

What Differences Make a Difference?

ERIK PARENS

Four years ago The Hastings Center initiated a "pluralism project." That project gave the Center staff a chance to explore one swath of the theoretical literature concerning how members of democratic regimes ought to think about and respond to the differences among themselves. Much of that literature, produced by philosophers like Charles Taylor, Martha Nussbaum, and John Kekes, is wonderfully articulate about difference in general. But it is nearly silent about how particular categories of difference actually make a difference in the lives of particular individuals negotiating particular institutions.

When we began our exploration of some of the theoretical issues, Barbara Koenig, Executive Director of the Stanford University Center for Biomedical Ethics, had already for some time been doing empirical research on the role ethnicity plays in end-of-life decision-making. In particular, she was studying the extent to which ethnicity made a difference for how people execute advance directives. Upon hearing about the Hastings Center's pluralism project, Koenig invited several of us to California to talk with her and her colleagues about their research.

Before arriving in California, I had a chance to read transcripts of interviews that Koenig and her team did with Chinese-speaking, Spanish-speaking, and English-speaking San Franciscans who were making end-of-life decisions. The first thing that struck me about those

interviews now seems so obvious that I am astonished I hadn't noticed it earlier: advance directives presuppose a very particular conception of the self, or what it means to be a person. The creators of these directives seem to presuppose, for example, that persons, even in the face of death, are and ought to be "rational," that, even in the face of death, persons want to speak and hear the truth about their condition, and that persons largely want to make treatment decisions by and for themselves. The second thing that struck me was that not all of the Anglo patients seemed to have the sort of self that the inventors of advance directives had presupposed. They didn't all seem to want to rationally and independently grapple with the truth of their impending demise. Moreover, not all of the "Chinese" and "Latino" patients seemed to possess the sort of self that those same inventors seemed to have in mind when they did speak about "others." Some of *these* "others" did not seem, in the throes of emotion, to turn their decisions over to family members. Some of these "others" did not seem to want to leave the truth about their diagnoses unspoken. Not all of the Anglos were acting like Anglos and not all of the "others" were acting like "others." In short, the transcripts from Koenig's project suggested to me that the category of ethnicity was neither as transparent nor useful as I had imagined.

Shortly after my return from California, the *Cambridge Quarterly of Healthcare Ethics* published a piece of mine, which came out of the Hastings Center's pluralism project and attempted to give the reader a lay of some of the theoretical land that we had surveyed. One of *CQ's* editors, Thomasine Kushner, told me that the theoretical issues surrounding pluralism were important to her and her colleagues, and she invited me to consider putting together a special section on one of those issues. Having just been puzzling about the nature of the categories that Koenig and her colleagues had been employing, I thought that it would be interesting to ask some scholars to reflect on this question: What categories of difference make a difference in the delivery of healthcare? And how ought those differences to be respected? If ethnicity is a category of difference that sometimes matters, then how does it matter and how ought it to be respected? And what about the category of religion? And race? And what about some of the categories that are nearly invisible in the discourse of bioethics, such as disability and social class?

Those are of course enormous questions. So when I tried to persuade people to write about them, I told them all they needed to do was try to get onto paper some preliminary thoughts. In those attempts at persuasion I'm sure I used "exploratory" and "tentative" quite as frequently as "the" and "is." In addition to using the idea of a very preliminary and tentative exploration as a lure, I used the chance to come to The Hastings Center to share ideas with scholars who were equally interested and perplexed. Originally I had thought we would have a one-day meeting at the Center, which would explore the theoretical issues surrounding the "What Differences Make a Difference?" question. But as Barbara Koenig and I

talked about her and her colleagues' contributions to that meeting, it occurred to us that it might be helpful if we could spend an additional day examining the empirical research concerning how some of the categories of difference make a difference in the delivery of healthcare. With generous support from The Greenwall Foundation, the Pettus Crowe Foundation, and the Robert Wood Johnson Foundation, we were able to hold such a meeting at The Hastings Center on 16 and 17 September 1996. The papers in this special section were first presented at that conference and represent the more "theoretical" work concerning what differences make a difference. The papers on the more "empirical" work concerning how (primarily) culture makes a difference in end-of-life care will appear in a volume edited by Barbara Koenig and Patricia Marshall in Cambridge University Press's *Medical Anthropology* series.

In this special section's first essay, "Desperately Seeking Difference," Erika Blacksher launches a salvo across the bow of empirical research into the difference that ethnicity makes in healthcare contexts. With some of the major figures who research the difference made by categories like "Navajo," "Mexican," and "Chinese" in the room, Blacksher forcefully laid out in her talk (and in the paper you will read) why she worries that such categories will "reinforce a reliance on stereotypes and introduce into clinical practice a very dangerous set of rules." Indeed Blacksher put on the table one of that meeting's and this special section's most pressing questions: Is it possible to attend to categories of difference like ethnicity, religion, race, class, and disability in ways that truly promote communication between healthcare providers and patients?

