

Desperately Seeking Difference

ERIKA BLACKSHER

Critics from a variety of camps have argued that bioethics has suffered an indifference to “difference.” Cases have been described as thin and the selves inhabiting them hollow. This criticism has been driven at least in part by a reworked conception of the self. The rational and autonomous self that once dominated bioethics discourse has been replaced with a more “textured” self, a self embedded in stories, relationships, families, communities, cultures, and other “thick” particularity—such as race, ethnicity, gender, sexual orientation, religion, and experience generally. The import of such a self is not simply descriptive accuracy; these contextual details—these differences—matter. They matter because they figure importantly into our ethical analyses of cases, affecting, for example, how we interact with and treat patients. And with this shift has come increasing attention to the processes of moral inquiry that enable inquirers to gather all of this moral information and find their way from complex cases to context-sensitive responses.

Although those working in bioethics may be intimately familiar with the advice of casuists, narrativists, feminists, and others on this front, there is another approach afoot: research studies that mine “different” populations for value information. Typically in these projects researchers interview people belonging to a group characterized by a category of “difference” regarding how they feel about a practice common in Western medicine. For example, Carrese and Rhodes studied how members of a Navajo tribe view open discussion of negative medical information¹ and Blackhall and colleagues studied how elderly persons from different ethnic groups view patient autonomy.² I should make clear that I am *not* referring to research that looks at racial, ethnic, or gender differences to determine whether these differences matter physiologically, for example in metabolizing drugs. The projects I am interested in appear to be seeking *moral* knowledge. Generally these projects seek to sensitize healthcare providers to the values and beliefs associated with specific patient populations, in the hope of improving physician–patient communication and in the process patient care.

Although I am deeply sympathetic to the intent and spirit of these projects, I worry about them. I worry because I think they run the risk of serious misuse, a use that will reinforce a reliance on stereotypes and introduce into clinical practice a very dangerous set of rules. The researchers themselves allude to these concerns. Carrese and Rhodes say explicitly that their study is limited by

I am grateful to Jim Childress and Erik Parens for reading and commenting on earlier drafts of this paper.

not representing “the full range or diversity of Navajo views on these matters.”³ Blackhall and colleagues warn that the purpose of their study “was not to convince ethicists that there should be one set of moral rules for Korean Americans and another for European Americans,” nor that they expect the information “will allow physicians to predict with certainty the attitude of any given person from a particular ethnic group.”⁴

Clearly, the researchers know that the chosen categories of difference cannot be counted on to matter and that when they do matter they may not do so in any particular or predictable way. That is, a Navajo’s heritage may or may not be significant to her, and, if it is, it may not inform in any uniform way her views on what should take place in a clinical encounter. Any number of contingent circumstances, experiences, or carefully made decisions may influence how she understands health, illness, death, and disease, as well as what she wants from her physician. And none of these may deal in her “cultural identity.” As Vicki Michel has pointed out about these kinds of studies, “There is a danger of moving from generalizations to stereotyping—from saying ‘this person might be behaving in a way characteristic of his or her culture’ to saying that ‘since this person comes from a particular culture I know how he or she will behave.’”⁵

Despite these limitations, might it be helpful for clinicians who serve these populations to know, for example, that *some* Navajos prefer not to discuss negative medical information? Perhaps. As Vicki Michel has suggested, this kind of knowledge “can be useful in helping us try to understand rather than judge behavior that is unfamiliar.”⁶ Indeed, beliefs and the systems of which they are a part often go unrecognized when they are strange to us. And once we do recognize them as values or expressions of a belief system, we often discount them and those who convey them as irrational or unreasonable. Given this, one might conclude that this kind of general information could, by increasing clinicians’ awareness, help them initiate and carry on these more delicate conversations with their patients.

I’m not at all confident about the prospect, though. The stack of factors against such appropriate use is tall. Indeed, the very circumstances that have made such information seem necessary have created an environment ripe for its misuse. For a variety of reasons—the storm of managed care and Americans’ own mobility among them—physicians and “their” patients often don’t know each other and rarely have the time to do so. Time is a luxury in the clinical setting, and it grows rarer as more and more Americans switch or are switched to a health plan administered by a managed care entity. Managed care organizations, at least the worst among them, have instituted a number of policies that seem almost hostile to patient well-being.⁷ Fee systems that reward physicians for “underserving” patients and “gag clauses” that limit what physicians can tell patients about treatment options are just two well-documented examples; meanwhile major newspapers offer a weekly dose of new, often horrible, stories. In an environment that’s this short on time and trust, I find it doubtful that rich and sensitive conversations will often take place.

