



# Outcome results of self-efficacy in children with sickle disease pain who were trained to use guided imagery



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## ABSTRACT

**Purpose:** The aim of this study was to describe self-efficacy as a theoretical component of behavior change in various therapeutic treatments such as the management of SCD pain.

**Method:** The participants were prepared to self-initiate the GI for 5 to 10 minutes three times each day regardless of pain and also during each pain episode. As part of the GI training a tape or CD with guided imagery messages was provided. Participants were monitored for 4 weeks pre and 4 weeks post intervention (GI training). Children kept a daily record of pain episodes. During this time, children continued to record as before in their personal study diary: pain episodes (intensity and treatment), school attendance, and also the frequency of GI use. At the conclusion of this 4-week period, usual pain patterns (PAT), visual imagery ability (KIAQ), and disease specific self-efficacy scale were measured again. The Sickle Cell Self-Efficacy Scale (SCSES) is a new nine-item scale measuring disease-specific perceptions of self-efficacy. The instrument's developers established internal consistency by Cronbach's alpha of 0.89.

**Results:** H1: Children with SCD who are trained in guided imagery will have greater disease-specific self-efficacy following the training than they had prior to learning guided imagery; the hypothesis was tested and supported using t-tests of mean interval-level scores on the SCSES.

**Conclusion:** Eighteen children had positive gained scores and sixteen children raised their scores more than one standard deviation above the mean score for this sample distribution. Greater self-efficacy scores are associated with better physical and psychological functioning.

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## 1. Introduction

### 1.1. Background/significance

The proposed study tested the outcomes of children with sickle cell disease (SCD) who were trained to use guided imagery as a self-help modality (Dobson & Byrne, 2014). This was done along with traditional pain management strategies including standard pharmacological regimens. The anticipated effectiveness of guided imagery (GI) is based on the principles underlying cognitive behavioral therapies and self-efficacy. GI uses the power of the imagination. GI also uses specific calming words, music, symbols or combinations of these to create mental images and elicit a positive physiological response and feeling of well-being. The proposed study was designed to test the effects of guided imagery on pain perception and medication use. Self-efficacy and imaging ability were studied in a sample of children with SCD aged 6–11 (Dobson & Byrne, 2014).

There is some evidence that the coping strategies learned by children with SCD will influence their overall adjustment, both during childhood and during adulthood (Ross & Ross, 1988). More systematic investigation into effective coping and its effect on early and later

adjustment is recommended (Gil, Williams, Thompson, & Kinney, 1991). By the time persons with SCD are adolescents; their experiences of recurrent pain can result in behavioral expressions not usually associated with the presentation of acute pain. For example, they are as likely to suffer silently and to be non-verbal as to cry or moan (Fletcher, 2002). In a study of 72 U.S. children ages 7 to 17 years with Hb SS, Hb SC, or sickle thalassemia syndrome, findings showed that their coping strategies were not related to pain frequency or duration but were significant in predicting overall adjustment. Children with passive adherence and negative thinking traits (measured by the Coping Strategies Questionnaire) were more psychologically distressed during painful episodes, had more emergency room visits, and were less physically active while children using cognitive behavior strategies, (diverting attention, calming self-statements, reinterpreting pain sensation) had significantly fewer emergency room visits and were more active, even during pain episodes (Gil et al., 1991). Interestingly, the child's coping style mirrored that of the parent. Parents with higher negative thinking reported more child behavioral problems and parents using cognitive behavior strategies reported that children were more active (Gil et al., 1991).

## 2. Overview of sickle cell disease

Sickle cell disease (SCD) is a recessive inherited gene that affects the red blood cells (RBCs). Individuals who are affected with SCD have an

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abnormal gene (HgbAS, the trait, or HgbSS, the disease). If a child has HgbSS, the disease, it indicates that both parents passed an affective gene to the child (Myers & Eckes, 2012). The RBCs are responsible for transporting oxygen to the cells. The affective gene is not able to perform normally, causing distortion of the RBCs, hence the name “sickle cell”. These changes in the shape of the cells result in breakdown and blockage of cells in small veins. As a result of the inflammatory process, damaged to tissue and severe painful crisis results (Myers & Eckes, 2012). Because of the overwhelming damage that the affective cell causes to the body of the patient with SCD, tremendous physical, and psychological changes occur in the life of patients' with SCD (Myers & Eckes, 2012). It is reported that SCD patients show evidence of psychological complications during the life span which may interfere with pain coping strategies (Anie, 2005). Adaptation and coping continue to be a struggle for children, adolescents and adults with SCD (Anie, 2005). Other multi-modality treatments can be effective in treating the psychological aspects of SCD. These modalities include meditation, yoga, distraction, and guided imagery, to name a few. All areas of such modalities should be explored which will have a greater impact on self-efficacy and the ability to assist patients' to deal with the challenges of daily living.

