

# CONVERSATIONAL ACCESSIBILITY: HEALTHCARE, COMMUNITY, AND THE ETHICS OF EVERYDAY ENCOUNTERS

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The fundamental responsibility of medicine, the clinical ethicist David Schenck writes, is to care for people's bodies when they "can no longer [do so] themselves" (1986, 49). Fulfilling this responsibility, he argues, requires acknowledging "the texture of embodiment" (43). In this article, I begin by exploring the ethical significance of this texture of embodiment for interactions between healthcare workers and patients. I then focus on trauma-informed care and narrative ethics, arguing that both practices recognize the risk healthcare workers pose to patients' life-worlds, a risk that is amplified when healthcare workers fail to acknowledge their responsibility to these life-worlds. Both practices also recognize that open conversation between healthcare workers and patients is fundamental to fulfilling this responsibility. I then draw on Maurice Merleau-Ponty's conception of human agency as embodied and interpersonal to argue that conversations with others, much like physical spaces, are places whose accessibility is not guaranteed. Finally, I examine how issues of conversational accessibility are at play in the larger context of healthcare research and how we might rethink existing practices in light of community-based participatory research.<sup>1</sup>

## I. THE TEXTURE OF EMBODIMENT

Drawing on the work of Merleau-Ponty, Schenck identifies several essential features of the texture of embodiment: the body is the "reference point" in terms of which a person's

<sup>1</sup> I want to note that two of the terms I am using, "healthcare workers" and "patients," are not entirely unproblematic. With respect to "healthcare workers," I want to use a word that is inclusive of all the different people whose work is connected with healthcare: doctors and nurses, of course, but also nurses' aides, home health aides, respiratory therapists, x-ray technicians, and even, as I will discuss shortly, clinic receptionists. With respect to the term "patient," I would prefer a term that better emphasized the agency of those interacting with healthcare workers like "the people healthcare workers work with," but that just gets confusing so I am going to stick with "patient."

world is lived both spatially and temporally (Schenck 1986, 44, 47); the body is “intimate” such that there is “*seldom any distinction* to be made between self and body” (45; emphasis in original); and the body is “always in communion with the world,” both through physical activity and as “inherently socially expressive” (46). A person’s body must, in other words, be understood as a lived body, as fundamentally the subject who experiences and not merely an object that is experienced. As such, a person’s body is the foundation of her identity and agency: “it is only through the body that we are present in the world, only through the body that we carry out projects in the social and physical world, only through the body that we have a self” (50). Yet even as our bodies are fundamentally constructive of our way of being-in-the-world, they are also fundamentally disruptive.

Our bodies, through illness or injury, can become obstacles to the very worlds they previously made possible; since the body “maintains our entire life-world . . . a bodily crisis becomes, inevitably, a total crisis of that world” (43). There is, Schenck writes “a tensed duality” (43) at the heart of embodiment: “the possibility, and indeed inevitability, of the alienation of our bodies from our wills, our minds, our selves, is an essential aspect of embodiment” (48). Illness and injury threaten the very foundation of our identity and agency and render us unable to address this threat ourselves: “[i]n illness, I am unable to care for that which is most ‘my own.’” (51). The relationship of patients to healthcare workers, then, is one of profound vulnerability.

Patients, in placing their bodies in the hands of healthcare workers, are also entrusting them with their life-worlds: “in this new relationship with those who are now caring for my body, people most likely in our society to be total *strangers*, I have of necessity ‘given’ to these others extensive (even total) power over my embodied life” (52; emphasis in original). Moreover, patients entrust their life-worlds to healthcare workers at moments of their lives when they have little, if any, ability to prevent or remedy any betrayal of this trust. In patients’ relationships with healthcare workers, Schenck writes, “all those issues of trust and power and honesty that are the hallmark of every human relationship take on suddenly dramatic importance” (51).

The texture of human embodiment makes even routine interactions between healthcare workers and patients ethically significant; patients’ life-worlds are at stake in these interactions, and healthcare workers’ responsibility to their patients entails responsibility to these life-worlds. To be indifferent to or dismissive of the texture of embodiment, to treat patients’ bodies as if they were merely objects, is, in a critical sense, to mistreat patients. Furthermore, the texture of embodiment means that how healthcare workers speak with patients—or even if healthcare workers speak with patients—has a bearing on whether healthcare workers fulfill their responsibility to patients. From the patient perspective, Schenck writes, when “[t]hose who care for my body speak of it as though it were a machine, perhaps even handle it that way,” this raises a question for the patient: “[c]an I trust these strangers who cannot even speak properly of this ‘object’ closest to my self?” (52). When hospitalized following complications of a heart attack, Kevin Aho writes that

experiences of strength, confidence and vitality that were so much a part of my self-interpretation before the heart attack suddenly seemed foreign . . . And the detached discourse of the health care professionals only exacerbated the experience, turning me into a passive object and stripping away any sense of agency. (Aho 2019, 195)

Healthcare workers cannot, in other words, assume that, so long as they are not performing a medical intervention, they pose no risk to patients. Any interaction between healthcare workers and patients, including their conversations, poses the risk of further diminishing patients' often already diminished sense of identity and agency.

