AMA Journal of Ethics®
November 2021, Volume 23, Number 11: E893-897

MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

How Bodily Integrity Is a Core Ethical Value in Care of Persons Experiencing Homelessness

Jennifer Markusic Wimberly, MD, MA and John Z. Sadler, MD

Abstract

Influences of chronic homelessness on patients' conceptions of bodily integrity can conflict with clinicians' recommendations about clinically indicated interventions, such as dialysis or amputations. This article considers such conflict by drawing on a capabilities-based model to reframe health care as shared between a patient and clinical team.

The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ *available through the* AMA Ed Hub™. *Physicians should claim only the credit commensurate with the extent of their participation in the activity.*

Body as Home

An individual experiencing chronic homelessness is a person with chronic disability who has "been living in a place not meant for human habitation, in an emergency shelter, or in a safe haven for the last 12 months continuously or on at least four occasions in the last three years *where those occasions cumulatively total at least 12 months*."[1] Such persons compose 24% of the US homeless population at any given time.[2] As with other social determinants of health, homelessness disproportionately affects racial and ethnic minorities.[3]

People experiencing homelessness, like all of us, have many values and beliefs that shape health decisions. Chronic homelessness, however, often reduces access to and the availability of interventions and exposes patients to increased risk of robbery and assault.[4] Constrained by these circumstances, the choices of patients experiencing homelessness can conflict with clinicians' everyday assumptions about reasonable, ethical care. There are also logistical and practical barriers to care continuity, which tend to compound when patients refuse interventions or don't adhere to clinicians' recommendations. When clinicians' recommendations force individuals experiencing homelessness to choose—for example, between housing that minimizes vulnerability by enhancing safety, security, and freedom of control of their own environment and bodily integrity that increases vulnerability—patients tend to feel subject to others.[5] Clinicians should be aware of their capacity to unintentionally exacerbate this kind of vulnerability often felt by patients experiencing homelessness.

Instead of considering the individual experiencing homelessness as noncompliant, nonadherent, or treatment refusing, we intend to reframe the care of persons experiencing homelessness as a shared endeavor between clinician and patient. This reframing involves clinicians' attention to the interdependence among core capabilities and values—such as bodily integrity and avoidance of vulnerability and material loss—that might conflict with the core capability of health and well-being. Considering the interplay of capabilities is a means of enriching the decision making of individuals experiencing homelessness and can support better outcomes when individuals experiencing homelessness are presented with the ethical challenge of body-altering medical treatments. Shared decision making based on individuals' broad capabilities enables individuals to pursue a life in accordance with what they are actually able to do and thereby to flourish.[6] In what follows, we utilize Martha Nussbaum's capabilities approach[5] to analyze the conditions for flourishing of individuals experiencing chronic homelessness, given their extraordinary circumstances and adaptive challenges.

Capabilities

Nussbaum's 10 core capabilities are categorized as follows: life (preserving a normal life span); bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; other species; play; and control over one's environment.[6] Here, we focus on bodily integrity and trade-offs among bodily integrity, preserving life, and control over one's environment (or, rather, freedom from unwarranted interference).[6]

Bodily integrity. Given that individuals experiencing chromic homelessness also have chronic disabilities, their bodily integrity becomes a core capability of immense importance. Rae Johnson[6] describes the homeless body as a de facto "home." We argue that the homeless body as "home" to the self amplifies the importance of the body over and above that of the domiciled self. The body is valued as sacrosanct, worthy of defense against violation. The "body as home" underpins the profound need for the individual experiencing homelessness to maintain, even elevate, Nussbaum's core capability of bodily integrity. The capability of bodily integrity is a strong driver of loss aversion, and avoidance of vulnerability enables 2 other core capabilities, according to Nussbaum: freedom from unwarranted interference and preserving a normal lifespan.[7] Yet clinical recommendations that affect bodily integrity can compromise other capabilities, thereby affecting the opportunities the individual has to achieve independence and control of their personal environment—the de facto body as home.[7,8]

