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Art Therapy with Hospitalized Pediatric Patients

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ART THERAPY
WITH HOSPITALIZED PEDIATRIC PATIENTS

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For James,
and
Healy,
and
David Wolf,
who simply said,
“I knew you would.”
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ABSTRACT

Research in pediatric medical art therapy is comprised largely of case studies. The motivation for this study was to contribute quantitative data to the literature on art therapy with children who experienced hospitalization and medical treatment. The study question focused on the efficacy of art therapy in reducing the anxiety of hospitalized pediatric patients. To address this issue, a subgroup of pediatric patients was selected; a single subject research design was initiated with a homogenous group of 6 to 9 year-old female patients hospitalized for treatment of sickle cell disease. In addition to extensive qualitative narrative, three instruments were utilized: (a) an Anxiety Behavior Schedule, (b) the Children’s Health Locus of Control Scale, and (c) the Children’s Hope Scale. The intervention phase of the study included art therapy interventions designed to familiarize subjects’ with the hospital environment, provide opportunities for control and expression, and respond to subjects’ established cognitive structures regarding their medical condition and treatment. The results of the study support the efficacy of art therapy in two very important ways: First, all of the subjects demonstrated reduced externality of locus of control following art therapy intervention. Second, the observable anxiety data on subject 2 definitively confirmed reduction in anxiety due to art therapy intervention, with statistical significance established at the .05 level. Finally, one subject’s subsequent hospitalization provided the opportunity to collect follow-up data; this data confirmed that the reduction in anxiety behaviors resulting from the art therapy protocol was sustained over time. Extensive qualitative narratives of the subjects’ experiences were provided. Implications for future practice and further research are discussed.
CHAPTER 1
INTRODUCTION

Introduction

When children are hospitalized for medical care, their health is the top priority of hospital personnel. However, hospitalization can be a psychologically challenging time for children and can lead to mental health problems. Children may be developmentally unable to assimilate the trauma of illness and hospitalization. Rode (1995) reported that isolation in an unfamiliar environment, perceptions of loss of control, and fear of bodily harm can disrupt emotional wellness and interfere with the psychosocial development of hospitalized children. Outcomes of the psychological stress of hospitalization and illness can range from overwhelming short-term anxiety to long-term or permanent emotional and developmental disabilities (Association for the Care of Children’s Health, 1977).

Recognition of the psychosocial needs of hospitalized children has generated interest in programming to address the developmental and emotional needs of the young patients. In fact, the Academy of Pediatrics (1986), concluded that facilities with 10 or more pediatric beds should implement developmentally appropriate programming to meet the psychosocial needs of patients. The normalizing, therapeutic, non-verbal, and expressive qualities of art making elucidate the propensity of art therapy to be an important and integral element in exploring, communicating, and resolving the formidable experiences of hospitalization and illness.

Opportunities for creative expression can help young patients cope with the psychological challenges of hospitalization. Malchiodi (1993) used the term medical art therapy to refer to the practice of art therapy in medical settings. She advocated the use of medical art therapy with individuals with medical illness or physical trauma, as well as with individuals undergoing medical treatment.
Medical art therapy intervention can be implemented to meet the emotional needs of hospitalized children. For example, fears commonly experienced by hospitalized children may be addressed through open ended art therapy experiences. These fears include fear of mutilation or castration, disfigurement, abandonment or separation, helplessness, loss of control, pain, needles, and death (Zager, 1980). Art making engages young patients in non-verbal communication of thoughts and concerns about their illness, medical treatment procedures, and body image (Council, 1999; Epping & Willmuth, 1994; Gabriels, 1999; Geraghty, 1985; Malchiodi, 1999; Russell, 1995; Viscardi, 1994).

Gabriels (1999) used art therapy to provide young asthma patients with a non-verbal means of expressing their feelings about their illness. She wrote, “Illness-specific art therapy tasks can provide the child with a non-threatening means of initially discussing how they perceive and are coping with their asthma” (p. 102).

Artistic expression with pediatric patients is particularly effective in supporting and cultivating psychological resources related to resiliency and successful adjustment to medically traumatic events (Malchiodi, 1999). Children in medical settings may experience two traumas which interfere with their mental well-being. The first is the event that necessitated hospitalization, such as an accident, abuse, fire, or manmade and natural disasters. The second is the hospitalization itself, including distress related to medical treatment and apprehension associated with the lack of familiarity with the hospital environment. Malchiodi (1990, 1999) described using art to revisit traumatic experiences and explore, master, and reframe feelings associated with trauma; “Art…serves as a way to externalize the problematic feelings traumatized children have, and provides the therapist with visual clues to help children see their illnesses as illnesses, and to help separate themselves from the illness” (p. 177).

Art therapy is a successful tool for addressing the psychosocial needs manifested in hospitalized children. The psychosocial needs of pediatric patients “are paramount in treatment and are a major concern in using art expression as therapy” (Malchiodi, 1999, p. 15). Art therapy interventions designed to create occasions for independence and control allow the expression and resolution of fears, familiarize pediatric patients with the hospital environment, provide opportunities for the visual expression of the healing process, and facilitate body awareness.
The art therapist serves as a vehicle for providing accurate, age appropriate information about the hospital environment. Bennett (1993) stressed that the availability of information relevant to the experiences and treatment plans of pediatric patients benefits their development and implementation of coping skills. The art therapist can provide relevant art experiences to assist young patients in effectively internalizing accurate environmental and treatment information. Gaynard, Wolfer, Goldberger, Thompson, Redburn, and Laidley (1990) argued that the provision of accurate, relevant information is essential in interrupting a cycle of anxiety, and that information can “increase the child’s sense of perceived control” (p. 18). The authors produced a model illustrating the habitual pattern established when patients receive insufficient information to generate accurate emotional responses. Low information, the provision of insufficient or inaccurate information, leads to high uncertainty and low perceived control. The inability to cope resulting from low perceived control translates to a high threat appraisal, which generates high emotional distress. Anxiety, fear and tension caused by psychological distress disrupts information processing resulting in the ineffective processing of the information that is provided, thereby leading once again to low information (1990). To avoid this pattern, in addition to the provision of appropriate information, Gaynard et al. (1990) and Prugh, Straub, Sands, Kirschbaum, and Lenihan (1953) suggested that opportunities for creative expression during and after hospitalization can help children adjust to illness and hospitalization.

A combination of the psychological approaches described by Rosal (1992) is applicable in art therapy intervention with hospitalized children; these include developmental, cognitive and adaptive approaches. A developmental approach applied with children in hospitals advocates provision of art interventions and experiences appropriate to patients’ mental and emotional development. Comprehensive understanding of children’s development is important in assessment, treatment planning, and designing relevant tasks. The main goal within the cognitive approach is for the young patient to gain self-control. Cognitive approaches are important in developing and implementing interventions which reveal and restructure existing cognitive beliefs, provide coping strategies, and allow psychological distance from the trauma of illness and hospitalization. Adaptive approaches are used with hospitalized children with special needs, particularly in
cases of physical and medical disabilities requiring collaboration with occupational and physical therapists. Thoughtful adaptive applications “minimize deficits and...maximize normalization experiences” (Rosal, 1992, p. 177).

Research Purpose and Problem

The purpose of this study is to collect empirical data regarding the efficacy of art therapy with children in hospitals. To this end, the research design was intended to provide data which would reject or accept null hypotheses: (a) The art therapy protocol would not demonstrate efficacy in reducing pediatric patient anxiety associated with hospitalization, (b) any benefits resulting from the art therapy intervention would not be sustained should a subject return to the hospital for further treatment. To evaluate the hypothesis, the following question was asked: Can an art therapy protocol, designed and implemented for children hospitalized with sickle cell disease, reduce pediatric patient anxiety associated with medical and hospital concerns?

The impetus for studying art therapy outcomes for hospitalized children is to investigate the benefits of art therapy treatment for this population. Research is needed to support the growing number of case studies advocating art therapy programs for children with special needs. Specifically, this investigation will study the efficacy of an art therapy treatment protocol designed for hospitalized pediatric patients with sickle cell disease. The goal of the protocol is to increase the emotional well-being of children in hospitals by reducing anxiety associated with hospitalization and illness. Validation of art therapy programming through research may expand opportunities for art therapy to be offered to children in hospitals, particularly if art therapy is found to contribute to a child’s active and successful participation in traditional treatment plans.

