Disparities in Utilization of Palliative Care in Patients Experiencing Homelessness

JANE M. SIMPSON, DO; JACOB RAMOS, MD; ANNIE LAURIE GULA, MD; MITCHELL WICE, MD; EDWARD MARTIN, MD; JAMES L. RUDOLPH, MD, SM

ABSTRACT

BACKGROUND: Patients experiencing homelessness have increased disease burden, increased severity of illness, and increased barriers to accessing care. The provision of high-quality palliative care is therefore essential for this population.

STATE OF HOMELESSNESS: 18 out of every 10,000 people in the US and 10 out of every 10,000 Rhode Islanders (down from 12 in 2010) experience homelessness.

CONCEPTUAL MODEL: High-quality palliative care for patients experiencing homelessness requires a foundation of patient-provider trust, well-trained interdisciplinary teams, coordinated transitions of care, community support, integrated healthcare systems, and comprehensive population and public health measures.

CONCLUSIONS: Improving access to palliative care for those experiencing homelessness requires an interdisciplinary approach at all levels from individual providers to broader public health policies. A conceptual model rooted in patient-provider trust has the potential to address high-quality palliative care access disparities for this vulnerable population.

KEYWORDS: homelessness; health services accessibility; end-of-life care; social determinants of health

BACKGROUND

During the depths of winter every year, a network organized by the US Department of Housing and Urban Development (HUD) seeks to obtain a census of people experiencing homelessness by performing a head count in shelters and community settings on a January night.[1] The figures are as bleak as the temperature – 580,466 people experiencing homelessness were counted in 2020.[1,2] The number represents 18 of every 10,000 people in the US and is increasing, while in Rhode Island 10 out of every 10,000 people were experiencing homelessness.[1-4]

Individuals experiencing homelessness have unique health needs that are intertwined with lack of housing. They experience higher rates of mental health issues, diabetes, substance use disorder, heart disease, HIV/AIDs, and overall mortality when compared to the general population.[5-8]

People experiencing homelessness often present to healthcare later in their disease courses with more severe illness, unpredictable outcomes, and complex care needs.[9] Barriers to healthcare in populations experiencing homelessness are similar to barriers to other services including cost, not knowing locations to access care, decreased access to transportation, and lack of legal identification.[10-12] Illnesses leading to unemployment and higher healthcare costs additionally limit access to care.[5] Even for patients experiencing homelessness that had employment in the previous year, the ability to receive care was limited by access to health insurance. This is the result of multiple factors, including the priority of employment over insurance and Medicaid restrictions.[13] Due to increased disease prevalence, delayed access to care, increased mortality, and increased severity of illness, people experiencing homelessness may benefit from increased access to palliative care (PC), which is specialized medical care for people with serious or life-limiting illness which focuses on the needs of the patient by providing relief of symptoms, stress, and improving quality of life for patients using a interdisciplinary team of providers.[14]

PC provides high-quality, goal-concordant care to alleviate suffering by improving quality of life[15-18] and has been shown to decrease mortality in serious illnesses,[19] including cancer.[20] PC services can follow patients through the trajectory of serious illness, are often available in inpatient and outpatient contexts, and are comprised of interdisciplinary teams.[15-20] Providing equitable access to PC is a challenge in many populations, including those experiencing homelessness.[15-18] Barriers to PC services for this population include poor understanding of one's health, limited family support, competing medical priorities, and stigma associated with both PC and homelessness.[9,21,22] PC also depends on a stable home and social support model for care, posing additional barriers for those who are experiencing homelessness.[23] Improving utilization of high-quality PC could significantly impact the overall health and quality of life for those facing specific barriers to care[6,9,13] and increased disease prevalence and severity[5-8] due to homelessness. As stated prior, high-quality palliative care broaches not only medical care but also societal issues and thus is uniquely primed to improve the lives of those with homelessness. Thoughtful and intentional planning and actions are important when confronting an issue like homelessness on this scale, and so we believe a conceptual model of how to better provide PC to those experiencing homelessness is needed.

