

IN THE LITERATURE

Why Marginalization, Not Vulnerability, Can Best Identify People in Need of Special Medical and Nutrition Care

Alexis K. Walker, PhD and Elizabeth L. Fox, PhD

Abstract

In a 2015 paper published in the *Journal of Bioethical Inquiry*, bioethicist Henk ten Have identifies vulnerability as a “controversial topic in bioethics” and argues that bioethical attention to vulnerability comes at the expense of sufficient attention to the social structures that shape human life. In this paper, we situate ten Have’s argument within the broader bioethical literature, emphasizing how critiques of vulnerability can enrich approaches in clinical settings, including in nutrition, where the concept of vulnerability is not foreign (eg, children are often labeled members of a vulnerable group). We use an example of food (in)security to show how reframing vulnerability to capture “layers of marginalization” can help clinicians and organizations more clearly identify who is most in need, develop solutions for what should be done, and determine how and by whom those solutions should be implemented.

Vulnerability and Marginalization

In a 2015 paper published in the *Journal of Bioethical Inquiry*, bioethicist Henk ten Have identifies vulnerability as a “popular though controversial topic in bioethics” and argues that bioethical attention to vulnerability focuses on individuals at the expense of sufficient attention to the social connections that shape human life.¹ The concept of vulnerability has been applied in a variety of contexts, including nutrition; children, adolescent girls, [pregnant and lactating women](#), displaced persons, indigenous persons, and the elderly are often labeled members of nutritionally vulnerable groups. In this paper, we situate ten Have’s argument within the broader bioethical literature and emphasize how [critiques of vulnerability in research contexts](#) can enrich approaches in clinical care broadly and nutrition care specifically. We close the paper using food (in)security as an example to demonstrate how a more nuanced view of marginalization can improve health care interventions. In so doing, we build on the work of Florencia Luna,² arguing that by reframing vulnerability in terms of “layers” we can capture how patients can be marginalized in many overlapping ways, as opposed to being marginalized by single group membership. We suggest that attention to marginalization

highlights the social *processes* underlying patients' lives and thus goes further than the concept of vulnerability in helping health care practitioners to identify who is most at risk of food insecurity, to develop solutions for what should be done, and to determine how and by whom solutions should be implemented.

Vulnerability and Its Critiques

Much attention to vulnerability has focused on the context of biomedical research, where the term has been extensively integrated into research policy and infrastructures. ten Have notes that the concept of vulnerability was used in the Belmont Report,¹ which argued that, as a matter of justice, "vulnerable subjects"—including "racial minorities, the economically disadvantaged, the very sick, and the institutionalized"—ought not bear undue burdens of frequent enrollment in research "owing to their ready availability in settings where research is conducted."³ The report also raised concerns regarding the adequacy of informed consent among such populations,³ and it ultimately formed the basis of protections for vulnerable populations in the United States' federal regulations on human subjects research.⁴

ten Have notes that the 2005 United Nations Educational, Scientific and Cultural Organization's Universal Declaration on Bioethics and Human Rights lifts the concept of vulnerability from the research context and promotes it as "a fundamental bioethical principle—no longer only relevant for medical research but also for healthcare."¹ Governments and their advisory boards have drawn attention to vulnerability as a significant concern in the provision of health care.⁵⁻⁷ In 1998, a United States President's Advisory Commission, for example, argued that "there is a clear need to increase the level of attention paid to vulnerable groups, including both those who, because of their chronic illness or disability, have many interactions with the health system, and those who have difficulty accessing the system and may be most likely to fall through the cracks."⁵

As this report suggests, what people are thought to be *vulnerable to* differs substantially in research and health care contexts. In research, vulnerability typically focuses on the possibility that some people might be taken advantage of and harmed through research efforts.² The implication is that a person or population might be **vulnerable to exploitation** or to undue burdens of research participation. The focus is on protecting people from research participation that might expose them to undue risk or conflict with their best interests. In today's research context, scholars and patient groups have focused not only on protection from such potential harms but also on access to the possible benefits of research participation. However, Hurst argues that what one is *vulnerable to* is quite different in health care delivery, where concerns focus on protecting people not from harmful participation or exploitation but from inadequate or inappropriate care.⁸ In research, vulnerability protection is generally conceived as a protection from *detrimental* engagement, while in health care delivery, protection focuses on *lack of* engagement.

