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Stigma in adults with sickle cell disease and family members: Scale development and pilot study in the USA and Nigeria

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ABSTRACT

Background: Sickle cell disease associated stigma impacts health-related quality of life and community participation. Stigma in adults living with sickle cell disease and family members was appraised via a pilot study for paired (adult and family) instrument development, face validity, and psychometrics.
Methodology: Likert type stigma scales were adapted from epilepsy and HIV literature with Bronfenbrenner's Ecology of Human Development Theory as the conceptual framework.
Findings: 42 adults from United States and Nigeria participated in the study. Chronbach's alpha of the 40 item *Stigma in SCD Scale(s)* = 0.86. Total score 0–120; mean = 40.6, SD = 20.9, range = 4–86. Nigerians report higher stigma ($r = .60$, $p < .01$). Adults from both countries "fear that their significant others will reject them" ($r = .44$, $p < .01$) and from the US that "service providers do not believe that people with Sickle cell disease have disabilities" ($r = .57$, $p < .01$). Factor analysis indicated four interpretable factors: societal impact regarding the disease and isolation; personal feelings of shame, rejection, guilt; treatment when in pain and concerns for the future; and a sense of burden and needing assistance.
Conclusion: Tools to assess stigma in adults with sickle cell disease are useful in individuals and family/social supports across cultural populations. The Conceptual model highlights the complexity of systems that can affect stigma. Implementation of the tool can identify issues such as isolation, fear and burden. Further development and analysis is needed to influence education, treatment, and policy.

What is already known about this topic?

- Stigma is a multi-dimensional concept
- Stigma tools have been developed for several disorders such as HIV, Epilepsy, and most recently Sickle Cell Disease (SCD)
- Individuals with SCD experience multiple physical and social challenges that influence stigma
- Feeling stigmatized may prevent individuals/ families from seeking health care services

What this paper adds:

- A cross-cultural perspective with data collection in the US and Nigeria
- A set of two tools; the Stigma in Sickle Cell Disease Scales (*SSCDS-A* and *-F*) were developed for adults living with SCD and their identified family support which can be utilized to study individual groups or dyads
- The study items address personal as well as environmental and social impacts of stigma and utilizes the Bronfenbrenner Ecological conceptual model to explore stigma in a broader context
- Identifies similar subdomains of stigma in adults living with SCD and family members (4 factor extractions) across three quantitative studies utilizing instruments of stigma

1. Introduction

Growing up with sickle cell disease (SCD) may be invisible but often affects an individual's relationships, access to health services, social and emotional independence and may bring with it the sense of stigma for oneself and family. Adults with SCD and their family may display social delays, isolation, denial or feelings of being different. Stigma is often defined as a mark of shame, disgrace, disease, or abnormality (Goffman, 1963). The goal for adulthood is to overcome this characteristic of being discounted and to achieve self-acceptance and a place in society (Turner-Henson, Holaday, Corser, Ogletree, & Swan, 1994).

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The purpose of this article is to describe the development and results of the pilot study *Stigma in Sickle Cell Disease Scale for Adults and Family (SSCDS-A &-F)*. These scales were developed in response to previous research in the area of SCD. The few studies in the literature at the time of this study that explored the concept of stigma included chronic health, disfigurement, and/or potentially life-threatening conditions such as in epilepsy (Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Fernandes et al., 2004) and HIV/AIDS (Berger, Ferrans, & Lashley, 2001; Emlet, 2005). Findings of these studies have centered on whether or not to disclose their condition and what risks, shame or discrimination may be involved by doing so. This scale can assist health care providers with identification of stigma in either the individual with SCD or family member. As life expectancy for those living with SCD has increased due to newborn screening and advancement in treatments, it is imperative that we consider the additional effects that stigma may have on an individual's quality of life.

2. Background

Sickle cell disease (SCD) is a genetic, multifactorial and often debilitating hemoglobinopathy characterized by painful episodes as a result of vaso-occlusion, and anemia from hemolysis (Kato, Steinberg, & Gladwin, 2017; Yawn et al., 2014). SCD is a prevalent occurring genetic condition worldwide and it can be found in people from sub-Saharan Africa, Turkey, Greece, Italy, Saudi Arabia, India, Southeast Asia, South and Central America, and the Caribbean (Centers for Disease Control and Prevention, 2016a; Piel et al., 2013). Worldwide, about 5–7% of the population have an altered hemoglobin gene (Modell & Darlison, 2008). However, the highest incidence of SCD is in sub-Saharan Africa where malaria is common, and Asia. It is estimated that of the more than 300,000 babies born annually worldwide with major hemoglobinopathies, 75% of them are in sub-Saharan Africa (Piel et al., 2013; Weatherall, 2010. Nigeria has the highest incidence with 100,000 babies born annually with SCD. Of the approximately 160 million Nigerians, about 2–3% have SCD while 20–30% have carrier states (Nwongoh, Adewoyin, Iheanacho, & Bazuaye, 2012; World Health Organization, 2006). In the USA, about 100,000 people are living with SCD and with birth rates of 1:365 black or African-American births and 1:16,300 Hispanic-American births (Centers for Disease Control and Prevention, 2016b).