STATE OF HOMELESSNESS IN RI

The US Interagency Council on Homelessness reports that 1,104 people were experiencing homelessness in Rhode Island in 2020,[3,4] 10 out of every 10,000 people, compared to the national 18 per 10,000.[1,3,4] In surrounding states, Massachusetts had a prevalence of 26 per 10,000 people and Connecticut 8 per 10,000 people.[3,4] In 2010, 12 in 10,000 Rhode Islanders were experiencing homelessness.[24,25] During the 2020 census, Rhode Island was also shown to have a poverty rate of 10.6% and 4.8% of the population under 65 did not have health insurance.[4] We must continue to work towards the goal of eliminating homelessness and its effects on our neighbors and patients.

Prominent community organizations working to address homelessness include the Rhode Island Coalition to End Homelessness and Crossroads Rhode Island. There are also many community-based organizations that function on a regional level within the state and provide important services to those experiencing homelessness. The Rhode Island Coalition to End Homelessness estimates that as of March 31, 2022 there are 896 Rhode Islanders living in shelters, 277 living out of doors, and 141 families waiting for a shelter.[26] These community organizations work to identify those experiencing homelessness, connect people to shelters and social services, and raise awareness about the issue of homelessness.[27]

The Veterans Affairs Medical Center in Providence is involved in the identification and reduction of homelessness in the Veteran community. The VA system uses specific medical coding to identify those at risk for homelessness and those currently experiencing homelessness to facilitate interdisciplinary approaches to providing housing and increased access to care.[28] Because of these coordinated approaches, Veteran homelessness fell almost 50% from 2009 to 2020,[1] suggesting that identification and an interdisciplinary approach can be effective at reducing homelessness.

CONCEPTUAL MODEL FOR IMPROVING UTILIZATION OF PALLIATIVE CARE IN PATIENTS EXPERIENCING HOMELESSNESS

In this review, we propose a framework for communities seeking to address these disparities in access to high-quality palliative care. The authors performed a literature review looking at PC in the setting of homelessness both in the US and Canada. While much qualitative data, and some quantitative data, was available we recognized that a framework for how to approach the care of homeless people did not exist and could be created to help better serve this population with unique needs.

Palliative care as a foundation of patient-provider trust

This conceptual model is based on a strong foundation of patient-provider trust, which is a facilitator to compassionate and dignity-focused care.[12,29] Building trust between patients and providers is important to increase access to care, engender honest communication, and encourage repeat encounters. Construction and maintenance of this trust is hardly formulaic or specific to palliative care, but is key in the field of palliative care as it focuses on sensitive and very personal psychosocial issues on top of medical issues, and thus our model seeks to denote some of the most important elements required for success in building these relationships.

Multimodal training and education

Given the unique factors and societal stigma faced by people with housing instability, working with patients experiencing housing instability requires knowledge of and sensitivity to the specific stressors they face. Multimodal provider education – such as patient-first language, open-ended interviewing rooted in curiosity, and consideration of personal and professional biases (explicit and implicit) toward homeless individuals – can help foster mutual respect and identify patient-specific goals.[11,21] Special skills may be required for nuanced conversations about goal-concordant care with people experiencing homelessness, particularly when considering the increased barriers to care (i.e., financial stressors, food insecurity, inadequate medication storage options, etc.).

Interdisciplinary teams

Teams composed of members from several disciplines working together are an important foundation of all healthcare areas, but especially important in PC when trying to support patients in all facets of the illness process.[30] We likewise acknowledge that caring for patients with housing instability is beyond the scope of any single profession. Therefore, we cannot overstate the importance of interdisciplinary approaches in serving this population. Efforts to mitigate the impacts of homelessness can follow a collective impact model, which utilizes a centralized infrastructure, a dedicated staff, continuous communication, and a shared agenda.[30] In such a model, healthcare teams must partner with shelter staff, public works departments, and social services (among others) to provide appropriate support.[30] Just as delivering high-quality palliative care relies on an interdisciplinary disciplinary team (including physicians, nurses, nurse assistants, chaplains, social workers, and volunteers), cultivating patient trust is the responsibility of all clinical and non-clinical providers within any given system.

