The Gap in Current Disparities Research

A Lesson From the Community

Paul S. Chan, MD, MSc

Once again this year, along with ≥300 outcomes and health services researchers, I attended the American Heart Association’s Quality of Care and Outcomes Research conference during the first week of June in Baltimore. I started coming to this unique conference nearly a decade ago. With some of the world’s leading authorities on quality and appropriateness of care, healthcare disparities, and research methods, this conference has been a critical venue for my academic and personal development because its intimate size has facilitated the development of several mentorship relationships for me.

Starting in 2012, some of us have stayed on after the conclusion of the conference to do community service for an afternoon in the host city before returning to our home towns. We typically work in a food bank or serve a meal at a shelter, and this experience has been one of my favorite parts of the conference, as a core group of us have gotten to know one another better outside of the traditional academic environment. This year, we deliberately planned a more thought-provoking experience by spending time talking with the founders of the organizations we visited. A diverse group of 14 of us, ranging from an editor-in-chief of a Circulation journal, a Dean of Nursing, various academic faculty, and 3 trainees devoted 4 hours at 2 local community organizations. As a group, we had collectively published ≥1000 articles, with several of them focused on socioeconomic and racial disparities in care.

We began at the Bea Gaddy Center in East Baltimore, on the periphery of the Johns Hopkins Hospital. Bea Gaddy was an iconic figure in her day, rallying diverse resources to feed and clothe the hungry. Called the Mother Teresa of Baltimore by the local Baltimore Sun newspaper, her center still feeds and clothes the hungry. We were confronted with the reality faced by the poor—“that would be arrogant,” she noted—but to walk in solidarity with the poor. She saw what they did as providing hospitality (and in her faith-based world view, to God in each one of the poor among them), and that this was a privilege to do on a daily basis. “We wait on our guests for a 3-course meal—many of whom have never had a sit-down privilege to do on a daily basis. “We wait on our guests for a 3-course meal—many of whom have never had a sit-down privilege to do on a daily basis. “We wait on our guests for a 3-course meal—many of whom have never had a sit-down privilege to do on a daily basis. “We wait on our guests for a 3-course meal—many of whom have never had a sit-down privilege to do on a daily basis. “We wait on our guests for a 3-course meal—many of whom have never had a sit-down privilege to do on a daily basis.

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We then crossed over to West Baltimore to spend time with Brendan and Willa Walsh at Viva House. The 2 of them have been living and working among the Baltimore poor for ≥4 decades, integrating works of mercy (housing the homeless and feeding the hungry) with social and political activism. Brendan was frank about conditions in West Baltimore—a pervasive drug culture that has eroded the social and spiritual fabric of the community, where the only gainful employment since Bethlehem Steel pulled out of Baltimore several decades ago is the drug trade. The violence is so severe that West Baltimore was the setting for the hit series, The Wire, on which Viva House was featured on 3 different occasions. Brendan shared that the show captured correctly the grim reality and despair confronting youth in West Baltimore today. In fact, in the 10 days leading up to our visit, 3 individuals were shot and killed within a 6 block radius of Viva House, including Oscar Torres, a 15-year-old shot in the head just 10 feet from their house.

As the afternoon went on and our group processed the stories, images, and experiences from the Bea Gaddy Center and Viva House, it became apparent that each of us grew increasingly uncomfortable. We had begun the afternoon with the objective to learn more about Baltimore, perhaps to do a little good. We were confronted with the reality faced by the poorest of the poor in inner city of America—a toxic combination of poverty, joblessness, despair, drugs, violence, and apathy from outsiders—without a clear path for a better future or a vision for hope. We struggled with how Brendan and Willa Walsh continued to devote their lives working and living among the poor in West Baltimore when it all seemed to make little, if any, difference. On our tour of Viva House, Willa shared with me that the goal of their efforts was not to solve poverty—“that would be arrogant”; she noted—but to walk in solidarity with the poor. She saw what they did as providing hospitality (and in her faith-based world view, to God in each and every one of the poor among them), and that this was a privilege to do on a daily basis. “We wait on our guests for a 3-course meal—many of whom have never had a sit-down meal with someone waiting on them—and we build relationships with them as individuals so they are no longer invisible to society.”
Our cardiovascular outcomes community spends enormous (and important) amounts of time writing guidelines, measuring disparities, assessing adherence to evidence-based therapy, and identifying gaps and variations in care. As each of us processed our experiences that afternoon in Baltimore, several things were apparent to members of our group:

