the culture of a medical community where this happens does not typically require clinical ethics consultation or mediation before being realized, but it is this culture change, and not an increase in the use of clinical ethics consultation services per se, that will go the farthest in improving the experiences of patients with SCD in the U.S. health care system.

REFERENCES


Pain, Chronic Pain, and Sickle Cell
Chronic Pain

Ron Amundson, University of Hawaii at Hilo

Bergman and Diamond’s “Sickle Cell Disease and the ‘Difficult Patient’ Conundrum” (2013) critiques the relation between physicians and people with sickle cell disease (“sickle cell”) by way of the notion of the “difficult patient” recently examined in Fiester (2012). My interest in the article is not about Bergman and Diamond’s suggested solutions. Rather, I try to show that the problems they describe are shared with many people who are not sickle cell patients, even though their similarities to that group are important.

Bergman concentrates carefully on sickle cell, and this concentration is well motivated. However, I think there is much to be gained by recognizing a wider application of the “difficult patient” notion to include others with chronic pain. My interest in the topic, unlike most philosophers, comes not from a background in ethics. My background is in history and philosophy of biology and, for the past two decades, in disability studies (DS) due to personal experience with physical impairment. Chronic pain is often considered a purely medical issue, not a disability. I disagree. Chronic illness and chronic pain are almost paradigmatic cases of disability, for a reason that Bergman and Diamond themselves point out. They both fit very poorly within the traditional Parsonian model of the “sick role.” People with chronic conditions, just like people with permanent disabilities, do not comply with traditional expectations of the sick role. The reasons make good sense from the DS point of view. For example, people with chronic conditions may have stopped “trying to get well” (as the sick role requires) because they have come to accept the permanency of their condition as a fact of life. Often they don’t find the condition as horrible as their friends and the medical authorities make it out to be. (Even Wikipedia has a reasonably
good discussion of why “sick” individuals might reject the duties presumed by the sick role.) This leads not to depression, as we have been led to expect, but to a realistic assessment of what personal choices will produce a fruitful life. In fact there are some grounds to believe that an early acceptance of the permanence of a disability will lead to better psychological adjustment in an individual than the crowd-pleasing Christopher Reeve style denial of medical facts: “I will walk again!” (Amundson 2010, 388ff; Gilbert 2006, 183ff). But even if the DS ideology that encourages accepting one’s impairment is absent in a patient, that person may still fit badly within the “sick role” simply because the sick role presupposes a relation with one’s curers that the supposedly sick individual does not accept. Those who are permanently uncured are poor models for Parson’s sick role. Nevertheless, they deserve health care and can benefit from it.

DS is a relatively young field that has modeled itself on the academic studies of such civil rights movements as those opposing racism and sexism. Many of its early practitioners discovered, to their own embarrassment, that their progressive political views had not sheltered them from strong criticisms from African American scholars. This happened because of DS scholars’ casual use of an analogy between two sorts of stigma: one based on race and the other based on impairment. This seemed to be a useful analogy to early DS scholars, but it hid an important pitfall. Suppose we visualize a (white) disabled person to be similar to a person of color (in the United States, today) because of the analogy between the race stigma and the impairment stigma. The analogy seems strong, until we consider African Americans with impairments. Do they simply have two impairments? The analogy doesn’t contain a clear answer to that question, and the simplistic “two impairments” solution is simply false. Stigmas are not additive. Racism and ableism (the stigma against impairments) interact to produce something new; the unique difficulty that a member of a racial minority experiences when trying to get accommodation for an impairment in an inaccessible and racially biased society. The general form of this problem was identified by black feminists critiquing mainstream feminist thought, and was labeled intersectionality (Crenshaw 1989). When two stigmas are present, the result is something new that must be examined on its own terms. The simplistic early use of the race/impairment analogy tended to trivialize racism and (I would argue) ableism as well (Bell 2011).

I hasten to add that Bergman’s paper does not violate intersectionality. By concentrating on the specific case of sickle cell (and implicitly accepting the generalization that it affects only people with African ancestry) Bergman avoids the early errors of DS scholars. But he also avoids some important generalizations of his insights regarding the “difficult patient.” Sickle cell does indeed present an intersectional problem. But that problem can be seen to be shared by people in other intersections than African American race and sickle cell. One more DS notion, besides intersectionality, is required to show this point: the DS doctrine that a “medical model” perspective is inferior to a “social model” perspective when trying to understand the problems caused by impairments (in this case chronic pain). Briefly stated, a medical model categorizes by diagnoses; the social model does not. Crude as it is, this will suffice for the present discussion. The phenomenon of the “difficult patient” is distorted if we characterize patients primarily by their medical diagnoses. The “difficult patient” problem that Bergman addresses is caused by the symptoms of chronic pain, of whatever etiology, together with the social relations between physician and patient. These social relations are partially explained by race.