Continuity of care and coordinated transitions

Patients experiencing homelessness have high rates of acute care (inpatient hospitalization, emergency department) utilization, which may be exacerbated by poor transitions in care.[31] This is particularly important when considering a hospital discharge, as patients experiencing homelessness may have unique barriers to discharge. In 2021, Greysen et al demonstrated that 27% of people experiencing

homelessness were discharged at night (after shelters have closed) and 11% reported sleeping outside on the first night after discharge.[31] People experiencing homelessness face competing priorities and unique hardships, such as limited resources, living within inflexible structures (e.g., shelters), inconsistent living spaces, and the time-intensive task of seeking adequate nourishment and shelter.[21] Thus, distinct and familiar patterns of follow-up - paired with additional attention during points of transition - is key in sustaining trusting relationships.

PC treats and interacts with patients as they require and move between various levels of care including care based at home, in hospitals, and in nursing homes. In this way PC is uniquely positioned to improve transitions for those experiencing homelessness. Possible interventions include discussions about housing and transportation as health issues, and communication with shelters as collaborators in discharge planning.[31]

Community infrastructure and support

Beyond optimization of trust and safe transitions within the healthcare system, involvement of existing community-based infrastructures and support systems can bolster individual patient success. Key examples may include community-based programs focused on securing stable housing for vulnerable individuals, especially as patient environments can directly impact the delivery and continuity of health care services.[9,21] Furthermore, community health workers with lived experience of homelessness can provide vital insight into how to most effectively create support systems for a given community. As our model approaches a goal of increased access to high-quality palliative care, other systems working in parallel towards distinct goals may present opportunities to concert efforts towards the unified goal of increased population health. We believe it is important to identify these groups and resources in the community and have PC interdisciplinary teams partner with them to increase access to services and care in both directions.

Integration with healthcare systems

In line with interdisciplinary and community partnership, the WHO advocates for implementing an integrated care model, defined as "an approach to strengthen people-centered health systems through the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. It should be effectively managed to ensure optimal outcomes and the appropriate use of resources based on the best available evidence, with feedback loops to continuously improve performance and to tackle upstream causes of ill health and to promote well-being through intersectoral and multisectoral actions."[32] Integrated care models

strive to provide patients a single, coordinated plan of care, which can positively contribute to health related quality of life.[32] Additionally, integrating care can improve outcomes in healthcare delivery with increased timeliness and communication, cost savings, and overall patient satisfaction.[33] It is important to note that integrated care models are not sufficient to quell healthcare disparities, as "integration is likely to enhance already well-established systems rather than fundamentally changing the outcomes of care."[33] Furthermore, marginalized groups were often last to see these benefits with disparities in care well documented based on race or socioeconomic status – to name a few – where Caucasians or well-off individuals receive more frequent PC.[19,33]

Population and public-health measures

As above, interventions to improve access to PC for people experiencing homelessness must extend beyond the healthcare system. Since homelessness has such broad impacts, it should be managed as both a medical and a social issue.[34] Population- and public health-level interventions that can improve access include efforts to eliminate homelessness, ensure adequate insurance coverage, and eliminate institutional and structural racism. Rapid Re-housing[35] and Housing First initiatives[36] prioritize rent subsidies and expedited housing searches to help people obtain stable housing as soon as possible. These approaches have been shown to reduce homelessness, improve food insecurity, and improve overall well-being.[36] These interventions are also cost effective.[36] As a significant amount of palliative care, including hospice, is provided in the home, the lack of stable housing becomes a crucial barrier to appropriate PC, thus these efforts to provide housing become even more critical.

Furthermore, efforts to improve access to healthcare overall can improve PC access. Issues of access may include difficulties with transportation, prohibitive cost of care, and challenges with accessing, storing, and administering medications, including analgesics.[21] In fact, an aim of the United Nations' 2030 Agenda for Sustainable Development is to "achieve universal health coverage, including... access to quality, essential healthcare services."[37] Changes to the payor structure that acknowledge and accommodate for healthcare disparities, such as comprehensive universal health insurance, are both in line with global and local efforts to improve healthcare access.