The setting in which most Americans now receive their healthcare is, however, not the only problem. Another, more intangible, factor may contribute to the misuse of this information, and it has nothing to do with the influx of profit-seeking managed care companies. This is a problem with a longer and more complicated history: physician discomfort with interpersonal communi-

cation. Barriers to physician–patient communication have been well documented, discussed at length, and are complex. A laundry list of possible sources has been identified, ranging from the verbal and nonverbal language used by medical professionals and the setting of their offices and examination rooms, to cultural expectations, socioeconomic class, and the emotional states of both patients and physicians.⁸ Although the physician is by no means the only party implicated when communication difficulties exist, physician discomfort, often resulting in patient avoidance, is no small problem. When a patient’s prognosis is dire or treatment is “futile,” the difficulty intensifies. For these reasons, I fear that the information from these studies, while intended to aid communication, will *replace* it. The data from these studies, which have been systematically researched by fellow professionals, presented in a scientific format, and published in a peer-reviewed journal, may simply be easier to ‘get to know’ than patients, especially when a patient’s first language is not the same as the physician’s or he has a different sense of what is important in matters of life and death.

As if these two features of the clinical encounter weren’t enough, there is yet a third, even more elusive, factor weighing in against the intended use of these studies—the very human and very common urge to categorize and simplify the world. Scholars from a variety of disciplines have written about the epistemic tendency, if not necessity, to make sense of experience, including persons, through the use of simplifying categories. Legal scholar Martha Minow describes it this way: “Given our limited ability to hold the complexity of the world in our minds, we summarize and simplify through language. Through these summaries, an individual’s uniqueness stems from the particular intersection of group memberships.”⁹ As much as this strategy may enable us to know at all, it often prevents us from knowing well, for the “trait” of difference that often initiates our knowing also often ends it. That is, the inclination to reduce the other to “a” trait and its attendant societal meaning is all too prevalent. And the categories of difference used by these studies are perfectly suited to such an epistemic move: they can be identified at a glance and are loaded with meaning, meaning that is all too often negative. Although cultural heritage and ethnicity were chosen because they were recognized as significant contributors to human identity, sources worthy of respect, it would be naïve to overlook the negative connotations so often associated with them. Stereotypes and their attendant stigmata are, sadly, resilient. Like other differences, we tend to use them “as though they matched rather than simplified the world we perceive.”¹⁰ Indeed, it is a short and slippery epistemic slope from treating these generalizing studies as an entree to knowledge to treating them as knowledge.

It is this mistaken and all too facile step that will, I fear, nudge the generalizations produced by these studies in the direction of “rules” or “norms,” a move the researchers foresee and warn against. Their worries are justified, for even though the results read as “mere” descriptive statements, they have the feel of rules. Take for example a finding of the Blackhall study:

Korean Americans (35%) and Mexican Americans (48%) were less likely than African Americans (63%) and European Americans (69%) to believe that a patient should be told of a terminal prognosis and less likely to believe that the patient should make decisions about the use of life-supporting technology (28% and 41% vs 60% and 65%). Instead,

Korean Americans and Mexican Americans tended to believe that the family should make decisions about the use of life support. On step-wise multiple logistic regression, ethnicity was the primary factor related to attitudes toward truth telling and patient decision making.¹¹

This finding does not tell clinicians to withhold the truth from Korean- and Mexican-American patients. And, moreover, the researchers are careful in their conclusions to say that, "This finding suggests that physicians should ask their patients if they wish to receive information and make decisions or if they prefer that their families handle such matters."¹²

The sincerity of the researchers' warning is no doubt utmost but fails to take account of the context in which these studies will be used. The moral inclinations of many American physicians, coupled with these apparently important categories of difference, make such misuse even more likely. Most American physicians recognize the values examined by these studies, such as truth telling and respect for patient autonomy, as salient if not prima facie binding, and the impulse to heed patient preference is especially well entrenched. These studies, by collecting patient preferences according to particularities that often can be discerned at a glance, readies the physician to link up these two sets of information and act, or not act, according to the guidance of this well-intended research. The move from individual patient to population study may be so swift and invisible that it may seem to the physician that he has indeed heeded none other than "the" patient's preference. I suggest this as a serious possibility not because physicians are ill-motivated, but because, as I have already argued, physicians are in a hurry, reluctant to share bad news, and simply human.

For all of these reasons, I fear the information produced by these studies will be used as the very rules the researchers warn against. And as serious a warning as this is, it doesn't seem strong enough, for these rules are worse than any I know. No matter how one understands rules to function in moral reasoning, they rely on particulars for their relevance; they don't *systematically* contain them. Depending on one's methodological commitments, rules enter the moral scene at different points in the process of moral understanding. Some view rules as preexisting norms whose justifications derive from on high, in ethical theory. The process of determining the relevance of a rule in a given case requires a briefing on the "facts," and, although the facts may be seen as somewhat self-evident on this view, they are nonetheless necessary. At the other end of the methodological continuum are those who view rules as mere summaries of wise decisionmaking that can be dismissed with little moral anxiety. In this scheme, the import of particulars cannot be overstated—they drive moral understanding and response. In the middle are those who view rules and the particulars of cases and moral experience generally as existing in a dialectical relationship, mutually important.