The art therapy interventions focus on the provision of art making opportunities in which the pediatric patients can experience occasions of control in a setting which offers minimal opportunities to experience control. The art therapy experiences are designed to encourage the pediatric patients to (a) engage in expressive activities to explore and communicate the psychological issues related to illness and hospitalization, (b) become familiar with the hospital environment and the medical treatment program, (c) demonstrate
cognitive understandings of medical treatment and hospital outcomes, and (d) engage in creative, normalizing opportunities for expression in the foreign clinical environment of a hospital.

**Justification**

Medical personnel, patients, families, and art therapists are recognizing the importance of art in the health care setting; the process of creating visual imagery has become an important vehicle for addressing the emotional needs of patients. McLeod (1995) reported that in the United States, about two dozen hospitals have arts programs. That number has grown slowly since that time. The table in Appendix A lists arts in medicine programs and some of their features. The majority of existing programs make art and creative experiences available to hospital patients through the appointment of volunteers and artists in residence; other hospital art programs focus largely on the aesthetics of the medical experience and the inclusion of fine art or music in the hospital environment. A small number of programs have recognized the need for trained art therapists to serve as providers of mental health services, ethics consultants, or supervisors to volunteers and artists; programs with professional art therapists can offer emotional support, facilitation of personal introspection, pain and stress management, opportunities for creative expression, and reinforcement of the human connection in the hospital environment.

As the paradigm of medical care shifts to viewing the whole patient, hospital care involves providing psychosocial care as well as medical care. National and international associations have been established to further the causes of arts in medicine programs. The Society for the Arts in Healthcare (SAH), and the International Art-Medicine Association (IAMA) are the primary informational and networking organizations. The *International Journal of Arts Medicine* publishes articles written by physicians, therapists, creative arts educators and expressive art therapists, therapists, and other healthcare professionals.

The intention of this study is to demonstrate the ability of art therapy to improve psychological well-being and decrease anxiety in children who experience hospitalization and undergo medical treatment. In addition to providing further evidence of the
psychological benefits of art therapy intervention, the data collected during this research and other studies in medical art therapy may also lay the groundwork for economically justifying the initiation of hospital art therapy programs for special needs populations. This is particularly crucial in the current political atmosphere regarding managed health care programs, including wide-spread enrollment in Health Maintenance Organizations (HMOs). Membership in managed health care programs and HMO enrollment have grown steadily over the past decade, and HMOs alone serve more than 30 million members in the United States (Fox, Wicks, & Newacheck, 1993).

In a research publication of managed care plan performance, Miller and Luft (1994) reported that HMOs had consistently shorter hospital stays per employee than indemnity plans. Three individual studies showed statistically significant or 18% to 29% fewer hospital days per hospitalization per enrollee. For example, in “Health Maintenance Organizations and Children with Special Health Needs,” Fox et al. (1993) concluded that HMOs generally made specialty services available to members only when significant improvement was expected within a short period of time (usually 60 to 90 days). The authors reported that some managed health plans require that patients meet multiple criteria to receive therapy services, such as significant improvement within a specified amount of time and that particular services be necessary to restore function.

HMOs typically place limits on the amount and duration of mental health, ancillary services, and special services provided to chronically ill children (Fox et al., 1993).

About 90% of the plans with ancillary therapy coverage contained their liability either by limiting the number of consecutive days that service would be provided or by limiting the number of visits that could be made. More than three quarters of these plans imposed a durational limit ...The other quarter imposed a cap on the number of visits... In a substantial majority of the plans, then, children with chronic conditions would not be able to obtain ongoing ancillary therapy benefits. (p. 54) Such statistics confirm the need for successful treatment within the constraints of the availability of traditional therapies. If art therapy could be shown to contribute to the success of traditional therapies by enhancing cognitive understanding of hospital processes, facilitating familiarity with the patient’s disease and its treatment, and generating active patient participation in treatment plans, then treatment objectives might
be reached in shorter lengths of time, or within the limited number of traditional therapy sessions permitted by managed health care plans. This, in turn, could provide economic justification for procuring art therapy services for hospitalized children.

Malchiodi (1999) argued, “Art therapy is one of few therapies where the individual becomes actively involved in treatment through the process of art making and through the creation of a tangible product” (p. 16). Malchiodi continued, stating that although medical treatments generally demand patients assume a passive role, “art making requires that they become active participants in their health care” (p.16). Councill (1999) echoed the significance of the partnership between art therapy and medical treatment in engaging the child in the healing process; she wrote, “Crayons and paper cannot replace the powerful drugs of modern cancer treatment, but they go a long way toward helping young people see themselves as active partners in the process of getting well” (p. 91).

Research Question and Hypothesis

The purpose of this study is to collect empirical data regarding the efficacy of art therapy with children in hospitals. Specifically, the research question is as follows: Can an art therapy protocol, designed and implemented for children in hospitals, reduce anxiety behaviors in hospitalized pediatric patients? To address this question, the design of this research will focus on one subset of pediatric patients. The age and diagnostic category chosen for convenience is specific to the pediatric population of a local hospital venue. Specifically, 6 to 9 year-old children with sickle cell disease will be studied.

A Cognitive-Field Model of Art Therapy with Hospitalized Pediatric Patients

The Cognitive Field Interactionist theory, upon which the art therapy protocol for this study is modeled, focuses on the interaction of a person and her psychological environment in a psychological field or “life space” (Bigge & Shermis, 1992). Within this theory, “person” refers to every thing, idea, and principle with which one identifies. For a child, this includes his or her body, speech, thoughts, home, family, reputation, personal property, and attitudes toward all these as well as the foundations, such as hope and LOC, for their realization. The psychological environment consists of every thing, function, or
relationship that embodies the person, as well as the meaning of each for the person. Within the life space of a hospital setting, the psychological environment also includes the art therapist, the approach(es) to art therapy utilized, the psychological responses to illness, treatment, and hospitalization, and hospital personnel. Art therapy, and the role of the art therapist, represents the driving force used to move the person toward the goal of normalized and maintained mental health and functioning. These elements come together in the life space, within which is “what one needs to know about a person in order to understand that person’s concrete behavior in a specific psychological situation at a given time” (1992). The purposeful, personal involvement of the individual within his or her psychological environment is surrounded by a non-psychological environment, called the foreign hull.

The basic paradigm of this theory suggests that cognitive structuring and restructuring take place within one’s life space. Locus of control plays an important role in this change. Restructuring refers to “making more or different sense of oneself and one’s world” (Bigge & Shermis, 1997, p. 209). For example, the images a pediatric patient creates in therapy assist the art therapist in assessing existing cognitive structures, and determining the level or nature of accurate, appropriate, information the patient requires to reframe the existing cognition. This information may come through interaction with the environment, practicing new behaviors, and engaging in opportunities to master emotions. Within this theory, learning (defined as attainment of new insights in cognitive structures or changes in old ones) takes place through differentiation and generalization and affords the patient occasions for control in her psychological life space. Accordingly, the art therapist working with hospitalized children can provide art experiences designed to familiarize a young patient with his or her physical environment, address trauma which has newly entered into the child’s life space, and allow a measure of control over psychological and environmental obstacles. The goals of normalization and psychological well-being represent the paramount human need that cognitive interactionists describe as the preservation and enhancement of the emergent self.

Within this theory, the impact of previous experience on a person’s life space is not ignored; however, the present scene is the focus of explaining and intervening in the causes of behavior (Bigge & Shermis, 1992). Moreover, the life space encompasses everything
psychological that is occurring to a given person at a given time; within the life space, everything occurs at once, and aspects of the present field are not viewed as isolated, “one’s person is definitive of one’s environment, and likewise one’s environment is definitive of oneself” (p. 201). This aspect of the theory suggests that the learning that takes place in the psychological space defined by the patient’s presence in the hospital environment will return as part of the psychological life space if a patient returns to the hospital on a separate occasion. The design of this research will focuses on the life space of the hospitalized child in addressing her psychological needs.

**Definition of Terms**

**Anxiety:** Sartorius, Andreoli, Cassano, Eisenberg, Kielholz, Pancheri, and Racagni (1990) acknowledge the unpleasant emotional state associated with anxiety. Anxiety is described as consisting of “feelings of tension, apprehension, nervousness, and worry, and activation of the autonomic nervous system” (p. 69). Physiological manifestations often include increased blood pressure, rapid heart rate, sweating, dryness of the mouth, nausea, dizziness, breathing irregularities, and muscular skeletal disturbances.

Anxiety reactions are common responses to perceived dangers and situations which threaten physical well-being, as well as to situations that pose threats to self-esteem or psychological well-being. Kleinknecht (1991) recognized three components of anxiety: (1) cognitive processes, (2) physiological processes, and (3) behavioral components. He stated that the three components interact to “provide us with an effective system for handling threats” (p. 10).

