

## ETHIC CASE

### Is Acute Care-Oriented Research Ethical in Resource-Limited Settings?

Commentaries by Anwar D. Jackson, MD, and Harold W. Neighbors, PhD

#### Abstract

In this case scenario, a medical student, Jenny, is conducting congenital heart disease research in a resource-limited setting faced with water insecurity. She has concerns about how ethical it is for her to conduct advanced clinical research in a region with more basic health needs. The first commentary argues that advanced clinical research in resource-limited settings follows the ethical principle of beneficence and interactional justice but violates the principle of distributive justice. The second commentary questions whether beneficence is enough, since the Belmont Report states that beneficence is the obligation to simultaneously reduce harm *and* increase benefit. It calls upon public health physician-scientists to think deeply about how to involve communities in their research—and how to insert themselves into health policy development processes.

#### Case

Medical student Jenny arrives in a developing country optimistic and eager to participate in congenital heart disease research under a world-renowned clinician and researcher. Jenny stays with a local family in a village. Each morning, she hears the eldest daughter of her host family rise before dawn on her way to the local river. Balancing a large, filled-to-the-brim basin on her head, she travels daily with other women from her village to bring water to her home for drinking, washing, cooking, and cleaning.

Jenny wonders whether it makes sense from an ethical point of view to focus research in this community on developing highly specialized interventions for congenital heart disease when the people here only have reliable access to clean drinking water because a woman from each home—like many women in the world—spends much of her day retrieving it. As a guest, Jenny is aware that members of her host family make do with less water so that she can have a share of it. Additionally, some of the women have expressed concern that their access to their current clean water source could be limited in the future, due to contamination threats from upstream farms and local petroleum extraction as well as potential privatization of a large tract of currently public land that the women traverse to get to the water source.

Jenny wonders whether she and other members of her research team should begin participating in the water retrieval journey with the neighboring women. She also wonders whether their research efforts might be better devoted to helping members of this community achieve more certain water security over the long term.

### **Commentary 1**

**by Anwar D. Jackson, MD**

Jenny's case represents what will undoubtedly become an increasingly common ethical dilemma in global health over the next 20 years. One of the major foundations supporting international development, the Bill and Melinda Gates Foundation, predicts that the economic gap between low-income and middle-income countries will disappear by 2035 [1]. This rapid economic development is expected to trigger and be accompanied by equally rapid developments in the health of their populations. Advancements in medical technology and health delivery systems in low-income countries can realistically reduce infectious, maternal, and child mortality to universally low levels within the next two decades [2-3]. However, achieving advances in medical technology does not always equate to the universal provision of basic public health needs. Even in high-income countries with fully developed and long-standing health systems, there are local populations suffering from persistent public health concerns such as food and water insecurity [4-5]. This dichotomy is more pronounced in nations that have not yet completed their economic transition and where many people reside in locations with limited resources. Researchers and health professionals working in these settings are thus faced with an ethical question of justice: How can they best allocate their talents and skills in order for the local population to receive maximum benefit [6]?

The complexity of this ethical conundrum's solution mirrors the complexity of the problem. Jenny is a member of a research team that specializes in congenital heart disease. Furthermore, the area where she is based might have an uncharacteristically high rate of congenital heart disease, which would make her research critical to the future well-being of her host village. Under these circumstances, Jenny's focus on congenital heart disease follows the principle of *beneficence*, which makes the welfare of research participants a primary concern, because she is using her knowledge and ingenuity to analyze and overcome a medical issue faced by her host village. Although Jenny exercises beneficence, she still falls short of upholding the principle of *distributive justice*. Distributive justice is the allocation of resources such that the community using the resources achieves the best outcome [7]. Under a utilitarian framework, the best outcome is synonymous with the maximization of benefit [7]. In settings where resource scarcity jeopardizes water security, it is unlikely that there are the additional resources needed to support specialized clinical research and thus to maximize benefit. Jenny and her team must choose between preserving local health resources while sacrificing quality research or diverting local health resources to uphold the standards of specialized

clinical research. While both options may yield good outcomes, neither yields the best possible outcome.