Like Blacksher, in "Difficult Difference" Karen Lebacqz articulates deep reservations about the categories of

what she calls “the litany of difference.” While Lebacqz speaks as a feminist, her piece is not exclusively about gender as a category that makes a difference. Rather, she examines how feminism’s self-understanding has changed over time and suggests how what feminists have learned might help others who are thinking about other morally relevant categories of difference. She begins by showing that categories of difference are “difficult” insofar as when we invoke them, we sometimes forget that they are not simply out there for us to “discover” and that our “making” of those differences is often in the service of particular individuals’ interests. On Lebacqz’s account, even the most apparently self-evident of categories, such as race and sexual orientation, are “socially constructed.” But saying that doesn’t mean either that those categories are unimportant or that they can simply be jettisoned. One can’t fight against, say, racism or homophobia without employing the categories black or gay. In Lebacqz’s view, differences matter if people are discriminated against on the basis of them. (People who love anchovies are different from people who don’t, but nobody gets discriminated against for hating anchovies.) Lebacqz argues that it is time to move past both “embracing” differences in ways that build barriers between “us” and “them” and “eschewing” differences in ways that make us inattentive to the impact those differences have on the lives of particular individuals. She suggests that it is time to begin “dislodging” difference—to start thinking as much about justice as we have thought about difference. But even as we start to think about justice in the way that Lebacqz exhorts us, we also need to hear her simple but important instruction: When you try to figure out what differences make a difference in people’s lives—and thus in how they

negotiate healthcare systems—attend to those categories of difference that are associated with histories of discrimination.

Ethnicity is of course one such category. And ethnicity is the category of difference that H. Eugene Hern, Jr., Barbara A. Koenig, Lisa Jean Moore, and Patricia A. Marshall explore in “The Difference That Culture Can Make in End-of-Life Decisionmaking.” Their exploration begins with two narratives, each of which has as its protagonist a “Chinese” woman in her early forties who has to make end-of-life decisions. One of these patients acts as one might expect if one read the ethnographic literature about how “Chinese patients” make decisions and relate to their families. The other patient does not. Because the first patient’s doctor brings to her encounter a peculiarly Western conception of how “normal” people make decisions and relate to their families, she thinks that this patient’s family is “abnormal in the way they dealt with the situation.” Hern et al. show that if that doctor had had a richer understanding of “normal Chinese responses” to such situations, she could have better responded to her patient’s needs. Now if the second patient’s doctor had had such a richer understanding *and* had assumed that this particular patient would act as the ethnographers say Chinese patients act, then he too would have made a mistake—albeit a well-intentioned one. For *this* “Chinese” patient did not want to share decision-making with her family. In light of this difficulty, Hern et al. make a suggestion. Borrowing from the work of Benjamin Freedman, they propose that healthcare professionals learn to “offer truth” to their patients. According to this model, healthcare providers learn to offer patients the choice to accept *or* refuse “the truth.” And healthcare providers learn to accept that “normal”

people can choose either way. As the authors make abundantly clear, this model, like any, has problems. But it remains one fruitful strategy with which to negotiate the difference that ethnicity can make.

As its title suggests, Betty Wolder Levin and Nina Glick Schiller's essay, "Social Class and Medical Decisionmaking: A Neglected Topic in Bioethics," puts on the bioethical map the largely unexplored territory of social class. While bioethicists often discuss issues of social class in relation to access to health services, a review of the bioethics literature reveals that class is rarely a focus in the analysis of medical decisionmaking. Levin and Schiller argue that bioethicists and interested others should stop trying to define class in terms of a set of socioeconomic indicators such as income level or occupation. Using four vignettes, they argue that class is better understood in terms of a person's social location in relationship to the system of production, distribution, and consumption. They explore (1) how class location is correlated to health status and access to care, (2) how healthcare provider responses to patients reflect provider perceptions of the patient's social location, and (3) how class location influences the values, experiences, and understandings that patients bring to the decisionmaking process. Much of their essay aims to show that what a given medical intervention means to a particular individual depends in part upon that person's social location. They also help the reader see the pernicious use to which their insight could be put. Indeed, their insight could be used to deprive people of needed medical interventions. One can imagine: "Well, we know that because of this patient's class location, the cost of aggressive life-saving treatment would put a great burden on him and his family. Therefore, we won't give him the intervention he needs; we'll give those interventions to

individuals whose class location makes treatment less burdensome." Thus, those who speak about the difference that class makes are obliged to ensure that their insights are put to salutary rather than pernicious uses.

While our history is strewn with examples of the religious difference being put to pernicious ends, Mark J. Hanson's essay is not primarily concerned with such discrimination. Rather, "The Religious Difference in Clinical Healthcare" is primarily concerned with the profound but sometimes invisible ways that religion can matter in the clinical encounter. In his essay Hanson attempts to "lay out in a broad and descriptive way the dimensions of clinical healthcare in which religion at least could make a difference" and "underline the unique status of the religious difference." The first area where religion may make a difference in healthcare regards how believers view healing itself. On Hanson's account, it is a mistake to ignore the potential role of faith in healing, either by failing to enlist the patient's belief in the power of prayer or by overriding the patient's refusal of treatment. Religion can also make a difference by influencing how patients interpret and respond to their suffering—whether as contrary to God's will and something to be escaped or as a vehicle to a transformation of the self. Given the extent to which religion pervades some individuals' conceptions of themselves, and given the extent to which such self-conceptions determine patient needs and wants, Hanson argues that it is in the interests of patients and healthcare providers for providers to think more deeply about the varieties of religious experience. Providers, especially those preoccupied with principles, are especially at risk for being inattentive to the ways in which religion pervades their patients' lives—and thus at risk for responding badly to patient needs. In the end, Hanson suggests that providers

can meet those needs well if they engage “each person and his or her own religious narratives in each clinical situation.”

