

Palliative care as a public health issue: understanding disparities in access to palliative care for the homeless population living in Toronto, based on a policy analysis

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ABSTRACT

Even in a developed country such as Canada, there are disparities in just access to adequate health care—and, more specifically, palliative care. That inequality is most notable in an underserved group such as the homeless population. Even the word “homeless” has become both a negative descriptor and a stereotype in our society. We posit that the provision of hospice palliative care is structured on several problematic assumptions: an expectation that patients will have an informal support network (family and friends), a stable and secure residence, a predictive terminal illness trajectory, and reasonable access to health care. Those assumptions create structural inequality within the system.

Homeless individuals have considerable experience with death and dying, and qualitative research has shown them to hold the expectation that their death will be both sudden and violent. Here, we look at the current data concerning known disparities in access to good palliative care services experienced by the homeless population, based on a stakeholder analysis of the available literature. That information, coupled with the use of a public health ethics decision-making tool, such as the Good Decision Making in Real Time framework, is used to explore the common ethics challenges that can arise in public health interventions aimed at the provision of end-of-life care to homeless adults. A broad exploration of the system that underlies our care is critical to the proper and appropriate provision of care for homeless individuals.

Key Words Homelessness, end of life, palliative care, health care disparities

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INTRODUCTION

A growing body of research is identifying the disparities that currently exist in access to adequate health care in general and, more specifically, to palliative care by individuals who are considered homeless¹. Even in a developed country such as Canada, a person's housing status can predetermine not only the degree to which they are treated with respect and dignity, but also their access to basic health care services¹. Regrettably, the word “homeless” has become both a negative descriptor and a stereotype in our society².

Palliative care—defined by the World Health Organization 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”³—is care that should be accessible to all despite social or socioeconomic status. Some authors have

argued that palliative care is a human right⁴; however, the underpinning of the modern palliative care movement is structured on several problematic assumptions: an expectation that patients will have an informal support network (family and friends) and a stable and secure residence, and that access to health care is free of financial and other barriers through the provision of publicly funded health services⁵. It is the premise of this paper that those assumptions fuel the existence of a fundamental structural inequality within our current system. By “structural inequality,” we mean that the system is designed in such a way that a certain category of people (in this case homeless people) are consequentially afforded an unequal status in relation to others in the form of both rights and opportunities⁶.

Here, we use policy analysis to look at current data from the available literature about the known disparities in access to palliative care services experienced by the homeless population. That information, coupled with the

use of a public health ethics decision-making tool, such as Good Decision Making in Real Time framework⁷, is used to explore the common ethics challenges that can arise in public health interventions that aim to provide palliative care to homeless adults.

Not surprisingly, given their challenging life environment in the shelter system and on the streets, many homeless people have considerable experience with death and dying⁵. Regrettably, reports based on qualitative research studies in this population have shown that many homeless men and women expect their own death experiences to be both sudden and violent¹. We remain optimistic that a broad critical exploration of the system will allow for appropriate upstream changes to improve equitable access to supportive palliative care for this marginalized population.

Definitions

Policy Analysis

Though not meant to be exhaustive or comprehensive, the present analysis involves a review of past reports, research findings, and policy proposals, and attempts to generate a narrow and goal-focused set of opportunities, recommendations, and strategies to address the issue of the disparities that exist in palliative care for homeless people.

After a review of the literature, the most significant documents at the core of our analysis are *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnerships and Commitment to Actions*⁸ (published in 2012, this report represents the collaborative effort of more than 80 stakeholders from across Ontario) and *An Overview of Compassionate Communities in England*⁹ (published in 2013). Together, those documents outline a global and local vision for shaping the future of palliative care, potentially affecting service delivery to the homeless population in very significant and different ways.

Disparity

“Disparity” is defined as a “lack of similarity or equality; inequality; difference or the condition or fact of being unequal”¹⁰. Braveman described health disparity as “a particular type of potentially avoidable difference in health or in important influences on health that can be shaped by policies; it is a difference in which a disadvantaged social group or groups experience worse health or greater health risks than the most advantaged social groups”¹¹. In that context, health disparity here refers to the lack of access that homeless people have to palliative care.

