McMaster University | HEALTH FORUM

Appendices for Rapid Evidence Profile #29

(31 March 2022)

Appendix 1: Methodological details

We use a standard protocol for preparing rapid evidence profiles (REP) to ensure that our approach to identifying research evidence as well as experiences from Canadian provinces and territories are as systematic and transparent as possible in the time we were given to prepare the profile.

Identifying research evidence

For this REP, we identified full systematic reviews and single studies from searches of the following evidence sources:

1. ACCESSSS;
2. HealthEvidence;
3. Health Systems Evidence;
4. Social Systems Evidence;
5. the COVID-END inventory of best evidence syntheses; and
6. PubMed.

In ACCESSSS we searched for relevant documents using the following terms: (homeless* OR hous*) AND (palliative OR hospice OR end-of-life OR end of life). In HealthEvidence we searched using the following combination of terms: (homeless* OR hous*) AND (palliative OR hospice OR end-of-life OR end of life). In Health Systems Evidence, we searched for overviews of systematic reviews, systematic reviews of effects and systematic reviews addressing other questions using the following terms in the open search: (homeless* OR hous*) AND (palliative OR hospice OR end-of-life OR end of life). In Social Systems Evidence we searched for overviews of systematic reviews, systematic reviews of effects and systematic reviews addressing other questions using the following terms in the open search: (homeless) AND (palliative OR hospice OR end-of-life OR end of life) AND care. In the COVID-END inventory of best evidence syntheses we searched for: (homeless*) AND (palliative OR hospice OR end-of-life OR end of life) AND care. Lastly, in PubMed we searched using the filters for reviews and systematic reviews using the following terms: (homeless*) AND (palliative OR hospice OR end-of-life OR end of life).

Search results were screened by one team member for relevant documents. A final inclusion assessment is performed both by the person who did the initial screening and the lead author of the rapid evidence profile, with disagreements resolved by consensus or with the input of a third reviewer on the team. The team uses a dedicated virtual channel to discuss and iteratively refine inclusion/exclusion criteria throughout the process, which provides a running list of considerations that all members can consult during the first stages of assessment.

During this process we include published, pre-print and grey literature. We do not exclude documents based on the language of a document. However, we are not able to extract key findings from documents that are written in languages other than Chinese, English, French or Spanish. We provide any documents that do not have content available in these languages in an appendix containing documents excluded at the final stages of reviewing.

Identifying experiences from Canadian provinces and territories

For each REP we search several sources to identify experiences. This includes government-response trackers that document national responses to the pandemic, as well as relevant government and ministry websites. For example, we search websites from relevant federal and provincial governments, ministries and agencies (e.g., Public Health Agency of Canada).

While we do not exclude countries based on language, where information is not available through the government-response trackers, we are unable to extract information about countries that do not use English, Chinese, French or Spanish as an official language.

Assessing relevance and quality of evidence

We assess the relevance of each included evidence document as being of high, moderate or low relevance to the question. We then use a colour gradient to reflect high (darkest blue) to low (lightest blue) relevance.

If we had found guidelines, two reviewers would have independently appraised the quality of the guidelines we identified as being highly relevant using AGREE II. We used three domains in the tool (stakeholder involvement, rigour of development and editorial independence) and classified guidelines as high quality if they were scored as 60% or higher across each of these domains.

Two reviewers independently appraise the methodological quality of systematic reviews and rapid reviews that are deemed to be highly relevant. Disagreements are resolved by consensus with a third reviewer if needed. AMSTAR rates overall methodological quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. High-quality reviews are those with scores of eight or higher out of a possible 11, medium-quality reviews are those with scores between four and seven, and low-quality reviews are those with scores less than four. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to health-system arrangements or to economic and social responses to COVID-19. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered 'high scores.' A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8.

Preparing the profile

Each included document is hyperlinked to its original source to facilitate easy retrieval. For all included guidelines, systematic reviews, rapid reviews and single studies (when included), we prepare a small number of bullet points that provide a brief summary of the key findings, which are used to summarize key messages in the text. Protocols and titles/questions have their titles hyperlinked given that findings are not yet available. We then draft a brief summary that highlights the total number of different types of highly relevant documents identified (organized by document), as well as their key findings, date of last search (or date last updated or published), and methodological quality.