Bioethical considerations are not, in other words, confined to crises of the kind that summon hospital ethics committees but instead permeate everyday interactions within healthcare settings, including conversations between healthcare workers and patients. Nonetheless, the ethical significance of such everyday interactions—their amelioration or intensification of disruptions to patients' life-worlds—is not usually the focus of bioethicists. Even as bioethicists have become increasingly interested, for example, in trust as a key aspect of healthcare, researchers have primarily focused on trust as an “input” in the relationship between patients and healthcare providers rather than an “outcome” (Taylor et al. 2023, S3). Furthermore, there has been little attention to the ways in which healthcare workers' interactions with patients make them more or less worthy of patients' trust. Lauren A. Taylor et al., in their introduction to the Hastings Center Report, “Time to Rebuild: Essays on Trust in Healthcare and Science,” write:

[i]n working on this special report, we have been struck by the absence of studies that attempt to define and measure trustworthiness. It seems that the research focus in health policy and health services has been disproportionately on patients and their attendant attitudes, when researchers might learn as much, or more, by studying the behaviors of institutions and providers. (2023, S6)

To better understand, then, how healthcare workers can, in light of the texture of embodiment, fulfill their responsibility to patients, I will now focus on trauma-informed care and narrative ethics.

## II. THE ETHICS OF EVERYDAY ENCOUNTERS

While research suggests that over seventy percent of people worldwide have experienced trauma, including, though not limited to, physical assault, sexual abuse, and exposure to combat, many healthcare providers remain unaware of these experiences (Kessler et al. 2017). Yet trauma can alter the structure of people's experience such that they encounter routine aspects of healthcare as highly distressing. Lying down on an exam table, for example, or being alone with an unknown healthcare worker can significantly increase the anxiety of a person who has experienced trauma (Raja et al. 2015). Furthermore, people

who have experienced trauma may cope with their increased anxiety by becoming angry or aggressive. When healthcare workers do not recognize patients' behaviors as symptoms of trauma, they may demand patients' compliance or attempt to physically restrain them, and in doing so retraumatize them.

Trauma-informed care begins with an awareness of how pervasive experiences of violence and abuse are, and it aims to design and deliver services and programs in ways that support, rather than undermine, a patient's recovery from trauma. Recognizing that even routine aspects of healthcare can be experienced by patients as threatening, trauma-informed care works to acknowledge this threat at the beginning of any interaction between healthcare workers and patients. Healthcare workers can ask patients if there are specific aspects of their interaction that worry them, such as "lying back, fear of not knowing what comes next, and the possibility of pain," and talk with patients about what might make them more comfortable: "[p]atients may have general preferences, for example, leaving the door slightly ajar or sitting closer to it" (Raja et al. 2015, 218). Trauma-informed care also works to diminish this threat by, whenever possible, offering patients choices about how their interactions with healthcare workers will proceed. It offers patients choices about how they will be physically examined, for example, giving them "the option of shifting an item of clothing out of the way rather than putting on a gown . . . or sitting in a chair rather than on the examination table for a respiratory system examination" (Raja et al. 2015, 218). Furthermore, when patients react to healthcare workers in unexpected or alarming ways, trauma-informed care seeks to respond in terms of the question of "[w]hat has happened to you?" rather than that of "[w]hat is wrong with you?" (Bloom 2013, 195). Trauma-informed care tries, that is, to gain insight into the person's experience, rather than simply concluding that they are unreasonable or hostile. Recent studies by Michael Sun et al. (2022) and Gracie Himmelstein et al. (2022) attest that healthcare workers do draw such conclusions and, furthermore, are likely to do so in racially biased ways. Black people's electronic health records are more likely than White people's to include stigmatizing or negative descriptions such as "not compliant" or "agitated."

