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Healthcare Access Implications and Psychosocial Effects of Sickle Cell Disease

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Millman (1993) defines healthcare access as "the timely use of affordable personal health services to achieve the best possible health outcomes," implying that healthcare access involves only access to insurance, patient satisfaction with physicians, and/or patient utilization of preventive health care (p. 5). However, I agree more with Rouse (2004), who uses the term "access" more broadly, such that patient access has two parts. The first part, which has multiple variables, is a patient's ability to be seen by a medical professional, and the second part is the quality of the patient/practitioner collaboration, which is affected by prior knowledge, communication, and professionalism. This second part has numerous cultural and social dimensions, and contributes significantly to racial disparities in health outcomes. The treatment of sickle cell disease can be very illustrative of our current access to healthcare issues in the development of patient services. One needs to realize that disparities in minority healthcare outcomes will not disappear if we simply base the idea of access on the existence and availability of health care services, as issues of unequal access today deal with more subtle matters. This paper will demonstrate the importance of physicians' perceptions, communication, and understanding in provider-patient relations, as well as the importance of psychosocial interventions in the treatment of sickle cell disease.

Sickle cell disease is an autosomal recessive illness that primarily affects persons of African ancestry, Arabs, and those of Asian ancestry. However, perhaps in part due to insurance reasons, all of the sickle cell patients I have seen thus far in our Sickle Cell Clinic have been of African descent. This disease, though described as "rare," in fact affects 1 in 400 or 500 African Americans in the United States

(Holbrook & Philips, 1994). The genotypes of sickle cell anemia are named for the regions of Africa from which the original gene migrated, and are each thought to impart a different natural history of clinical expression (Holbrook & Philips, 1994). Many physicians find sickle cell disease difficult to treat. For one thing, the intensity of an acute sickle cell crisis can be so severe that it has been qualitatively compared to terminal bone cancer pain. However, because pain is subjective and immeasurable, the patient, rather than somatic distress, is often thought to be the "problem." Moreover, there is no obvious precipitating factor for a painful (acute vaso-occlusive) crisis, which can and does occur without objective physical signs (Sutton, 1999).

While in the past the disease was a metaphor for blood or race pollution, currently sickle cell pain is a metaphor for social dysfunction and the lack of self-control in the African American community (Chestnut, 1994). Thus, although acute, recurrent, painful episodes are often the predominant feature of this illness, sickle cell disease is not one-dimensional. The frequent use of narcotics to treat severe pain leads to drug dependence in some patients, which results in their stigmatization by some health care professionals. The majority of sickle cell patients are African American, and when sickle cell patients enter the emergency room asking for strong opioids, the overwhelming response by physicians is to view them as "drug-seeking and difficult to manage"—both medically and socially (Rouse, 2004, p. 371). Shockingly, this perception is so pervasive that many hospitals try to dissuade sickle cell patients from seeking care in their facilities and refuse to establish affiliated sickle cell clinics.

For many patients with sickle cell disease, pain is a part of their daily lives, and this can indeed lead to misuse of the opioid therapy prescribed. Such misuse, in turn, can lead to tolerance, dependency and overutilization of hospital services—but this is a very small subset of sickle cell patients. Much like (and perhaps in part due to) racial stereotyping, these patients are labeled as "drug seekers," and can induce the staff to form false beliefs about all sickle cell patients who come to the Emergency Room. This kind of stereotyping carries over and interferes with the quality of pain treatment for other sickle cell patients.

As Sutton, et al. (1999) states, "the failure by healthcare providers to distinguish between addiction, dependence, and tolerance is a major component in the failure of effective management of the sickle cell patient with pain" (p. 284). Such misunderstanding can lead to negative provider-patient relationships and conflicts, and would thus feed into a vicious cycle in sort of a self-fulfilling prophecy, where future patients do not get the pain treatment and care they need, act and voice out of frustration, are seen as "bad" sicklers, reinforce a provider's stereotype due to his/her lack of understanding of the disease, and thus further negatively influence the provider's future interactions with sickle cell patients. One devastating example of the consequences of this type of misunderstanding and "drug-seeker" stereotyping is described by Rouse (2004) in recounting an interview, where a resident refused to check on a girl whose parents were trying to communicate that something was not right. The resident also refused to call the attending physician, and reportedly slammed the door in the mother's face. The teenage girl died of a morphine overdose that could have easily been prevented if the resident had checked on the patient or had called the attend-

ing. On a different level (that which the resident's perceptions and reasoning lies), the tragedy could have also been avoided if he believed that sickle cell patients suffer—at least as much as cancer patients do. It was likely that the resident instead viewed sickle cell patients and/or African Americans as drug seeking, and therefore treated the morphine he prescribed like a fix for the patient rather than a treatment for her pain.