**Art Therapy:** The American Art Therapy Association (1997) offered the following definition of art therapy:

Art therapy is a human services profession that utilizes art media, images, the creative art process and patient/client responses to the created productions as reflections of an individual’s development, abilities, personality, interests, concerns, and conflicts. Art Therapy practice is based on knowledge of human development and psychological theories which are implemented in the full spectrum of models of assessment and treatment including educational,
psychodynamic, cognitive, transpersonal, and other therapeutic means of reconciling emotional conflicts, fostering self-awareness, developing social skills, managing behavior, solving problems, reducing anxiety, aiding reality orientation, and increasing self-esteem.

The British Association of Art Therapists (2001) also offered a definition of art therapy:

Art Therapy is a process involving a transaction between the creator (the patient), the artifact, and the therapist. Art therapists provide for their patients an environment, art media, and very importantly, themselves-in terms of time, attention, and a clearly defined relationship. The aim… is to develop a symbolic language which can provide access to unacknowledged feelings and a means of integrating them creatively into the personality, enabling therapeutic change to take place. The therapist focuses on the therapeutic process—that is, the patient’s involvement in the work, their perception of it, and on the possibility of sharing this experience with the art therapist.

Locus of Control: The theory of locus of control maintains that individuals differ in their perceptions of control over their environment and life events. Individuals with internal locus of control believe they are in control of their successes and failures; individuals with external locus of control believe their successes and failures are due to luck, fate, chance, or powerful others (Rotter, 1966). People with an internal locus of control appear to perceive less stress, utilize more task-related coping behaviors, and engage in fewer emotionally-based behaviors than individuals with an external locus of control (Anderson, 1977).

Medical Art Therapy: Malchiodi (1999) defined medical art therapy as “the use of art expression and imagery with individuals who are physically ill, experiencing trauma to the body, or who are undergoing aggressive medical treatment such as surgery or chemotherapy” (p. 13). Medical art therapy with children refers specifically to the use of therapeutic art experiences and techniques with young patients, generally under the age of eighteen, who are enduring medical treatment or the symptoms of disease.

Psychosocial: The term psychosocial refers to the interdependence of psychological and social factors. Within the context of this study, psychosocial concerns
result from children’s emotional responses to hospitalization including the physical environment of the hospital, interaction with hospital personnel, absence of family and support systems, removal from the home, and the symptoms and treatment of disease.

**Sickle Cell Disease:** Sickle cell disease (SCD) refers to a group of inherited blood cell disorders characterized by the presence of an abnormal form of hemoglobin, (U.S. Department of Health and Human Services, 1990). Hemoglobin molecules are the component of the red cells in the blood responsible for carrying oxygen from the lungs to the body, and bringing back carbon dioxide to the lungs. In individuals with SCD, the defect in the hemoglobin causes chains of hemoglobin molecules in the red blood cells to cluster together to form long rod shaped structures. The red blood cells take on elongated, sickle shapes which cannot squeeze through blood vessels and interfere with the exchange of oxygen in the body.

**Summary**

As medical institutions acknowledge a relationship between physical and mental well-being, addressing the emotional needs of patients becomes central to caring for hospital patients. Indeed, the National Institutes of Health, Office of Alternative Medicine, has termed art therapy a mind-body intervention (National Institutes of Health, 1994). Malchiodi (1999) argued that meeting the psychosocial needs of pediatric patients is the major concern of art therapy intervention with hospitalized children:

All health care professionals who work with physically ill children agree that the experiences of illness, medical treatment, and hospitalization are extremely stressful, and depending on the extent of illness, treatment, and hospitalization, can have a major influence on children’s development and emotional growth. (p. 15)

Art therapy is a natural selection for intervention with pediatric patients. Art making offers normalization through age appropriate expressive activities. Art therapy also provides opportunities to explore the hospital environment, encourage non-verbal communication, address fears, physical symptoms, and body image, and create essential occasions for perceived control for pediatric patients.
CHAPTER 2  
LITERATURE REVIEW

Historical Background

In the eighteenth century, when young children were first admitted to hospitals, perceptive individuals expressed concern for the psychological impact of their hospitalization. For example, in 1777 distinguished physician George Armstrong, concerned about the emotional well-being of pediatric patients, protested the separation of sick children from their mothers (Still, 1931). Unfortunately, even the fundamental psychosocial concern regarding connection of mothers and children remained largely unacknowledged into the later half of the twentieth century. The first mother-and-child hospital was established by Sir James Spence (1946) a pediatrician at the Babies’ Hospital, Newcastle-on-Tyne in 1927; it was nearly thirty years before a similar facility was established in the United States (Spence, 1951).

In 1956, a committee was formed in Britain to collect documentation from hospital professionals (social workers, nurses, doctors, administrators, and psychiatrists) concerning the welfare of children in hospitals. The resulting publication, the Central Health Services Committee’s (1959) “Platt Report” noted the importance of addressing the mental health of pediatric patients. However, despite official policy based on the report’s recommendations, Robertson (1962) found that the endorsed practices outlined in the report were not widespread.

Growing attention to the emotional well-being of children in hospitals has been marked by multiple publications on the subject. Several texts described the individual experiences of healthcare workers and the programs implemented at particular hospitals (Bergman & Freud, 1965; Geist, 1965; Pettrillo & Sanger, 1972; Plank, 1962; Robertson, 1958). These publications focused on the personal observations of the authors and the
practical guidelines they suggested for interaction with pediatric patients and their families. Vernon, Foley, Sipowicz, and Schilman (1965) worked to identify theories and data regarding why hospitalization is psychologically upsetting to children. Jellinek and Herzog (1990) expressed the frustrations of medical professionals working with hospitalized children given their lack of information and training on the psychological care of the children and families they encountered. The editors created a handbook emphasizing the collaborative effort between pediatric medical and mental care providers.

The specific modality of art therapy has been used to address the well-being of hospitalized children since the formal organization of the profession (Malchiodi, 1999). Malchiodi wrote, “the practice of art therapy in medical settings has been an important thread of art therapy’s collective history since its beginnings” (p. 13). Despite the recognized ability of art making to help children cope with the stress of hospitalization and illness, little had been written about the application or effects of art therapy with pediatric medical populations until recently. In the last 25 years, art therapists working with children in hospitals have begun to document their experiences (Crowl, 1980; Epping & Wilmuth, 1994; Geraghty, 1985; Prager, 1983 & 1995; Rode, 1995; Russell, 1995).

The following sections will present current literature regarding psychological issues related to children in hospitals. Since the concept of LOC contributed significantly to empirical evidence supporting psychological intervention, information on LOC is provided in the following section. This is followed by a review of literature investigating empirical support for current practice. A section on medical art therapy with children is then presented. Finally, a general description of sickle cell disease will be provided in conjunction with information regarding the psychological adjustment of children with the disease.

**Locus of Control**

The theory of locus of control (LOC) maintains that individuals differ in their perceptions of control over their environment and life events. Individuals with internal LOC believe they are in control of their successes and failures; individuals with external LOC believe their successes and failures are due to luck, fate, chance, or powerful others.

Over 30 researchers have developed scales to measure LOC (Lefcourt, 1983). In 1973, to fill a need for an instrument with construct validity, Nowicki and Strickland created a general LOC scale for children. Publication of this instrument emphasized the need for measures of LOC for subjects under the age of nine and over the age of 18. This led to the creation of a LOC scale for adults (Nowicki & Duke, 1974a) and instruments measuring LOC in young children (Nowicki & Duke 1974b; Nowicki, 1981). Researchers developed additional scales to measure LOC in other populations, such as the elderly (Duke, Shaheen, & Nowicki, 1974), learning disabled children (Parrell-Burnstein, 1975), young Black children (Duke and Lewis, 1979), individuals with drinking problems (Keyson and Janda, 1972; Stafford, 1980), and married people (Miller, 1981). The applicability of the LOC construct to issues of health and illness prompted the development of LOC instruments to address issues of health and self-esteem, vulnerability to illness, and performance of healthy and unhealthy behaviors. Wallston, Wallston, and DeVellis (1978) created the Multidimensional Health LOC Scale to investigate the relationship between LOC and health-related beliefs and behaviors. Parcel and Meyer (1978) adapted the instrument for children.

Although many authors use language that implies LOC is a stable characteristic, Lefcourt (1982) attempted to “dispel this ready perception of LOC as a trait, or worse, a typology with all the connotations of intractability and fixedness that those terms imply” (p. 148). He agreed that LOC may be relatively consistent; however, he contended that there are natural, accidental, and deliberately contrived events which may change an individual’s LOC. Since an external LOC is an impediment to coping with stressors, the shifting of LOC is important to therapists and psychologists. This was the impetus for Lefcourt’s consideration of research which suggested that LOC is a malleable characteristic.