Homelessness

Homelessness in Canada is defined by the Canadian Observatory on Homelessness as “the situation of an individual or family without stable, permanent, appropriate housing, or the immediate prospect, means and ability of acquiring it. The etiology of homelessness is complex and multifaceted. Typically it stems from both systemic and societal barriers such as a basic lack of affordable and appropriate housing; individuals and households living below the poverty line; a constellation of either mental, cognitive, behavioural or physical challenges; and/or racism and discrimination”¹².

Quantifying the Problem: Demographic and Epidemiologic Data

In 2013, a census identified the total homeless population in Toronto, Ontario, at approximately 5220. Of that total, 8% (447 individuals) were found living “rough” (on the street), and 76% were living in city-administered shelters. Given a total population of 2,615,056, homeless people in Toronto account for approximately 0.2% of the population¹³. Meanwhile, in 2010, the Centre for Research on Inner City Health at St. Michael’s Hospital completed the health and housing in transition study, which showed that, for every homeless individual in the city, 23 individuals are vulnerably housed—that is, they spend more than 50% of their income on rent, live in poor conditions, or have only episodic housing stability. The vulnerably housed population was found to have a disease prevalence similar to that seen in people who were defined as homeless¹⁴.

It has been reported that between 50% and 57% of homeless people have a serious diagnosable mental illness, 80% of whom go untreated⁵. In addition to mental health issues, 62% have addictions to alcohol, and 58%, to other forms of drugs¹. Homeless men have a life expectancy of only 42–52 years, and their mortality rate is 3–4 times the national average^{1,2}. Given the high mortality rate in the population, it is not surprising that only 2%–28% of homeless individuals are elderly (65 years of age and older)⁵. A study published in 2000 identified, for men using the shelter system in Toronto, the following mortality ratios (mortality rate for homeless men divided by the mortality rate for the general population) by age group: 8.3 for men 18–24 years of age; 3.7 for men 25–44 years of age; and 2.3 for men 45–64 years of age¹⁵.

A recent report noted that upward of 50% of homeless people do not have a primary care physician, which results in a higher use of hospital emergency departments as the primary care location for this population¹⁶. It was noted that acute health care utilization for homeless people can be 3–4 times that of the general population, with visits by homeless individuals to the emergency department accounting for 25% of the total volume in some large urban centres. In addition, patients defined as homeless will typically have a 36% longer length of stay because of a lack of the social supports and safe housing that could normally expedite discharge¹.

Although vulnerably housed and homeless individuals have been identified as representing only 0.2% of the total urban population in Toronto, the current precarious economic situation in Canada’s largest city could result in a sudden increase in those populations at any time. A recent survey noted that apartment vacancy rates are only 1.8% and that individual income assistance programs were averaging \$656 per month when the average apartment rental is \$1028, indicating that many people are currently living in at-risk conditions. In 2014, only 94,520 public and subsidized units existed, and the wait list for such accommodation had reached 77,150 people¹³.

POLICY ANALYSIS

A Vision for the Future of Palliative Care

The key stakeholder document for a provincial strategy on the future of palliative care was the product of a provincial

declaration of partnership and commitment to action struck in 2011 under the auspices of both the local health integration networks and the Quality Hospice Palliative Care Coalition of Ontario. The final product was the report *Advancing High Quality, High Value Palliative Care in Ontario*, which calls for a broad-scope strategy for the targeted delivery of palliative care that is person-centred; integrated at the clinical, organizational, and overall system level; and delivered by a multi-professional team skilled in all aspects of palliative care⁸. It is important to note that, of the more than 80 stakeholders engaged in the creation of the report, none distinctively represented the homeless population or services speaking on behalf of low-socioeconomic-status individuals⁸.

