The Penumbra

The right decisions need the right voices

Community-engaged care is an essential and powerful part of high-quality health care. Its premise is that the voices of those who are impacted, who experience a condition, or who have relevant lived experiences should be considered authoritative in situations where decisions are made and human, time, or financial resources are being allocated. Similarly, the voices of scholars who represent the affected group are most powerful when they are aligned with community experiences, while providing the scientific rigor to assess needs and develop and test effective solutions. When community voices are missing, accountability and transparency are impossible to achieve, which creates the potential for not only exclusion but also harm, harassment, and waste.

Take Black women's health. Black women in the USA are more likely to die in childbirth than women in some developing nations. Even among Black women with a college education or higher in the USA, the pregnancy-related mortality ratio is 5·2 times that of their white counterparts. Progress to improve Black maternal mortality has been inhibited by damaging narratives, including that of the "high risk patient"—ie, the individual comes with a set of inborn risk factors for poor health—and the concept that race is simply a proxy for socioeconomic status. These narratives, which conveniently ignore the toxic health effects of gendered racism, have flourished due to the persistent habit of systematically leaving those who should be leading the conversation out of the conversation. Some would say we should "include" these voices—a word that makes one think of a reluctant afterthought on a birthday party list. Rather, we should centre these voices.

Unfortunately, gendered and racial hierarchies define the guiding voices of health care. Every platform where an opinion is shared, from social media to traditional media to academic publications, is resplendent with examples of how women, especially Black women, are ignored and dismissed. Even with topics most relevant to women, men all too often feel comfortable opining among themselves in a zone that is free of women. Men typically collaborate with other men on scholarly projects that lead to papers and grants, and primarily cite each other in scientific work, creating a cycle of "expert" framing in published work that can be inaccurate yet is perpetuated in grant proposals, scientific meetings, and clinical health services provision. These cycles contribute to the persistently low number of women as tenured professors, department chairs, and decision makers within health-care institutions. Exclusions are compounded when experienced by gender non-conforming, non-binary, and other scholars whose lived experiences directly align with their research interests.

Is it right and good for everyone to speak up for the needs of a vulnerable population? Yes, of course. But in the process, we must pay special attention to the research, opinions, and recommendations of those from within the very group we claim to be advocating for, and when their voices are absent, commit to addressing the factors that systematically keep them out of the rooms where they are needed. The absence of these perspectives in health education, provision of health services, and biomedical research means we miss a prime opportunity to unlock promising new discoveries to improve health outcomes and mitigate harm across populations.

A collective effort is required to bring these neglected voices to the surface. Journal editors have a responsibility here. Conference planners do too. So, too, do federal funders, clinical and research training sites, university departments and selection committees, promotion and tenure committees, hospital administrators, and licensure and regulatory bodies. Together, we can develop a shared roadmap to ensure that the voices of communities are drawn out of the margins and into the epicentre of the effort to improve health-care experiences.

Those most impacted by inequities and discrimination are ready to lead the way to a better future. Ceding the floor to them should move us closer to understanding how to achieve health equity for the public we serve and those of us fortunate enough to be providers of care.

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For more on **The Penumbra** see **Comment** *Lancet* 2019; **394:** 453 and **Perspectives** *Lancet* 2019; **394:** 461

Further reading

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