Deliberate attempts to alter the LOC of students in three studies by Reimanis (1971) resulted in increased behaviors associated with internal LOC and increased measures of internality. Despite weaknesses found in Reimanis’ methodologies, the results
of the three studies indicated positive changes in LOC scores and behaviors. Subjects that received personal causation training in studies by deCharms (1972), Koenigs, Fiedler, and deCharms (1977), and Shea and deCharms (1976) exhibited intrinsically motivated behaviors indicating locus of causality, a construct congruent with internal LOC. Dweck (1975) attempted to generate persistence in children determined to be helpless (defined as passive when challenged with tasks they were capable of achieving). Training the subjects to attribute failure to effort rather than ability was successful in changing their performances; the subjects internalized belief in the possibility of success, and viewed failures as challenges for which they were responsible.

Lefcourt concluded that the studies demonstrated the efficacy of educational and counseling strategies in changing perceptions of control and achievement relevant activities in students. Although Lefcourt (1982) appealed for additional research, he accepted that “behavioral modification procedures aimed at increasing contingency awareness are apt to be effective at shifting clients’ perceptions of control” (p. 167).

Foster (2000) recognized the potential value in understanding children’s health LOC. For therapists working with medical patients, Foster postulated that the construct of health LOC could be employed to help clients “develop coping strategies to deal effectively with physical limitations, severe pain, or diagnosis of a fatal illness” (p. 2). Furthermore, Brunnquell and Hall (1982) suggested that for pediatric oncology patients, perception of control would be helpful when confronting issues such as loss of privacy, compliance with medical regimes and rules, and controlling adults.

This section has been presented to familiarize the reader with the concept of LOC and to introduce measurement of LOC in relation to children’s health. LOC is a significant factor in the examination of psychological adjustment in pediatric patients. In the following review of literature, LOC is examined within the context of empirical support for psychological intervention with hospitalized children.

**Empirical Support for Current Practice**

Increased reporting and commentary based on individual experiences appear to indicate a growing interest in the psychosocial well-being of hospitalized children.
However, much of the literature conveys qualitative or theoretical information which does not articulate empirical outcomes. The following represents a search for studies within disciplines related to medical art therapy which contribute to the body of knowledge informing current practices for the emotional health of pediatric patients.

**Search Techniques and Article Inclusion**

The collection of literature supplying empirical support for current practice included an Educational Resource Inventory Center (ERIC) search of articles, texts, and dissertations, using combinations of the key words: children, hospitalized children, emotional needs, psychological needs, well-being, PTSD, art, and art therapy. The broadness of the search was necessary to incorporate each element of a complex subject; the search included the population, the setting of the population, the psychological factors associated with the trauma of hospitalization, and the treatment modality. Medline searches were also conducted on all medical, psychology, and psychiatry journals. Finally, searches of published art therapy journals and conference proceedings were conducted.

For inclusion in the empirically based literature review, each article needed to meet specific criteria. Only articles reporting empirical research or reviews of literature are included. Articles needed to address children in hospitals or diagnosed with medical problems, and at least one of the following, as related to this population: (a) emotional needs, (b) intervention designed to meet psychosocial needs, (c) environmental stressors, (d) responses to trauma or disaster, and/or (e) psychological well-being.

The articles which met the strict standards for inclusion fell into two categories: (a) five articles in the category of perception of control and coping with stressors were found; and (b) four articles in the category of psychological responses to specific medical diagnosis were found.

**Perception of Control and Coping with Stressors**

Five articles revealed by the literature search addressed perceptions of control and coping with stressors. One article reviewed current literature and studies within this domain, and three articles documented empirical studies on LOC. The fifth article
addressed measurements of children’s hopefulness, defining hope in terms directly related to LOC.

In the literature review by Thompson and Spacapan (1991), perceptions of control on vulnerable populations were examined. The authors investigated recent thinking and research on perceptions of control to identify the positive outcomes associated with effects sense of control, and presented four critical themes for further development. This information was examined in regard to individuals at risk for negative outcomes of stressful experiences. This included individuals who have little opportunity to exercise control, such as children in hospitals.

Thompson and Spacapan (1991) identified five categories of positive outcomes associated with perceived control. The authors determined that positive outcomes of perceived control in vulnerable populations, or those with minimal opportunity to exercise control, include: (a) emotional well-being, (b) coping with stress, (c) physiological and health outcomes, (d) behavioral changes, (e) improved performance. The review of positive outcomes revealed a particularly useful application of perception of control. The ameliorative effects of control are residual, extending beyond the immediate situation over which an individual perceives control. Furthermore, benefits of control are realized prior to aversive experiences when there is expectation of control.

Four themes emerged from the Thompson and Spacapan (1991) review which the authors argue are “critical for further work” (p. 7): (a) the conceptualization and measurement of control, (b) factors that threaten perceptions of control, (c) conditions that determine the effects of control, and (d) interventions to enhance control (p. 7).

First, Thompson and Spacapan (1991), argued it necessary to acknowledge the complexity inherent in the term control, stating that “perceived control is a multidimensional concept” (p. 11). They offered three important distinctions among types of control which require clarification in research designs seeking to generate a deeper understanding of control: (a) contingency vs. competence vs. control beliefs, (b) primary vs. secondary control, and (c) global vs. specific measures of control (p. 11). The authors point out that research studying perception of control may be unable to explain and understand the behaviors in question without distinguishing the type of control being studied.
The authors also identified four threats to control experienced by vulnerable populations. The first of these was social contexts and their agents. An example of this threat for children in hospitals is the exclusion of patient participation within traditional medical models. The second area of threats included life events, such as chronic illness, disability, and bereavement issues. Third, developmental changes can pose threats to pediatric patients, as “children’s lack of some skills can leave them less able to control certain areas of life” (p. 13). Finally, the authors argued that personal characteristics impact feelings of control. Attributions children make for their successes and failures, and the comprehension of available medical options are two examples of personal characteristics which are particularly important for pediatric patients (Thompson & Spacapan, 1991).

In discussing conditions that determine the effects of control, Thompson and Spacapan (1991) noted that perceptions of control and assigned causality need to be appropriate and adaptive in order to result in positive outcomes. They confirmed that it “is helpful to have perceptions of control when the situation is objectively controllable, but not when control is not possible” (p. 14). Furthermore, the authors suggest that “positive effects will occur when there is a fit between the person’s desire for control and the amount of control the environment affords” (p. 14).

Finally, Thompson and Spacapan (1991) acknowledged the positive outcomes associated with interventions designed to enhance control. They identified the following as characteristic of interventions which enhance perceptions of control:

1. Encouraging mindfulness of control exercised in everyday life,
2. Providing patients a model of the components of a decision to help them participate in decision making,
3. Reminding patients to take responsibility for changing their setting,
4. Providing success experiences,
5. Teaching self-responsibility,
6. Teaching stress management,
7. Providing control over visitors and schedules, and
8. Providing individuals with options to make minor decisions.
The authors concluded that quality of life can be enhanced by the influence of perception of control on performance, physical health, and mental health. They concluded their review by reiterating their hope that integrating existing related information and studies would yield a deeper understanding and broader application of perception of control.

Bolig, Brown and Kuo (1992) presented the results of a self-reported, retrospective study of adolescents comparing the self-esteem and LOC of adolescents who had never been hospitalized with those hospitalized during adolescence, those hospitalized prior to adolescence, and those hospitalized during and prior to adolescence. Participants of the study were 13 to 19 year-olds who attended a general adolescent outpatient medical clinic. Instruments measuring self-esteem, LOC, and stressful life events were utilized. The results of the study suggested that “different developmental periods may not be related to long-term differences in self-esteem and LOC” (p. 232).

Dubow et al. (1993) reported an empirical study focused on teaching children to cope with stressful experiences. The authors implemented a primary prevention program designed to teach problem-solving and coping skills and then practice applying those skills. A primary prevention program was implemented with a group of children and did not target those who had recently been exposed to stress. The curriculum focused first on general coping skills, a problem handling sequence, and seeking social support; the following units were devoted to each of five separate childhood stressors. Measures designed to evaluate the curriculum assessed the following: (a) children’s knowledge about stressors; (b) children’s efficacy to implement effective coping strategies, (c) children’s problem-solving skills in relation to stressors, and (d) children’s support networks. The outcomes of the study suggested that children can learn skills to help them cope with future stressors, as well as support peers who may experience stressors in the future.