### 2.1. Pain studies of children with SCD

While there are unique and crucial issues associated with the recognition and treatment of pain in SCD, the study of pain management in this disorder can be informed by the general pain research already summarized. The concept of pain as a multi-factorial phenomenon with individual subjective definitions is relevant to the study of SCD pain. As in the general population and other clinical populations, the nature of pain as a symptom in SCD has received less attention than the pharmacologic control of pain. Pain treatment is increasingly acknowledged to be more effective when psychological, social and behavioral components are included (Gerik, 2005; Kwekkeboom, 1999; Rosenthal & Keefe, 1983). There has been much emphasis on the pharmacological aspects of SCD pain management and limitations in these studies to the most intense type of pain associated with SCD vaso-occlusive events (VOE) or crises. There have been very few studies exploring non-pharmacologic strategies, including those initiated by patients themselves. Also, parallel to the general pain literature, pain in adults with SCD has been studied far more than pain in children with SCD, and acute pain episodes have been studied to a much greater extent than chronic pain or the effects of repeated episodes of acute pain.

In spite of the common presentation of pain as a physical symptom associated with SCD, very little is known about the range of pain experiences in children with SCD beyond the most severe crisis pain. It can be anticipated that children with SCD experience the types and frequencies of everyday pain reported by the general population of healthy children as well as the unique and intense pain associated with SCD and its crises. There are no formal studies of the ordinary pains experienced by children with SCD. However, in a diary study of pain incidence and home pain management, information was obtained from 37 children and adolescents with SCD about all pains experienced daily across a time period which varied from 6 to 36 months (Burnes, Antle, Williams, & Cook, 2008). Pains were categorized as mild, moderate or intense and compared among three age groups (5–9 years, 10–13 years, and 14–19 years) and by medication use. The oldest group self-reported more days with medication use and used more potent opioids than the other two age groups. Days of unmedicated pain were more frequently reported on days with mild intensity of pain but, overall, pain was under-medicated Dampier, Ely, Brodecki, and O'Neal (2002). The authors concluded that interventions to improve pain management behaviors at home, especially for more severe and frequent pains, needed to be addressed.

Several studies of more severe pain, in particular the pain of sickle cell crisis, have been conducted for both children and adolescents with

SCD. In one survey, both children self-reports and parent reports described the pain of SCD as more intense and gave more vivid sensory descriptions than those reported with other childhood diseases associated with pain (Varni, Thompson, & Hanson, 1987). In a preliminary study focused on the child's perception of SCD pain, self-reports from ten United Kingdom children between the ages of 6 and 16 years revealed that during the past year five had one pain crisis, three had two crises, and two had three crises. Eight of these children said that pain crises, and hospitalization were the worst things about SCD. Seven reported their mothers were worried and sad during the child's crises, three said their mother got angry and two told a sibling rather than a parent about the onset of a crisis (Davies & Fuggle, 1992).

Pain has not only physical but also psychological components and consequently it is generally accepted that pain influences not only the body but the ability to function and quality of life in adults, adolescents and children (American Academy of Pain Medicine, 2005; Gerik, 2005; Roth-Isigkeit, Thyen, Stöven, Schwarzenberger, & Schmucker, 2005). Pain is recognized as a subjective experience with physical and psychosocial components. It can be assessed by several indicators such as verbal descriptions, nonverbal expressions, specific tests, and empathy; therefore pain can be defined as a subjective experience when communicated. Pain has psychological implications which modulate the way pain is experienced and suggests differences in pain perceptions (Frischenschlager & Pucher, 2002). In order to understand the effects of pain, the bio-psycho-social factors must be examined. Pain perception and experience are influenced by numerous factors such as biological (endorphins, drugs, etc.), situational, social, personality and cultural factors. Therefore, pain can be viewed as emotional and/or psychological as well as physical (Frischenschlager & Pucher, 2002). Because pain has many dimensions, it may respond to cognitive processes.

### 3. Hypothesis

Children with SCD who use guided imagery will have greater disease-specific self-efficacy following training with GI, than they had prior to training (Dobson & Byrne, 2014).

### 4. Review of literature

#### 4.1. Cognitive behavioral strategies for pain management in children

The role of children as decision-makers in the management of any chronic illness has long been urged (King & Cross, 1989) and the learning of cognitive and behavior strategies for coping with pain episodes and disease management has been specifically recommended on the basis of studies with children who have painful disorders including SCD (Gil et al., 1991; Kachoyanos & Friedhoff, 1993a, 1993b; Siegel & Smith, 1989). These strategies are mentioned in reviews of pain protocols for SCD (Marlow & Chicella, 2002; Wethers, 2000) but little detail is included. Cognitive and behavioral therapies (CBTs) deal with both psychological and physiological experiences of pain in a way that enables the person to realize that pain is not merely related to physiological experiences, but that psychological reactions to pain which also affect pain perception. These therapies include hypnosis, guided imagery, distractions, with or without music, relaxation, supportive groups, and positive talk. The outcome of CBT is geared toward comfort, strength and confidence (Kwekkeboom, 1999). Cognitive and behavioral therapies (CBT) are not yet widely emphasized as either preventive or treatment approaches to pain management.

Alternative CBT methods of non-pharmacologic pain management have been widely overlooked in SCD even when they have shown promise for patients with other disorders. Among these, the use of guided imagery has the potential to be a modality important in the management of pain associated with SCD. There are both empirical studies and theoretical papers that support the benefits of the use of imagery and related methods in nursing practice with both adults and children.

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