# Educational Intervention to Improve the Health Outcomes of Children With Sickle Cell Disease

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## ABSTRACT

**Introduction**: Although sickle cell disease (SCD) is the most common single gene disorder worldwide, caregivers of children do not have adequate knowledge about the illness and its management. The purpose of this study was to assess the efficacy of education along with tailored written materials in changing the behaviors of caregivers to help them provide better care for children with SCD.

**Methods**: A preintervention and postintervention quasi-experimental design was used. A convenience sample of 43 caregivers of 57 children were asked to complete a questionnaire related to their knowledge of SCD before and after educational sessions. The educational sessions (the intervention) were provided to caregivers at the Children's Cancer Center in Lebanon by one registered nurse, one certified pediatric nurse practitioner, and one pediatric hematologist. Emergency department (ED) visits and hospitalizations were compared 2 months before and 2 months after the intervention.

**Results**: A statistically significant increase was found in the knowledge of caregivers about the cause, symptoms, and management of the disease. A statistically significant decrease occurred in the number of hospitalizations before and after the intervention but not in the number of visits to the ED. Multiple regression analysis found that none of the background variables were related to knowledge, ED visits, or hospitalizations.

**Clinical implications**: Education and written materials written in a simple language that is understood by 5th-graders were beneficial in improving the knowledge of caregivers and in decreasing the number of hospitalizations of children with SCD. J Pediatr Health Care. (2015) *29*, 54-60.

## KEY WORDS

Sickle cell disease, education, readmission, Lebanon

Sickle cell disease (SCD) is the most common single gene disorder worldwide, with an autosomal mode of inheritance and different clinical manifestations in various ethnic groups and populations. It affects 1 in 500 Blacks in the United States and more than 30 million people worldwide with predominance in populations of the sub-Sahara, India, and the Middle East (Inati et al., 2007; McGann, Nero, & Ware, 2013; Okpala, 2005). Different types of SCD exist, including sickle cell anemia, sickle-hemoglobin C disease, sickle beta-plus thalassemia, and sickle beta-zero thalassemia, with prevalence of certain types in particular ethnic groups. Although it is inherited genetically, the symptoms of the disease are affected by environmental factors and are due to the replacement of more than 50% of the hemoglobin-beta gene with the hemoglobin S

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gene. SCD results in serious complications, with high rates of morbidity and mortality. Some of these complications include but are not limited to hemolytic anemia, acute vaso-occlusive events (VOEs), cerebrovascular accidents, pain, and chronic end organ damage that often manifest early in life (Ballas, 2009; Frei-Jones, Field, & DeBaun, 2009; Inati et al., 2007; Inati, Koussa, Taher, & Perrine, 2008; Lanzkron, Carroll, & Haywood, 2013; Rees, Williams, & Gladwin, 2010).

As a result of better management strategies in the past four decades, the bleak outlook for persons with SCD has improved, and the life expectancy has increased from 14 years in 1973 to the mid to late 40s in 2004. However, prolonged longevity has made SCD a long-term chronic illness requiring frequent hospitalizations, extensive medical attention, and long-term management (Lanzkron et al., 2013; McGann et al., 2013; Meier & Miller, 2012; Quinn, Rogers, & Buchanan, 2010). The well-documented management strategies include (a) early identification by neonatal screening programs; (b) education of parents and patients about medical complications and early recognition; (c) preventive measures with prophylactic penicillin and pneumococcal immunizations; (d) aggressive treatment of acute VOEs including hydration, analgesics, antibiotics, and transfusions; (e) screening programs for early signs of organ damage, especially primary stroke risk using transcranial Doppler examinations; and (f) therapeutic intervention with transfusions, chelation, hydroxyurea, and stem cell transplantation (McGann et al., 2013; Wang & Dwan, 2013). The focus of this study is on the second strategy, which is the education of caregivers and children.

The limited number of studies in the USA, Europe, and the Middle East document that the majority of patients with SCD and their caregivers have an inadequate degree of knowledge about the disease and its management (Acharya, Lang, & Ross, 2009; Boyd, Watkins, Price, Fleming, & DeBaun, 2005; Mayor, 2008; Smith & Aguirre, 2012; Treadwell, McClough, & Vichinsky, 2006). In addition, there is a scarcity of culturally sensitive health education programs for high-risk populations, such as in the Middle East (Al Arrayed, & Al Hajeri, 2010; Al Nasir & Niazi, 1998; Famuyiwa & Aina, 2009). Educating caregivers is essential to ensure that they manage symptoms, maintain control of the disease adequately, and seek medical attention promptly for their children (Frei-Jones et al., 2009; Inati et al., 2008). In some countries in the Middle East where SCD is prevalent, laws have been passed requiring all couples who plan to get married to undergo free premarital counseling, and newborn screening and extensive educational campaigns have been offered. However, despite these efforts, researchers continue to report inadequate knowledge about the disease and its management. In addition, religious convictions and lack of informed reproductive health decisions prevent caregivers from accepting premarital counseling or limiting the number of children they have through the use of contraception (Acharya et al., 2009; Al Arrayed & Al Hajeri, 2010).

One method to increase the knowledge of caregivers of children with SCD is to provide education with written materials that are culturally sensitive to the population for which the materials are intended. Furthermore, although specific guidelines are available in the United States for the management of SCD, these guidelines are not being followed by most American physicians (Solomon, 2008) and may not be applicable to other populations and cultures (Yarbrough & Klotz, 2007; Katz, Smith-Whitley, Ruzek, & Ohene-Frempong, 2002).

Educational materials have been noted to be cost-effective and time-efficient adjuncts to the medical care of persons with SCD (Bastable, 2003; Mahat, Scoloveno, & Donnelly, 2007). Written materials are particularly useful because they can be tailored to fit the management plan of each center and each population, they are available at home, and they can outline therapeutic steps in simple terms, especially for parents with low levels of literacy (DeWalt & Hink, 2009).

The conceptual framework for this study was Bandura's self-efficacy theory (1977). According to Bandura (1977), self-efficacy has two components: efficacy expectation (the belief that one can carry out the desired behavior), and outcome expectation (the belief that the behavior will bring about the desired outcome). In Bandura's model, sustaining knowledge over time requires a transformation of the lessons learned to having control over managing the symptoms and complications of SCD. Reciprocity exists between perceived self-efficacy and achievement; that is, the more confident caregivers are that they can control the disease, the more likely they are to continue efforts toward management of SCD.

For this study, caregivers were engaged in the learning sessions and were encouraged to participate in the discussions, which were influential determinants of increasing self-efficacy, confidence, and changing behaviors. Sustained knowledge was assessed through a questionnaire 2 months after the educational sessions were provided, and change in behavior was assessed though the number of hospitalizations and emergency department (ED) visits 2 months before the initiation of the educational sessions and 2 months after the sessions.

The purpose of this study was to assess the efficacy of education and written materials on the health outcomes of children with SCD in Lebanon. It was postulated that education along with tailored written materials will change the behaviors of caregivers, enabling them to better care for children with SCD. The Children's Cancer Center of Lebanon (CCCL) manages the majority of patients with SCD, but no written or educational materials were available for caregivers.