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Making Ethics Happen: Addressing Injustice in Health Inequalities

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Submitted abstract:

Health disparities-reduction research and implementation efforts are based on high ethical ideals. Given the cultural milieu in which research often occurs: How do we make these ideals happen? How do we bring about justice and fairness in health? Sisk and colleagues propose “implementation science” as a key to making an “is” from an “ought.” They suggest that bioethical and bioethics-motivated research be collaborative and interdisciplinary, including both researchers of many types and the communities and individuals motivating the research activities who will most benefit from that research and outreach. We agree. However, we argue that Sisk and colleagues underemphasize the many cultural and cross-cultural factors in bringing research efforts to fruition, especially when researchers and research subjects inhabit somewhat different cultures. We illustrate this and offer guidelines for implementation based on known best practices for engaging and addressing racial health disparities in the US.

Research and implementation efforts to address health disparities are motivated by high ideals concerning ethics and social justice:

- nobody should be unfairly deprived of health care;
- nobody’s health should be worse than anyone else’s because of unjust social and economic conditions;
- everyone should have access to the same quality and quantity of care, irrespective of race or socio-economic background:

In sum, applied conscientiously, these egalitarian views can help mitigate health- and health-care related injustices.

Given the cultural milieu in which research and health-related initiatives often occur, how do we actualize these ideals? How do we bring about justice and fairness in health and health-care? How do we turn how things *are* into how they *should be*?

Sisk and colleagues propose “implementation science” as a key to making an “is” from an “ought.” These are, or should be, related and a quote often attributed to Immanuel Kant

makes clear the relationship: “theory without practice is empty; practice without theory is blind.” *Practice* is needed to understand what’s needed, possible and probable in seeking the goals that *theorizing* develops, and *theory* is developed and refined in light of practical needs: the relationship is dynamic and synergistic.

Sisk and colleagues operationalize the implementation of ethical ideals in terms of five domains: *intervention characteristics*, *outer settings*, *inner settings*, *characteristics of the individuals involved*, and *the process of implementation*. This way of characterizing these categories, however, is likely not self-evident to many people, and we suggest that better language be developed to clarify this process of implementation.

Nevertheless, we strongly support their proposal and its implications that bioethical and bioethics-motivated research be collaborative and interdisciplinary, including both researchers of many types: bioethicists, scientists, community educators and advocates, and the communities and individuals motivating the research activities who will most benefit from that research and outreach.

Sisk and colleagues, however, seem to underemphasize the many cultural and cross-cultural factors in bringing research efforts to fruition, especially when researchers and research subjects inhabit somewhat different cultures. We will illustrate this and offer guidelines for implementation based on known best practices for engaging and addressing racial health disparities in the US. These guidelines, however, are applicable to *any* research or intervention where the researchers and the research subjects find themselves to be different in ways that might undermine the research because of various culture, communication, and values gaps.

In their “Strengthening Diversity in Research Partnerships: Knowledge to Action Guide,” (2019) Coleman and colleagues urge that research with diverse partners be guided by these principles:

- Trust
- Reciprocal Relationships
- Honesty
- Transparency
- Cultural Competency
- Co-Learning
- Partnerships

These values are interrelated. Trust, Honesty, and Transparency depend on clear communication and accurate understanding with both researchers and subjects. They require that researchers engage the research subjects in ways they will understand, with culturally-appropriate communication, and they require that subjects effectively communicate their perspectives and concerns with researchers (although the burden, of course, is on researchers to ensure this happens). Effective and respectful communication requires Cultural Competency on behalf of the researchers, so they engage subjects in ways that *they* find

respectful and honoring: researchers must listen to subjects and learn from them. While research subjects might not quite find researchers to be “one of us,” they cannot be “Other,” or else these communication principles won’t work.

In an important review of cultural competence, Reich and Reich (2006, 51) argue that respecting diversity in research partnerships require that:

... each participant in interdisciplinary collaborations must value diversity, develop the capacity for self-assessment, work towards understanding one’s own disciplinary culture, and be sensitive to the dynamics inherent when cultures interact. Additionally, members of any interdisciplinary endeavor must be cognizant of power dynamics at play and avoid such things as tokenism, informal hierarchies, and disciplinary policing. Through awareness of one’s own disciplinary culture and sensitivity to others, interdisciplinary research and practice may provide creative solutions to important problems.

And there is other excellent scholarly work on the nature and value of Cultural Competence and how to best put it into practice (Harvard Crimson, 2010; López, et al, 2017).

Concerns about communication and Cultural Competence lead to concerns about Reciprocal Relationships: if community members come to suspect that a research project is really more about researchers chasing grants and their own status-seeking, and not about genuinely helping the community, Trust is lost and researchers will be perceived as not Honest or Transparent: this jeopardizes the current and future research attempt: “Remember what happened last time? That wasn’t so good, so let’s not do that again.”

The interrelations between these principles, however, take us back to the theoretical question of what a problem really is: if researchers believe something in a community is a problem worth addressing, but the community members generally don’t find it to be a problem, is it a genuine problem? It is often disrespectful to impose “solutions” that would be genuinely beneficial if they are unwanted. However, not achieving achievable benefits for a community requires moral justification also. This takes us to a theoretical dilemma: what’s more important, benefits or respecting preferences? However this is answered, this makes it clear that identifying the processes for achieving ideals, and identifying those ideals themselves, are best done in Partnerships.

In sum, ethics-motivated social-justice work of all kinds is based on the theoretical insight that “ought implies can”: if we *ought* to do something, then it must be that we *can* do it: there is no sense in pursuing the impossible. Implementation science here is essential to this task of specifying what we can do in clear and concrete ways. Specifying the details on who, what and how an ethical ideal would be realized is essential to making ethics happen, and we applaud Sisk and co-authors for their urging us all to work together on these tasks, for the good of all.

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