What's important to notice is that, even for those who privilege rules, rules can function only as generalizations. Their relevance can be established only after an examination of the particulars. This process of closing the gap between rule and case reveals the critical function of particulars in moral understanding and decisionmaking: they are what an inquirer must attend to, discern, encounter. And it is just these activities that I fear studies of "difference" will render unnecessary. Because the studies under examination embed an apparently salient particular into a generalization, they run the risk of preempting these critical

activities. Of course, it is the case that in the process of moral inquiry and reasoning particulars can emerge as salient, so salient that they may cause a “paradigm shift”¹³ or help to tighten a norm, a process sometimes referred to as “specification.”¹⁴ And even committed inductivists recognize the logical possibility of a highly particularized universal. Martha Nussbaum, inductivist exemplar, says: “[S]hould the very same circumstances, with all the same relevant contextual features, present themselves again, it would again be correct to make the same choice.”¹⁵ But notice: such a shift in paradigm, specification of norm, or particularization of universal requires thorough investigation, attention, and care.

A certain irony surfaces from this cautionary note: at the beginning of this essay I suggested that studies of difference in healthcare were animated by the idea that differences matter, and in doing so I lined these studies up with projects committed to the hard work of painstaking moral inquiry, the very work I fear they may preempt. I remain unconvinced that such bioethical projects ought to use a methodology that systematically gathers data on populations to help inform clinicians about the “populations” they serve. It is the case, of course, that clinicians serve populations of patients, but they do so *one at a time*. It may be that physicians who serve patients with cultural backgrounds that differ from their own may benefit from familiarizing themselves with stories and histories about those cultures and the individuals within them. Still, the indisputable resource for coming to know the other is the other. As Minow has said simply and well: “The real chance to learn about the other is by talking with that person.”¹⁶ I don’t see any way of getting around the hard job of asking what may be difficult and uncomfortable questions, each and every time of each and every patient. Only the individual patient can know what an illness or disease may mean to him, how he wants to deal with it, or not deal with it, and probably only once he finds himself in these unfortunate circumstances.

Deeply Ambivalent

In pointing to the dangers of these projects I have alluded to what Minow calls the “dilemma of difference.”¹⁷ It is simultaneously simple and deeply perplexing: In attempting to ameliorate harm created by difference, we may recreate and reinforce it. And this ambivalence can lead to a sort of paralysis or, worse, indifference. If, after all, the other is so complex and unpredictable as to elude genuine attempts at an empathetic knowledge of her, why bother? It seems to me the answer is simply that we cannot afford not to bother, anymore than we can afford to attend to difference in ways that are harmful. And that leaves just a sliver of space in which to work.

Notes

1. Carrese JA, Rhodes L. Western bioethics on the Navajo reservation: benefit or harm? *Journal of the American Medical Association* 1996;274:826–29.
2. Blackhall L, et al. Ethnicity and attitudes toward patient autonomy. *Journal of the American Medical Association* 1995;274:820–25.
3. See note 1, Carrese, Rhodes 1996.
4. See note 2, Blackhall et al. 1996.

5. Michel V. Factoring ethnic and racial differences into bioethics decision making. *Generations* 1994;Winter:23–26.
6. See note 5, Michel 1994.
7. See, for example, Stakes High as California Debates Ballot Issues to Rein in HMO's, *New York Times* (3 October 1996) and an editorial by Clancey CM, Brody H. *Managed Care: Jekyll or Hyde? Journal of the American Medical Association* 1995;273:338–39. Healthcare provided by some managed care companies is so bad that Clancey and Brody found it appropriate to describe the contrast between good and bad care in terms of the infamous Dr. Jekyll and Mr. Hyde.
8. See, for example, Gregory DR, Piven Cotler M. The problem of futility III. The importance of physician-patient communication and a suggested guide through the minefield. *Cambridge Quarterly of Healthcare Ethics* 1994;3:257–69; and Quill T. Recognizing and adjusting to barriers in doctor-patient communication. *Annals of Internal Medicine* 1989;111:51–57.
9. Minow M. *Making All the Difference*. Ithaca, N.Y.: Cornell University Press, 1990:94.
10. See note 9, Minow 1990, 234.
11. See note 2, Blackhall et al. 1996:820.
12. See note 2, Blackhall et al. 1996:820.
13. Jonsen A, Toulmin S. *The Abuse of Casuistry: A History of Moral Reasoning*. Berkeley: University of California Press, 1988:253–54.
14. Richardson HS. Specifying norms as a way to resolve concrete ethical problems. *Philosophy and Public Affairs* 1990;19:279–310, at 295.
15. Nussbaum M. *Love's Knowledge*. New York: Oxford University Press, 1990:38.
16. See note 9, Minow 1990.
17. See note 9, Minow 1990, chapter 1.