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# Caregiver Perspectives of Stigma Associated With Sickle Cell Disease in Adolescents



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**Purpose** Patients and families affected by various medical conditions report experiencing health-related stigma, which contributes to detrimental physical, psychological, and social outcomes. Sickle cell disease (SCD) is a genetic disorder that affects 89,000 individuals in the United States and is often associated with negative stereotypes and incorrect assumptions. The present study explored the perception of stigma as reported by caregivers of adolescents with SCD.

**Design and Methods:** Focus groups were conducted with 20 caregivers of patients with SCD. Focus groups were audio recorded and transcribed. The data were coded independently by two authors, and then reviewed conjointly until consensus was reached.

**Results:** Caregivers reported the perception of stigma in academic, medical, community, and family settings. They also reported internalized stigma including negative feelings toward having a child with SCD, feeling upset with others, and seeing negative emotions in their child due to SCD. Caregivers reported a general lack of knowledge about SCD across settings.

**Conclusion:** These results demonstrated that stigma may affect individuals with SCD across multiple settings. These results also highlighted areas for intervention, with a focus on increasing communication and education toward medical providers, schools, and communities.

**Practical Implications:** Interventions can utilize technology, social media, and advertisement campaigns. Additionally, support groups for patients with SCD may help decrease stigma and validate patients' experiences. © 2016 Elsevier Inc. All rights reserved.

SICKLE CELL DISEASE (SCD) is a recessive genetic disorder that is estimated to affect 1 in 365 African Americans, and approximately 89,000 individuals in the United States (Jenerette, Brewer, Crandell, & Ataga, 2012). An estimated 400,000 children worldwide will be born with SCD each year (Dennis-Antwi, Dyson, & Ohene-Frempong, 2008). Additionally, one to three million Americans carries the recessive trait for the disease (American Society of Hematology, 2015).

Complications from SCD can be life threatening and include unpredictable pain crises, organ and tissue damage, and anemia (Atkin & Ahmad, 2001). Treatment for SCD often consists of prophylactic penicillin, hydroxyurea, pain management, blood transfusions, and bone marrow transplant (Jenerette, Funk, & Murdaugh, 2005). Individuals with SCD may demonstrate frequent use of the emergency room and may also require repeated hospitalizations (Mayer, Konrad, & Dvorak, 2003). Factors such as the need for pharmacological pain management, frequent hospitalizations, and use of the emergency department relate to patients with SCD being at risk of experiencing

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health-related stigma as these patients are sometimes labeled “drug seeking” and report a sense of distrust with healthcare providers (Jenerette et al., 2005; Lattimer et al., 2010).

Stigma is a multi-level process involving an individual or group labeling another as different and undesirable, which often includes stereotyping, discrimination, devaluation, and exercise of power (Link & Phelan, 2006; Mukolo, Heflinger, & Wallston, 2010). Stigma can be based on a number of factors, including race, religion, intelligence, sexual identity, and medical status. Stigma is a source of chronic stress, which subsequently leads to physical and mental harm (Link & Phelan, 2006). Health-related stigma has emerged as a public health issue (Link & Phelan, 2006), and includes devaluation, judgment, exclusion, or rejection on the basis of medical status (Scambler, 2009). Stigma contributes to the detrimental physical, psychological, and social effects of medical illness (Weiss, Ramakrishna, & Somma, 2006). A variety of sources can contribute to health-related stigma, including family members, friends (Jenerette et al., 2012), the community, healthcare providers (Slade, Molloy, & Keating, 2009), and teachers (Hurtig & White, 1986). This stigma may begin in early childhood, though it becomes more apparent through late adolescence and early adulthood (Jenerette & Brewer, 2010).