Trade-offs. Consider the example of amputation that leaves one with a disability—for example, a lower limb loss requiring a wheelchair or prosthetic. For a domiciled individual, this is a major adaptation but not an ongoing threat to personal safety. However, for the individual experiencing homelessness, the loss of personal freedom through reduced mobility is profound, and the loss of safety from victimization is equally profound. Maintaining bodily integrity can promote freedom, safety, and security and respects the inviolability of the body for an unspecified time. The likely outcome of the refusal of amputation, however, might further reduce the lifespan of the individual experiencing homelessness. Yet such an individual's vision of the life well-lived[5] might well include a lifespan that is shorter but free from vulnerability and undue loss of mobility. This is the same kind of trade-off regarding one's personal values that we would respect, say, in cancer patients who are willing to have a lifespan that is shorter but with more mobility and bodily integrity to pursue projects and personal relationships. Patients' trade-offs between their capability for bodily health and their capability for

bodily integrity with freedom from vulnerability is not routinely considered in ordinary care of the would-be amputee. The capabilities approach thus facilitates a realization of other values bearing on the amputation decision.

Capabilities and Caregiving

In addition to basic capabilities, Nussbaum proposes *combined capabilities* as a way to conceive of internal preparedness for flourishing combined with external conditions that do not impede the individual's flourishing. This readiness for flourishing within the capabilities approach is relevant to both clinicians and patients. Clinicians must be prepared to engage (psychologically and emotionally) with patients, as well as be positioned within a supportive environment, in order to engage effectively with patients and realize the ideals of shared decision making.[7] For patients experiencing homelessness, the hospital has the responsibility to create a supportive environment to prepare the patient to engage in life-critical discussions that too often devolve into simple consent-refusal discussions rather than an examination and appreciation of distinctive values that are important to the patient. The traditional role of the physician as "captain of the ship" in the health care environment does not readily permit this kind of engagement,[9] as care relationships are efficiency oriented and top-down.

Health decision making informed by a capabilities approach reduces the potential for physicians to act as captain of the ship and impose their values on patients experiencing homelessness. Although shared decision making is a widely endorsed approach to care decisions, for patients with impaired decision-making capacity, this approach has significant limitations, especially when suitable surrogates are absent.[10,11] Consistent with Annette Rid and David Wendler's suggested use of a "patient preference predictor,"[12] which uses aggregate data based on patient characteristics to predict the preference of a given patient lacking decision-making capacity, the capabilities approach can help inform care decisions when clinicians appreciate the unique circumstances and preference for bodily integrity of individuals experiencing chronic homelessness.

Implementing a care plan that is not aligned with the personal values of a patient experiencing chronic homelessness will likely yield the result of recurring challenges to acceptance or adherence. Such tunnel vision misses the goal of medicine, or what Pellegrino calls "acting for the good of the patient," which should be guided by the virtue of phronesis, or practical wisdom—that is, honoring right choice based on right reason with appropriate intent.[13]

Implementation

How might an engagement-supportive environment be facilitated? The clinician is wise to approach emotional and value-laden health care encounters with involvement of multiple expert members of the health care team, as well as the social support system of the patient experiencing homelessness, if available, to learn how best to meet that patient's health care needs in alignment with their core personal values and life choices. Team members, such as nursing staff, care managers, social workers, patient advocates, and psychologists, can provide a compassionate approach to assessing the individual in the context of their life circumstances. To negotiate a care plan that is clinically appropriate and optimal from the patient's perspective, clinicians must recognize that individuals experiencing homelessness need to be supported within their social environment.