1. Health is one of many pressing priorities for poor people. It seems obvious to say this, but we as healthcare professionals often focus only on the medical condition of the patient and not the patient as a whole. It is really challenging for a patient with heart failure who is poor to adhere to their medication and fluid restriction treatment plan because they inevitably have to deal with competing economic challenges when they are discharged from the hospital. Decisions about whether they can pay for their medications are common, as even the small $4 copay for generic medications equals their daily Food Stamps allotment, let alone whether they have the means to buy fresh fruits and vegetables and avoid much cheaper but less healthy canned soups and foods. Poor patients with extremely meager financial resources are routinely labeled as noncompliant and frequent-flyers in our healthcare system, but the underlying reasons for their inability to adhere to our medical treatment plans may have more to do with their competing daily challenges of extreme poverty, hunger, health illiteracy, gang violence, and single parenthood.

2. The status quo of disparities research is untenable. The experiences at the Bea Gaddy Center and Viva House made us uncomfortable because they challenged the core of our research mission: at the end of the day, have any of our papers on racial and socioeconomic disparities (some of them even in high-impact journals) really improved our brothers’ and sisters’ lots in the healthcare world? During the past 3 to 4 decades, our research community has successfully described socioeconomic and racial gaps in healthcare outcomes, but it is less clear that we have succeeded in developing effective programs and interventions that have reduced these disparities. Despite our best intentions, we seem to have fallen into the proverbial Ivory Tower trap, with our articles advancing our research agenda that promotes real solutions for reducing disparities and improving the health of the poor. This will require innovative thinking in problem solving and implementation because thinking of our patients who are poor as only disease X is bound to fail without addressing the myriad challenges they need to overcome just to focus on their health. Although successful programs and interventions that reduce disparities in care remain undefined, we as academic researchers need to hold ourselves to a higher standard and not simply procure yet more descriptions of existing disparities. Journals and funding agencies, in turn, should demand in the future more creative problem-solving and interventions in disparities research.

3. As a healthcare community, we need to find ways to make it easier for people to be healthy. As with many short-term overseas medical mission trips, which focus on corrective surgeries for a handful of individuals but leave untouched much larger needs of potable water, latrines, dependable sources of income, microcredit financing, and girls going to school, we as healthcare professionals have a unique opportunity—and some would argue a responsibility—to become engaged in the social and economic issues of the poor so that we can give voice to their concerns. If we want our efforts to promote health and prevent disease to succeed, we may need to walk in solidarity with those we write about and start educating ourselves and fight for programs, which would make it much easier for people to become healthy. There is, of course, no one-size-fits-all prescription of what we can or should be doing. However, by becoming engaged in our patients’ worlds in incremental but meaningful ways, we move away from medicalizing their conditions and gain a more complex and fuller appreciation of how their disease conditions are shaped by social and economic constructs.

We all felt uncomfortable during our experiences that afternoon in Baltimore because we felt powerless and helpless, after immersing ourselves, however briefly, in the real-world issues of poor folks in 1 inner city. As a talented group of researchers, we were not used to feeling that our volumes of disparities papers may have achieved little after all. However, if we are serious about disparities, we need to keep in mind that (1) health is one of many pressing priorities for poor people, (2) the current format on disparities research needs to shift to developing programs and interventions, which can make a difference, and (3) as a healthcare community, we need to find ways to make it easier for people to be healthy. We need to practice what Simone Weil, the 1930s French philosopher and mystic, called “intellectual honesty”, and redouble our efforts on disparities research so that the chasms separating white from black, poor from rich, uninsured from privately insured, can start to narrow. And if we have the humility to walk this walk, realizing that even if that gap does not close quickly in a year or 10 years, such a journey of earnestly walking in solidarity with the marginalized in our midst will break down the barrier of “us” talking about “them” as poor people and refocus the discussion about “we” as a human community.

Acknowledgments
I thank Drs Anderson, Nallamothu, and Spatz for their inspiration, encouragement, and constructive comments for this commentary.

Disclosures
None.

Key Words: healthcare disparities ■ outcome assessment (health care)
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Circ Cardiovasc Qual Outcomes. published online August 5, 2014;
Circulation: Cardiovascular Quality and Outcomes is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2014 American Heart Association, Inc. All rights reserved.
Print ISSN: 1941-7705. Online ISSN: 1941-7713

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://circoutcomes.ahajournals.org/content/early/2014/08/05/CIRCOUTCOMES.114.001234.citation

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