectories of people who are homeless. PEACH was cited as an example of a service that effectively does this. PEACH considers the benefits of palliative care for patients earlier on by considering their prognosis for the next year. By contrast, palliative care units and hospices consider prognoses of three months or less, with some adopting criteria of 6 months or less. Using broader definitions and criteria for palliative care and adapting the services to be more accessible and acceptable by people who are homeless, was strongly supported by many participants.

## 2.4 PALLIATIVE CARE SERVICES

### Organizations discussed in the key informant consultations

The key informant consultations also focused on understanding the services that currently exist in Toronto, and how they are delivered to people who are homeless. During the interviews, participants focused on their own organizations as well as the actors and services they commonly engage with to provide care to people who are homeless. During these consultations, we also asked participants to send in documents and reports about other services in the community, regardless of whether they have used them. The description and list we present here is not exhaustive of all the palliative care services in Toronto. Instead, they represent the services our participants provide and are aware of in the city of Toronto. When describing mainstream services, participants put a specific focus on services provided to people who are homeless so these descriptions also do not represent the breadth of services at each place.

Our interviewees described and/or sent descriptions of the following organizations:

- Kensington Hospice – a 10-bed hospice that is a part of Kensington Health. They provide end of life care for adults with a prognosis of three months or less. The hospice has an agreement with the Toronto Central LHIN and CCAC to provide care for people who are marginalized and homeless with a guarantee of up to 25% of occupancy. The proportion of beds that are reserved for people who are homeless often go unused by the population. During the consultation, the hospice reported that they have accepted all applications to date from people who are homeless, and have an effective working relationship with PEACH. Some participants described the hospice as a mainstream service that provides care to people who are homeless and discussed how the service may not always be suitable and accessible because of the environment and policies they have. We also heard from a few participants that they have experienced challenges with accessing beds for their clients at the hospice. The use and possession of illicit substances is prohibited on The Kensington Hospice property, but the hospice is guided by a harm reduction approach. In their *Harm Reduction – Substance Use* policy they state “the care team will explore and offer alternatives to the currently used substances.”
- *Inner City Health Associates (ICHA)* – is a group of physicians and psychiatrists that provide care within the community and go into shelters around the City of Toronto. PEACH is a part of ICHA and formally provides palliative care to patients identified by ICHA physicians.
  - *Palliative Education and Care for the Homeless (PEACH)* - is a mobile service currently made up of one physician and one nurse practitioner. It aims to be a partnership between ICHA and Toronto Central CCAC. It uses intensive case management, an outreach team and functions within a harm reduction model with mental health knowledge. PEACH delivers mobile care to people who are homeless by meeting with them in shelters, hospitals, hospices and other environments. In their first year, PEACH saw 42 patients that ranged in age from 39 to 76, with the average age being 57 years (ICHA 2015). PEACH also provides education and consultation services to providers, to assist them in better understanding palliative care, the needs of the homeless population and early identification of patients.

They work closely with the Toronto Central CCAC to bring together a mobile and interdisciplinary team to meet the palliative care needs of clients who are homeless. PEACH does not use a takeover model. Instead, it aims to use a shared care model where they can work with other physicians to provide palliative care for people who are homeless. PEACH engages with clients to identify their wishes and place them in a space that is in line with their palliative care plans. PEACH often does a lot of advocacy to get patients into services and stays involved in their care when they move into different environments.