### **Balancing Clinical Research with Community Needs**

The amount of resources required to appropriately perform and act on Jenny's research might be extraordinary. Although people living in resource-limited settings are entitled to the same benefits of clinical research that are available to those in the developed world, these benefits are only possible if the clinical research from which they are derived is held to the same rigorous standards that govern clinical research in wealthier regions [8]. These standards include having adequate infrastructure in place for quality assurance and quality improvement of the study, having appropriate staff and resources necessary to execute the study, and being able to adequately educate and gradually assess the comfort and willingness of research participants in the study [9]. Given the potential drain on resources that could be required to achieve these standards, all measures should be taken to maximize the research's impact on the local population.

However, in a community where basic public health needs are difficult to achieve, advanced medical care may be a secondary concern. According to the renowned psychologist Abraham Maslow, people cannot address higher human needs until they have addressed basic necessities for survival such as food and water security [10]. In Jenny's host village, the principle of Maslow's hierarchy dictates that water security must be addressed before more advanced forms of health care can be successfully implemented. Otherwise, the people of the village would likely have difficulty in making the commitments necessary to ensure the quality of the study. These conditions could create an unfavorable risk-benefit ratio for the community if the risks of diverting resources away from water security outweigh the benefits that would be gained from a poorly executed study [8]. An unfavorable risk-benefit ratio would undermine Jenny and her team's ability to ethically perform their research [8]. Jenny and her team's research might meet other qualifications that govern clinical research ethics in resource-limited settings, but many of these components are tied to ensuring a favorable risk-benefit ratio, which would be difficult to do without first ensuring water security. Given these circumstances, Jenny and her team should first direct their attention to addressing water insecurity in the village. While addressing these concerns might be time consuming for Jenny and her team and would possibly require more than one trip to the village, Jenny and her team can ethically proceed with their research only after these concerns have been addressed.

Nevertheless, students and health professionals who perform advanced clinical research in resource-limited settings can be valuable assets to their host communities, and these communities often reciprocate the benefits researchers provide with generous hospitality. As the beneficiaries of their gratitude, researchers may find themselves facing a new dilemma. The purveyors of such generosity are usually the same individuals

who tend to a household's basic needs, such as food and water acquisition. In many resource-limited settings, this means the provision of hospitality becomes the primary responsibility of women and children [11].

While conducting specialized research in resource-limited settings might raise questions about distributive justice, the treatment researchers receive from their host communities might elicit concerns about *interactional justice*. Interactional justice is primarily concerned with how people are affected by decisions enacted by others and with treating the people affected by these decisions with [dignity and respect](#) [12]. Host families are subject to decisions made by their guests in several ways, with the provision of food and water being chief among them. Even if host families are compensated for accommodating visiting researchers, the household members responsible for providing and maintaining the accommodations must still expend additional time and effort that might have been used in other ways. For example, reductions in water collection times have been shown to allow women and children more opportunities for education, quality family time, and other proactive activities [13]. Jenny's desire to aid in water retrieval reflects her understanding of the ramifications of her presence for her host family. While it is appropriate and within the bounds of interactional justice for Jenny and other members of her research team to assist with water retrieval and other household tasks, they should offer their assistance while respecting the cultural and social practices of their hosts.

### **Conclusion**

In summary, Jenny's research and other research like hers can and should be ethically performed in resource-limited settings if the communities' basic needs have been fulfilled. Although her research exemplifies beneficence, it does not meet the qualifications for distributive justice, as it does not maximize benefit for the local population experiencing water insecurity. As such, Jenny and her research team should review the process through which their research is implemented in order for it to have the greatest impact on the local population and address water insecurity in the village. Jenny and others might also ease any burden caused by their presence by providing assistance with household tasks; however, they should do so in a manner that is culturally and socially acceptable to their host communities. If Jenny and her team are able to successfully implement distributive justice in their research and interactional justice in their host community, they can be the catalysts for both short-term and long-term positive change in that host community.

### **References**

1. Healy J. A case for the future of global health. *Harvard Public Health Rev.* 2015;6. <http://harvardpublichealthreview.org/a-case-for-the-future-of-global-health/>. Accessed July 10, 2017.