Three locations in the text of the report speak directly to the needs of the homeless population. The first talks about the provision of equitable access for all populations—most notably, in developing ways to identify people from the homeless community who could benefit from palliative services, but who are not currently identified as having that need. That measure was to be tackled by further stakeholder engagement with the Quality End-of-Life Care Coalition of Canada and the Vulnerable Persons Network of researchers in Manitoba. The Vulnerable Persons Network published a report making recommendations for system design and care settings that involved consideration for homeless shelters. In addition, the Vulnerable Persons Network report advocated providing improved responses for all marginalized populations. However, it was interesting to note that in their report, children, disabled people, and veterans were also—in addition to homeless people, those living with mental health and addiction needs, and prisoners—considered to be marginalized populations⁸.

Moral Claims of the Stakeholders

The current vision for the future of palliative care could be myopic when applied to the special needs of homeless individuals.

Underserved populations, such as those who are homeless, are struggling daily with basic care needs that include food insufficiency, exposure, violence, discrimination, and a lack of resources in general². As previously noted, homeless individuals have a heavy disease burden and higher levels of psychiatric conditions and addictions; many are also chronic smokers¹⁷. Any attempt to envision a palliative care service that truly meets a patient-centred philosophy of care will require a re-exploration of known barriers to equitable service provision: exclusionary policies, poor continuity and episodic care, prohibitive low-threshold policies for behaviors and attitudes toward progressive harm-reduction strategies, and ineffective linkages between the various service agencies currently mandated to provide support to the homeless population². In that light, addressing the adoption of harm reduction or identifying that the “street” itself should be added as a potential site for the delivery of palliative care services could be appropriate avenues of exploration to generate sustainable change.

BARRIERS, GAPS, AND CHALLENGES

Impaired Trust and Individual Respect

Mistrust is a significant and often silent barrier to improving palliative and end-of-life care for those who experience

homelessness. The daily lived experience of many homeless individuals is filled with exposure to social discrimination, stigmatization, and poor access to support services and health care^{1,2,18}. Many people who are homeless have developed an inherent distrust of most authority-based institutions, and the health care system is not an exception^{5,17}. Reciprocally, the current literature shows that health care providers can at times share that same distrust toward underserved populations¹.

The ongoing experience of what some have called “minority stress”—described as chronically high levels of stress faced by members of stigmatized minority groups—enhances a sense of vulnerability and a perception that no one is advocating on behalf of their group, which in turns leads to isolation that further impedes the ability to extend trust¹.

The effect of a lack in basic trust has distinct implications for access to palliative care. Trust is a cornerstone of good pain management. Physicians who do not believe or trust in the reports of pain and symptom distress will be unable to properly provide palliation in the spirit in which it was intended¹. The prior negative experiences of homeless people with the health care system¹⁹ has led them to believe that appropriate treatments are being withheld from them, and in compensation, they ask for more aggressive care. In one study, cardiopulmonary resuscitation was noted to be requested more frequently by homeless individuals than by others^{1,5}. Moreover, when asked about their wishes to forgo life-sustaining treatments in various scenarios, only 37% of homeless individuals said that they would if in coma, and 31%, if they were dying—which compares with 78% and 94% respectively in a general population²⁰.

Justice: When the Palliative Care System Is the Problem

Currently in Canada, palliative care services are generally underdeveloped. It is estimated that, of the general population, only 16%–30% receive palliative care near the end of life. Undoubtedly, increasing overall access to palliative care will also increase support to homeless people². However, assumptions about patients by the palliative care delivery system—such as having a home, family supports, and money for ancillary care needs—will continue to act as barriers². Currently, the palliative care system continues to be challenged by suggestions of those middle-class underpinnings¹⁸. Similarly, many in the palliative care community champion death at home and provide services structured to limit access to homeless people (abstinence policies and so on)², which is structurally a challenge for that population.

Palliative Care As a Public Health Issue: Necessity, Proportionality, and Least Infringement

Our next assessment looks at the work being accomplished by Public Health Palliative Care International⁹, a collaborative that was inaugurated in 2013 after the 3rd International Conference on Public Health and Palliative Care, when a subgroup of delegates unanimously decided that there was a need for an association to communicate the importance of public health ideas and approaches in palliative care at a global level. The group has worked to instill the core

functions of public health into palliative care practices—namely, health promotion, health protection, disease and injury prevention, population health assessment, surveillance, and emergency preparedness through research, education, and international collaboration⁹.