- *Inner City Family Health Team (ICFHT)* – is a team of ICHA physicians, psychiatrists and allied health professionals that provide care to current or former Seaton House residents. The ICFHT has physicians and psychiatrists on site at Seaton House and also a clinic on Queen Street East. This team of providers identify patients that are in need of palliative care at Seaton House. During the interviews, some participants talked about the role these primary care physicians play when clients at Seaton House do not want to leave the shelter and/or do not want to enter palliative care. When this happens, the physicians continue to care for the patient and will move them into palliative care if they change their mind. Additionally, there are people at Seaton House who remain there while waiting for a spot elsewhere. The ICFHT also attends to these patients. The ICFHT refers patients to PEACH when they become palliative.
- *The Temmy Latner Centre for Palliative Care* – is a group with the Sinai Health System that provides home based palliative care within the Toronto Central and Central LHINs, by partnering with people at the CCAC to provide home care supports. In the past few years, PEACH has received most of the referrals for people who are homeless. Prior to PEACH, they were often called into shelters to see clients that were palliative. At night, they would experience challenges providing care to patients in shelters, as the shelters were often in ‘no go’ zones. There is always a doctor on-call for patients and families.
- *St. Michael’s Hospital Palliative Care Unit* – is a 10-bed unit where patients have a life expectancy of three months or less. The unit also works as a consult service to assess and implement palliative care services. They also see outpatients in oncology and cardiology. The unit works with PEACH to care for people who are homeless and entering palliative care. This can be people with a high symptom burden who get admitted, attended to and then discharged, or people with a more clear prognosis. The unit engages an interdisciplinary group of professionals to attend to the different physical and psychosocial needs of individuals.
- *Toronto Central Community Care Access Centre (Toronto Central CCAC)* – provides a dedicated resource coordinator to PEACH, amongst many other palliative care services. They can refer patients to PEACH after being contacted by other care providers in the community. The Toronto Central CCAC will meet with clients to see if they are appropriate for palliative care and how they can connect them with supports in the community. They also provide supports to shelters and home based care.
- *LOFT Community Service* – uses a harm reduction model. While it currently does not have any palliative care beds, it does have a range of different supportive housing structures that currently

operate at full capacity. Amongst the large breadth of services they provide to the community, LOFT provides mental health and addictions housing and support for adults. PEACH works with LOFT and has patients throughout the LOFT sites.

- *Toronto Grace Health Centre* –is located in the downtown core and uses a harm reduction approach. They have 119 hospital beds, of which 19 are palliative care beds. They operate at full capacity. They have limited experience with people who are homeless, but do have an agreement with the PEACH program.
- *Rekai Centre at Sherbourne Place* – started a palliative care program in 2010 and provides a breadth of integrated services including pain management. While they have not worked with PEACH, they do have experience working with people who are homeless.

### **Actors and other organizations for collaborations**

Participants also listed out many other organizations and actors with which they collaborate to provide palliative care services to people who are homeless.

During the interviews, we also heard about the following organizations:

- *Casey House*
- *Hospice Toronto*
- *Bridgepoint Health*
- *Dorothy Ley Hospice*
- *Scarborough Health Community*
- *Wellspring*
- *THE GOOD WISHES project*

Participants also talked about the following services that they often work with:

- *Hospital-based palliative care units*
- *Nursing providers*
- *Shelters*
- *Bereavement and grief groups*
- *Funeral Homes*

Overall, participants believed that there were a lack of services that focused *specifically* on people who are homeless. Most services that they use are mainstream organizations that may try to be adaptive and progressive in their views of palliative care. PEACH was the only service that was discussed as providing palliative care to people who are homeless in a focused way.

## 2.5 INTEGRATING AND OPTIMIZING PALLIATIVE CARE SERVICE DELIVERY IN TORONTO

Participants provided much discussion about better integrating and optimizing palliative care service delivery across the continuum of care.