2. Dybul M. A grand convergence and a historic opportunity. *Lancet*. 2013;382(9908):e38-e39.
3. Jamison DT, Summer LH, Alleyne G, et al. Global health 2035: a world converging within a generation. *Lancet*. 2013;382(9908):1898-1955.
4. Cunningham TJ, Barradas DT, Rosenberg KD, May AL, Kroelinger CD, Ahluwalia IB. Is maternal food security a predictor of food and drink intake among toddlers in Oregon? *Matern Child Health J*. 2012;16(suppl 2):339-346.
5. Tindall JA, Campbell AA. Water security—national and global issues. US Department of the Interior Geological Survey; November 2010. <https://pubs.usgs.gov/fs/2010/3106/pdf/FS10-3106.pdf>. Accessed July 10, 2017.
6. Dauda B, Dierickx K. Viewing benefit sharing in global health research through the lens of Aristotelian justice. *J Med Ethics*. 2017;43(6):417-421.
7. Capp S, Savage S, Clarke V. Exploring distributive justice in health care. *Aust Health Rev*. 2001;24(2):40-44.
8. Emanuel EJ, Wendler D, Killen J, Grady C. What makes clinical research in developing countries ethical? The benchmarks of ethical research. *J Infect Dis*. 2004;189(5):930-937.
9. US Department of Health and Human Services. Standards for clinical research within the NIH intramural research program. [https://clinicalcenter.nih.gov/ccc/patientcare/pdf/cc\\_research\\_standards.pdf](https://clinicalcenter.nih.gov/ccc/patientcare/pdf/cc_research_standards.pdf). Published October 2009. Accessed August 28, 2017.
10. Melloul AJ, Collin ML. Harmonizing water management and social needs: a necessary condition for sustainable development. The case of Israel's coastal aquifer. *J Environ Manage*. 2003;67(4):385-394.
11. Graham JP, Hirai M, Kim SS. An analysis of water collection labor among women and children in 24 sub-Saharan African countries. *PLoS One*. 2016;1(6):e0155981. <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0155981>. Accessed July 10, 2017.
12. Dai L, Xie H. Review and prospect on interactional justice. *Open J Soc Sci*. 2016;4:55-61.
13. Cairncross S, Cliff JL. Water use and health in Mueda, Mozambique. *Trans R Soc Trop Med Hyg*. 1987;81(1):51-54.

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## Commentary 2

by Harold W. Neighbors, PhD

In 1974, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was convened to identify basic principles for the ethical conduct of research involving humans [1]. Five years later, the commission published the Belmont Report, which established three basic ethical guidelines for research: respect for autonomy, justice, and—the focus of this essay—*beneficence*. According to the Belmont Report, the principle of beneficence obligates researchers to minimize harm *and* “maximize possible benefits” to study participants and the community [1]. This essay addresses the challenge of what it means, on a practical basis, to embrace the notion that the ethically responsible public health physician-scientist should maximize community benefits within the context of research.

In this case, a medical student, Jenny, wonders if it is ethical for her to conduct research on congenital heart disease when those living in the community of study have such poor access to something as basic as drinking water. This case raises two important questions: (1) Should medical students pursue specialized research in resource-poor communities with water security concerns? (2) What is the researcher’s ethical obligation to community residents while conducting specialized research when residents do not have reliable access to clean drinking water?

I will address Jenny’s dilemma within the context of research on human health that seeks to provide the data, and the evidence, necessary to move the scientific process closer to providing a benefit. I write about Jenny’s case in the voice of an African American male and public health social scientist who is committed to health equity. I also write as one engaged in community-based participatory research (CBPR). CBPR is an especially appropriate research vehicle to use in exploration of beneficence because CBPR, perhaps more than other research approaches, is based heavily upon the ultimate goal of improving the social, political, and health conditions of the communities within which research is conducted. CBPR also requires researchers to ensure that the research provides benefits *equally* to the scientists, study participants, and community members [2, 3]; in fact, CBPR is ultimately a social change strategy [4]. However, conducting research that so clearly emphasizes community change to improve community health is a tall task.