Such a proactive, competence-building approach might lay the groundwork, by enhancing basic problem solving skills and developing a sense of self-efficacy, for later intervention involving those children who actually experience specific stressors in the future. (p. 437)

Goertzel and Goertzel (1991) examined health LOC, self-concept, and anxiety in pediatric patients with cancer. The authors administered two standardized measures of
health LOC to 38 cancer patients between the ages of 8 and 18, and examined responses to a qualitative interview. Results of the research suggested that “hopefulness may be more salient for pediatric cancer patients than LOC” (p. 531), and that children with cancer may have a more internal LOC than healthy children. However, the authors did qualify the results of the study, suggesting that hopefulness could be the outcome of believing that both the patient and medical personnel are in control of the illness. The authors proposed that good adjustment to illness may be realized by shared control stating, “It may not matter so much whether control is internal or external, but whether the child believes that the disease can be controlled” (p. 539).

Snyder, Hoza, Pelham, Rapoff, Ware, Danovsky, Highberger, Rubinstein, and Stahl (1997) examined the development and validation of the Children’s Hope Scale, a six item instrument for children between the ages of 8 to 16. As well as the self-report scale reflecting individual dispositional differences, the authors described the role of goal-setting and the pursuit of goals in the hopeful thinking of children.

How children think about their goals can make a difference in how they handle stressors, especially those related to specific illnesses. Children who think hopefully can imagine and embrace goals related to the successful treatment of their physical problems....problems related to health can offer impediments to the child’s usual goal pursuits…children with health problems need to focus upon new goals, find alternative ways to do things, and muster the mental energy to begin and continue treatment regimens. (p. 401)

Snyder et al. (1997) argued that an important factor in the development of hope is how children learn to think about themselves in relation to the barriers they encounter. Similar to constructs of LOC, they defined children’s hope as “a cognitive set involving the beliefs in one’s capabilities to produce workable goals…as well as the self-related beliefs about initiating and sustaining movement toward those goals” (p. 401). They found the concept of hope analogous to that of resiliency. However, they point out that their model may be preferable, as it offers two succinct components: (1) Agency thoughts, which reflect the perception that children can initiate and sustain action toward a desired goal (competence), and (2) pathway thoughts, which reflect children’s perceived capability to produce routes to those goals (control).
The authors assumed that hope is a stable characteristic with foundations established in the first 2-3 years of life and secured during adolescence, and that it applies to children when they are healthy as well as when they are ill. The stability of children’s hope, the authors argued, make the Children’s Hope Scale an important tool for predicting outcomes of stressful life experiences. Pediatric researchers, the authors wrote, may find the instrument promising. The Children’s Hope Scale, they wrote, “is an individual-differences measure that reflects a risk-resistant factor that would be useful in the prediction of psychosocial adjustment, pain, and medical adherence outcomes in acute and chronically ill children” (p. 418).

**Conclusion.** In addition to indicating that children respond to hospitalization with diminished feelings of control, the research presented in this section presents three reoccurring themes: (a) perceptions of control and coping skills can be acquired and yield residual benefits, (b) personal control over aspects of illness can be adaptive and is associated with positive adjustment, and (c) constructs of control, hope, and resiliency are closely related.

The first motif introduced by the presented articles informs the practice of art therapy with children in hospitals. The articles suggest feelings of control can be acquired or learned, and perceptions of control are retained and, therefore, may be beneficial in future stressful situations. The theme of retained benefits impacts the research methodology of this study in two ways. First, art therapy intervention will employ coping skills which will engage the mental processes necessary to maintain change in observed anxiety behaviors; decreases in anxiety behaviors should not subsequently deteriorate when intervention is withdrawn. Furthermore, sustained changes in anxiety would impact observable indicators upon readmission to the hospital, permitting follow-up study.

Secondly, perceptions of control can increase emotional and physical well-being and reduce anxiety when feelings of personal control are contextually appropriate. To form realistic and appropriate expectations of control, developmentally appropriate and pragmatic information is necessary for pediatric patients. This includes accurate information about their diagnosis, expected medical procedures, and the hospital environment.
Finally, the articles reveal that the constructs of control, hope, and resiliency are closely related. Additionally, the absence of anxiety behaviors appears to be one measure of perception of control and characterizes hope and resiliency. The authors acknowledge the multi-dimensionality of these constructs, and endorsed their application across diverse areas of research, particularly with vulnerable populations or individuals experiencing environmental, psychological, or medical stressors. The constructs of hope and control were also important in the collection of qualitative information during interviews and interactions with subjects.

The motifs uncovered in the review of LOC in children, informs medical art therapy programming for pediatric patients. Significant to patients with chronic illnesses such as sickle cell disease, art therapy interventions can be designed to teach skills and emphasize accurate cognitive structuring which can be beneficial in future stressful situations, including experiences of acute symptoms or medical crisis, as well as readmissions to the hospital. Additionally, the literature suggests that emotional and physical well-being are increased when contextually appropriate perceptions of control are experienced. Art therapy programming for pediatric populations, therefore, should incorporate opportunities for patients to visually and/or verbally demonstrate cognitive understandings and distortions regarding the treatment process, the effects of illness, and the hospital environment. The art therapist may then assist the patient to reframe misperceptions and develop accurate understandings of the processes of treatments and disease through the provision of developmentally appropriate feedback and information. Finally, the literature on LOC in children informs medical art therapy programming by acknowledging similarities across the constructs of hope, control, and resiliency. The successes and cognitive restructuring opportunities inherent in art therapy are both proactive and competence building. Significantly, hopefulness and control can be experienced through the thoughtful provision and cognitive internalization of appropriate information.

**Psychological Responses Associated with Specific Diagnosis**

The second category of empirical studies includes articles reporting psychological responses associated with specific diagnoses. The literature search revealed four articles
which met the criteria for inclusion in the review. One article reviewed the findings of four related studies. The remaining three articles presented empirical studies, and provided insight into psychological considerations for children diagnosed with various diseases.

Speltz and Richmen (1997) addressed the progress and limitations in psychological study of children within a diverse group of congenital disorders categorized as craniofacial abnormalities (CFA). In a review of four articles, the authors noted various psychological risk factors which may compromise children’s psychological adjustment to the disorders. These included (a) parental guilt or over-protectiveness, (b) stigmatizing social responses to speech impairment or facial disfigurement, and (c) neurological limitations. Although specific psychological interventions for children with craniofacial abnormalities, including parent training, pre-surgery anxiety reduction, and social skills training were listed, the authors argued that many psychologists are “unaware of the distinctive psychological sequelae of these disorders and the interventions most likely to reduce the risk of poor outcomes” (p. 434). They continued, stating, “empirical findings have not supported a specific, robust effect of facial dysmorphism on psychological adjustment” (p. 434). The authors point to four articles which illustrate progress in research in this area (Endira & Speltz, 1997; Pope & Ward, 1997; Richman & Millard, 1997; and Demellweek et al., 1997). Brief summaries of these four articles follow.

Endira and Speltz (1997) documented pre-surgery interactions of mothers and their children with cleft lip and palate, isolated cleft palate, or craniofacial morphology. The authors encountered problems in recruiting subjects of the underrepresented gender for two of the three diagnosis (more males have cleft lip/palate, and more females have cleft palate only). However, for the subjects in the study, the authors concluded “mothers of infants with cleft palate were more likely than mothers of infants with cleft lip/palate to disengage when the infant was attending to the mother’s face” (Speltz & Robinson, 1997, p.435).

Pope and Ward (1997) reported results of a study designed to test the theory that social competence in preadolescent children with CFA correlates to parental characteristics. The authors found that the children of parents who actively supported their children’s interactions with peers, and worried less about their children’s friendships raised children with greater social competence. The authors suggested replication of the study using a larger sample size and multi-method assessments of social functioning.
Richman and Millard (1997) conducted a longitudinal study which included parental reports of subject status for 8 consecutive years. The authors of this study found that age and gender are factors in the behavioral adjustment of children with cleft palate. For example, female subjects displayed increases in both externalizing and internalizing problems with age. The authors also stressed the importance of non-cleft-related factors in future studies of the long-term prediction of psychological outcomes in children with cleft palates.

In the final article addressed by Speltz and Richmen (1997), Demellweek, Humphris, Hare, and Brown (1997) studied the responses of school age children to children with and without fabricated port-wine stains (PWS). The important advancement in the research methodology for this study was its use of video clips in which target children talked and smiled and moved their heads from side to side; previously, only still pictures were used in this type of study. The study results suggested that character judgements and judgements of physical attractiveness by peers showed minimal evidence of prejudice against children with PWS. The authors also concluded that the social impact of PWS are “complex and multidimensional, with some effects moderated by gender” (p. 436).