The physician perceptions that Bergman and Diamond report as “difficult-patient-making” in the sickle cell case are shared by many patients who experience chronic pain (Frantsve 2007; Werner et al. 2004). Bergman and Diamond describe them as mistrust, and perceived addiction to opioid painkillers. True and important, but this is equally true of non-sickle-cell chronic pain. Similarly, they report (quoting Zempsky) that “the reality of the patient’s pain” as perceived by the health care professional “is likely inversely proportional to the social distance between clinician and patient” (Zempsky 2009, 2480). Again true. But being of a different “race” from your physician is only one way to be socially distant. Even with patients and physicians of the same “racial” groups, there are many causes of chronic pain besides sickle cell. Consider an African American whose chronic pain is caused by post-polio syndrome, or by spinal cord injury, or diabetes, or any of a number of other causes. These patients are vulnerable to the “difficult patient” category for the same reasons as sickle cell patients. Finally, let us consider patients who may share the physician’s racial category, but who are perceived to be socially distant for other reasons (youth or age, bodily ornamentation, inappropriate behavior, or whatever). Same result. Read Bergman and Diamond’s elegant descriptions of the physician/patient relation with these examples in mind. Such patients may not share the social history of most sickle cell patients being seen today by Caucasian physicians—the history of racism and slavery. But the set of problems created by physician–patient relations is broader than the set of problems created by a specific history of racist science. I am arguing that the set of problems labeled “chronic-pain caused difficult-patient labeling” is broader than “sickle cell diagnosis caused difficult-patient labeling.”

The history of scientific racism is crucially important for us to recognize. I have recently devoted considerable energy to the racist history of leprosy in Hawaii and elsewhere, and the results resonate with the history of sickle cell as Bergman reports them (Amundson and Ruddle-Miyamoto 2010; Watts 1997). Bergman’s report on the history of sickle cell is important. The “difficult patient” problem that he identifies is, in one way, a result of racist medicine. But in another way, the problem is broader than either a medical or a “racial” categorization can capture. People with chronic pain distrust and are distrusted by their physicians for many reasons, and vice versa. Race is an important factor, but not the only one.
REFERENCES


Acknowledging Levels of Racism in the Definition of “Difficult”

Melissa Creary, Emory University
Arri Eisen, Emory University

Bergman and Diamond (2013), referencing Fiester’s article on the “difficult patient conundrum” (Feister 2012), have utilized sickle cell disease (SCD) as a case study to further refine and define the “difficult” patient. This definition cannot be appropriately appreciated without taking into full consideration the epistemic privilege and authority of those who have created it. While attention in their article is given to the historical, cultural, and clinical implications of why “difficult” has been ascribed to the sickle cell population, we elaborate some nuanced but important elements missing from these explanations.

The diagnosis of illness never occurs in a vacuum. Historical and social factors are often embedded in the naming process. This social construction of illness includes the voices of patients, physicians, advocacy groups, government, media, insurance companies, scientists, and the pharmaceutical industry, to name a few. It also includes an invisible context: transmissibility, moral judgment, and stigma. All of these ingredients make for a complex frame on which to hang what may seem like a simple diagnosis. Disease in this way goes far beyond pathology and genetics, and into the realm of medical sociology. Janus-like assignments are made: normal/abnormal, victim/villain, guilty/innocent, heroic/ptible, good/bad, easy/difficult (Feister 2013; Herek 1990). These assignments dictate how physicians, family members, and society perceive and respond to medical conditions and those who embody them.

In the case of sickle cell disease (SCD), the social factors that impact the perception of the disease (race, ancestral disease origin, education levels, poverty levels) begin with the diagnosis and translate to the perception of “difficulty.” It has been noted by Bergman and Diamond (2013) and further explained by Boatrigh and Abbott (2013) that the “social distance” between the clinician and patient dictates the level of trust around the perception of pain. Social distance is a uniquely sociological term and is defined using four concepts (affective, normative, interactive, and cultural) that broadly recognize race, class, religion, nationality, occupation, and political ideology as distance determinants (Karakayali 2009; Triandis 1960). This social distance should not be assumed to impact only members of the opposite race, but importantly should also consider internal oppresion by members of the same race.

SCD is a biologically based disease that is not race limited yet is associated with differential investment and treatment; racism is likely a root cause for this disparity. Racism is defined as a system of structuring opportunity and assigning value based on the social interpretation of how we look (“race”) and operates on three levels—institutionalized, personally mediated, and internalized. Institutional racism