It is also important to note that racial disparities to quality PC exist independent of insurance status.[16] This is especially concerning as non-Hispanic Black and Hispanic populations are vastly overrepresented in the population experiencing homelessness (lifetime incidence of 16.8% and 8.1%, respectively, compared with 4.8% for White people).[38] These race-based differences are perpetuated by lasting impacts of institutional racism, including historic redlining policies and current discriminatory lending practices, which increases risk for homelessness.[39] While it is beyond

the scope of this review to describe the impacts of structural racism on healthcare, it is clear that BIPOC (Black, Indigenous, and People of Color) experiencing homelessness represent a group with an even greater need for targeted advocacy and support. To truly address this healthcare disparity, we must address and eliminate structural racism.

CONCLUSIONS

Patients experiencing homelessness represent a population who could benefit from high- quality PC services to alleviate suffering and improve quality of life. While our review is not exhaustive or representative of the efforts at multiple levels that communities take to support their vulnerable populations, it is evident that there are many barriers to receiving PC for patients experiencing homelessness. Efforts should be made on an individual level to cultivate patient-provider trust, on an institutional level to minimize bias and improve interdisciplinary partnerships, on a community level to improve stability and support, and on a population level to implement public health interventions to minimize homelessness and its impacts. Comprehensive, holistic interventions could improve utilization of high-quality PC services for patients experiencing housing insecurity.

References

1. U.S. Department of Housing and Urban Development. HUD Releases 2020 Annual Homeless Assessment Report Part 1. March 18, 2021. Accessed April 5, 2022. https://www.hud.gov/press/press_releases_media_advisories/hud_no_21_041#:~:text=The%20report%20found%20that%20580%2C466,or%202.2%20percent%2C%20from%202019.

2. U.S. Department of Housing and Urban Development. HUD Releases 2021 Annual Homeless Assessment Report Part 1. February 4, 2022. Accessed April 5, 2022. https://www.hud.gov/press/press_releases_media_advisories/HUD_No_22_022

3. United States Interagency Council on Homelessness. Homelessness Statistics by State. 2020. Accessed April 5, 2022. https://www.usich.gov/tools-for-action/map/#fn[]=1300&fn[]=2900&fn[]=6400&fn[]=10200&fn[]=13400

4. United States Census Bureau. QuickFacts. 2021. Accessed April 5, 2022. https://www.census.gov/quickfacts/fact/table/CT,MA,RI/PST045221

5. National Health Care for the Homeless Council. Homelessness and Health: What's the Connection? 2019. Accessed April 5, 2022. https://nhchc.org/wp-content/uploads/2019/08/homelessness-and-health.pdf

6. Hwang S. Mental illness and mortality among homeless people. Acta Psychiatrica Scandinavica, 103: 81-82. Doi: 10.1034/j.1600-0447.2001.103002081

7. National Alliance to End Homelessness. Health. 2022. Accessed April 5, 2022. https://endhomelessness.org/homelessness-in-america/what-causes-homelessness/health/#:~:text=Health%20and%20Homelessness,-An%20acute%20physical&text=On%20a%20given%20night%20in,10%2C000%20people%20had%20HIV%2FAIDS

8. U.S. Department of Housing and Urban Development. The 2016 Annual Homeless Assessment Report (AHAR) to Congress Part 2. December 2017. Accessed April 5, 2022. https://www.huduser.gov/portal/sites/default/files/pdf/2016-AHAR-Part-2.pdf

9. de Veer AJE, Stringer B, van Meijel B, Verkaik R, Francke AL. Access to palliative care for homeless people: complex lives, complex care. BMC Palliat Care. 2018 Oct 24;17(1):119. doi: 10.1186/s12904-018-0368-3

10. National Coalition for the Homeless. Healthcare and Homelessness. 2009. Accessed April 5, 2022. https://www.nationalhomeless.org/factsheets/health.html#:~:text=Unfortunately%2C%20many%20homeless%20people%20who,identification%20(Whitbeck%2C%202009)