### Improving the continuum of care

- *Big picture thinking* – participants discussed the frequency that people who are homeless engage with health care services for acute care. One provider highlighted how these short and episodic care experiences are often missed opportunities to look at the ‘bigger picture’ and identify other health concerns. The participant spoke about how improvements can be made for providing health care to the homeless population, by using these opportunities to assess beyond the top few concerns a patient presents with. The participant believed that looking beyond what they are presenting with, can often lead to identifying patients that could benefit from a palliative care approach. Attending to acute conditions while also considering the chronic health concerns a patient has, can help improve the quality of care being provided. Additionally, participants thought that palliative care services should consider the ‘big picture’ when admitting patients to hospice and palliative care units. While a patient may not present with a linear disease trajectory and with the possibility of getting better, palliative care environments must be adaptive and flexible to admit patients that may not always follow their guidelines and in the long run would benefit from their services.
- *Early introductions to palliative care and diagnosis* – many participants discussed the importance of introducing palliative care much earlier in someone’s disease trajectory. Acknowledging the disengagement with health care, high symptom burdens, comorbidities and overall challenges to stay in communication, participants believed that providing palliative care to people who are homeless should start much earlier on to ease the transition into palliative care. Additionally, participants stressed how important this is when considering the high symptom burdens, nonlinear disease trajectories and comorbidities experienced by people who are homeless. Their disease burden is often different from the rest of the population, and when considering the barriers to care that they face, efforts to engage earlier in care become important. Many participants discussed caring for patients that came along to palliative care much later than when they could have initially benefitted. This can often be the result of a late diagnosis, lost to follow-up and lack of awareness of available services. Increasing awareness within the community was also something mentioned by participants. One participant discussed how beneficial it would be if her organization did outreach to people who are homeless and went into shelters to talk about their services, instead of PEACH always having to send people to them. She proposed that this may make their services more recognizable, if and when someone gets to a palliative stage.
- *Integrate palliative care into more places* – further discussing the need for earlier identification, many highlighted the different intervening points where a better engagement with palliative care services could happen. Some participants believed that palliative care is not integrated well into a lot of clinics. Liver failure clinics, dialysis clinics and emergency departments were listed as a few examples of places to have conversations with patients about palliative care early on, so they are lot

more prepared when their situations becomes more palliative. Flagging emergency department patients and having resources within the department to assess for their needs and refer to CCAC for care, was also suggested. Some also suggested increasing the resources available to departments that already provide palliative care, emphasizing the larger needs people who are homeless have. One participant discussed providing more social workers or at least flagging patients to receive more support, in oncology departments. It was also suggested that primary care providers should be given the training and resources to take on a larger role. Participants talked about primary care providers needing more education on the specific needs and health concerns of people who are homeless. This was mainly discussed around doing advance care planning in the community, long before entering palliative care or a life threatening illness. It was suggested that primary care providers could do a campaign a few times a year to educate people on advance care planning and have them think about it early on.

- *Recognition and understanding of what home care is for this population* – participant acknowledged that home based palliative care is often what is desired amongst the general population. During the interviews, it was discussed that the system should recognize and accommodate what this means for people who are homeless. Home based care often means mobile palliative care that goes to people in shelters or meets with people in different spots in the community. Just as the current palliative care systems provides home care to others, it must be able to adapt to what ‘home’ is for people who are homeless or have acceptable responses to finding people suitable housing for their end of life care. Furthermore, some discussed the need for more supports in place to ease the transition of people into supportive housing.
- *Shared care model with interdisciplinary teams* – discussion focused on the current success and further need for more shared care in the delivery of palliative care services for people who are homeless. To both maintain the continuity of care and to also grow capacity to reach more people, participants discussed the importance of a shared-care model that engages programs such as PEACH and environments such as palliative care units and hospices to work together. One participant emphasized that it is not possible to take care of everyone within the shelter system and on the streets, but it is also undeniable how important staying involved in their care can be. Other participants talked about the need to maintain care plans, involve people the patient already trusts and to recognize the varying needs that a patient needs a team of people to address. Some participants did recognize the challenge of this, however. As one participant pointed out, many people who are homeless need additional psychiatric services that bring in new care team members. While very much needed, it can still be challenging to align different health care approaches in a shared care model.
- *Communication* – structured partnerships with regular communications about care across different settings was discussed by some participants as a driver to improvement in palliative care service delivery to people who are homeless. It was suggested that monthly rounds with other people within the community could be a good strategy. Structured communication partnerships were also discussed, as it can take a lot of organization and initiative to keep everyone informed in a timely way. While communication amongst individual providers is needed, some participants argued the

need for a much higher level communication structure. Some participants cited the rounds and daily communication strategies they use in their own organizations to keep team members updated, but the need to better facilitate communication outside of the organization was highlighted.