Appendix 2: Key findings from evidence documents that address the question, organized by document type and sorted by relevance to the question and COVID-19

Type of document	Relevance to question	Key findings	Recency or status
Guidelines	None identified		
Full systematic reviews	• Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) ○ Those at risk for homelessness (e.g., those in precarious housing situations) • Who is involved in providing palliative care? ○ Social workers ○ Peer workers ○ Community or outreach workers • Where is palliative care provided? ○ Shelter ○ Mobile or community-based • What implementation barriers and enablers need to be considered or addressed? ○ For those accessing palliative care ○ For organizations or systems to create new or enhance existing programs	• This review identified 11 descriptive themes related to palliative care for homeless and vulnerably housed people; three of these were identified as core themes • The first core theme identified was experiences, beliefs and wishes ○ Homeless people were found to hold strong beliefs about what makes a 'good' or 'bad' death due to their exposure to and experiences with deaths ○ Homeless and vulnerably housed people were found to perceive end-of-life care services to provide sufficient choice and dignity around death ○ This review identified challenges in advance directives and advance care planning for homeless and vulnerably housed people, and suggested further research to better understand and adapt advance directives and advance care planning to these populations • The second identified core theme was relationships ○ Homeless and vulnerably housed people were identified to have more difficulty building trust in relationships ○ The potential for hostels to provide support to this population was identified, however, limitations exist concerning the type of care that can be provided by hostels ○ Shelter-based care was identified as cost-effective, however, the effectiveness of this is also unclear ○ Those providing palliative care to homeless and vulnerably housed people could learn from the approaches used by services specializing in supporting homeless and vulnerably housed people which commonly offer diverse and judgment-free person-centred care	Published May 2021

		○ A systematic exclusion in accessing care at end of life for this population was identified, as well as a lack of communication between homeless services and healthcare services • The third identified core theme was end-of-life care ○ A need for training for workers providing services to this population was identified to address the complex and changing needs of this population ○ Open communication can allow harm-reduction and shelter outreach workers to better identify social needs of homeless people that need to be addressed, such as housing, food, hygiene and security ○ The harm-reduction approach to manage substance use at end of life could offer benefits to homeless and vulnerably housed people ○ A need for consistent, flexible, multidisciplinary, open, respectful and non-judgmental care was identified at the service-provision level • A need to combine expertise in palliative care, expertise in the care of homeless and vulnerably housed people, and expertise from homeless and vulnerably housed people was identified • Suggested approaches should be considerate and consistent, while bridging gaps in hostels, social, harm-reduction and primary-care services Source (AMSTAR rating 5/9)	
	• Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) • What implementation barriers and enablers need to be considered or addressed? ○ For those accessing palliative care ○ For those providing palliative care	• This scoping review explored the barriers for homeless people in accessing palliative care • Six themes emerged from the 57 relevant articles identified: ○ Characteristics of homeless persons who require end-of-life care ○ Preferences and concerns of homeless persons approaching the end of life ○ The role of spirituality for homeless persons at the end of life ○ Barriers to care at the patient, provider, and institutional or structural levels	Literature last searched March 2018

		○ Inclusive models of palliative care ○ Implications for policy and practice • The review highlights that there is a need to address patient, provider and structural barriers in parallel, and that many obstacles in both the provision and receipt of palliative care must be negotiated by practitioners and homeless persons • There is a lot of potential and opportunity to improve the quality of life at the end of life for this vulnerable population Source (AMSTAR rating 5/9)	
	• Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) • What is included in palliative care models for those who are experiencing or at risk of homelessness? ○ Pain management	• Health and social-care professionals face challenges in meeting the end-of-life needs of people who use substances • Addressing issues like safely prescribing drugs for pain management becomes more difficult in the context of substance use, requiring flexible service provision from both alcohol/substance use services and end of life care providers • The evidence identified from this review were categorized into three broad themes: ○ Pain management ○ Homeless and miscellaneous populations ○ Alcohol-related • There was limited evidence found overall on end-of-life care for people with substance problems • Most studies emphasized the need for comprehensive assessments with clinicians to help people using substances to manage pain, as well as the importance of screening for alcohol problems as substance users may try to compensate for inadequate pain relief at the end of life • The review recommended that models of good practice be developed considering co-existing substance use and end-of-life conditions, and that prevalence studies should be conducted to provide a wider context for policy development • Source (AMSTAR rating 4/9)	Literature last searched August 2017

	• Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) • What are the outcomes? ○ Health related (including quality of life) ○ Patient experience ○ Costs	• There is some evidence that interventions to improve advance care planning, palliative care, and end-of-life care interventions for homeless persons (such as support homes, cost reduction through shelter-based palliative care, and better access via coordination with harm-reduction services) may be effective, but their effectiveness remains uncertain • Advance care planning for this population is feasible and should be encouraged • Continuity of care for homeless individuals may be improved by integrating and coordinating among palliative and homelessness-related services • Interventions should be intensive, comprehensive, and flexible in delivering services to this population • High-quality, rigorous studies of interventions that consider and reflect the unique and complex circumstances of homeless populations, and that investigate patient-related outcomes, caregiver burden, and cost-effectiveness, are needed Source (AMSTAR rating 8/11)	Published February 2017
	• Who is palliative care provided to? ○ People experiencing homelessness • What implementation barriers and enablers need to be considered or addressed? ○ For those accessing palliative care ○ For those providing palliative care ○ For organizations or systems to create new or enhance existing programs	• This systematic review explores the challenges for palliative-care access and delivery to homeless populations, and potential suggestions for facilitating access and delivery • A thematic analysis was conducted to explore similarities, differences, and relationships between studies and to develop an understanding of the perspectives of the homeless populations and the professionals providing support • Some of the challenges to access and provision to palliative care for homeless populations included: ○ Chaotic lifestyles sometimes associated with being homeless ○ Challenges to the delivery of palliative care within a hostel/shelter for homeless people due to inadequate resources	Published December 2016

		○ Lack of and uptake of available palliative-care options in mainstream healthcare for homeless people due to multiple issues, including co-morbidities, substance use, distrust in the health system and health professionals • Obstacles were related to homeless populations' competing day-to-day priorities, the stigma in mainstream settings, the high burden on hostel/shelter staff in supporting residents at the end of life, and inflexibility in mainstream healthcare systems • Suggestions that were identified for improving access to palliative care included: ○ Building trust between homeless persons and health professionals ○ Increasing collaboration between services ○ Providing more training and support for all professionals Source (AMSTAR rating 5/9)	
	• Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) • What implementation barriers and enablers need to be considered or addressed? ○ For those accessing palliative care ○ For those providing palliative care	• Individuals experiencing homelessness often expressed concerns regarding palliative care related to end-of-life care not being a priority, substance dependence hindering adequate care, limited insight into their condition, as well as little support from family and relatives • Barriers and facilitators for palliative care often concerned the attitude of healthcare professionals towards homeless people • Respect, both in approach and for dignity, is important in good-quality palliative care • Overall, a patient-centred, flexible, and low-threshold approach which embodies awareness of the concerns of people experiencing homelessness is needed for appropriate palliative care to be provided in a timely manner • This may be accomplished with the help of training and educating professionals, as well as their experiences Source (AMSTAR rating 9/9)	Literature last searched May 2016

	• Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) • What groups may palliative care need to be tailored to? ○ People with addictions/substance-use issues ○ Veterans	• A high prevalence of tobacco use and respiratory conditions were found in homeless populations • The majority of studies identified in this review investigated the prevalence of respiratory conditions, including COPD, asthma, respiratory-related cancers and tuberculosis • This review found that a low proportion of homeless people with respiratory diagnoses were receiving care, despite the provision of dedicated services for this population • This review found no studies exploring issues relating specifically to supporting palliative care in homeless populations • Further research is suggested to be done on how to deliver palliative care to homeless populations, as well as the barriers and facilitators that currently exist • Research about the impact on, and role of, family, friends, or informal networks in the provision of palliative care is also needed Source (AMSTAR rating 4/9)	Published September 2020
	• Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) • Who is involved in providing palliative care? ○ Nurses	• The healthcare-delivery system may leverage the skills of registered nurses to make positive health-related changes for the homeless populations, improving their overall quality of life • Existing interventions include having nurses as primary contacts for interventions, nurse case-managed delivered interventions, nurse-delivered educational interventions, and nurse-delivered group therapy intervention • The overarching recommendation is to employ a holistic nursing approach when working to improve outcomes for homeless populations; this aims to ensure optimal treatment for their complex physical, mental, and social health needs and problems Source (AMSTAR rating 3/10)	Published October 2018
Rapid reviews	None identified		