11. Klop HT, de Veer AJE, van Dongen SI, Francke AL, Rietjens JAC, Onwuteaka-Philipsen BD. Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. BMC Palliat Care. 2018;17(1):67. Published 2018 Apr 24. doi:10.1186/s12904-018-0320-6

12. Purkey E, MacKenzie M. Experiences of Palliative Health Care for Homeless and Vulnerably Housed Individuals. J Am Board Fam Med. 2019;32(6):858-867. doi:10.3122/jabfm.2019.06.190093

13. Baggett TP, O'Connell JJ, Singer DE, Rigotti NA. The unmet health care needs of homeless adults: a national study. *Am J Public Health*. 2010;100(7):1326-1333. doi:10.2105/AJPH.2009.180109

14. Center to Advance Palliative Care. Palliative Care Definition: What Is Palliative Care. Accessed January 23, 2023. https://www.capc.org/about/palliative-care/

15. Gelfman LP, Barrón Y, Moore S, et al. Predictors of Hospice Enrollment for Patients With Advanced Heart Failure and Effects on Health Care Use. JACC Heart Fail. 2018;6(9):780-789. doi:10.1016/j.jchf.2018.04.009

16. Lewis JM, DiGiacomo M, Currow DC, Davidson PM. Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. J Pain Symptom Manage. 2011;42(1):105-118. doi:10.1016/j.jpainsymman.2010.10.265

17. Walshe C, Todd C, Caress A, Chew-Graham C. Patterns of access to community palliative care services: a literature review. J Pain Symptom Manage. 2009;37(5):884-912. doi:10.1016/j.jpainsymman.2008.05.004

18. Xu Z, Chen L, Jin S, Yang B, Chen X, Wu Z. Effect of Palliative Care for Patients with Heart Failure. Int Heart J. 2018;59(3):503-509. doi:10.1536/ihj.17-289

19. Liu X, Dawod Y, Wonnaparhown A, Shafi A, Doo L, Yoo JW, Ko E, Choi YS. Effects of hospital palliative care on health, length of stay, and in-hospital mortality across intensive and non-intensive-care units: A systematic review and metaanalysis. Palliat Support Care. 2017 Dec;15(6):741-752. doi: 10.1017/S1478951516001164

20. Rocque GB, Cleary JF. Palliative care reduces morbidity and mortality in cancer. Nat Rev Clin Oncol. 2013 Feb;10(2):80-9. doi: 10.1038/nrclinonc.2012.211

21. Hudson BF, Flemming K, Shulman C, Candy B. Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. BMC Palliat Care. 2016;15(1):96. Published 2016 Dec 3. doi:10.1186/s12904-016-0168-6

22. Huynh L, Henry B, Dosani N. Minding the gap: access to palliative care and the homeless. BMC Palliat Care. 2015;14:62. Published 2015 Nov 18. doi:10.1186/s12904-015-0059-2

23. Song J, Bartels DM, Ratner ER, Alderton L, Hudson B, Ahluwalia JS. Dying on the streets: homeless persons' concerns and desires about end of life care. J Gen Intern Med. 2007;22(4):435-441. doi:10.1007/s11606-006-0046-7

24. U.S. Department of Housing and Urban Development. 2010 Homeless Assessment Report. 2010. Accessed April 6, 2022. https://www.huduser.gov/portal/sites/default/files/pdf/2010HomelessAssessmentReport.pdf

25. United States Census Bureau. 2010 Census: Rhode Island Profile. 2010. Accessed April 6, 2022 https://www2.census.gov/geo/maps/dc10_thematic/2010_Profile/2010_Profile_Map_Rhode_Island.pdf

26. The Rhode Island Coalition to End Homelessness. Homeless Management Information System (HMIS). March 31, 2022. Accessed April 6, 2022 https://www.rihomeless.org/

27. Pixley CL, Henry FA, DeYoung SE, Settembrino MR. The role of homelessness in community-based organizations during COVID-19. *Journal of Community Psychology*, 1– 15. 2021. doi: 10.1002/jcop.22609

28. US Department of Veterans Affairs. 2021-2025 Homeless Programs Office Strategic Plan. 2019. Available from: https://www.va.gov/HOMELESS/strategic-plan.asp. Accessed April 4, 2022.