Despite its origins in the Belmont Report and its enduring role in human subjects research regulations, the concept of vulnerability has been heavily critiqued in the research context. Levine et al. argue that vulnerability is a poor tool for protecting people from possible harms of research as it does not track peoples' morally relevant features with sufficient precision.⁹ For example, the term has been applied to pregnant women and to people of color as well as to children and the cognitively impaired.^{3,9} However, to lump pregnant women and people of color in with children and people with cognitive impairment is not only imprecise but also potentially infantilizing. Levine et al. also suggest that the concept of vulnerability weakens research review by focusing attention on participants rather than "on characteristics of the research protocol and environment that present ethical challenges."⁹ Henderson et al. take this critique further by likening the label of vulnerability to "status crimes like vagrancy or homelessness," arguing that labeling people vulnerable "is highly likely to exacerbate stigma."¹⁰ Several papers highlight how the term "vulnerable" insinuates personal weakness rather than drawing attention to the contexts that place people in vulnerable positions.^{1,2} We argue that the term "marginalized" is in many cases more apt, as it draws attention to the social processes behind the status.

Although critiques of the term "vulnerable" in the research context should make practitioners and scholars wary of its use in clinical environments, it is clear that attention to the background and contexts of patients' lives are crucial to care. A substantial body of research demonstrates that discrimination in health care environments limits health care for people of color and members of other marginalized groups, such as sex workers and the homeless.¹¹ Levine et al. suggest that the concept of vulnerability be supplemented with a designation for research that requires "special scrutiny."⁹ We suggest that a similar designation of *special care* be operationalized to draw attention to the extra resources needed to counter the effects of social marginalization on the provision of health care. Rather than emphasize vulnerability, with all the implications noted above, health care workers could speak of patients who deserve special care to ensure that they are treated optimally despite social barriers.

ten Have's paper highlights the ongoing need for improved theorizing about vulnerability; he argues for focusing less on individual agency and more on respecting our common human vulnerability.¹ But how should these concepts best be realized in practice? Luna's work on "layers of vulnerability" calls attention to the different factors, contexts, and processes that lead to marginalization²; we argue that this framework is particularly salient in the context of food insecurity, and we provide suggestions for how attention to marginalization can be put into practice in nutrition.

Food Insecurity and Marginalization

Food insecurity is defined as the economic or social condition of unreliable access to adequate, affordable, nutritious, and safe food for an active, healthy life.¹² It is linked to

adverse outcomes, such as inadequate diet, poor physical and mental health, challenges to cognitive development, and noncommunicable diseases in adulthood.^{13,14} Programs addressing food insecurity often appropriately prioritize children due to their unique nutritional needs. However, issues related to food insecurity are, at root, issues of marginalization (based on social identities and positioning). Understanding the contexts of marginalization that result in food insecurity is essential to addressing it.

Food insecurity is a multilayered problem rooted in interconnected economic, social, environmental, and political systems.¹⁵ Luna's concept of "layering" is a useful tool to capture the multiple and often overlapping conditions that might result in food insecurity. For example, an immigrant child is not food insecure by virtue simply or solely of her immigration status. Rather, an immigrant child living in a community that is a new destination for immigrants, who has less access to well-developed safety nets, social networks, culturally competent health care practitioners, and advocacy organizations, might be more likely to be food insecure than an immigrant child in a destination that has a tradition and track record of meeting the needs of immigrants appropriately.¹⁶ If the child's caregivers are well educated and have access to resources, they might be able to overcome the barriers faced at a new destination, whereas an immigrant child of parents with fewer resources is further marginalized. Additional layers, such as caregivers' proficiency with the language of the new destination, documentation status, access to transportation, and so on, might also influence the child's food security status. Going beyond the concept of vulnerability, the concept of "layers of marginalization" helps illuminate why some people are more likely to experience food insecurity and thus provides insight into whom to target in interventions and how to intervene.¹⁷