If Jenny’s challenge sounds familiar, it is because it is hauntingly similar to the ongoing unnatural disaster in Flint, Michigan. Both communities are challenged by water insecurity and are under-resourced financially. Both communities have attracted the attention of researchers and, as a result, must confront the question of whether, and how, research actually benefits study participants and the broader community. While water insecurity has received the bulk of public attention in Flint, some research investigators are working on other health problems, such as heart disease, similar to

Jenny. It is also very apparent that those researchers in Flint must, in some way, address the issue of water insecurity, just as Jenny must.

Though similar to Flint, Jenny's situation is not exactly comparable. For example, Jenny's heart research is not *directly* related to water insecurity and does not seem to have any immediate or direct benefit to the community in which she is working. Nevertheless, by virtue of her living in the area, Jenny cannot avoid consideration of the impact that water insecurity has on her community responsibilities.

As mentioned, much, but certainly not all, of the research conducted in Flint bears directly on water insecurity, and, in some respects, Flint has benefitted from that research. It is clear that research played a vital role in drawing attention to the most recent episode of the ongoing water "crisis" [5]. In Flint, if it were not for the research showing high levels of lead in the water combined with the analysis showing an association between lead in the water and lead in children's blood [5], there may never have been the level of community outrage that mobilized the political action that has ensued. Research conducted in Flint has, to some extent, benefited city residents by providing scientific evidence consistent with community knowledge that the water was damaging to residents, especially children. Unlike the beginning of the crisis, when many doubted, refused to consider, or even denied that lead in the water was damaging the health of Flint residents, presently everyone believes this to be the case. However, this is an important but modest victory. The reality is that many Flint citizens do not fully trust researchers or governmental officials. Nor do they believe that their water is safe to drink [6]. In short, the research conducted in Flint has yet to deliver on the ethical obligation of maximizing community benefits for the residents of Flint [7]. Flint residents are still waiting for research to deliver a solution to the water crisis. This remains a work in progress.

Herein lies the difficulty with beneficence. It is an aspiration that can go unfulfilled. Research participants and the community residents they represent certainly deserve some benefits from research; and the Belmont Report clearly demands as much. The problem is that communities often have to wait to obtain those benefits. Even when there is benefit, it often takes decades before an intervention program is deemed effective enough to be widely disseminated [8, 9]. Offering *study participants* financial incentives is certainly a benefit. However, it must be made clear during the recruitment and consenting process that any potential community benefits are heavily dependent upon years of subsequent work, follow-up studies, and scientific debate.

Given this state of affairs, what is Jenny or, for that matter, any community-based research scientist to do regarding benefitting the community within which they are working? I offer three paths for consideration.

First, public health physician-scientists need not conduct research. Unlike most researchers, they have the option of patient care. Since, in my experience, most medical students are attracted to the profession because of a desire to help people by treating and healing their wounds, they need not engage this particular research ethics challenge. The treatment benefits are more obvious and immediate.

A second option is for the public health physician-scientist to remain primarily in the world of academia, conducting basic and applied research. It is not necessary for any research scientist, clinically trained or otherwise, to join the politically driven community activism characterized by CBPR. In fact, it might be the case that all research, no matter how far removed from local residents, may eventually provide community benefits, albeit *indirectly*. Some physician-scientists focus on the quest for knowledge and may not be especially concerned with the practical application of that knowledge or how their research affects community residents. As a result, they are less encumbered by the challenge of how to maximize benefits for marginalized and economically oppressed communities.

I am promoting a third option. Medical students, like Jenny, can forge a transdisciplinary research identity that places medicine more directly within the context of public health and CBPR. Medicine can be a natural ally with the CBPR public health approach to community change. It is true that public health is primarily involved in prevention and medicine primarily in treatment. However, public health and medicine overlap; they share much common ground.