- *Support for palliative care providers and social services staff* – creating networks to better connect and support palliative care providers was also discussed during the interviews. Participants acknowledged the impact this work can have on providers - both in health care and social services – and discussed the need for creating professional networks that can increase communication, education and support of each other. During palliative care and end of life care, providers and staff become very close working with clients and support should be provided when a death occurs.
- *Foster peer support networks* – some discussion happened around the need for peer support networks to support people who are homeless and going through palliative care. One participant discussed the suitability of peer support over mainstream volunteer organizations. Another participant discussed having peers support other shelter clients. As she explained, often deaths at Seaton House can really impact other residents in the shelter.

*“When there’s a death at Seaton House, there’s a ripple effect in that building. We suspect the number of units of alcohol being drunk in their managed alcohol program goes up dramatically when there’s a death on that site. These people are very connected in ways that we don’t fully grasp and understand.”*

- *Bereavement groups* – during the interviews, some participants highlighted the need for more bereavement supports for people who are homeless. As one participant discussed, when someone who is homeless passes away, bereavement services often miss or do not reach out to their friends and others that were close to them. The people who support them can go ignored or unattended and they do not get the same supports other people may get, by way of counseling. Greater consideration needs to be given to their loved ones.
- *Increased awareness and education* – participants agreed that there seemed to be a large range in palliative care education and awareness of services. Discussion about more training and knowledge of services came up often in the interviews. Some participants felt that more is needed around educating community providers about the whole range of palliation and what can be done at each stage. Additionally, a greater awareness around the illnesses and access issues experienced by this population was highlighted. Participants believe that while the services and resources exist, the current education and training of providers and people in the community, is compromising the most optimal utilization of the services to care for those who are homeless. Additionally, some discussed the need for education targeted to the patients so they can have a better understanding of their health and palliative care services.
- *Mobilization of services* – throughout the interviews many participants argued for the mobilization of services. Through experience and networks of colleagues, participants argued that the expectation that people who are homeless will seek out care is unrealistic and at times, not possible. Services like PEACH and the work of the CCAC has shown the impact of engaging patients by going to their communities. Participants recognized the many social and physical barriers that people who



are homeless face when they are in need of palliative care. Mobilizing services to take them outside of the health care environment and to the patients is often what is needed.

- *Funding* – some participants discussed the challenge of funding in palliative care services. One participant highlighted how hospices rely on private donations to fund part of their operation. Historically, these donations can come from family members after a loved one has died. Often these donations do not get made for people who are homeless. Estrangement from family amongst other reasons can often mean these donations are not made. Some participants brought up past hospices that existed and struggled to maintain these donations.
- *Harm reduction approaches* – one of the most discussed topics was the need for more palliative care environments to embrace harm reduction approaches. Participants believed that abstinence based approaches can often make services inaccessible to patients and even unrealistic to their needs. Some participants believed that there still remains a discomfort around harm reduction and that has led some health care organizations to not implement it. The past and current substance use of people who are homeless, must be acknowledged and considered when creating care plans. Harm reduction approaches are needed to not only create palliative care plans, but to also have that initial engagement of people. Many participants felt the lack of harm reduction approaches in palliative care services remains one of the largest barriers in care.
- *Proactive instead of reactive solutions* – while many participants acknowledged that the system makes progress in being adaptive to the needs of people who are homeless, they still believe there is work to be done. As one participant highlighted, it often feels like a system of short and temporary solutions, rather than more permanent structures. Participants found that often the system seems reactive to the needs of people who are homeless, more than they are proactive in planning. This has often left providers feeling like they are scrambling for resources and doing a lot of advocating on an individual level basis.
- *Dedicated hospice in the city of Toronto* – all the interviewees discussed the idea of a dedicated hospice for people who are homeless. In the past, there has been a hospice dedicated to this population but currently there are none in the city of Toronto that are dedicated to people who are homeless. Participants believed that a dedicated hospice can be located in a neighbourhood that is more accepted by this population, and designed closer to environments they are used to. One participant suggested a shelter-based hospice that could be added onto an existing shelter to ease the transition of some clients when they become palliative. Participants also believed that PEACH is missing a destination for end of life that meets this population's needs. A hospice where they can send patients they identify was seen as something that was very much needed, as it is not always possible and appropriate to find them a spot elsewhere in the city.

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