Trauma-informed care recognizes, in other words, that every encounter in a healthcare setting, however seemingly inconsequential, has ethical implications. Every interaction can amplify or ameliorate a crisis in the patient's lifeworld; every interaction can cultivate experiences of safety, trustworthiness, choice, collaboration, and empowerment, or, instead, escalate conflict and reenact traumatic events. Because anyone working in a healthcare setting may interact with someone who has experienced trauma, and because the specific situations that a person who has experienced trauma may find distressing are unpredictable, trauma-informed care requires everyone who interacts with patients to acknowledge the ethical significance of these interactions:

all staff of an organization, from the receptionist to the direct care workers to the board of directors, must understand how violence impacts the lives of the people being served, so that every interaction is consistent with the recovery process and reduces the possibility of retraumatization. (Elliott et al. 2005, 462)

Beyond trauma-informed care, the ethical dimensions of healthcare workers' everyday encounters with patients have also been a focus of the narrative approach to biomedical ethics. While many approaches within biomedical ethics tend to focus on the questions that arise for healthcare workers, narrative ethics focuses on the questions that arise for patients and their families. As Arthur W. Frank explains:

Narrative ethics asks first what the problem might be for patients and their families, not for health care professionals and institutions. This shift in perspective does not devalue professional or institutional problems, but it does mark a need for a complementary form of ethics, proceeding from a different point of view. (2014, 16)

Furthermore, the primary focus of narrative ethics, Frank writes, is to “prevent situations from turning into cases” (16), that is, to facilitate communication between patients and healthcare workers so that full-scale ethical dilemmas, like the ones that summon hospital ethics committees and fill textbooks on biomedical ethics, do not actually arise.

Narrative ethics focuses on the power of stories for making sense of our lives and, more specifically, on how patients who have the opportunity to give an account of their lives and their experiences of illness are better able to navigate difficult healthcare decisions. When encounters between healthcare workers and patients do not enable patients to give such accounts, both patients and healthcare workers suffer. A patient who is, for example, facing a decision about whether they should continue a certain treatment or undergo a certain operation can, by articulating their life as a story, come to understand how they want their story to continue and what choice they should therefore make.<sup>2</sup> A patient who is instead denied such an opportunity for story-telling may remain confused and uncertain, and their health care providers may struggle to act on their behalf. Thus, the telling of and listening to such stories should, narrative ethics argues, be central to healthcare practice. Healthcare workers should not only be listening for their patients' stories but should also be creating opportunities for patients to tell these stories more fully.

The writings of Richard M. Zaner (1993), a philosopher who worked in hospitals as an ethicist, testifies to the need for narrative ethics' complementary form of ethics. Much of his time was spent talking with patients who were critically ill and with the families of these patients. As he describes it, one of his most critical tasks was facilitating conversations between healthcare workers, patients, and patients' families in which all involved could articulate their most pressing concerns and, in doing so, make sense of their situation. It was not uncommon for him to discover that patients and their families were simply being left out of conversations healthcare workers were having about patient care. This did not usually reflect any unwillingness by the healthcare workers to talk with patients and their families. Rather, occupied by the intricacies of administering tests, procedures, and

<sup>2</sup> Yet as Frank recognizes, the very experience of being ill can make it more difficult for patients to tell their stories: “[s]eriously ill people are wounded not just in body but in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away.” (1995, xx)

operations, it often did not occur to healthcare workers that they could—or should—speak with their patients about what the patients perceived as the goal of all the medical care that had been—and still might be—provided.

Yet as Zaner writes, patients want to know “whether the people who *take care of* them also care *for* them” (1993, 144; emphasis in original). When healthcare workers and their patients actually began to speak about what, for example, further medical care could actually accomplish and whether it was, in light of this, worthwhile to pursue further care, healthcare workers often discovered that the patients shared their concerns. A situation that had seemed to be leading to an intractable ethical dilemma led instead to mutual understanding and agreement.

### III. CONVERSATIONAL ACCESSIBILITY

Having noticed first that everyday encounters between healthcare workers and patients, insofar as they can amplify or ameliorate a crisis in the patient’s lifeworld, have ethical implications, and second that the absence of certain kinds of conversations between healthcare workers and patients can itself be an ethical issue, I want to spend some time thinking about what enables healthcare workers and patients to have the kinds of conversations that Zaner describes and that narrative ethics strives to make standard practice: conversations in which everyone will, in fact, voice their most pressing concerns and questions. We cannot take for granted that this will always happen. There are, of course, material conditions required for such conversations to take place. Patients and their families need a place, either physical or virtual, where they can gather to talk with healthcare workers. If family members do not have access to transportation or cannot take time off from work, it may not be possible for them to gather at a hospital or skilled nursing facility, and if family members do not have access to the internet, it may not be possible to gather virtually. Also, translators may be needed to facilitate communication, and distractions must be limited to allow for serious conversations.