In the first of the articles within this section reporting empirical studies, Pendley, Dalquist, and Dryer (1997) examined body image and social adjustment in adolescents following treatment for cancer. The study compared 21 adolescents who had completed cancer treatment with a comparison group without cancer. Multiple instruments were used to measure body image and psychosocial adjustment. The results of the study indicated that adolescents “who had been off treatment longer reported lower self-worth, more social anxiety, and more negative body image” (p. 29). The authors concluded that concerns with body image and social adjustment may not develop until several years after termination of treatment for cancer. The results of the study also suggested several hypotheses for further research, including factors influencing positive self-reporting immediately following treatment cessation, such as physical changes, changing peer group comparisons, and available social supports. The authors emphasized the need for longitudinal studies and examination of mediating factors.
Stuber, Nadar, Yasuda, Pynoos and Cohen (1991) examined the long-term psychological problems associated with bone marrow transplantation (BMT) and found that long term symptoms are similar to those of children traumatized by violence. Six children between the ages of 3 3/4 and 6 3/4 at the time of transplantation were followed for a full year following the procedure. The children were assessed for PTSD symptomatology immediately at the transplant stage, and again at 3, 6, and 12 months after BMT. Post-traumatic stress symptoms were identified in the subjects 12 months after undergoing BMT.

The authors explained that BMT survivors’ psychological symptoms may be understood through examination of post traumatic stress as a model. However, the distribution of symptoms of the children traumatized by the invasive, painful BMT procedure were different than the post traumatic symptoms exhibited by children exposed to violent life threat (such as witnessing a school shooting). For example, denial was extremely common in the BMT patients, while there was no evidence of the dissociation associated with violent life threat.

Extended fear of a life threat remained salient for the BMT patients throughout the follow-up study. One young male in the study remained concerned about his life being threatened by a tumor despite successful BMT treatment. Like the other children in the study, he expressed his uncertainty about being cured when he:

…drew a picture of his neuroblastoma before the transplant as much smaller than he knew it to be. However, after the BMT, he continued to draw himself with a tumor inside despite objections and obvious distress from his mother. (p. 955)

The authors concluded with several assumptions related to the study. For example, they surmised that the psychological symptomatology associated with the double life threat of a potentially fatal illness or injury, along with the experience of intensive, often painful, medical intervention can be attributed to medical circumstances other than BMT. Additionally, they argued that the strong denial exhibited by the subjects exemplified the need for psychological and medical intervention following hospital release.

Noll, Vanatta, Koontz and Kalinyak (1996) compared the peer relationships and psychological well-being of children with sickle cell disease (SCD) with same class peers without SCD. The researchers were interested in three components of peer relationships
and psychological well-being: (a) the social competence of children with SCD from the perspective of their peers, (b) the subjective well-being of children with SCD, and (c) the relationship of disease severity to social and emotional functioning of children with SCD. The study involved the classroom collection of data on peer relationship, and home visits to collect additional information from the children with SCD and their comparison peers.

The results of the study indicated that SCD, in addition to contributing to serious physical and medical symptoms, may contribute to experiences affecting the psychosocial adjustment of individuals with the disease. For example, 8-14 year-old females with SCD within the study group were perceived by their peers to be less sociable and less well accepted than their peers without SCD. However, the authors concluded that although SCD impacts peer relationships, minimum effects were discernable regarding emotional well-being:

Despite chronic exposure to numerous stressful life events associated with SCD, the youngsters with the illness were remarkably similar to comparison peers, showing evidence of considerable hardiness. (p. 423)

**Conclusion.** The researchers cited in this section found common challenges in the designs of their empirical studies. The first of their dilemmas was the small sample sizes dictated by the populations being studied. Additionally, several of the researchers suggested that future studies incorporate methodology which would make differentiation between genders possible. Finally, particularly in research designs comparing hospitalized children or those with specific diagnoses with their peers, researchers found it difficult to address mitigating factors. Each of these concerns was a factor in detailing the methodology outlined in chapter four.

Authors also suggested that the psychosocial care available within the study venues may have contributed to underestimations of measured symptomatology. For example, Stuber et al. (1991) noted that “psychological interventions are a routine aspect of pediatric BMT care at UCLA and would be expected to alleviate some distress and trauma during BMT” (p. 956). Noll et al. (1996) acknowledged that all of the subjects in their study were receiving comprehensive treatment from a large sickle cell center; this may have been a contributing factor to the unexpected resiliency of subjects with sickle cell disease.
From the articles on psychological responses to specific medical diagnosis emerged issues common to pediatric patients. Noted psychological consequences related to illness, hospitalization, and medical conditions included: (a) the trauma associated with illness or injury, as well as trauma related to hospitalization and medical treatment, (b) confused or negative body image, and (c) cognitive misunderstandings of medical treatment and outcomes. These concerns can be viewed as interrelated for pediatric patients. For example, the trauma of hospitalization and the hospital environment can be exacerbated by inadequate provision of accurate, developmentally appropriate information, leading to inappropriate stress responses when misinformation or lack of information does not allow for the cognitive processing of events, the environment, or procedures. Comparably, a lack of attention to information, deliberately or unintentionally communicated to pediatric patients, coupled by absence of purposeful processing of responses, can be problematic for children consumed by the psychosocial challenges presented by illness and hospitalization.

Misunderstandings of medical procedures can cause distress and misconception of body function. One article referred to an adolescent patient whose persistent drawings and verbalizations of a tumor remaining in his abdomen, despite the patient’s cancer having been successfully treated, confirmed his doubt that he was “cured.” In such cases, cognitive restructuring may be instrumental in assisting pediatric patients to internalize accurate information regarding their health status. Also, as in this case, visual expression of cognitive misunderstandings validates the need to assess and process information with pediatric patients.

**Art Therapy Articles**

Art therapy journal articles found through the search did not meet the standards for inclusion in the empirical research section of the literature review. However, articles on medical art therapy with pediatric patients met all of the standards for inclusion except the required empirically based research methodology, yet had the added benefit of being specific to art therapy. Six of these qualitative articles addressed the use of art therapy with children in hospitals, and one addressed adolescents diagnosed with genetically transmitted neuromuscular diseases in a state supported educational facility. The principal
features of these articles are noted in this section and the articles are outlined in a table in Appendix B. The remaining two articles presented strategies and applications employed in art therapy programming for pediatric patients.

Art Therapy with Children in Hospitals

Review of the 6 qualitative articles in this category (Crowl, 1980; Epping & Wilmuth, 1994; Geraghty, 1985; Prager, 1993; Russell, 1995; Viscardi, 1994) revealed themes common to art therapy with children in hospitals. These motifs included:

1. The art therapists were concerned with establishing art therapy sessions as safe and non-threatening.
2. The art therapy provided opportunities for non-verbal expression of emotions, fears, and concerns.
3. The art therapy provided occasion to experience mastery and exert control.
4. The art therapists encouraged art making with open-ended directives, or the provision of choices of art media.
5. The art therapists viewed patient artwork as critical in comprehending patients’ cognitive understanding of illnesses, treatments and procedures, and medical outcomes.

The establishment of art therapy sessions as a “safe place” was crucial. Art therapists endeavored to make art therapy a “no needle” time, free from the interruptions of medical staff and painful treatments. Russell (1995) qualified the importance of this by recommending that the member of the multidisciplinary team who was responsible for the emotional needs of the patient not be a provider of direct medical care. Empathetic acceptance was also regarded as fundamental in fabricating art therapy as a safe place (Geraghty, 1985; Prager, 1993; Russell, 1995).

The articles pointed to the important function of art therapy in providing opportunities for non-verbal expression, and thereby communication, of emotions. According to Prager (1993) the anxiety associated with hospitalization was relieved through visual expression of intense, negative emotions; soothing images then followed this outlet. In her work with pediatric burn patients, Russell (1995) found that visual expression was beneficial in each of the psychological phases of recovery: (a) expressing
survival anxiety, (b) coping with pain, (c) searching for meaning, (d) investing in recuperation, and (e) accepting losses (p. 40). Epping and Willmuth (1994) wrote that the art making that takes place during art therapy is “an effective alternative means of self-expression that serves as a catalyst for adjustment” (p. 79). Feelings of isolation, separation, and abandonment, and fear of medical procedures were examples of the reoccurring expressive content of patients’ artwork.