When looking at an issue such as palliative care for the homeless population, the single fact that the average lifespan of a homeless person is only between 42 and 52 years speaks to a greater need for health care beyond just end of life¹. The value of a public health approach to palliative care is its focus on both prevention and protection.

OVERCOMING BARRIERS: PROMISING MODELS AND SUPPORTIVE RESEARCH

The public health approach advocated by Public Health Palliative Care International advocates a health promotion strategy that supports a harm reduction philosophy (which is identified as critical in supporting the homeless population) and a commitment to community development, partnerships, and participatory relations, with an ecologic and setting emphasis concerning when and how care is delivered⁹. Caring communities can be created from supports currently in place: shelters, soup kitchens, out-of-the-cold programs, the Ontario Disability Support Program, needle exchanges, drop-ins, emergency departments, street-involved agencies and supports, and religious groups².

One retrospective Canadian study reported promising outcomes from a shelter-based palliative care model operating in Ottawa, Ontario²¹. The study looked at the experiences of 28 patients who died while receiving palliative care at the hostel over a 2-year period. Significantly, the mean age in the cohort was 49 years, and the primary diagnoses were liver disease (43%), HIV/AIDS (25%), and malignancy (25%). In review, 82% of the patients had addictions to either drugs or alcohol, and mental illness, and 71% required continuous opiate administration to properly manage pain. The average length of stay was 120 days, and the predicted cost savings of the project was estimated to be \$1.39 million, based on a comparative acute hospitalization equivalent²¹.

The Ottawa study confirmed that homeless people who are dying deal with an extremely high burden of illness in the end stages of their disease and that their care needs in the shelter were at times as extensive and demanding as those offered in general institutional or tertiary care settings. Harm-reduction practices, boundary setting, and patient contracting were some of the elements required to support other hostel residents and to keep staff safe²¹.

In similar settings, success in dealing with complex pain management issues when trust is lacking was facilitated with thorough multi-professional assessments and approaches¹. It has been shown that, in working with a homeless population, intensive case management approaches are critical because each case is unique and complex^{2,5}.

Programs offering evidence of reduced risk and harms have identified a need for supervised drug consumption services², enhanced cultural competence training to all palliative care staff involved², and a recognition that staff working regularly with people who are homeless do not have experience or training in end-of-life issues^{5,16}.

A paucity of research data adds additional challenges when considering programs to provide hospice care to individuals living on the streets, where issues such as theft, refrigeration, safekeeping of narcotics, lack of access to power, and basic sanitation are daily realities⁵.

The use of advance care planning in the homeless population has been explored in a few studies; however, because of a discomfort with the topic and what has been characterized as a “trust in God” approach to life, completion rates for an advance care plan have been found to be lower in homeless individuals than in the general population—unless specific support is provided^{5,19}.

One study found that only 60% of homeless people have some limited contact with family. However, when in hospital and incapable, they are frequently unbefriended and must rely on a physician’s interpretation of their best medical interest for decision-making. Given that situation, it is posited that some potential exists for advance care planning in this group⁵.

SUMMARY

As it stands, the health care system involved in the delivery of palliative care services is ill-equipped to provide equitable palliative care for homeless people¹⁷. To come close to meeting the standards of equitable access to palliative care, system-wide structural changes to effectively remove barriers and to add the necessary services in the right places are needed². Using a policy and ethics analysis, the present paper identified how the current palliative care system is structurally unable to meet the complex needs of the homeless population. In advocating for a public health approach to improve palliative care delivery, this paper illustrates the ethical need for health prevention and promotion to be developed hand-in-hand with good palliative care. Care integration and partnerships with homeless shelters and various service providers are crucial in bringing palliative care services to the places where homeless people feel most comfortable—in their home communities, as defined by them¹⁷.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology*’s policy on disclosing conflicts of interest, and we declare that we have none.

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