29. Ramsay N, Hossain R, Moore M, Milo M, Brown A. Health Care While Homeless: Barriers, Facilitators, and the Lived Experiences of Homeless Individuals Accessing Health Care in a Canadian Regional Municipality. Qual Health Res. 2019;29(13):1839-1849. doi:10.1177/1049732319829434

30. Abdel-Samad M, Calzo JP, Felner JK, et al. Conceptualizing an Interdisciplinary Collective Impact Approach to Examine and Intervene in the Chronic Cycle of Homelessness. Int J Environ Res Public Health. 2021;18(4):2020. Published 2021 Feb 19. doi:10.3390/ijerph18042020

31. Greysen SR, Allen R, Lucas GI, Wang EA, Rosenthal MS. Understanding transitions in care from hospital to homeless shelter: a mixed-methods, community-based participatory approach. J Gen Intern Med. 2012;27(11):1484-1491. doi:10.1007/s11606-012-2117-2

32. WHO. Strengthening people-centred health systems in the WHO European Region: Framework for action on integrated health services delivery WHO Regional Office for Europe; 2016. Available from: http://www.euro.who.int/__data/assets/pdf_file/0004/315787/66wd15e_FFA_IHSD_160535.pdf?ua=1

33. Lê G, Morgan R, Bestall J, Featherstone I, Veale T, Ensor T. Can service integration work for universal health coverage? Evidence from around the globe. Health Policy. 2016;120(4):406-419. doi:10.1016/j.healthpol.2016.02.007

34. Stafford A, Wood L. Tackling Health Disparities for People Who Are Homeless? Start with Social Determinants. Int J Environ Res Public Health. 2017;14(12):1535. Published 2017 Dec 8. doi:10.3390/ijerph14121535

35. Cunningham M.K., Batko S. Rapid Re-Housing's Role in Responding to Homelessness. Urban Institute; Washington, DC, USA: 2018.

36. Gubits D, Shinn M, Wood M, Brown SR, Dastrup SR, Bell SH. What Interventions Work Best for Families Who Experience Homelessness? Impact Estimates from the Family Options Study. J Policy Anal Manage. 2018;37(4):735-766.

37. Sustainable Development Goals. United Nations Department of Economic and Social Affairs. Accessed 6 June 2022. https://sustainabledevelopment.un.org/index.php?menu=1300

38. Fusaro VA, Levy HG, Shaefer HL. Racial and Ethnic Disparities in the Lifetime Prevalence of Homelessness in the United States. Demography. 2018;55(6):2119-2128. doi:10.1007/s13524-018-0717-0

39. Lynch EE, Malcoe LH, Laurent SE, Richardson J, Mitchell BC, Meier HCS. The legacy of structural racism: Associations between historic redlining, current mortgage lending, and health. SSM Popul Health. 2021;14:100793. Published 2021 Apr 20. doi:10.1016/j.ssmph.2021.100793

Authors

Jane M. Simpson, DO, Rhode Island Hospital and Lifespan Health System, Providence, RI.

Jacob Ramos, MD, Rhode Island Hospital and Lifespan Health System, Providence, RI.

Annie Laurie Gula, MD, Rhode Island Hospital and Lifespan Health System, Providence, RI.

Mitchell Wice, MD, The Warren Alpert Medical School of Brown University and the Providence VA Medical Center, Providence RI.

Edward Martin, MD, The Warren Alpert Medical School of Brown University, Providence, RI.

James L. Rudolph, MD, SM, Center of Innovation in Long Term Services and Supports, VA Providence Healthcare System, Providence, RI; Division of Geriatrics and Palliative Medicine, Warren Alpert Medical School of Brown University and Center of Gerontology and Health Services Research, Brown University School of Public Health, Providence, RI.

Disclosures

We are not aware of any potential conflicts of interest. The authors have no financial interests to disclose.

Correspondence

Mitchell Wice, MD
Center of Innovation in Long Term Services and Supports
Providence VA Medical Center
830 Chalkstone Ave
Providence, RI 02093
mitchell.wice@va.gov