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Vicki Marsh , George Mocamah , Emmanuel Mabibo , Francis Kombe & Thomas N. Williams

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# The “Difficult Patient” Conundrum in Sickle Cell Disease in Kenya: Complex Sociopolitical Problems Need Wide Multidimensional Solutions

**Vicki Marsh**, KEMRI Wellcome Trust Research Programme and Oxford University

**George Mocamah**, KEMRI Wellcome Trust Research Programme

**Emmanuel Mabibo**, KEMRI Wellcome Trust Research Programme

**Francis Kombe**, KEMRI Wellcome Trust Research Programme

**Thomas N. Williams**, KEMRI Wellcome Trust Research Programme, Oxford University, and Global Sickle Cell Disease Network

From our perspective, working on sickle cell disease (hereafter “sickle cell,” following Bergman and Diamond’s lead in their target article) in a large and busy international health research program in coastal Kenya, we were very interested to read Bergman and Diamond’s (2013) analysis of a “difficult patient” conundrum for some sufferers of this disorder in the United States, influenced by critical historical and political understandings and aspects of the patient–physician relationship in that setting. We are a group of medical and social scientists, community facilitators, and counselors whose work includes health research, service provision and community engagement and counseling on sickle cell at a research program<sup>1</sup> based at the District Hospital in Kilifi, in partnership with the Ministries of Med-

ical and Public Health Services in Kenya. Much of Bergman and Diamond’s analysis rings true to us, albeit with different manifestations of being “difficult,” given the particularities of our setting. We describe a local form of a “difficult patient conundrum” in sickle cell in this commentary, noting that difference here serves to underline the importance of sociopolitical influence on experiences of this and other diseases. Given this background, our conclusions, on the other hand, place far more emphasis on the need for wide multidimensional strategies to effectively address complex challenges than on the creation of a specialist clinical ethics niche. In this, we echo some responses (e.g., Berger 2012) to Fiester’s original article on the “difficult patient conundrum” (Fiester 2012) that Bergman and Diamond draw on

1. KEMRI Wellcome Trust Research Programme ([www.kemri-wellcome.org](http://www.kemri-wellcome.org)).

Address correspondence to Vicki Marsh, KEMRI Wellcome Trust Research Programme, PO Box 230, Kilifi 80108, Kenya. E-mail: [vmars@kemri-wellcome.org](mailto:vmars@kemri-wellcome.org)

in their analysis of gaps in sickle cell clinical services in the United States.

While sickle cell was described in the United States more than 100 years ago, the wide distribution of sickle cell carriers throughout much of Africa was not appreciated until very much later. The first case report with an extended description did not appear until 1945 (Trowell 1945); most early reports described sickle cell as rare, a fact that was attributed to the almost universal mortality associated with the condition in the African environment at that time. More recently, however, genetic disorders like sickle cell have worked their way up the international list of health priorities, spurred on by recognition of an epidemiological transition from infectious to noncommunicable diseases as major causes of ill health in these settings, and more recent developments in genomics and health (Weatherall 2003). Most recent analyses show that the burden of sickle cell in malaria-endemic countries is, in any case, higher than estimates made even 5 years ago (Piel et al. 2013).

These shifts are not yet reflected in national sickle cell policy in Kenya. Sickle cell is not at present counted in national disease surveillance activities, and there is—for example—low awareness of its prevalence among many residents and health managers and providers in Kilifi (Marsh, Kamuya, and Molyneux 2011), a malaria-endemic area where just under 1% of children are born with the condition and have a high risk of dying in early childhood (Grosse et al. 2011; Williams et al. 2009). Recognition in national policy in Kenya is not straightforward, given its patchy geographic distribution, tracking malaria endemicity, and the fact that prevalence is highest in some of the poorest and least empowered parts of the country. But overall, in many parts of Africa, children born with sickle cell often do not get the chance to become adults (Grosse et al. 2011), let alone "difficult adult patients." As survival improves, given the prevalence of the sickle cell gene, the implications for a national health budget of providing services for this condition will become considerably more important; in high-income countries, a quarter of the chronic pediatric health care budget is accounted for by genetic disorders (Weatherall and Clegg 2001). The challenge of managing chronic pain in adults with sickle cell in Kenya is likely to be part of a much bigger ethical issue over prioritization in health care funding and over the place of preventive measures including screening.

