

# Respect for Communities in Health Justice

Charlene Galarneau<sup>1,2,3</sup>  
and Patrick T. Smith<sup>4</sup>

1: HARVARD MEDICAL SCHOOL, BOSTON, MA, USA; 2: WELLESLEY COLLEGE, WELLESLEY, MA, USA; 3: BOSTON UNIVERSITY, BOSTON, MA, USA; 4: DUKE UNIVERSITY, DURHAM, NC, USA.

**Keywords:** Health Justice, Respect, Community, Communities, Public Health Ethics

**Abstract:** Health justice seeks, both conceptually and in practice, to strengthen community engagement and empowerment as an integral means of addressing health disparities. In this essay, we explore the nature of communities and their roles in health care/public health. We propose that an ethical *principle of respect for communities* is a requisite part of health justice. It is this respect for communities that ethically grounds health justice's calls for greater community engagement and empowerment. Conceptions of health justice, we claim, will gain ethical power and coherence as this principle is more clearly recognized and further developed.

"I believe that respect is the most powerful ingredient in creating authentic relationships, ... and in building healthy communities."

Sara Lawrence-Lightfoot<sup>1</sup>

Barely a decade old, the already vigorous health justice movement seeks to shift health law's historical focus on "market competition, professional autonomy, and patient rights paradigms" toward social justice including "using law as a tool to eliminate health disparities."<sup>2</sup> Among the core tenets of the health justice framework is a commitment "to listening, to engaging, and developing affected communities,"<sup>3</sup> and similarly, "to collective action grounded in community engagement and empowerment."<sup>4</sup> As such, communities play a key role in health justice both conceptually and in practice. To this largely legally framed movement we begin here by using the lenses and tools of ethics to delve into the nature of communities as moral actors, their multiple and diverse roles in the health arena, and their moral/ethical relationship to justice. Notably, we find a foun-

**Charlene Galarneau, Ph.D.**, is Senior Lecturer, Department of Global Health and Social Medicine, and Faculty, Center for Bioethics at Harvard Medical School; Associate Professor Emerita, Wellesley College in Women's and Gender Studies; and Affiliate Researcher, Center for Antiracist Research, Boston University. **Patrick T. Smith, Ph.D.**, is Director of the Bioethics Program at the Trent Center for Bioethics, Humanities, and History of Medicine at Duke University School of Medicine. He is also Associate Research Professor of Theological Ethics and Bioethics at Duke University Divinity School.

dational respect for communities latent in the concept of health justice which includes a respect for communities' understandings, values and priorities regarding health and health care that is part of the justness of the framework and the movement. We explore scholarly links made between respect and justice as well as the meaning of respect and of respect for communities. We propose that an ethical *principle of respect for communities* is a requisite part of health justice; that it is this respect that ethically grounds health justice's calls for greater community engagement and empowerment. Conceptions of health justice, we claim, will gain ethical power and coherence as this principle is recognized and developed. We end by signaling some operational challenges raised by this justice imperative to respect communities.

munities.<sup>6</sup> As we discuss below, these and other communities play significant roles in the health arena that make them critical moral actors in the creation of the meanings of justice.

Several features of communities are vital to understand. First, many communities are constituted by multiple smaller, often overlapping communities, for example, most local communities have numerous ethnic, religious, and other communities within them. Another feature is that communities have somewhat fluid memberships as members' community identification and involvement shift over time. Relatedly, while a community holds something in common, a community's members are not homogeneous in belief or in practice. Notably, many persons are simultaneously members of multiple communities, communi-

**Notably, we find a foundational respect for communities latent in the concept of health justice which includes a respect for communities' understandings, values and priorities regarding health and health care that is part of the justness of the framework and the movement. We explore scholarly links made between respect and justice as well as the meaning of respect and of respect for communities. We propose that an ethical *principle of respect for communities* is a requisite part of health justice; that it is this respect that ethically grounds health justice's calls for greater community engagement and empowerment. Conceptions of health justice, we claim, will gain ethical power and coherence as this principle is recognized and developed. We end by signaling some operational challenges raised by this justice imperative to respect communities.**