Applying the concept of layering to practice can improve implementation of food insecurity interventions in at least 3 ways. First, attention to layers can help practitioners identify families and individuals who deserve special care as a result of their social marginalization, without blaming or stigmatizing them. To do so requires that health care practitioners and trainees reflect on the social processes by which certain people are more marginalized than others.¹⁷ It involves clinicians reframing their language (in charts, interactions with patients, and interactions with other practitioners) to avoid judgments based on stereotypes. For instance, chart notes can portray patients negatively through word choice or the presentation of irrelevant details and can cast doubt on patients' veracity or imply that they are responsible in problematic interactions; such stigmatizing notes are associated with more negative attitudes towards patients and poorer patient care.¹⁸ Reflections and actions that help practitioners address their own implicit biases can improve care provided to patients,¹⁹ suggesting that such interventions would also improve food insecurity interventions.

Second, by drawing attention to the overlapping contexts contributing to a person's social situation, layering as a metaphor accommodates a notion of collaboration among health care practitioners and patients that seems likely to promote sensitive accounting

of patients' concerns, priorities, and needs.²⁰ For example, instead of employing the 2-item screening questionnaire for household food insecurity discussed by the American Academy of Pediatrics (in which a positive screening result entails an affirmative response to 1 of 2 questions about fear of running out of food and actually running out of food in the last 12 months),¹³ some pediatric clinics have found that asking patients if they would like help or assistance (eg, "Would you like help with any of the following?") is more effective in addressing patients' needs.^{21,22} While families might not always be ready or able to access resources, a referral process that solicits the patient's preferences and input gives power to the patient and more sensitively captures social needs that might not meet screening thresholds.²¹ Here, attention to layers helps shape approaches to care that are more sensitive to the complexity of patients' lived experience than broad categories might otherwise be.

Finally, heightened attention to the layers of marginalization that contribute to food insecurity encourages clinical contexts to become "communities of care," in which staff members, trained volunteers, or community health workers connect and refer patients to community-based resources.¹⁴ Direct relationships between clinics and organizations such as the Supplemental Nutrition Assistance Program (SNAP), the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), and local food banks also contribute to communities of care.¹⁴ Such [systems of social support](#) that are connected to or integrated into facility-based settings can increase families' receipt of resources to address their unmet needs.²²

Conclusions

We argue that identifying marginalized groups as vulnerable can be inadequate and, at worst, stigmatizing and unfair. Health care interventions, including those addressing food insecurity, could benefit from considering the multiple layers of a person's life that reflect social marginalization. This approach would help to better target and adequately reach persons most at risk of food insecurity through improved patient-centered care.

References

1. ten Have H. Respect for human vulnerability: the emergence of a new principle in bioethics. *J Bioeth Inq*. 2015;12(3):395-408.
2. Luna F. Elucidating the concept of vulnerability: layers not labels. *Int J Fem Approaches Bioeth*. 2009;2(1):121-139.
3. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, US Department of Health, Education and Welfare. The Belmont Report: ethical principles and guidelines for the protection of human subjects of research. <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>. Published April 1979. Accessed February 11, 2018.
4. Protection of Human Subjects, 45 CFR pt 46 (2018).
5. President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry. Focusing on vulnerable populations.

<http://govinfo.library.unt.edu/hcquality/meetings/mar12/papch08.htm>. Published March 1998: chap 8. Accessed February 11, 2018.