In “Approximation and Negotiation: Clinical Pragmatism and Difference,” Joseph Fins explores cases involving both religious and cultural differences. While Fins may be less sanguine than Hanson about the possibility of understanding another’s religion or culture, they both—along with all of the contributors—believe that attending to the particularities of individual patients is the order of the day. Exploring two case narratives involving objections to determinations of brain death, Fins shows how what he calls clinical pragmatism works. “Clinical pragmatism operates through a shared process of investigation, planning, decisionmaking, and action in which all the stakeholders concerned with the moral problem collaborate to create an ethically appropriate consensus.” Again, consensus is not easily or perfectly realized in Fins’s view. With marvelous insight and honesty, Fins reveals in his first case how often anger accompanies cases involving difference. The difficult process that is the first case ends in “a tenable, if not perfect, consensus.” The second case shows how mistrust can undermine the therapeutic relationship—even if, as in the second case, the family of the brain-dead child ends up doing what the doctors think is right. According to Fins, if healthcare providers are going to become more attentive to difference in ways that help patients, then they are going to have to think less in terms of particular outcomes and more in terms of cultivating processes in which the real issues and needs of all the participants are honestly addressed.

In highly nuanced ways, the essays in this collection on ethnicity, class, and religion all urge us to attend to difference lest we miss something important about individual patients. Adrienne Asch,

however, urges us to avoid erring in another direction. In “Distracted by Disability,” Asch exhorts us to make sure that our attention to disability does not keep us from seeing the respects in which those differences are irrelevant to the delivery of healthcare services. For example, that Sandra Jensen has Down syndrome is, on Asch’s account, irrelevant to the question concerning whether she ought to receive a heart-lung transplant. Much of Asch’s essay helps the reader see why healthcare professionals are often distracted by the patient’s disability: they fail to understand that deviations from species-typical function are not directly related to quality of life nor in obvious ways correlated to patient needs and goals. Many professionals neither understand the extent to which disabled patients have the same goals as able-bodied patients nor are they familiar with the multiplicity of means that can achieve those goals. As long as providers can’t see past the disability, they will fail to notice that what many of their disabled patients need is help in finding alternative means to achieving their goals.

Thus in some sense the special section comes full circle with Asch’s essay. It began with concerns about the use to which healthcare providers might put empirical research on difference; it moved to discussions of difference in general and to several categories that can make a difference in the delivery of healthcare; and it ends with the warning against being distracted by difference. There seems to be no simple way past healthcare’s version of what, in *Making All the Difference*, Martha Minow calls “the dilemma of difference.” If healthcare providers do not attend to categories of difference that matter to patients, then they compromise their ability to deliver care. But we have seen at least three ways in which providers can attend to differences—and equally compromise their delivery of care. In cases

of what we might call *misdirected attention*, the provider attends to a difference that doesn't matter to the patient in the ways that the experts say it will—for example, the Chinese patient who doesn't act like ethnographers say Chinese patients act. In cases of what might be called *exaggerated attention*, the provider places so much attention on a particular difference that she misses how that difference is largely irrelevant to the patient's most important needs. Being distracted by disability is an example of this. In cases of *cynical attention*, the provider attends to a difference in order to deprive a patient of a service. Telling a poor patient that she shouldn't receive treatment because it would be too great a burden for her family would be an example of such "attention."

It would of course be terrific if we had an algorithm that could tell us what differences really matter to what patients at what times and in what contexts. But none of the authors in this special collection thinks that such an algorithm is plausible. For these authors, the ultimate question seems to be: How do particular differences matter to particular recipients of healthcare? One can only answer that question by asking patients. Ultimately, one has to learn to listen. While this special section takes a small step in the direction of helping health-

care providers see *that* they need to listen to patients in unaccustomed ways, the next and much bigger step will be to think systematically about *how* to promote such listening. That goal may sound too easy to be worth mentioning if one thinks that listening is easy—or too difficult if one knows the ways of healthcare education and the time constraints on healthcare professionals. None of the contributors to this special section has any illusions about how easy it is to teach listening nor about the imminent transformation of our healthcare system in ways that will enable providers to listen well. The contributors to this special section and the other participants in the Hastings Center's "What Differences?" conference do, however, think that learning and teaching about *how* to attend to differences that make a difference is the next step. And that is the step we will try to take in the next stage of our "pluralism" work here at the Center.

Before inviting the reader to dig into these rich essays, I would like to thank Thomasine Kushner for her kind invitation to put this special section together. Were it not for Tomi's generosity, neither our "What Differences?" meeting nor this special section would have happened.