Health-related stigma has been described in the context of various medical diagnoses, including cystic fibrosis (Pizzignacco, de Mello, & de Lima, 2010), epilepsy (de Boer, Mula, & Sander, 2008), HIV/AIDS (Alonzo & Reynolds, 1995), chronic pain (Slade et al., 2009), and sickle cell disease (Burnes, Antle, Williams, & Cook, 2008; Jenerette & Brewer, 2010). Recently, a conceptual model of patient-reported stigma was described within a lung cancer population (Hamann et al., 2014), which differentiates two types of stigma: perceived (felt) and internalized (self) stigma. Perceived stigma consists of the feeling of devaluation or negative appraisal from others, while internalized stigma is marked by guilt, anger, and regret. These general domains are consistent with the model of childhood mental health stigma proposed by Mukolo et al. (2010), which identified public attitudes, the self, and institutions/service providers as sources of stigma. The experience of health-related stigma may affect medical decision-making, as individuals may delay or avoid treatment due to fears of being labeled or fear of discrimination (Link & Phelan, 2006). One study examining the perspectives of caregivers of patients with SCD revealed themes relating to both perceived (e.g., people thinking the patient is contagious) and internalized (e.g., guilt about having a child with SCD) stigma (Burnes et al., 2008).

Health-related stigma appears to have negative repercussions for those diagnosed with SCD. Feeling stigmatized may prevent families from seeking healthcare (Weiss et al., 2006) and they may feel that healthcare providers perceive patients as drug addicts seeking pain medications (Jenerette et al., 2005). Families may feel alienated from others (Burnes et al., 2008). Young adults with SCD are at high risk for health-related stigmatization for many reasons, including pre-existing racial and psychosocial factors, frequent need for pharmacologic pain management, social deprivation due to frequent hospitaliza-

tions, and lack of understanding from adult healthcare providers (Jenerette & Brewer, 2010). These authors note that interventions designed for reducing SCD stigma may address multiple concerns, which span topics consistent with both perceived and internalized stigma, which are the two types of stigma delineated by Hamann et al. (2014).

Health-related stigma can result in poor medical treatment. Specifically, distrust between adult patients with SCD and their healthcare providers is related to problematic hospitalizations, feeling insufficiently involved in one's own care (Lattimer et al., 2010), and premature hospital self-discharge (Haywood et al., 2010). Additionally, adults with SCD are less likely to participate in clinical trials if they have felt disrespected by healthcare providers and have encountered negative medical experiences (Haywood, Lanzkron, et al., 2014).

One study examined the perspectives of mothers raising children with SCD in Canada (Burnes et al., 2008). A portion of the interviews explored assumed community perceptions of SCD. The mothers reported that SCD has a low public profile and the community lacks awareness about SCD. They indicated a culture of silence surrounding SCD, and a sense of stigma related to lack of knowledge about SCD. Stereotypes and assumptions relating to the disease included that SCD is contagious, that SCD is the result of a curse placed on families, and that mothers are to blame for giving birth to a child with a medical illness. Mothers reported feelings of guilt and shame as well as feeling stigmatized by health insurance companies. Another study demonstrated that mothers and fathers in Ghana often cope with the stigma of SCD by denying that their child has an illness (Dennis-Antwi, Culley, Hiles, & Dyson, 2011). Additional misconceptions reported by these families include that SCD is a form of revenge from other families and that children with SCD will not survive long enough to live a meaningful life.

Additional studies have included caregiver perspectives which have generated themes relating to the caregiver experience of stigma without directly addressing the issue of stigma. For example, one study included the perspectives of parents of children with SCD and identified concerns such as adult providers' lack of medical knowledge as a concern (Porter, Graff, Lopez, & Hankins, 2013). Graff et al. (2012) spoke of parents' emphasizing the importance of teamwork and collaboration with healthcare professionals to facilitate care. These authors also noted that parents are sometimes hesitant to disclose their child's illness to family members, a fear of being judged, and the need to advocate.

Overall, there is a general lack of research related to exploring caregiver perspectives on the stigma of having a child with SCD (Burnes et al., 2008), and to date, no studies have examined caregiver perspectives specific to stigma in the United States. While one study has proposed a conceptual framework for stigma associated with childhood mental disorders (Mukolo et al., 2010), there are no models of stigma within pediatric medical populations in the current literature base. Additionally, there is a paucity of research examining health-related stigma in pediatric (under age 18) populations. The purposes of this paper

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