6. Davis J, Lovegrove M; Allied Health Solutions; National Inclusion Health Board; Queen's Nursing Institute. Inclusion health: education and training for health professionals: appendices. <https://www.bl.uk/britishlibrary/~media/bl/global/social-welfare/pdfs/non-secure/i/n/c/inclusion-health-education-and-training-for-health-professionals-appendices.pdf>. Published January 2016. Accessed February 11, 2018.
7. Siqueira SAV, Hollanda E, Motta JJ. Equity promotion policies in health for vulnerable groups: the role of the Ministry of Health. *Cien Saude Colet*. 2017;22(5):1397-1406.
8. Hurst SA. Vulnerability in research and health care; describing the elephant in the room? *Bioethics*. 2008;22(4):191-202.
9. Levine C, Faden R, Grady C, Hammerschmidt D, Eckenwiler L, Sugarman J; Consortium to Examine Clinical Research Ethics. The limitations of "vulnerability" as a protection for human research participants. *Am J Bioeth*. 2004;4(3):44-49.
10. Henderson GE, Davis AM, King NMP. Vulnerability to influence: a two-way street. *Am J Bioeth*. 2004;4(3):50-52.
11. Smedley BD, Stith AY, Nelson AR, eds; Institute of Medicine. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: National Academies Press; 2003.
12. US Department of Agriculture. Definitions of food security. <https://www.ers.usda.gov/topics/food-nutrition-assistance/food-security-in-the-us/definitions-of-food-security>. Published October 2017. Accessed February 11, 2018.
13. Committee on Nutrition, American Academy of Pediatrics Council on Community Pediatrics. Promoting food security for all children. *Pediatrics*. 2015;136(5):e1431-e1438. doi:10.1542/peds.2015-3301.
14. Barnidge E, Stenmark S, Seligman H. Clinic-to-community models to address food insecurity. *JAMA Pediatr*. 2017;171(6):507-508.
15. Hendriks SL. The food security continuum: a novel tool for understanding food insecurity as a range of experiences. *Food Secur*. 2015;7(3):609-619.
16. Derose KP, Escarce JJ, Lurie N. Immigrants and health care: sources of vulnerability. *Health Aff (Millwood)*. 2007;26(5):1258-1268.
17. Sharma M, Pinto AD, Kumagai AK. Teaching the social determinants of health: a path to equity or a road to nowhere? *Acad Med*. 2018;93(1):25-30.
18. Goddu AP, O'Connor KJ, Lanzkron S, et al. Do words matter? Stigmatizing language and the transmission of bias in the medical record. *J Gen Intern Med*. 2018;33(5):685-691.
19. Bailey ZD, Krieger N, Agénor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: evidence and interventions. *Lancet*. 2017;389(10077):1453-1463.
20. Garg A, Boynton-Jarrett R, Dworkin PH. Avoiding the unintended consequences of screening for social determinants of health. *JAMA*. 2016;316(8):813-814.
21. Bottino CJ, Rhodes ET, Kreatsoulas C, Cox JE, Fleegler EW. Food insecurity screening in pediatric primary care: can offering referrals help identify families in need? *Acad Pediatr*. 2017;17(5):497-503.

22. Garg A, Toy S, Tripodis Y, Silverstein M, Freeman E. Addressing social determinants of health at well child care visits: a cluster RCT. *Pediatrics*. 2015;135(2):e296–e304. doi:10.1542/peds.2014-2888.

Alexis K. Walker, PhD is a Hecht-Levi Postdoctoral Fellow in the Berman Institute of Bioethics at Johns Hopkins University in Baltimore. A political and medical anthropologist trained at Cornell University's Department of Science and Technology Studies, her research critically investigates relationships among finance, expertise, and health across a variety of settings, such as the global health efforts of international financial institutions and genomics startup companies.

Elizabeth L. Fox, PhD is a Hecht-Levi Postdoctoral Fellow in the Berman Institute of Bioethics at Johns Hopkins University in Baltimore. A nutritionist and social scientist trained at Cornell University's Division of Nutritional Sciences, her work focuses on improving the design and implementation of nutrition policies with the goal that they effectively reach intended beneficiaries in culturally sensitive ways.

Citation

AMA J Ethics. 2018;20(10):E941-947.

DOI

10.1001/amajethics.2018.941.

Acknowledgements

Alexis K. Walker and Elizabeth L. Fox contributed equally to this work. The authors also thank Anne Barnhill, Claire Davis, and Ruth Faden for their feedback during development of this paper.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.