When I look at my time at the Pediatric Hematology Clinic and the sickle cell services that we provide, I cannot help but feel a sense of pride in the stark contrast that I have experienced first-hand. Dr. Acharya, for one, is very understanding when it comes to a sickle cell child's pain crisis, and makes sure that the parent has pain medications on hand at home in case there is a need to alleviate suffering. I have yet to experience how these patients are treated in the ER or as inpatients when they come in for serious pain crisis episodes or fevers, but I do know that Dr. Acharya goes on rounds and attends to these patients to ensure they are taken care of outside the outpatient clinic as well. Perhaps there would be more prejudices and difficulties visible when it comes to the adult sickle cell sufferers, but I have yet to have any reason to believe this at New York Presbyterian Hospital. From what I have garnered from the Pediatric Sickle Cell Clinic model at New York Presbyterian, I wonder if the best approach to understanding the origins of myths and misconceptions, stereotyping and stigmatization that surround blacks and sickle cell disease would be to cast away bias (including those that are subconscious or not overly overt) by employing empathy and focusing on the issues of pain and pain management.

Ethnocultural factors will impact on our subjective (individual) experience, cognitive, and physical reaction to disease, and one's perception of how these ethnic and cultural factors impact their experience will in turn shape cognitions (including beliefs, values, attitudes) that guide, direct, alter, and motivate behavior (Chestnut, 1994). Results of Chestnut's 1994 study on perceptions of ethnic and cultural factors in the delivery of services in the treatment of sickle cell disease show that race was perceived as the most influential factor in healthcare delivery. Both medical staff and family respondents consistently viewed whites as getting better service than blacks. If blacks perceive whites as getting better service simply because they are white, it might create a feeling of "second class citizenship," which could easily result in resentment toward the medical system and the healthcare process. This resentment may translate into lateness and cancellations, noncompliance, miscommunication, and hostility in interpersonal relationships with medical staff—all factors that delay and inhibit access to quality healthcare.

Since routinized procedures, or protocols as we at New York Presbyterian Hospital call them, often ignore "the human element" in treatment and may not provide for the broad physical and psychological needs of the patient, health care professionals usually assess the situation from their own perspective and proceed with treatment based solely on those perceptions in an attempt to render services (Ahmad, 1989). However, from what I have observed during my clinical rotations across different specialties, the most effective treatment would appear to occur when the patient/parent is actively concerned and involved in the patient's treatment and experience. Empathy and compassion on the part of the provider plays a major role in the provider-patient alli-

ance in arriving at the most effective treatment, as I feel making an effort to gain information of the patient's perspective will influence utilization, compliance, appointment keeping, overall responsiveness to treatment, and psychological reactions to the illness (something that is especially important when it comes to pain management). The need for such information becomes even more crucial when delivery of service is to ethnically, culturally, and/or socio-economically diverse individuals, who may have ideas about healthcare that are very different from those of the providers ("Unequal Treatment," 2003). Understanding the individual from his/her own frame of reference, also known as the "phenomenological approach" becomes so important because, as psychologists assert, behavior evolves from cognitive processing of what they believe and perceive the situation to be and the action taken (Hanna, 1973). This reality, or realities, becomes powerful in governing behavior—including that of healthcare practitioners. Thus, I believe the physician who truly empathizes with a patient will actively provide the best possible care for the patient, regardless of the patient's background, race, or socio-economic status.

In my experience with the Sickle Cell Clinic at New York Presbyterian, I have also found that good communication is important for quality care, and providers must make an active effort to ensure they are communicating with patients. Healthcare professionals need to understand that coming to the clinic may have many negative aspects for patients, but a staff, such as Dr. Acharya or a nurse, that is seen as friendly, caring, and concerned helps to mitigate the experience. In contrast, poor communication can result in suspicion and mistrust. Understandably, many blacks feel they stand outside the medical system and are skeptical of opening themselves to it ("Unequal Treatment," 2003). "Not understanding" is sometimes a form of resistance to something someone does not trust or want to accept. However, perhaps due to the quality of care that we do indeed provide, I have yet to have seen this type of resistance on the part of the patient or parent during my time with the clinic.

In addition to good communication, compassion is also an important quality I feel good physicians should learn to employ in dealing effectively with sickle cell patients. According to a study by Robbins (1997), nurses' perceptions of sickle cell patients, with few exceptions, were overwhelmingly negative, in contrast to their expressions of sympathy with their cancer patients. Specifically, the study documents that overwhelmingly nurses and residents think sickle cell patients exaggerate their pain significantly more than patients suffering from seven other illnesses. As a result of these perceptions, practitioners treat their pediatric sickle cell patients with lower doses of pain medication in comparison to their cancer patients with similar symptoms. The lack of compassion as an impediment to healthcare access is further illustrated in the following narrative:

> There were at least three other staff members who validated the perspective of the social worker and who expressed concern about the quality of sickle cell patient care, the lack of compassion, and the use of diagnostic labels to limit patient access to health care. These institutional practices […] were the result of racism (Rouse, p. 380-381).