### Communities and Health Justice

Drawing on the thick social science literature about "community," we understand communities to be "relatively wide and deep social groups: the more extensive the shared activities and the more wholly that group members participate in, identify with, and take responsibility for the group, the stronger is its community nature."<sup>5</sup> We understand communities as subnational in scope, sharing history, culture, place, goals, or experiences. The communities highlighted in the health justice literature are typically identified generally as "marginalized," "impacted," "affected," and "historically subordinated" communities. Communities are also sometimes more specifically named: the Black community, communities of color, LGBT, immigrant and low income communities, also local com-

ties that may hold compatible and/or conflicting values regarding health and health care. Furthermore, communities are relationally connected to larger social collectivities — society or the nation, as well as to smaller collectivities such as families. Finally, communities vary significantly in power and stability, a feature of communities that makes them highly salient to health justice.

Health and health care are often framed as societal or as individual goods, overlooking the fact that they are also community goods, perhaps even primarily community goods due to the many critical ways that communities are involved in health care and public health.<sup>7</sup> We mention four of those critical ways here. First, communities as "spaces" contribute to the health and illness of its community members as well as of

the community as a whole. Together the physical and social environments of a community condition human health. The quality of the water and air; the presence of toxins, violence, segregation, social solidarity and much more contribute to making us healthy or ill. The contagion of infectious disease makes clear how important the interrelatedness within and among communities is to health.

Second, health activities, be they health care or public health efforts, take place largely in local communities: geo-politically defined areas wherein health care institutions and practitioners and public health departments care for the health and illness of individuals and of the community. Cultural and religious communities also offer such care as do community building organizations that work to empower communities. Third, communities as a whole and their individual community members are impacted by the presence or lack thereof of public health and health care activities beyond their immediate health effects. One such way is that health systems support other core community institutions and functions including schools, political governance, and economic stability. Another way is that health systems may provide community leadership and participation opportunities, thus contributing to community cohesion and/or to community distress.

Finally, and the focus of our ethical attention here, communities are important sites of meaning-making. While the individualistic biological meanings of health, disease, and healing promoted by professional biomedical communities dominate the US health landscape, public health approaches that understand health and healing as fundamentally shaped by social, political, economic, and cultural factors are also significantly present. Meaning-making about health/health care also takes place in numerous cultural and religious communities: Indigenous, Black, Latinx, Christian Scientist, and other communities create, recreate, and embrace community-specific ideas and values regarding life, health, healing, and death. Various health movements including the 20th century women's health movement, the disability rights movement, and the anti-racism movement are broad communities that have created alternative understandings to dominant ways of thinking. These activist and scholarly efforts — to demedicalize childbirth and menopause, to understand “domestic” and police violence and racism as public health concerns, and to frame disability as a social rather than a biomedical concern — show the power of community meaning-making to shape health and care and hence, to inform notions of health justice.

Together these four types of community involvement in health/health care show how deeply and complexly engaged communities are in health/health care. But communities are not “equally” engaged. In its focus on health disparities and its call for greater community engagement, the health justice movement underscores the fact that not all communities experience the same health shaping conditions and thus health status; the same care for their health and well-being; nor do they gain equal benefits from health activities. Moreover, not all communities have their understandings of health and health care heard, seriously considered, or responded to. In other words, communities are accorded unequal power and respect in the health arena. One example is when marginalized communities as a whole as well as their community members are treated as solely responsible for their ill health, or as inherently powerless, and thus become “targets of discipline or charity” rather than participants in the meaning-making regarding their care and justice.<sup>8</sup>

As noted above, health justice understands that as a matter of social justice, the elimination of health disparities involves marginalized communities becoming more fully engaged and empowered. Here an important ethical question arises: what is it about community engagement and empowerment that makes it a core commitment of and essential to health justice? The answer to this question we believe is found in a (largely) latent assumption in the health justice framework, namely that community engagement/empowerment signifies respect for community. We suggest that *respect for communities* be recognized, developed, and codified as an ethical principle requisite for health justice. In other words, a *principle of respect for communities* should become an explicit moral norm and standard that serves as a criterion for guiding and assessing health justice frameworks as well as for the policies and laws proposed in health justice's name.