Children in hospitals have few opportunities to make decisions regarding what happens to them. By making art materials available to patients, Russell (1995) invited control and mastery of emotions through the manipulations of various art media and the reorganization of conscious thought processes. Crowl (1980) stated that the intervention of an art therapist allowed a patient to “allay the infinite threat of the unknown by giving it form and thus bringing it under a measure of control” (p. 51). The concept of the art making process being a vehicle for personal control was echoed by Viscardi (1994). She found that, for adolescents with muscular dystrophy, art experiences allowed the exceptional experience of mastery. Art making, the author wrote,

allowed….the rare experience of getting outside themselves, outside their disability, outside feelings of loneliness, alienation, and reluctance to discuss their situation. The art…ushered them into a world of learning, supporting, challenging, and growing together. (p. 68)

The review of these articles revealed that the art therapists working with pediatric patients used both open-ended directives and self directed art experiences. Verbal directives were open-ended and prompted exploration and expression of emotions or processing of the patients’ responses to illness and hospitalization. When no verbal directives were given, patients were provided with choices of art media; the art therapist might encourage use of specific media based upon a patient’s previous enjoyment of that media, or the expressive characteristics of specific media.

Finally, the art therapists reported that artwork was instrumental in determining patients’ cognitive understandings, and misunderstandings, of illness, medical treatments and procedures, and hospital outcomes. For example, to relieve the anxiety of a young patient, Crowl (1980) encouraged him to draw about what was going to happen to his hernia. In addition to assisting the patient to master his anxiety, the art therapist learned
that the child was “fully aware of the details of the impending procedure and of the physical environment…of the operating room” (p. 51). Also, changes in body function or aesthetic, resulting from trauma or medical intervention, presented concerns which were communicated to art therapists through patient artwork.

The art product, in addition to the art making process, served an important role in the therapy context. The artwork functioned as a container for emotional material, a visual record of communication, and is the tangible link between patients’ internal and external worlds. Crowl (1980) suggested that it was through giving two dimensional, external form to feeling that her patient was able to transform the threat of the unknown into a physical entity she could control. Russell (1995) observed the art product literally become a container, or holder, when a patient used her bandages as part of her artwork. She wrote, “The patient was transforming her bandages which had a connection with her painful dressing changes and injuries in to a colorful, playful object” (p. 42). Russell summarized the function of artwork for patients, stating, “Their artwork is a tangible product in which they can take pride and see their accomplishments. Their art also serves as a permanent record of their thoughts and feelings that can be evaluated and used in assessment” (p. 45). Prager (1993) proposed that the link to LOC afforded by the art product can be found in the restructuring of cognitive material; even “raw, primary process material” (p. 3) can be externalized for reorganization and examination. It is transformed into a vehicle for indirect exploration.

Programming Applications

Two articles addressed strategies and functions of art therapy programming within hospital settings (Prager, 1995; Rode, 1995). Although one of the articles offered case a study example as support, their primary function was to impart practical applications for inpatient medical art therapy practice. Prager (1995) described strategies implemented on the pediatric unit of a large, urban hospital which served as a trauma center. Rode (1995) described the partnership of art therapy and child life practices in an urban medical center.

Both articles emphasized the growing interest in attending to the psychosocial needs of hospitalized children, and the use of art therapy to address the psychological aspects of illness in children, reduce anxiety, and encourage non-verbal expression. Rode
(1995) declared, “Physical recovery that leaves emotional scares in its wake is now unacceptable in pediatric practice” (p. 104).

The overriding parallel between the articles was the discussion of control afforded pediatric patients through art making and the creative process. Rode (1995) stressed the importance of individual control within what she described as a disempowering hospital culture; for patients confronted with serious illness, the use of imagination was paramount for “order and connectedness” (p. 106). The creative process, Rode argued, allowed patients and their families to shape and form their lives, and “make their mark.” The stories told through hospitalized children’s imagery engaged patients as story tellers, allowing them to “participate in their illnesses without ‘falling into’ them” (p. 109).

Prager (1995) echoes the magnitude of providing individual control in art therapy settings in describing the efficacy of art making to patient’s families: “I introduce the concept that children in the hospital generally have very limited choices, whereas while creating art they have the opportunity to be in charge…this helps to maintain their independence” (p. 33). She also underscores the importance of opportunities for control in educating team members about art therapy during weekly rounds.

Even for children with severe limitations, the art process provided opportunity for control. Prager (1995) explained that children who are unable to speak due to chemotherapy or tracheostomies retained control through the non-verbal communication of visual imagery, and children with limited movement due to injury, paralysis, or medical equipment found power in giving directions to the art therapist in assembling a collage.

Mastery of emotions through non-verbal expression also permits hospitalized children to exhibit control over their situations or environments. Art making creates a dialogue between the inner and outer experiences of illness and hospitalization and encourages pediatric patients to give form to concerns or fears. Rode (1995) postulated:

During hospitalization, patients and families often express frustration and a sense of diminishment or disempowerment…the arts offer the opportunity to create community and re-empower individuals. Creative arts processes offer more than ‘normalizing’ or diversionary experiences during hospitalization; creative arts activities provide…the means to engage in…dialogue with some of illness’s essential themes: loss, mortality, vitality, and transcendence. (p. 107)
Both authors also described their efforts to establish a protected environment for art therapy to take place and in which to process art experiences and the demands of illness and the hospital environment. Finally, the authors endeavored to provide safe and engaging art materials for pediatric patients, and opportunities to create a relationship with the hospital environment.

Conclusion

The art therapy literature presented two primary functions of medical art therapy with children. The first addressed the importance of a venue for processing information and psychological material non-verbally. The second significant function of art therapy addressed by the literature was the fundamental and indispensable provision of choice.

Art therapy provided opportunities for patients to examine cognitive structures and demonstrate emotional experience. The art making process provides children with occasions to explore and express their emotional responses to illness, medical procedures, separation from loved ones and peers, and the hospital environment itself. Furthermore, the processing and mastery of these emotions takes place within a psychological safety zone carefully created by the art therapist.

When art therapists make creative and expressive experiences available to children in the hospital, the result is more than normalizing and diversionary. The gravity of choice making as a normalizing and empowering exercise cannot be overstated. For children in hospitals, creating art incorporates multiple opportunities for making decisions and investigating choices in a milieu that rarely permits independence or individuation, and in which decisions are made for children and medical procedures are performed on children. The result of occasions for control inherent in art making, and the cognitive restructuring that transpires with the assistance of art therapist, engage the patient in a shifting LOC. Patients with increased LOC may move from reliance on medical professionals and powerful others for interpretation of symptoms and treatment of disease to increased reliance on their own ability to cope with psychosocial challenges, act on prophylactic practices, and negotiate the challenges of infirmity. The research on LOC in this chapter confirm its malleability (deCharms 1972; Dweck, 1975; Lefcourt, 1982; Koenigs, Fiedler, and deCharms, 1977, Reimans, 1971; and Shea & deCharms, 1976; Snyder et al, 1997; and
Thompson & Spacapan, 1991). Therefore, thoughtfully implemented art therapy interventions can provide psychosocial fortitude, impart appropriate and accurate cognitive restructuring skills, and grant experiences with success that will endow patients with a greater internal LOC and increased emotional well-being.

**Sickle Cell Disease**

The research design outlined in chapter 3 specifies the study of children with Sickle Cell Disease (SCD) as a subgroup of hospitalized pediatric patients. The decision to investigate this subgroup necessitated a search for information specific to children diagnosed with SCD. The search for general literature regarding this population included Educational Resource Inventory Center (ERIC) and Medline searches using combinations of the key words: children, sickle cell disease, and pediatrics. Interestingly, in addition to articles describing the medical characteristics of the disease, this search revealed five articles addressing the psychological adjustment of children and adolescents with SCD which were not found using the initial search for empirical research addressing the psychosocial needs of children in hospitals. The findings of those five empirically based articles will follow a general medical description of SCD.

**Description of SCD**

Sickle cell disease refers to a group of inherited blood cell disorders characterized by the presence of an abnormal form of hemoglobin, a component of the red cells in the blood (U.S. Department of Health and Human Services, 1990). Normally, hemoglobin molecules carry oxygen from the lungs to the body, and bring back carbon dioxide to the lungs. In individuals with SCD, the defect in the hemoglobin causes chains of hemoglobin molecules in the red blood cells to cluster together to form long rod shaped structures. The red blood cells take on elongated, sickle shapes which cannot squeeze through blood vessels. These clogs deprive the organs and tissues of oxygen resulting in pain and leading to organ and tissue damage and other serious medical problems (Massimini, 2000). Furthermore, healthy red blood cells last about 120 days in the bloodstream. Sickled red
blood cells die after only 10 to 20 days. This causes anemia, a chronically short supply of red blood cells.