Protocols for reviews that are already underway	None identified		
Titles and questions for reviews being planned	None identified		
Single studies	• Who is palliative care provided to? o People experiencing homelessness • What is included in palliative care models for those who are experiencing or at risk of homelessness? o Spiritual and bereavement support	• This narrative literature review explored what is currently known about the spiritual concerns of people experiencing homelessness towards the end of life • The literature search yielded 11 literature reviews, in which most of them are based in the United States • The findings show that for the U.S. homeless populations, spiritual beliefs have been documented as a barrier to advance care planning • One U.S. study revealed that 75% of the homeless participants feared that no one would know they had died, and that 85% worried about the end-of-life care that they would receive • Other U.S. studies confirm the primacy of religious beliefs and spiritual experience for homeless people considering end-of-life issues • However, research reporting the end-of-life priorities of homeless populations is sparse, particularly research drawing from global perspectives Source	Published 2 September 2018
	• Who is palliative care provided to? o People experiencing homelessness (e.g., living on the street, in shelters, in encampments) • Who is involved in providing palliative care? o Nurses • Where is palliative care provided? o Hospital o Mobile or community-based • What implementation barriers and enablers need to be considered or addressed? o For those accessing palliative care	• The literature review aimed to understand why people experiencing homelessness in the U.K. cannot access palliative-care services to address their complex needs • The authors identified that there is difficulty in predicting disease trajectory and existing gaps in the health system for people experiencing homelessness • The review determined that there is a lack of education about end-of-life and complex needs of people experiencing homelessness (e.g., complex physical and mental health, substance misuse), stigma from both the general public and healthcare providers, and lack of suitable places to deliver palliative care for the population	Published 2 April 2019

	○ For organizations or systems to create new or enhance existing programs - What are the outcomes? ○ Health related (including quality of life) ○ Equity related (e.g., did the intervention/program address the identified health disparities for the population it served) ○ Patient experience	(e.g., inflexible services, low tolerance for substance misuse) - The authors suggested that nurses could facilitate collaboration with other health professionals to improve end-of-life outcomes Source	
	- Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) - Who is involved in providing palliative care? ○ Nurses - Where is palliative care provided? ○ Shelter ○ Mobile or community-based - What implementation barriers and enablers need to be considered or addressed? ○ For those accessing palliative care ○ For organizations or systems to create new or enhance existing programs - What are the outcomes? ○ Health related (including quality of life) ○ Patient experience	- This narrative literature review assessed advance care planning (ACP) interventions for end-of-life (EOL) care for people experiencing homelessness - The review found high rates of advance directive (AD) completion (27%-50% overall) amongst homeless populations with ACP interventions, with clinician-assisted interventions having significantly higher rates than self-guided interventions - Settings in which the included study interventions took place included drop-in service sites in Minnesota, U.S., homeless shelters in Toronto, Canada, and transitional housing in California, U.S. - EOL concerns among the homeless included fear of dying alone or unnoticed, dying violently, and remaining unidentified after death, as well as burial and notification of family members - Participants across the included studies expressed differing views about healthcare providers, with some trusting the judgment of physicians to make decisions about their EOL care and others perceiving them as overly controlling - The review highlighted that education of homeless populations about different types of EOL care is important, and that public-health nurses are well-suited to promote ACP for this population Source	Published September 2017
	- Who is palliative care provided to?	- The study reviewed disparities in access to palliative care for the homeless population in Toronto	Published 27 June 2017