At the same time, we are aware that a "difficult patient" conundrum in sickle cell does exist in Kilifi. Given the difficulty in recognizing the fleeting and variable manifestations of sickle cell in very young children, and the high levels of distress for parents looking after children with recurrent severe pain, there is a high likelihood that many affected parents work over time on a trial-and-error basis across a range of traditional, biomedical, and faith-based healers, looking for a "cure" for this condition without recognizing or accepting its lifelong status (Dennis-Antwi et al. 2011; Marsh et al. 2011). Even where biomedical explanations are understood and accepted, parents may face impossible challenges

in reaching health clinics from remote rural areas. A Kilifi father explained that he would no longer be able to attend a sickle cell clinic after the birth of a second affected child since he could not carry two young children on his bicycle, and paying for public transport was beyond his budget. The most likely manifestation of a "difficult patient" is therefore of a "difficult parent," who appears inconsistent in his or her use of—or completely rejects—biomedical clinics and medication, and is often blamed by health practitioners for perceived "ignorance" underlying this behavior. Further, in Kilifi, a traditionally patrilineal society (that is, where social and political identity and ancestry are located in the male line), mothers are often blamed by their husbands' families for health problems in their children, including through faulty parenting, inappropriate behavior during pregnancy, and faults running in the maternal line, and through accusations of marital infidelity and misaligned paternity (Marsh et al. 2011). In the most extreme forms of blame, mothers may be sent away from the paternal home and returned to their own clan with their chronically sick child/children, where much-needed social and financial support is traditionally very uncertain. Finally, the lack of a national health policy on sickle cell in Kenya contributes to challenges for health providers in recognizing and diagnosing the disorder. Some parents in Kilifi described bringing their children several times to government health clinics with early symptoms before a diagnosis is made, generating further potential for being seen as "difficult." One mother described her desperation in this situation, commenting on how many clinic attendance books she used before the diagnosis was made.

The implications of low recognition of sickle cell, and of low use or nonuse of effective forms of health care in Kilifi and other similar settings, are a group of particularly severe and interrelated harms: unnecessary levels of suffering and risks of early death for affected children; and emotional distress, serious economic costs, and potential breakup for affected families, with serious livelihood implications for many mothers. These harms are different but at least as severe and common as those described for adults with sickle cell in the U.S. context that Bergmann and Diamond describe. We strongly agree that medical practitioners who provide services for affected children, including those whose primary role is research, have a professional ethical responsibility to limit these harms to the best of their ability, and that effective communication, including negotiation of difference between the perspectives of practitioners and patients, is a crucial skill in taking on this role. This argument applies equally well in Kenya as in the United States. But we differ with Bergmann and Diamond's assessment of the need for an expert group, the equivalent of the ethics consultation service, to tackle "difficult patient conundrums" in sickle cell.

Putting aside resource considerations, which cannot be done for long, our view is that effective engagement with patients is an essential skill for all health practitioners, and that delegating this role to an expert group undermines this principle, with potential implications across all

health services provided. Further, particularly in malaria endemic settings, we do not see that “difficult patients” with sickle cell have issues fundamentally different from those of others with chronic health problems, particularly once the influence of context is fully taken into account. And, most importantly, since we agree with Bergmann and Diamond that wider contextual features form the bedrock from which “difficult patient conundrums” emerge, we are led to conclude—differently—that an emphasis on a narrow form of ethics, for example, as accomplished through individual-level negotiation by specialist providers, risks losing focus on more substantial ethical issues around inequities in wealth, health, and gender, as well as the importance of supportive health policy. In relation to sickle cell, it seems likely that these latter concerns apply equally well in the United States as in Kenya. ■

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# Intractable Difficulties in Caring for People With Sickle Cell Disease

Helen Jane Crowther, Westmead Hospital  
Ian Kerridge, University of Sydney

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,

Address correspondence to Helen Jane Crowther, Westmead Hospital, Haematology, Hawkesbury Rd, Westmead, Westmead, 2145 Australia. E-mail: crowtherh@hotmail.com