But even if these material conditions are met, we should not assume that such serious conversation will be possible. Natali Cvetanovska et al. note that while “patient participation in healthcare communication has been shown to improve recall and understanding, satisfaction with care, adherence to treatment and health outcomes in patients,” patients find it challenging to “ask questions and be involved in treatment planning . . . and most participation does not extend beyond answering direct questions posed by clinicians” (2023, 1). The literature on epistemic injustice offers insight into the obstacles speakers may face when they attempt to communicate with others.<sup>3</sup> As Dotson, drawing on the work of Jennifer Hornsby, writes: “[e]very speaker needs certain kinds of reciprocity for successful linguistic exchanges . . . [T]o communicate *we all need an audience willing and capable of hearing us*” (2011, 238; emphasis in original). Yet audiences are not always willing and capable of hearing a speaker. Those with whom a person speaks may, for example,

<sup>3</sup> See, for example, Miranda Fricker (2009), Kristie Dotson (2011), and Gaile Pohlhaus (2012).

fail to understand her intent or may fail to take her seriously, thereby silencing her. For example, a patient may encounter what Dotson (2011) identifies as “testimonial quieting”: she may speak only to find that healthcare workers fail to recognize her as a valid source of knowledge and simply dismiss what she says as unimportant.

The realities of such practices of silencing reveal that the power of speaking cannot be understood as a kind of private possession, distinct from the contexts within which and the people with whom we speak. Nonetheless, given the individualistic and rationalist understanding of agency that informs much contemporary thinking, including our thinking about health and illness, we may tend to assume that if we can speak in one situation, then, barring any physical restraint, we should be able to speak in any other situation.<sup>4</sup> Understanding our actions as primarily a matter of personal responsibility, and, relatedly, understanding our bodies as objects that are—or at least should be—controlled by rational minds, is so engrained in us as to go unnoticed and unquestioned. It is, as Laura McMahon writes, “what we might call the ‘natural attitude’ of liberalism” (2020, 3).

As the work of phenomenologists like Merleau-Ponty (2012) demonstrates, this individualistic and rationalist conception of agency fails to recognize the embodied and interpersonal character of our existence. Merleau-Ponty’s discussion of the phantom limb in the *Phenomenology of Perception* makes clear that our bodies are neither merely physical objects whose interactions with other objects are devoid of all intention, nor are they merely objects of thought whose interactions with other objects are governed by conscious choice.<sup>5</sup> Rather, whatever meanings our environment holds for us, whatever possibilities for action appear to us, reflect our bodies’ engagement with the world in ways that allow these meanings and possibilities to arise: “[c]onsciousness is originally not an ‘I think that,’ but rather an ‘I can’” (139). Furthermore, the specific meanings our environment holds for us also always reflect our relations with other people, including our childhood relations with others that cultivated the specific habits that undergird our adult existence. The social world, Merleau-Ponty writes, is the “permanent field or dimension of existence” (379).

Thus our freedom, Merleau-Ponty argues, is not realized in separation from the world and others but instead through our relations with them. Extending a phenomenological conception of agency to the voice, therefore, means recognizing that our voices are neither possessions nor private but instead interpersonally accomplished ways of being-in-the-world. To better understand what this means, I want to first focus on another bodily power: the power of mobility. For people with mobility devices like wheelchairs, this power may involve arm movements or even—with motorized wheelchairs—mouth movements, and for people without wheelchairs, this power may involve leg movements. Yet the power of mobility is not simply these movements; it is, more significantly, a way of making sense of the world, a way of having the world appear as it does. The power of mobility is, for example, a power of experiencing the world as accessible: of having sidewalks and streets and buildings and subway systems appear as routes rather than obstacles to where one

<sup>4</sup> For a discussion of how an individualistic conception of agency informs contemporary healthcare practices and policies, see Talia Welsh (2021).

<sup>5</sup> See, for example, Merleau-Ponty (2012, 78–85).

wants to go and what one wants to do. It is a power of having neighborhoods appear as welcoming rather than unwelcoming of one's projects.

Yet while we speak about a person's power of mobility, this power does not so much belong to the individual person as to the relation between a person and the world. Without surfaces that a body can, to use Merleau-Ponty's (2012) language, "gear into," or, to use psychologist James J. Gibson's (1986) term, surfaces that "afford" mobility, a person's leg movements remain mere movements and the power of mobility remains unrealized. As Gibson points out, while the surface of a lake affords walking to a water bug, it does not do so for people; people, unlike water bugs, cannot walk on water (1986, 38). Furthermore, the things with which a person interacts have largely been created by other people, and even interactions with natural things are mediated by laws and social norms. To engage in phenomenology as a critical practice is to recognize that the relations between a person and the world are always deeply informed by her social and political situation. As Perry Zurn writes, "[c]ritical phenomenology is poised to attend with unusual attention not only to the body schema, intercorporeality, and lifeworld of walkers, but also to the socio-political structures and histories that shape them and which they in turn shape" (2021, 13).<sup>6</sup>

What the world affords any one person is a cultural—rather than a simply natural—phenomenon, and these affordances are often not equally available to everyone. A surface that affords mobility for a person without a wheelchair, for example, is not always also a surface that affords mobility for a person with a wheelchair, and at the present moment, far more surfaces afford mobility for those without wheelchairs than for those with them; many sidewalks still do not have curb cuts, and ramps are still not as common as stairs.<sup>7</sup> Thinking of the power of mobility as simply a power of an individual person does not, therefore, adequately appreciate the myriad ways in which the world has not only been designed and built by others, but has also been designed and built in ways that, while enabling to some human bodies, are also disabling to other human bodies.<sup>8</sup> Indeed, insofar as racism, sexism, ableism, colonialism, and other forms of discrimination and violence continue to structure our lives, the availability of affordances for some people will often be premised on the unavailability of affordances for other people.

