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Disrespectful Care in the Treatment of Sickle Cell Disease Requires More than Ethics Consultation

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In their Target Article "Sickle Cell Disease and the 'Difficult' Patient Conundrum", Bergman and Diamond draw much needed attention to some of the clinical and ethical challenges present in the care of persons with Sickle Cell Disease (SCD) in the U.S. The authors draw on history, sociology, ethics, and clinical research to illuminate for the greater bioethical community injustices that occur in the treatment of this underserved population of patients. In this commentary, I will make a few additional observations about the ethical issues that arise in SCD treatment, and then challenge clinical ethics consultation as a sufficient solution.

As noted by Bergman and Diamond, a number of characteristics intersect to contribute to the ethical and clinical challenges in the treatment of SCD pain. The racial demographics of SCD were one factor that was discussed. There are several pathways not highlighted by Bergman and Diamond by which race and stereotyping may impact the quality of care experienced by SCD patients. Because the majority of patients in the U.S. with SCD are of African descent, most SCD patients are subject to the same biases, stereotypes, and other attitudinal factors that contribute to the problems of racial and ethnic inequalities in health care that have long been observed to be a problem in the U.S. healthcare system.¹ In the particular case of SCD, the primary complaint, severe pain, has no accompanying objective sign that can be used to validate its existence or severity.² As intimated by Bergman and Diamond, many clinicians incorrectly believe that there are direct or indirect measures (like blood counts or blood pressure) that can be used to assess SCD pain, when in reality there are none. Clinicians must rely on and believe the patient's self-report of pain. In such situations of clinical uncertainty, attitudes or stereotypes that clinicians may have about patients from certain racial, ethnic, or disease-specific populations that affect the clinician's level of trust in the patient will likely affect the quality of the care delivered.¹ Research has shown that physicians tend to believe that African-American patients compared to white patients are likely to have less education, are less likely to be the kind of person they could see themselves being friends with, that they are less likely to adhere to medical recommendations, and that they are more likely to abuse drugs or alcohol.³ These same attitudes are often held by clinicians about patients with SCD.⁴ Particularly troubling for SCD patients is the mistaken belief carried by many clinicians which holds that SCD patients experience high levels of addiction to the narcotic medicines used to treat their pain.⁵ This belief could certainly impact the level of trust that the clinician has in the patient, and these attitudes and doubts about how much the patient can be trusted may lead to the clinician providing inadequate opportunities for the patient to contribute to decision-making about his or her own care. Having insufficient involvement in their care, or the experience of other similarly problematic aspects of their relationship with clinicians, can itself lead to a number of harmful clinical and behavioral outcomes for the patient.⁶

The racial stereotypes that are applied to SCD patients, negative attitudes held by clinicians about SCD patients, and doubts about the trustworthiness of SCD patients are signs of the same underlying problem often experienced by SCD patients.... a lack of respect.⁷

Clinicians fail to show respect for SCD patients when they devalue them, or when they fail to recognize them as individuals by stereotyping based on race or some other feature of their disease (e.g. by assuming that they are addicted to their pain medications). Clinicians fail to show respect for SCD patients when they verbally or symbolically reduce them to some aspect of their biology rather than recognizing them as a unique individual with a particular experience of their disease. For example, spend any time on a medical unit in which persons with SCD are treated, and one will likely hear reference to the “sicklers” currently on the ward, or the “sickler in the room at the end of the hall”.

For Bergman and Diamond, the primary solution to the troubles encountered by SCD patients due to their inappropriate assignment as “difficult” appears to be a recognition of this often inappropriate assignment, as well as a re-framing away from the “difficult” label altogether. Further, the authors recommend the presumptive use of clinical ethics consultation services, mediation, or similar services in resolving conflicts that occur between SCD patients and clinicians. While we certainly agree with the need to critically examine the reasons why SCD patients are framed as difficult and to engage in a re-framing of this patient labeling when warranted, we believe that clinical ethics consultation services will only benefit a small minority of SCD patients who experience these problems. Because ethics consultations are typically initiated by clinicians, they tend to occur only when the clinician perceives there to be a problem, and therefore will not help the overwhelming majority of patients who are experiencing disrespectful care but who have not been “troublesome enough” to their clinicians to prompt a call for help. From the patients’ perspective, it is important to remember that it is the clinicians who are difficult. For example, we have found that hospitalized adults with SCD are much more likely than other hospitalized adults to report deficits in the quality of their care such as not being treated with respect, not having enough involvement in decisions about their care, not being listened to, or experiencing inadequate levels of pain management.⁸ Problems such as these are not best addressed through mediation or clinical ethics consultation. Rather, these problems can be better addressed through medical education designed to affect the quality of the interpersonal processes of care delivered by clinicians, and through a healthcare system-wide commitment to the principles of patient-centered care.

There are no doubt a small number of cases involving SCD patients where the complexity of the issues involved in the case would benefit from the depth and intensity of intervention provided by clinical ethics consultation, mediation, or similar services. These are situations in which there may be one or more complex interpersonal, clinical, or ethical dilemmas that are in need of resolution so that the patient can receive the best care. Nevertheless, we contend that the majority of the problems faced by SCD patients and the clinicians who care for them are not best characterized as highly charged ethical or clinical dilemmas that need resolution.

Our own work has focused on increasing the opportunities that clinicians, or clinicians in training, have to view SCD patients as real people. That is, instead of thinking of the typical image of a “sickler presenting yet again for pain medicines”, we try to encourage clinicians to view SCD patients in the context of their every day lives. We want to increase the opportunities that clinicians have to view SCD patients as people with their own unique sets of needs, goals, values, and preferences. Much of our work has taken the form of videos that depict SCD patients describing in their own words what it is like to seek treatment for their pain and to be confronted with clinician doubts as to the legitimacy of their pain experiences. We have actually found that interventions using videos like that we have produced here (tinyurl.com/sicklecellrespect) can be used successfully to improve the attitudes that clinicians have toward SCD patients.⁹ In the end, it will take a multifaceted

approach using a comprehensive mix of interventions of various types to realize the improvements in care quality that SCD patients desire.

Ultimately, SCD patients, just like every other patient population, want and deserve to be treated with respect. Unfortunately, SCD care is often marked by insufficiencies in the respect that is shown to these patients. Reducing the extent to which SCD patients are subject to stereotypes based on their race or disease status, allowing SCD patients to participate in decisions about their care, building true partnerships between SCD patients and the clinicians who care for them...these are the changes that SCD patients would like to see take place in the care provided to them. SCD patients who express their desire to be treated in these ways often get labeled with the “difficult patient” tag. Changing 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. healthcare system.

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