Negotiating requires empathic listening in order to gain understanding of the unresolved issue, discover the individual's vision of a life well lived,[5] and identify the needs of the individual to pursue such a vision. Such engagement likely will not be accomplished in a single visit by even the most capabilities-attuned clinician. The negotiation process is one of iteration.[14] An iterative process to identify conflict among enabling and constraining core capabilities may promote the patient's self-determination to integrate core personal values with capabilities. This process permits individuals experiencing homelessness to engage in action aimed at the flourishing they are capable of attaining. Donald Berwick supports a call to action for clinicians to guide quality improvements in health care provided to the underserved.[15] We strive to advance the health care capabilities of the individuals experiencing homelessness and advance Berwick's imaginative moral image of healers as guides to action.[15]

References

1. What are the main differences between the previous definition of "chronically homeless" and the definition included in the final rule? HUD Exchange. April 2016. Accessed March 10, 2021. https://www.hudexchange.info/faqs/programs/continuum-of-care-coc-program/program-requirements/definition-of-chronic-homelessness/what-are-the-main-differences-between-the-previous-definition-of/
2. US Interagency Council on Homelessness. Homelessness in America: focus on chronic homelessness among people with disabilities. August 2018. Accessed May 27, 2021. https://www.usich.gov/resources/uploads/asset_library/Homelessness-in-America-Focus-on-chronic.pdf
3. Moses J. Demographic data project: race, ethnicity, and homelessness. Homeless Research Institute. Accessed June 28, 2021. https://endhomelessness.org/wp-content/uploads/2019/07/3rd-Demo-Brief-Race.pdf
4. Kushel MB, Perry S, Langberg D, Clark R, Moss AR. Emergency department use among the homeless and marginally housed: results from a community-based study. *Am J Public Health*. 2002;92(5):778-784.
5. Nicholls CM. Housing, homelessness and capabilities. *Hous Theory Soc*. 2010;27(1):23-41.
6. Evans S. What should social welfare seek to achieve? Applying the capability approach. *Ethics Soc Welfare*. 2017;11(1):19-32.
7. Nussbaum MC. *Hiding From Humanity: Disgust, Shame, and the Law*. Princeton University Press; 2009.
8. Johnson R. Body as home: a critical somatic approach to working with homeless youth. In: Dunn PA, ed. *Holistic Healing: Theories, Practices, and Social Change*. Canadian Scholars; 2019:348-355.
9. King NM, Churchill LR, Cross AW, eds. *The Physician as Captain of the Ship: A Critical Reappraisal*. D. Reidel Publishing; 1988. Engelhardt HT, Spicker SF, eds. *Philosophy and Medicine*; vol 29.
10. Sulmasy DP, Hughes MT, Thompson RE, et al. How would terminally ill patients have others make decisions for them in the event of decisional incapacity? A longitudinal study. *J Am Geriatr Soc*. 2007;55(12):1981-1988.
11. Rid A, Wendler D. Can we improve treatment decision-making for incapacitated patients? *Hastings Cent Rep*. 2010;40(5):36-45.
12. Rid A, Wendler D. Use of a patient preference predictor to help make medical decisions for incapacitated patients. *J Med Philos*. 2014;39(2):104-129.

13. Pellegrino ED, Engelhardt HT, Jotterand F, eds. *The Philosophy of Medicine Reborn: A Pellegrino Reader*. University of Notre Dame Press; 2011.
14. Voss C, Raz T. *Never Split the Difference: Negotiating as if Your Life Depended on It*. Random House Business; 2017.
15. Berwick DM. The moral determinants of health. *JAMA*. 2020;324(3):225-226.

Jennifer Markusic Wimberly, MD, MA is the chair of the Institutional Ethics Committee and the medical director of resiliency at Parkland Health and Hospital System in Dallas, Texas. She is also a board-certified urologist, a clinical faculty member of the Department of Urology, and a faculty member of the Program in Ethics in Science and Medicine at the University of Texas Southwestern Medical Center.

John Z. Sadler, MD is the Daniel W. Foster, MD Professor of Medical Ethics at the University of Texas Southwestern Medical Center in Dallas, where he is also director of the Program in Ethics in Science and Medicine as well as a professor of psychiatry and population/data sciences.

Citation
AMA J Ethics. 2021;23(11):E893-897.

DOI
10.1001/amajethics.2021.893.

Conflict of Interest Disclosure
Dr Sadler reported receiving royalties from Oxford University Press. Dr Wimberly had no conflicts of interest to disclose.

ISSN 2376-6980