Thus, if a staff member harbors prejudice about a patient (whether or not it be conscious, overt, or aversive), he/she will most likely continue to employ what is considered medically sound healthcare, making this decreased "access" harder to detect. This is why we must look at

how healthcare decisions are rationalized to identify how prejudices may influence knowledge, and examine instances when physicians sometimes unwittingly mask hegemonic discourse about race/ethnicity, class, and gender in treatment decisions, or when physicians cloak insurance mandates in the guise of rational medicine (Bloche, 2001; Daniels et al. 1999).

In addition to equalizing access via changing healthcare personnel attitudes and perceptions toward sickle cell patients, one must also consider the need to provide external healthcare services that dictate and impact what happens at the clinic—and sometimes even whether or not the patient comes to the clinic in the first place. Since many sickle cell sufferers are from a lower socio-economic group, healthcare providers must understand how transportation problems, economic problems, or daycare problems greatly influence utilization of, and hence access to, medical services.

The availability of emotional and social resources is also crucial, since the individual's experiences with episodic pain crises could often affect the emotional life of the patient (Ohaeri, et al., 1995). For instance, sickle cell patients have been shown to experience high levels of anxiety in regards to their illness (Chestnut, 1994). Other challenges associated with sickle cell disease that can result in psychosocial difficulties include growth retardation, behavioral problems, learning problems, and possibly a decreased IQ compared to their peers (Malach, et al., 2002). Moreover, sickle cell disease children are more likely to report social impairment such as restriction in their play and domestic activities, feeling inferior to others, having bad luck, fear of under-achievement in life and fear of potential early death than both the control groups with bronchial asthma and with some acute medical illness (Tunde-Ayinmode, 2005). One needs to understand that social issues like educational attainment, employment status, and social networks are important determinants of illness course and care-seeking behavior.

Here, we see the benefit of building support systems such as sickle cell self-help and support groups. However, though I see Dr. Acharya briefly addressing these concerns during the examination, I think these patients would benefit if a more comprehensive, multidisciplinary, division-of-labor- approach was implemented. As Trzepacz, et. al (2004) suggests, vigorous screening programs for mental health programs should be included in the routine care of children with sickle cell disease, and psychosocial intervention research should be implemented to ameliorate problems for the children at greatest risk. Comprehensive sickle cell programs have played a role in the reduction of morbidity and mortality "by providing easily accessible healthcare services administered by individuals knowledgeable about the disease and its complications" (National Institutes of Health, 1995, p. 5). Ideally, I believe that a comprehensive care clinic, much like the hemophilia clinic I have been participating in, consisting of hematologists, occupational therapists, social workers, psychiatrists, and specialized nurses, would enable one to provide early diagnosis, preventive health maintenance, early treatment of life threatening complications, and development and implementation of new treatment modalities for young sickle cell patients. This multidisciplinary approach, where bio-psycho-social issues are dealt effectively under one umbrella, not only allows whole teams to efficiently work together with the patient to reduce morbidity and mortality, but also do so while increasing

quality of life psychosocially. This, to me, is true access to healthcare.

I hope that this paper has conveyed the point that "access" to healthcare may have a far broader meaning than simply having insurance and/or the ability to pay. Access can be translated to the lack of an adequate amount of medical professionals who can help to create a feeling of empathy and belonging, to social and health policies which often do not include adequate numbers of multiculturally competent persons in the policymaking process, to funding for research and facilities which most often reflect a disproportionate concern for issues of minority health, and even to provider-patient communication. Thus, treatment programs that are going to be effective in treating ethnically and culturally diverse individuals indeed must stress open communication, convenience, ethnic and cultural sensitivity, caring, and concern—qualities that I have seen firsthand with Dr. Acharya in dealing and interacting with sickle cell families.

Physicians construct access based upon moral perceptions of the patient and determinations of what constitutes a life well lived. Coupled with the lack of knowledge about sickle cell disease, one of the problems with sickle patients is that health care professionals make a connection between African Americans using drugs and existing negative stereotypes. If ease of access and understanding of the medical system are so crucial, there is also a need for broader education and exposure to the medical system for patients in times other than medical crisis, such as for much-needed psychosocial services. It is apparent that more research needs to be done in an effort to explore how patients feel their ethnic and cultural characteristics influence the availability and quality of healthcare service they receive.

Not many people will view qualities such as empathy and compassion as means of achieving objectivity with patients, but I argue that these are important skills to employ when one wants to give the best possible treatment one can to his/her patient, unfettered by racial, cultural, or socio-economic stereotypes or stigmatizations that exist. To do otherwise will mean that one is not providing true equal access to healthcare. I firmly believe that education, research, multicultural competence and sensitivity, as well as hands-on experience, resulting in changes in attitudes and behaviors, will ultimately lead to a more empathic approach to the sickle cell patient.

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