I propose three recommendations regarding this case. First, both medical and public health approaches are equally necessary. As a medical student, Jenny must use her biomedical expertise to help build knowledge about congenital heart disease while also participating in the broader public health activities of water safety and retrieval. Periodically, Jenny must step away from the individual study participants in order to more clearly view the big picture of how both [medical healing and community research](#) exist within a larger ecological framework. By "stepping away," I suggest that there is an advantage to periodically engaging a broader perspective that considers the role of economic, political, gendered, and racial factors in the production of chronic disease [10]. The limitations of patient care for improving population health demands that medical students like Jenny expand beyond individual patient care to obtain additional training, such as a certificate in public health or a second graduate-level degree (e.g., MPH, MS, PhD).

Second, there is a preferred sequence to helping. Helping the community to address, reduce, or eliminate water insecurity must be the first priority, although this need not be addressed within the context of research or patient care. Jenny, like all of us, has a civic responsibility to address such basic necessities before, or at least in conjunction with,

treating and/or conducting research on heart disease, diabetes, hypertension, depression, or cancer. Research and social activism are separate activities, although they are closely linked within CBPR. Jenny's study is not CBPR. That does not, however, release her from the responsibility of getting involved in such an important community problem. To be specific, Jenny should help the women in her community carry water.

Third, as research scientists, we must do more than reduce harm. Researchers should do as much as possible to maximize immediate and long-term benefits to the residents from the communities where studies are conducted. A good place to start is by asking community residents which problems need to be studied and why. Simply ask, "How can we help?" Researchers also need to share executive decision-making power with community residents. This means the research team, and especially the principal investigator, must include community representation *before* submitting research proposals. In this way, public health physician-scientists like Jenny can ensure that community residents are equal partners in the initial [research planning process](#). And in this way, community members can counsel, guide, and educate researchers about how best to identify and incorporate tangible community benefits, such as budget line items, appropriate respondent incentives, hiring local talent as research assistants, and the appropriate use and [dissemination of research findings](#).

In conclusion, rigorous research is the basis of evidence. Everyone deserves access to evidence-based treatment and intervention programs. For this to happen, public health physician-scientists must do at least two things: they must invite community members to help shape research proposals, and they must insert themselves into the health policy process. This is the path to community beneficence.

## References

1. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 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/index.html>. Published April 18, 1979. Accessed August 29, 2017.
2. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998;19:173-202.
3. Shore N. Re-Conceptualizing the Belmont Report: a community-based participatory research perspective. *J Community Pract*. 2006;14(4):5-26.
4. Minkler M, Garcia AP, Rubin V, Wallerstein N. *Community-based participatory research: a strategy for building healthy communities and promoting health through policy change*. Oakland, CA: PolicyLink; 2012. <http://www.policylink.org/mwg-internal/de5fs23hu73ds/progress?id=q1IWNPR1ZcqpWtRQJI-QciWGxBCd5RZXvXXwkJmb3IM,&dl>. Accessed August 29, 2017.

5. Hanna-Attisha M, LaChance J, Sadler RC, Champney Schnepf A. Elevated blood lead levels in children associated with the Flint drinking water crisis: a spatial analysis of risk and public health response. *Am J Public Health*. 2016;106(2):283-290.
6. Fonger R. With Flint water improving, officials at town hall work on convincing residents. *MLive*. January 11, 2017. [http://www.mlive.com/news/flint/index.ssf/2017/01/flint\\_town\\_hall\\_on\\_water.html](http://www.mlive.com/news/flint/index.ssf/2017/01/flint_town_hall_on_water.html). Accessed August 29, 2017.
7. Sadler RC, LaChance J, Hanna-Attisha M. Social and built environmental correlates of predicted blood lead levels in the Flint water crisis. *Am J Public Health*. 2017;107(5):763-769.
8. Brownson RC, Colditz GA, Proctor EK, eds. *Dissemination and Implementation Research in Health: Translating Science to Practice*. New York, NY: Oxford University Press; 2012.
9. Green LW, Ottoson JM, García C, Hiatt RA. Diffusion theory and knowledge dissemination, utilization, and integration in public health. *Ann Rev Public Health*. 2009;30:151-174.
10. Cockerham WC, Hamby BW, Oates GR. The social determinants of chronic disease. *Am J Prev Med*. 2017;52(1)(suppl 1):S5-S12.

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