2.1. Genetics

SCD is an autosomal recessive genetic disorder with the inheritance of a sickle gene and a mutated beta globin gene from both parents. The most common SCD is sickle cell anemia (Hb SS). Other familiar genotypes are sickle hemoglobin C disease (Hb SC), sickle cell with hereditary persistence fetal hemoglobin (S/HPFH), and the sickle beta-thalassemia's (Hb Sb° and Sb+). Rare genotypes include Hb SE, HbSD Los Angeles, Hb SG-Philadelphia, Hb SO Arab (Centers for Disease Control and Prevention, 2016a). Genetic health conditions affect families and the community at large differently than acquired chronic health conditions adding increased psycho-social-economic burdens (Christensen, Wagner, Coleman, & Appell, 2017). Globally there is increased awareness in population genetics and the multidimensional health burden of hemoglobinopathies (World Health Organization, 2006, 2009; Williams & Weatherall, 2012).

2.2. Pathophysiology

SCD is a chronic illness that is punctuated by acute pain episodes. Chronic, acute and neuropathic pain episodes have debilitating and lifelong consequences that vary in severity (Ballas, Gupta, & Adams-Graves, 2012; Kanter & Kruse-Jarres, 2013).

Vaso-occlusive pain episode is the hallmark of SCD and the most frequent reason for hospital visits and hospitalizations in adults with SCD because they suffer from unpredictable, recurrent episodes of severe, unrelenting pain (Ballas et al., 2012). Pain associated with SCD and other complications have negative impact on the physical, social, emotional, psychological, and spiritual domains of affected patients and their family members (Adegoke & Kuteyi, 2012; Anie, Egunjobi, & Akinyanju, 2010; Ola, Yates, & Dyson, 2016; Sogutlu, Levenson, McClish, Rosef, & Smith, 2011). Frequent pain episodes and co-morbidities often require several trips to the emergency department, health care providers and or hospitalizations (Brodsky et al., 2017; Taylor, Stotts, Humphreys, Treadwell, & Miaskowski, 2010).

Adults with SCD experience poor health related quality of life when compared to adults with other chronic conditions (Sogutlu et al., 2011). Poor health-related quality of life (HRQOL), inadequate coping, and poor self-care management skills in adults with SCD continue to foster episodic care leading to poor health outcomes. The development of leg ulcer, osteonecrosis and retinopathy strongly suggests potential for early disability and death due to the development of lethal forms of organ damage (Powars, Chan, Hiti, Ramicone, & Johnson, 2005).

SCD complications also have significant influence on patient's level of self-efficacy and sufficiency (Matthie, Hamilton, Wells, & Jenerette, 2016). There is a relationship between self-efficacy, sickle cell pain and sleep quality (Adegbola, 2015; Sogutlu et al., 2011). The prevalence of overt or silent strokes resulting in cognitive deficits in adults with SCD varies but has significant implications for activities of daily living including disease management.

The fatigue, functional limitations, emotional effect, exhaustion from sleep deprivation as well as the stigma associated with both the disorder and its management have been well documented (Adegbola, 2015; Ballas et al., 2012; Haywood et al., 2014; Jenerette & Brewer, 2010). In addition to multiple follow up and specialty clinic appointments, pain episodes constantly interrupt life activities and are sources of stress resulting in increased absences from work, school, and fear of job loss or class placement (Olatunya et al., 2015). One study identified that 6 of the 18 unique patients accounted for more than 50% of the emergency department (ED) visits and 40% of hospitalizations while 60% of patient visits to the ED did not have a primary care provider or individual health care plan (Odesina et al., 2010). These repeated interruptions in life coupled with depression can affect pain coping skills, self-care management, and quality of life. As a result, some become preoccupied with their illness and may have poor health outcomes from negative medical experiences (Jenerette & Brewer, 2010; Jenerette, Brewer, & Ataga, 2014; Matthie et al., 2016; Mouscou-Jackson et al., 2016; Ola et al., 2016).

2.3. Health disparities

Access to advanced quality health care and support services have played a major role in improved quality of life and life expectancy of adults with SCD. While penicillin prophylaxis, broad spectrum antibiotics and other interventions have drastically reduced death related to bacterial infection in children and adults with SCD, people with SCD in some low or middle income countries do not have access to such. Infections and acute chest syndrome are still the leading cause of death in Nigerian children with SCD (Ogun, Ebili, & Kotila, 2014). A study by Rodrigues, Adegoke, Campos, Figueiredo, and Silva (2017) revealed that some children in Brazil are deprived of the benefit of transcranial doppler study. This would have identified children susceptible to early stroke and allowed for recommended intervention.

Health disparities, including delay in early detection of organ damage and disabling conditions in childhood can lead to lifelong limitations in cognitive and executive functions. These and other health and functional limitations effect morbidity and mortality. It is of note that the survival rate of those living with SCD in the USA is higher (mean = female 42 years; male 38 years) (Lanzkron, Carroll, & Haywood, 2013) compared with Nigeria (mean = 21.3 years) (Ogun et al., 2014).

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