Thus while we may refer to a person's power of mobility, we should recognize that mobility is actually realized communally rather than individually. Each of us depends on other people designing and constructing this world in ways that enable our bodies to realize

<sup>6</sup> On phenomenology as a critical practice, see also Lisa Guenther's (2021) account of critical phenomenology and Kim Q. Hall's (2021) account of crip phenomenology.

<sup>7</sup> For a discussion of the kinds of obstacles that a person who uses a wheelchair may experience on a regular basis, see S. Kay Toombs (1995). Public bathrooms can be particularly disabling to those who use wheelchairs; see, for example, Jackie Velez (2023)

<sup>8</sup> This idea is central to the social model of disability, which argues that disability is not inherent to individual bodies but instead results from social and political practices that discriminate against people whose bodies deviate from what society deems "normal." For a discussion of this model, see Joel Michael Reynolds (2022, 75–78).



the power of mobility.<sup>9</sup> As Judith Butler, in conversation with Sunaura Taylor, states, “I’m just thinking that a walk always requires a certain kind of technique, a certain support. Nobody takes a walk without there being a technique of walking” (2009, 187).<sup>10</sup> In other words, every person who walks down the street is receiving an accommodation, even if it is the accommodation of those who use mobility devices that is more often remarked upon than the accommodation of those who do not; the sidewalk is, for example, constructed of a material that supports the weight of human bodies, with a width and a grade that allows the passage of human bodies.

Furthermore, while I have focused on the physical objects that can support or impede mobility, other people’s responses to a person’s mobility can be as, if not more, significant sources of support or impediment. Hall (2021), drawing on the work of Rosemarie Garland-Thomson (2009), notes that those whose way of walking does not conform to ableist and cisheteronormative conceptions of bodily movement, are often stared at—or even glared at—by others. Their own “limping-swaggering” walk, Hall writes, not uncommonly encounters

a stranger’s stare that first goes to my foot or leg and then takes in the rest of me . . . In limping along, I confess that it’s difficult, if not impossible, for me to know whether the stare is directed at my limp or my gender non-conforming, swaggering occupation of space, but from a crip phenomenological perspective, both converge to shape how I am enmeshed in and navigate the world and thus my embodied self. (25)

Toombs (1995), who has multiple sclerosis, describes how others’ perception of her can have a direct impact on her mobility:

I remember the occasion of receiving my doctoral degree. I could still walk a few steps if supported, and I could climb stairs with assistance. The day before the ceremony, a colleague and I went over to the auditorium to practice climbing the few steps onto the stage where I was to be seated. I negotiated the steps without too much difficulty. However, on the following day—in the concrete experience of about sixteen thousand eyes watching me—I was completely unable to lift my right leg. It was not just that I was conscious of the fact that my body moved in a peculiar fashion. Rather, I was temporarily paralyzed. (19)

Toombs draws attention to how critical our being-with-others is to our way of being-in-the-world. Others’ perception of our movement as graceful or awkward, confident or tentative can affect how—or even if—we will continue to move.

<sup>9</sup> For a discussion of how the world is designed and built in ways that enable certain bodies while also disabling other bodies, see Sara Hendren (2020).

<sup>10</sup> For further discussion of this passage, see Hall (2021, 17–18).

