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Intractable Difficulties in Caring for People With Sickle Cell Disease

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Bergman and Diamond (2013) have articulately and accurately identified many of the reasons why, and the problems associated with, the identification of people with sickle cell disease (SCD) as “difficult patients.” In our view, however, by suggesting that this problem is best dealt with through an ethics service consultation (ESC), they misconstrue the source of the difficulties of SCD and fail to appreciate the limitations of bioethics in seeking to improve the health care experience of people living with SCD. We provide empirical data describing an Australian perspective of SCD care, which highlights not only the complex issues raised by this illness but the challenges it creates for medical decision making and for bioethics. We suggest that the difficulties of SCD are protean in nature and that more can be gained from thinking again about the limits of bioethics and contemporary medicine than it can by seeking solace in clinical ethics consultation.

The historical, cultural, and political setting of SCD in Australia is somewhat different to that of North America where most of the work cited by Bergman and Diamond originates. Following the white settlement of Australia by Europeans in 1788 and restrictions on immigration in the first part of the 1900s typified by the “White Australia Policy,” the arrival of people from world regions with populations who carry the genetic determinants of SCD occurred only within the past 60 years. This has resulted in a heterogeneous group of people who currently access SCD services. The majority of people in New South Wales, Australia, identified in the “NSW Haemoglobinopathy Project” (Crowther et al. 2013) were born outside of Australia (78.5%)—with the majority arriving from Africa and the Middle East. Importantly, more than one-third of these people entered Australia classified as refugees and 50% had annual family incomes below the Australian poverty line (Melbourne Institute of Applied Economic and Social Research 2010). While these people are subject to the racial prejudices identified by Bergman and Diamond, many of those with SCD living in Australia have also experienced war, loss, dislocation, disruption, exploitation, and migration; continue to experience economic disadvantage, cultural isolation, and cultural and religious prejudice in their adopted homeland; and struggle to negotiate living in a foreign country without fluency in English. There are also relatively lower numbers of people living with SCD in Australia when compared to the United States, Canada, and the United Kingdom, so comprehensive, specialist services either are limited or do not exist. And while there are no Australian studies of

clinicians perceptions of drug dependency or opiate-seeking behaviour by people with SCD, we have certainly encountered prejudice among health professionals in our clinical practice and would agree with Bergman and Diamond that this, in addition to the complex medical, social, and cultural context of SCD, contributes to the normative and categorical error of labelling of such people as “difficult patients.”

As has been widely described, prejudicial judgments frequently arise as a consequence of ignorance. In this regard, as Bergman and Diamond make clear, it may indeed aid in having the narratives of patients with SCD properly heard, and this can only positively contribute to the therapeutic interaction. It would be a mistake, however, to expect too much from an ethics consultation, as the experience of people with SCD is so different from that of their health care provider, and from experts in clinical ethics, that it challenges both the processes of medical decision making and the adequacy of clinical ethics.

In interviews with 12 haematologists involved in the care of patients with haemoglobin disorders, including SCD, about their clinical decision making and their use of evidence in their practice, we found that many clinicians used “self-referential” strategies, both in their decision making and in their communication. This usually involved clinicians asking themselves what they would do if they or their own child had SCD, or describing to their patient episodes from their own life that appeared to be salient to their experiences with SCD. In both cases the aim was to generate empathy and understanding and consolidate the therapeutic relationship. It is arguable, however, that achieving these aims requires more than simply hearing a person’s story—it also requires some shared experience. Inasmuch as tourists may better understand their destination through close observation, through discourse, and through education, they always remain manifestly observers. Hearing the narrative of a patient with SCD, therefore, makes the clinician an informed tourist, which is immeasurably important but falls short of the hopes that clinicians may have when they use self-referential strategies to inform and enrich their practice. In this regard it is worthy of note that a study of U.S. haematologists prescribing hydroxyurea in patients with SCD (Lanzkron et al. 2008) demonstrated higher prescribing rates by non-White doctors, suggesting that race-concordant relationships facilitated the complex interactions needed to commence hydroxyurea.

So what alternatives are there to ethics consultation? While we are broadly supportive of the approaches that Bergman and Diamond advocate for meaning-making in clinical care, we suggest that examination of disability theory and disability bioethics provides a particularly useful for means for understanding the situation confronting difficult patients with SCD. First, this is because they challenge the very notion that it is even possible to imagine what it is like to be someone else, particularly someone with disability. In *Disability Bioethics: Moral Bodies, Moral Difference*, Jackie Leach Scully (2008) notes that contemporary Anglo-American bioethics relies, almost entirely, upon “able-bodied” frames of reference in developing an understanding of health and illness and of specific issues such as genetic testing, end-of-life care, and access to community-based care. Normative positions about what treatments should or should not be offered to people with physical and mental disability therefore inevitably embody the ontologies and epistemologies external to their own lived experiences. Furthermore, while Scully is sympathetic with calls for both practitioners and bioethicists to be more imaginative and empathetic, she notes that because these rest upon an individuals’ own experiences and circumstances, any effort to understand a patient’s reality is ultimately compromised by differences in gender, age, culture, religion, and/or class. In the case of people with SCD, all of these exist. This problem is twofold. First, it is a problem that we have few, if any, doctors, nurses, allied health personnel, and health bureaucrats who speak languages other than English, who have experienced discrimination, or who have been threatened by war, poverty, or injustice, and it is a problem that we do not have adequate health services for people with SCD. (Indeed, the reality of Australian medical care is that most practitioners are white, English speaking, non-refugee, and Christian and come from privileged backgrounds.) But it is also a problem if we fail to comprehend the enormity of these differences and believe, perhaps for the

right reasons, that Western institutional “solutions”—like ethics committees—are the answer, or even that we can adequately understand the difficulties that people with SCD may face. As Rosalind Diprose, a feminist philosopher quoted by Scully in *Disability Bioethics*, notes of claims of understanding in academic or public discourse, “Any dialogue which claims absolute understanding of the other is, in effect, a monologue which subsumes differences under norms already in place. The social fabric may alter as an effect of dialogue and action but the inequalities within it will remain in place” (Scully 2008, 39).

But the literature on disability is also useful for thinking about the difficulties of SCD because it reminds us that disability is simultaneously an embodied experience, a biological phenomenon, and a consequence of social relationships and practices. This points to the necessity for both practitioners and bioethicists to recognize what it is about SCD, and about people living with SCD, that is so difficult. Ultimately, this is because the experience of SCD is, at once, a disabling biological condition causing pain, infertility, and organ failure, a disease more prevalent within the communities of the South than the North (and so relatively neglected by the latter), and an illness experience inscribed with the cultural experience of poverty, conflict, movement, colonization, dispossession, and discrimination. Thus, while ethics consultation may assist with medical decision making in institutional settings (making them more reflective and more inclusive of alternative cultural frames of reference), it does nothing to address the social determinants of ill health in people with SCD, change government policies around the management of illness in refugees, increase the amount of research dollars committed to haemoglobinopathies in resource-poor communities, or contribute to international discussions around the plight of people escaping conflict, economic insecurity, and cultural disintegration. The benefits of ethics consultation, therefore, are very limited.

In our view, while we support any processes that encourage care, critical thinking, and moral imagination in health care settings, we believe that the care of people with SCD would be best served by thinking more deeply about what it is that makes them so “difficult” and by critical examination of the political, social, and cultural determinants of their experience of illness and of health care. Bioethics, likewise, would be best served not by rehearsing calls for clinical ethics services constrained by the walls of institutions and by the normative restrictions of analytical philosophy, but by openness to the insights and humility gained by a sensitive reading of disability and feminist bioethics.

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