### **Toward a Principle of Respect for Communities as Requisite for Health Justice**

What is needed is an ethically robust, full-fledged *principle of respect for communities*. In this section we begin to give substance to this principle by demonstrating how this link between respect for communities and health justice echoes the close association between justice and respect found in community activism and in some theories of justice. Next, we sketch a community-relevant notion of respect; and finally, we highlight a *principle of respect for communities* that has been proposed in research ethics.

The chant, “We can't get no justice; no respect” was repeated by protestors in Ferguson, Missouri, in

response to the 2014 death of Michael Brown and more generally to police violence in Black communities.<sup>9</sup> This close tie between justice and respect is found also in some philosophical theories of justice. Here we note two theories that affirm respect for social groups including communities as foundationally important to justice. Michael Walzer's theory of complex equality posits justice as respect for the communal meanings given to social goods." He writes:

We are all (all of us) culture-producing creatures: we make and inhabit meaningful worlds. Since there is no way to rank and order these worlds with regard to their understanding of social goods, we do justice to actual men and women by respecting their particular creations. And they claim justice, and resist tyranny, by insisting on the meanings of social goods among themselves. Justice is rooted in the distinct understandings of places, honors, jobs, things of all sorts, that constitute a shared way of life. To override those understandings is (always) to act unjustly.<sup>10</sup>

According to this particularist notion of justice, groups "must figure out for themselves what justice requires" in relation to social goods including health and health care.<sup>11</sup> Communities have normative conceptions of justice, whether implicitly embraced in their praxes or explicitly stated and then operationalized in various ways.

Similarly in his liberal-communitarian conception of justice, Ezekiel Emanuel argues that "[j]ustice is not realized by comparing entitlements to individual services, but by respecting the community's particular conception of the good life in its distribution of goods."<sup>12</sup> In this perspective, different communities have different shared values, traditions, and practices and all commit to respectful democratic deliberation among various community-based notions of justice. Both these theories of justice seek to respect community voices and values in health care. In this way, they resonate with health justice's explicit commitment to "collective action grounded in community engagement and empowerment" and with its implicit commitment to respect community values and priorities.<sup>13</sup>

To understand justice as respect we need to appreciate what it means *to respect*. And specifically, what it means to respect communities. Among the many philosophical and psychological meanings of respect is the idea that *to respect* means to give serious consideration. To respect is to respond with what philosopher Robin Dillon calls perceptive attention: "The person who respects something pays attention to it and per-

ceives it differently from someone who does not and responds in light of that perception."<sup>14</sup> Conversely, disrespect for something is shown by "being oblivious or indifferent to it, ignoring or quickly dismissing it, neglecting or disregarding it, or carelessly or intentionally misidentifying it."<sup>15</sup> According to sociologist Sara Lawrence-Lightfoot, attention is a key dimension of respect: "When we are respectful of another, we offer our full, undiluted attention. We are fully present, completely in the room ... sometimes engaged in vigorous conversation, sometimes bearing silent witness."<sup>16</sup> Though typically framed in terms of respect for individual persons, these understandings of respect are also relevant to communities.

In the ethics of health research realm, Emanuel and Charles Weijer have called for a *principle of respect for communities* based on their belief that "communities have values and interests worthy of protection."<sup>17</sup> This principle, they argue, bestows "upon the researcher an obligation to respect the values and interests of the community in research."<sup>18</sup> It is worth emphasizing that this protection is not grounded in the vulnerability or historical marginalization of communities but rather in the moral worthiness of communities, including the shared meanings and values they have created.