Having recognized that the power of mobility is not a private possession, let us now turn back to the voice. First, it is important to recognize that just as not everyone can walk, not everyone can speak. Nonetheless, just as people who cannot walk can still have powers of mobility, people who cannot speak can still have voices.<sup>11</sup> Still, the very situations that afford a voice for speakers may not do so for non-speakers. In their podcast interview with Sharlene Cooney, a non-verbal visual artist, Rachel Gray and Debbie Ratcliffe (2022) note that listeners “will not hear Sharlene talk, but you will hear her voice.” Cooney communicates by pointing to images and words in an album and through gestures, drawings, and writing. “Art,” Cooney states in the interview, “is not just beautiful for me . . . . Art is a way for me to give my opinion, put something beautiful into the world, advocate, express feelings, and communicate with people.” For the podcast, Cooney worked with both her long-time support worker, Linda, who read and interpreted the words and images Cooney pointed to, and with a storyteller, Kim Kilpatrick, who spoke Cooney’s words. Thus, while a spontaneous meeting, for example, generally affords a voice to speakers, it may very well not afford a voice to non-speakers. Without significant advance planning, Cooney’s podcast interview would not have been possible. Dave Finch and Barry Prizant (2023), the hosts of the podcast “Uniquely Human,” note that when they interviewed Elizabeth Bonker, a non-speaker who uses an augmentative and assistive communication device, they submitted their questions “ahead of time due to the length of time it takes to formulate and type responses. This is a common procedure when non-speakers are asked to respond to interview questions.” Likewise, situations that leave limited time for conversation may afford a voice to speakers but not to non-speakers who, like Bonker, need time to type out their responses.<sup>12</sup>

Thus, just as we can recognize that movements of legs or wheelchairs do not alone constitute mobility, so too can we recognize that the movements of mouths, tongues, and throats and the resulting sounds, or the movements of fingers on a keyboard and the resulting words, do not alone constitute a voice. The voice, like mobility, should be understood as a way of making sense of the world; it is the appearing of a world through these movements, rather than the appearing of these movements themselves, that is definitive of these powers. In much the same way that walking enables us to experience certain things in the world as accessible—as supporting, rather than hindering, the projects to which we are committed—so, too, does speaking or communicating with an augmentative and assistive communication device. Yet while for mobility these things that appear as accessible include sidewalks and buildings, for the voice, these “things” are conversations. The voice is a power of experiencing conversations as accessible, of experiencing others’ voices as constructively developing, rather than undermining, whatever we are trying to say. Moreover, having a voice, like being mobile, requires traction. While for mobility

<sup>11</sup> See also Eva Feder Kittay’s (2019, 7) discussion of speaking for her daughter, who cannot speak for herself.

<sup>12</sup> In a conversation between Bonker and Judy Heumann, Heuman (2023) noted that “when I’m talking with you and other friends who use communication devices, there are these long pauses when I’m listening. And I’m wondering when you are also speaking with others who are also using communication devices, what do you think about when you’re waiting for an answer?” Bonker replied, “I try to clear my mind. Those of us who don’t speak tend to be careful listeners.”

this traction is directly with things and indirectly with the people who design and create these things, with the voice, this traction is directly with other people.<sup>13</sup> Unless other people recognize the sounds or movements a person makes as a form of communication, then understand what is being communicated, and then also experience what is being communicated as making demands upon them—as calling for conversation—a person’s voice remains unrealized. In other words, a person’s voice is also a power that does not belong so much to an individual person as to relations between people.

In addition, therefore, to offering rich descriptions of people’s experiences of built and natural spaces and noticing how what they experience always reflects their relations with others, we can also offer similarly rich descriptions of people’s experiences of conversation. By considering conversations as part of the existential landscape we are always navigating—as sites, or to use Edward S. Casey’s (2013) term, “places,” that are continuous with or an aspect of the places that are ours or others’ homes, workplaces, commutes, places of worship, seats of power, and so forth—we can begin to notice dimensions of our experiences of conversation that we might not otherwise notice and to make sense of differences between our experiences that we might otherwise have difficulty making sense of. We can notice, for example, that we can feel at home in some conversations more than in others, and that we can navigate some kinds of conversation more adeptly than others.

As trauma-informed care shifts healthcare workers’ response to patients from a question of “what is wrong with you?” to one of “what happened to you?,” so can we shift the response to a person who remains quiet during a conversation from a question of “why didn’t you speak up?” to one of “was this conversation accessible for you?” Moreover, when people do not experience conversations as accessible, this should inspire reflection on the ways in which the others engaged in the conversation may have contributed to its inaccessibility. In other words, the question of whether the conversation was accessible should focus as much, if not more, attention on those who were participating than on those who were not.<sup>14</sup>

By thinking about encounters between doctors and patients in terms of conversational accessibility, we can notice if the material conditions for conversations between patients, their families, and healthcare workers are present: the transportation, time off from work, translators, and so forth that enable everyone to, so to speak, get to the borders of conversations about what matters most to them. But we can also notice whether, as they talk with each other, avenues of discussion actually appear for them to speak about what matters most. Do patients, for example, who start down such an avenue get any traction from the healthcare workers with whom they are speaking? Do healthcare workers recognize, in effect, where their patients are trying to go and respond in ways that make this possible?

<sup>13</sup> John L. Austin (1975) refers to such traction as “uptake.” For a discussion of uptake in relation to issues of trust and trustworthiness, see Nancy Nyquist Potter (2002, 147–79).