	○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) - What implementation barriers and enablers need to be considered or addressed? ○ For those accessing palliative care ○ For organizations or systems to create new or enhance existing programs	- The authors indicated that barriers to palliative care involved impaired trust and individual respect, underdevelopment of palliative care, and lack of promotion of prevention and protection - The study described a retrospective study about shelter-based palliative care, which reported that harm-reduction practices, boundary setting, intensive case-management approaches, and patient contracting enabled staff and other hostel residents to feel safe - The authors recommended that a public-health approach that involves care integration and partnerships with homeless shelters and service providers may help bring palliative care to where people experiencing homelessness feel comfortable Source	
	- Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) - Where is palliative care provided? ○ Hospital - What implementation barriers and enablers need to be considered or addressed? ○ For those accessing palliative care ○ For organizations or systems to create new or enhance existing programs	- A qualitative study examined the perspectives of people experiencing homelessness or vulnerable housing in southeastern Ontario about accessing hospital-based services, including palliative care - The authors acknowledged that palliative care for homeless and vulnerable populations needs to be mobile and flexible, as there were some examples of current inflexibility in a requirement to have housing before receiving treatment, and a lack of openness to a harm-reduction approach - In some cases, stigma and shame were so painful that they superseded health complaints, previous trauma, or other concerns a patient might have - Participants articulated the responsibility of healthcare providers to provide empathic care to everyone, regardless of their socio-economic status, substance-use history, or life circumstances - Participants felt welcomed when providers upheld dignity, autonomy, and choice for patients Source	Published 1 July 2019

	• Who is palliative care provided to? ○ People experiencing homelessness (e.g., living on the street, in shelters, in encampments) • What implementation barriers and enablers need to be considered or addressed? ○ For those accessing palliative care ○ For organizations or systems to create new or enhance existing programs	• A qualitative study explored the experience, goals, fears, and hopes surrounding death in settings of homelessness or vulnerable housing • Participants described a sense of being perpetually surrounded by death or the threat of death when on the street; one participant had been in a near palliative situation after a cancer diagnosis, receiving chemotherapy while on the street, and was kicked out of shelters because he was vomiting too much • Fears included not being afraid of death, but rather, a fear of dying alone; receiving inadequate care or pain medication; being resuscitated against their wishes; or being buried in an unmarked grave if there was no one to claim their body • Participants articulated home as an ideal space to die, followed by a comfortable and flexible institution that allowed their loved ones to be with them • Participants suggested improving palliative care by having it delivered by people with lived experience of homelessness and substance use and having care that is welcoming and flexible, minimizes stigma and enhances dignity, and respects people's desires to use substances at end of life • Participants advised to improve access to affordable housing, allowing people to access homecare and die at home Source	Published 7 May 2019

Appendix 3: Documents excluded at the final stages of reviewing

Type of document	Hyperlinked title
Guidelines	None identified
Full systematic reviews	Hospice care access inequalities: A systematic review and narrative synthesis Palliative care needs and models of care for people who use drugs and/or alcohol: A mixed methods systematic review Effects of Housing First approaches on health and well-being of adults who are homeless or at risk of homelessness: systematic review and meta-analysis of randomised controlled trials A systematic review of interventions by healthcare professionals to improve management of non-communicable diseases and communicable diseases requiring long-term care in adults who are homeless Health supports needed for homeless persons transitioning from hospitals Homeless persons' experiences of health- and social care: A systematic integrative review
Rapid reviews	None identified
Protocols for reviews that are already underway	None identified
Titles and questions for reviews being planned	None identified
Single studies	Palliative care for a homeless person Hearing their voice: Advance care planning for the homeless

Bhuiya A, Bain T, Al-Khateeb S, Soueidan S, Wang A, Jarvis T, Sood T, Mehta V, Wilson MG. Appendices for Rapid evidence profile #29: What do we know from evidence and experiences from other jurisdictions about providing palliative care for those who are experiencing or at risk of homelessness? Hamilton: McMaster Health Forum, 31 March 2022.

This work was supported in part by Healthcare Excellence Canada (HEC). HEC is an independent, not-for-profit charity funded primarily by Health Canada; the views expressed herein do not necessarily represent those of Health Canada. Those preparing and/or contributing to this report disclaim all liability or warranty of any kind, whether express or implied.

McMaster University | HEALTH FORUM

>> Contact us
1280 Main St. West, MML-417
Hamilton, ON, Canada L8S 4L6
+1.905.525.9140 x 22121
forum@mcmaster.ca

>> Find and follow us
mcmasterforum.org
healthsystemsevidence.org
socialsystemsevidence.org
mcmasteroptimalaging.org
mcmasterforum