The claim that communities are moral entities worthy of an obligation of respect or justice is not uncontroversial as some commentators believe that only persons, not social groups, have moral standing.<sup>19</sup> With Emanuel and Weijer, we believe that communities are more than the sum of their individual members and are deserving of moral standing.<sup>20</sup> Precisely because communities are important sites of meaning-making about social goods including health and health care, communities are moral entities worthy of "collective respect."<sup>21</sup>

In sum, the *principle of respect for communities* embedded in health justice entails giving serious and perceptive attention to the health-related community norms and values embraced by community members. As philosopher Yolonda Wilson reminds us, "a Black feminist conception of justice foregrounds the needs of the overall community...The community rises and falls together, and so justice must account for the whole, not merely the well-heeled."<sup>22</sup> To disregard such community values would be to disrespect communities and thus to treat them unjustly.

### **Operationalizing a Principle of Respect for Communities: Two Key Challenges**

We identify two significant challenges to the *principle of respect for communities* in health justice that must be acknowledged and engaged. First, as Miller

has noted, is that “collective respect is unevenly distributed.”<sup>23</sup> This inequity is reflected in health justice’s focus on marginalized communities, that is, on communities whose understandings, needs, priorities, and values are not listened to, seriously considered, and adequately responded to in health-related policy making. In Lawrence-Lightfoot’s words, “respect creates a relational, generative symmetry”<sup>24</sup> and that symmetry is related to empowerment: “When we are respectful of others, we want to offer them the knowledge, skills, and resources that they need that will allow them to make their own decisions and take control of their lives.”<sup>25</sup> Likewise, say Harris and Pamukcu, empowerment is “collective power and control.”<sup>26</sup>

The health justice movement has produced numerous community empowerment strategies. One example is the community-defined and community-based research efforts that seek to shift power to communities.<sup>27</sup> In another example, organizations like the Praxis Project work to build community power so that health “[i]nterventions will be better aligned with community-defined health priorities.”<sup>28</sup> This Project encourages public health initiatives to build relationships with community organizations “based on respect for their experience and expertise.”<sup>29</sup> Yet another strategy is Truth and Reconciliation Commissions, especially local in scope, wherein communal “narratives and lived experience drive the agenda for social change” for implementing the *principle of respect for communities* within a health justice framework.<sup>30</sup> These empowerment strategies work to more evenly distribute community respect and thus fulfill the *principle of respect for communities*.

The second significant challenge for the operationalization of the *principle of respect for communities* is that of democratic deliberation in light of diverse ethical values. The heterogeneity of health meanings, values, and priorities within and among communities presents an abiding challenge for democratic decision-making in the health arena. This includes the challenge of dealing with community values that some deem fundamentally disrespectful or unjust. Nearly every community is internally diverse in its diverse values and priorities. Similarly different communities hold different health related values. The *principle of respect for communities* means that these heterogeneities of values must be recognized and seriously considered in community based decision-making processes that are understood as just. The challenge is exacerbated by the absence of political governance infrastructures that respect communities in health-related decision-making.

A decade ago, Lawrence-Lightfoot lamented, “The shadows of darkness and violence that have preoccupied us recently compel us to recognize how very precious and fragile are our democratic principles, how very hard it is to sustain and nourish respect, and how complex the work of authentic inclusivity turns out to be.”<sup>31</sup> These concerns remain today. Nevertheless, the rising health justice movement holds promise for improving the health and well-being of all communities. It will gain ethical power and coherence in mitigating the impact of health disparities when it recognizes, develops, and operationalizes an ethical *principle of respect for communities*.

#### Note

The authors have no conflicts to disclose.

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9. See Galarneau, *supra* note 5, at 56.
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