<sup>14</sup> I want to thank Martina Ferrari for suggesting this line of thinking to me. In other words, we should take care that asking the question “was this conversation accessible for you” not, in effect, force the person who has been quiet into a conversation that continues to be inaccessible, thereby exacerbating the problem rather than beginning to remedy it.

## IV. COMMUNITY

Having focused on conversations between individual healthcare workers and patients, I now want to think about issues of conversational accessibility with respect to a broader topic in healthcare: public health research. Nina Wallerstein and Bonnie Duran argue that in the past few decades, a new “participatory” paradigm of scientific research has been emerging (2008, 26). This new paradigm challenges an older paradigm in which researchers with academic credentials such as university professors and healthcare professionals unilaterally decide what the “problem” is that they will be studying, how they will study it, how the results of the study will be disseminated, and, often, how these results will impact healthcare practice and policy.<sup>15</sup> In this older paradigm, the community members whom the researchers study may be referred to as research participants, but their participation in the research process itself is quite limited. In other words, the subjectivity of these “research subjects”—their own capacity for asking questions and offering answers, their own capacity for knowledge—is recognized in only a very minimal sense. Community members may, for example, sign a consent form and engage in the services or interventions the university researchers make available, but they are not expected or invited to contribute to the design of the study. They are not consulted about what they experience as the primary challenges to their health or what kind of responses they think will best address these challenges. Moreover, they likely never learn what conclusions researchers draw from the study and likely never play a part in shaping healthcare practice and policy in light of these conclusions. This unilateral relationship between researchers and communities is particularly stark in what is now referred to pejoratively as “helicopter” or “parachute” research in which a researcher flies in and takes information from a community “without leaving anything in return” (2008, 31).<sup>16</sup>

The field of bioethics emerged in part as a response to the inhumane treatment of research subjects exhibited by Nazi doctors in Germany. The trial of a group of these doctors for war crimes in 1946 and 1947, often referred to as the Nuremberg Doctors’ trial, “drew unprecedented attention from the public, from the medical and scientific professions, and from public authorities. That attention marks a new beginning in the moral traditions of medicine, a beginning that would become bioethics” (Jonsen 1998, 134).<sup>17</sup> Yet one might wonder, in addition to preventing research subjects’ objectification, if it is also possible to

<sup>15</sup> Linda Tuhiwai Smith (2021) notes that with respect to research involving Indigenous communities, “many researchers, even those with the best of intentions, frame their research in ways that assume the locus of a particular research problem lies with the Indigenous individual or community rather than with other social or structural issues.” One result of this is that “[f]or many Indigenous communities research itself is taken to mean ‘problem’; the word research is believed to be, quite literally, the continued construction of Indigenous peoples as the problem” (106).

<sup>16</sup> For a discussion of “parachute” research with respect to research on the Zika virus, see David L. Heymann et al. (2016). See also *The Lancet Global Health* (2018).

<sup>17</sup> The judges’ verdict in this trial articulated principles for permissible research involving humans, now often referred to as the Nuremberg Code, which were influential in the development of practices and policies, including consent forms and institutional review boards, to ensure that research subjects are not treated as mere objects.

promote research subjects' subjectivity and their own capacities for knowing. This question has been central to the development of community-based participatory research (CBPR).

In contrast to the older paradigm, CBPR conceives of public health research as a collaboration between researchers and communities. CBPR “invests community members in the processes and products of research” (Mullany et al. 2012, 505). The theoretical foundations for CBPR include the work of the Brazilian educator and philosopher Paulo Freire (1995). In the *Pedagogy of the Oppressed*, Freire argues that education, beyond teaching particular topics—geometry, grammar, and biology, for example—also teaches us how to be a person. Some forms of education teach us to be passive and obedient, while others teach us to be active and questioning. In other words, some forms promote our agency while others undermine it. Freire refers to the former model of education as the “banking” model and to the latter as the “problem-posing” model. The banking model conceives of teachers as alone possessing knowledge that they then deposit into their students, and thus conceives of the relationship between teacher and student as one of domination and subordination. Educational systems that adopt a banking model, Freire argues, reinforce existing systems of social, political, and economic oppression. The problem-posing model conceives of both students and teachers as knowers, and thus conceives of the relationship between teacher and student as a collaborative process of mutual learning. Problem-posing education, Freire argues, is fundamentally liberating, and educational systems that adopt this model enable all participants to recognize oppressive economic, social, and political structures and to transform them in ways that more fully realize human freedom.

Rather than assuming that university researchers have all the knowledge about the communities they study while the communities themselves have none, CBPR recognizes community members as knowledgeable about both the problems they face and about the resources that can be brought to bear on these problems. Researchers who use a CBPR approach partner with community organizations and community members—often referred to as “stakeholders”—to identify the community’s most pressing problems. Discussions between university researchers and community members can significantly redefine university researchers’ understanding both of a community’s problems and of the possibilities for addressing these problems.<sup>18</sup> Community members then work with university researchers to create and implement a research project that reflects their collaborative definition of a key problem and their collective agreement about a desirable response to this problem. Together, community members and university researchers collect and interpret data, present findings, and perhaps most importantly, put these findings into practice in the community through further transformation of existing programs and services. By engaging with community members as active participants in the research process, in effect engaging with them as fellow researchers, CBPR projects aim to dismantle, rather than reproduce and reinforce, oppressive social and political conditions, including racism and colonialism, that may have previously defined a community’s interactions with educational, healthcare, government, and other institutions.

<sup>18</sup> For discussion of how community members can shape university researchers’ conception of the issues to be addressed by their research and how they will address these issues, see Britta Mullany et al. (2012) and Darren Ranco et al. (2018).

Any kind of research can take a CBPR approach, yet CBPR is increasingly recognized as essential to research projects that involve under-resourced, marginalized, and oppressed communities who, though often the focus of research projects, have rarely had their values and priorities reflected in these projects.<sup>19</sup> Mullany et al. (2012), for example, describe how their team of public health researchers from Johns Hopkins University partnered with several Indigenous communities to design and implement a research project focused on reducing behavioral health disparities for members of Indigenous nations in the southwest United States. The project began with collaborative discussions between the university researchers and community members about the healthcare challenges their community experienced and how these challenges might be best addressed. Community members identified teen mothers and their children as most vulnerable to behavioral health disparities, identified a family-based approach to promoting effective parenting as a preferred strategy to address them, and proposed that services be delivered to community members in their homes to reduce the stigma associated with receiving services in public places. To overcome barriers to accessing services, community members also proposed that services be delivered by local paraprofessionals to overcome language and cultural barriers. These discussions led to the creation of the Family Spirit program in which local paraprofessionals visited teen mothers at their homes forty-three times over the course of about two years to deliver a series of lessons about parenting skills, maternal drug abuse prevention, and maternal life skills. Results from the study of this program suggested that these home visits were effective at reducing behavioral health disparities for both the teen mothers and their children, and similar studies are now being conducted elsewhere.

In inviting community members into university researchers' conversations—or, perhaps more accurately, in making an invitation into community members' conversations a condition of university researchers' projects—CBPR projects like the Family Spirit program give community members access to conversations in which voicing their concerns enables them to have a say about what kind of healthcare services exist within their communities and about the policies and practices of these services. Furthermore, CBPR creates opportunities for conversations whose implicit lesson is one of collaboration rather than one of domination and submission. CBPR thus contributes to community well-being not only by ensuring that the healthcare programs and services provided in that community answer to it but also by increasing community members' capacity for self-advocacy.

Thinking back, then, to the kinds of conversations I discussed earlier between healthcare workers and patients, we can now ask what these conversations may implicitly be teaching all involved. Do the conversations between healthcare workers and patients teach patients to voice their concerns and teach healthcare workers to listen for these concerns? Or do these conversations instead teach patients to keep quiet and healthcare workers to continue depositing knowledge? That is, we can ask whether a conversation, in addition to itself being accessible or inaccessible, also contributes to or undermines patients' capacity for experiencing future conversations with healthcare workers as accessible. In other words, the discussion of CBPR enables us to notice another aspect of conversational accessibility.

<sup>19</sup> On the increased interest in CBPR in public health contexts, see, for example, Meredith Minkler et al. (2003) and Mullany et al. (2012).

Not only is the power of speaking a power of a person in relation to the world, it is a power of a person whose habits are integral to this relation. The habits a person has with respect to speaking, like the habits a person has with respect to other activities such as walking, reflect their past engagements with the world and with others. We can now appreciate, therefore, that what is at stake in patients' interactions with healthcare workers is not only the amelioration or exacerbation of the present crises in their lifeworlds but their very ability to speak with healthcare workers and others about such crises in the future. A person's experience of conversational accessibility within one conversation has implications for their experience of the conversational accessibility of future conversations.

Practices like CBPR ask us to rethink much of what we take for granted about how healthcare research is conducted and how healthcare services are provided. Given the complexity of the systems within which such research is conducted and such services are provided—systems that can include hospitals, skilled nursing centers, county, state, and federal social services programs, non-profit agencies, and many more—imagining alternatives to these systems is not easy. Yet CBPR projects remind us that the systems of policies, practices, programs, and services we find ourselves implicated in are not givens to which we must submit but instead reflections of human choice. We cannot choose that they immediately be replaced by different systems, but we can choose to align ourselves with people, programs, and institutions that recognize the inherent freedom—and the attendant ethical responsibilities—of our human situation and work to realize this freedom more fully for all.

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