A defect in the gene that tells the body how to make hemoglobin causes SCD (Massimini, 2000). SCD is passed on to children who inherit the defective gene from both parents. Children who inherit the defective gene from only one parent will not have SCD, but will carry the sickle cell trait. This trait can be passed on to offspring. Scientists have learned that sickle cell trait offers an interesting benefit for individuals living in parts of the world where malaria is problematic. Individuals who carry the trait but do not have the actual illness are protected from a severe form of malaria. Unfortunately, in countries such as the United States in which malaria is not a problem, the trait presents a serious threat to carriers’ children, rather than a survival advantage.

In 1990, the World Health Organization estimated that each year 250,000 babies were born with the disease worldwide (US Department of Health and Human Services, 1990). Researchers disagree about the number people in the United States with SCD. Massimini (2000) estimated that approximately 72,000 people in the United States are affected by the disease. Tigner (1998) argued that number was closer to 90,000. Most of the individuals with SCD in the United States are of African descent, and many other races and nationalities also carry the genetic defect.

The clinical course of SCD can vary greatly in different individuals. Symptoms can be mild to severe. A variety of clinical manifestations that resulting from the disease are detailed in a table in Appendix C. Currently, there is no cure for SCD. However, researchers are hopeful that new drugs may prevent the symptoms of the disease, and that ongoing research of bone marrow transplants, stem cell transplants, and gene therapy may offer a chances for a cure (Massimini, 2000; Tigner, 1998). Currently, the treatment of the disease consists mainly in addressing symptoms and attempting to prevent complications. For example, intravenous fluid and pain-killing drugs are frequently utilized during a painful crisis. Bone marrow transplants, blood transfusions and new drugs are also used to treat and prevent SCD complications. Surgeries are often recommended to treat organ and tissue complications. Oral penicillin is administered to very young children with SCD to prevent infections and early death. Finally, patients are educated about the role of regular
health maintenance, such as proper nutrition, good hygiene practices, rest, and stress management, in preventing complications.

It is unknown if SCD originated in Africa or the Middle East. However, scientists have identified four individual types of sickle cell mutations (US Department of Health and Human Services, 1990). Each of these genetic mutations corresponds with a different geographic area: (a) Benin, (b) Central Africa, (c) the Middle East, and (d) Senegal. Identification of the specific mutation is important for providers of medical treatment, as the mutation type appears to predict severity of the disease. Furthermore, scientists can study the migration of populations across the planet based upon sickle cell mutations carried.

Psychological Adjustment of Children with SCD

The search for general literature describing SCD revealed five articles directly related to the psychological adjustment of children with the disease. The articles concurred that although research demonstrating the overall positive adjustment of children with chronic illnesses (such as diabetes and cancer) had been published, there were limited reports specific to study of children with SCD. The authors thought it possible that the feelings of pain, separation, and helplessness associated with SCD could impede psychological well-being. The five articles and their findings are presented in the following paragraphs.

Gibbs (1995) studied the LOC and self-esteem of pediatric patients with either cancer or SCD hospitalized in an institution in which there was a Child Life program. The author found that the self-esteem and LOC of the hospitalized children were similar to published standardized scores for normal children. However, the author noted that children with SCD reported feeling more anxiety than children with cancer, and male patients denied feeling nervous or worried more often than the female subjects in the study. The author suggested that the efforts of Child Life specialists may have contributed to the unexpectedly positive well-being reported by the patients.

Hurtig and White (1986) investigated the relationship between chronic illness and psychosocial adjustment in children and adolescents with SCD. The 50 subjects in their study had mild to severe symptoms, and were out-patients seen at a large urban sickle cell
A variety of personality and social-interpersonal assessments were used in the study, including the Nowicki-Strickland LOC Scale (Nowicki & Strickland, 1973). The results of the study demonstrated the impact of SCD on the developmental process, particularly social adjustment. Adolescent males revealed problems in a range of adjustment variables, including exhibiting behavior problems. Of interest was the results of the LOC assessment. Compared to national norms, “there was a trend toward greater externality in both the younger and older girls and in the older boys” (p. 419).

The relationship between severity of illness and adjustment in children and adolescents with SCD was examined by Hurtig, Koepke, and Park (1989). The authors collected self, parent, teacher, and medical reports on seventy 8 to 16 year-old subjects with SCD. The results of the study did not support the hypothesis that severity of illness serves as a predictor of adjustment. However, the authors found that children with significant pain resulting from SCD had trouble functioning at school, and suggested that families of children with the disease who suffer from frequent pain “should be alert to the potential for school problems and special services within the school system” (p. 130). Furthermore, the authors established a relationship between one type of SCD (SS hemoglobinopathy) and reduced intellectual function; the degree to which this relationship was the result of higher incidence of stroke for patients with this type of SCD, however, was not investigated.

Lemanek, Moore, Gresham, Williamson, and Kelly (1986) compared a group of 30 children with SCD with 30 healthy children who attended a charitable medical clinic for routine health problems. In addition to collecting medical histories and academic achievement records on the patients, the authors used multiple standardized measures to collect data from the children, their parents, and their physicians. The results of the study indicated no differences in psychological measures between the two groups. However, compared to the normal population of children, sickle cell patients showed evidence of behavioral problems. Importantly, this finding did not appear to be the result of physical illness. Instead, the authors believed that the differences were related to the low socioeconomic status (SES) of the children in the study. The authors pointed to methodological problems of earlier studies which did not use controls groups with
comparable SES to the experimental group, in explaining previous assumptions that behavioral problems in children with SCD were a result of the illness.

Finally, Morgan and Jackson (1986) compared body satisfaction, depression, and social withdraw in 24 adolescents with SCD with 24 healthy adolescents matched for age, gender, race, and SES. The adolescents and their mothers were administered self-report instruments and participated in a structured interview. The results of the study suggest that adolescents with SCD experience problems with all three areas of psychosocial adjustment (body satisfaction, depression, and social withdrawal). The psychosocial responses appeared to be realistic in terms of the characteristics of the illness. However, the authors argued that the study results had implications for SCD treatment programs; they stated, “Perhaps the most basic implication is that adolescents with sickle cell anemia may have greater difficulty in meeting the developmental task demands of adolescence than their healthy peers and may therefore benefit from professional intervention” (p. 438).

Conclusion. The results of the above studies provide useful information for designing research studies to explore psychological responses of children to chronic illness and hospitalization. In addition, the studies identify important factors, outside the realm of chronic illness, which provide insight regarding the psychological adjustment of children with SCD. The implications for research designs and outcomes are discussed in the following paragraphs.

Four of the five articles reported studies conducted with out-patient children diagnosed with SCD who were not experiencing acute symptoms of the disease. Only one of the five studies on psychological adjustment looked at the immediate anxiety experienced by SCD patients while hospitalized. That study examined self-esteem and LOC of currently hospitalized children. The researcher (Gibbs, 1995) was interested in comparing children hospitalized with SCD or cancer with published standardized scores of normal children; she did not examine the significance of the intervention contended to impact the results of the study. No studies were found which examined changes in behaviors or measures of self-control following therapeutic intervention. Gibbs speculated that by normalizing the hospital environment, child life specialists may have provided pediatric patients with a sense of control over their environment and reduced patients’ anxiety. This may be a rational presumption. However, a causal relationship was inferred
based upon the measures of LOC compared to healthy peers, not compared to patient status before and after the intervention by the Child Life specialists. The study methodology outlined in chapter four was designed to address the efficacy of the interventions assumed to effect the psychological responses of the hospitalized pediatric patients. Additionally, the results of the studies indicated that individual differences may contribute more significantly in determining overall psychological adjustment than factors specific to SCD. For example, age, gender, family structure, and external support systems were factors the authors suggested may effect the coping strategies of children with SCD. Therefore, future efforts to investigate the psychological well-being of children with SCD may attempt to control for, or at least document, individual differences in subjects. Furthermore, the articles recognized the potential effect that SES may have on the psychological adjustment of children with SCD. Lemanek, Moore, Gresham, Williamson, and Kelly (1986) clarified their assumptions regarding this relationship. They reported that in the United States, SCD is a disease appearing primarily within the black community. Furthermore, relative to the general population, a higher percentage of black citizens fall within a lower SES classification. Therefore, the authors argued, since low socioeconomic status is a strong factor in the development of behavior problems, and children with SCD are frequently observed to have behavior problems, adjustment difficulties may be a result of factors related to SES rather that SCD. SES classification, then, is a relevant consideration in the outcomes of studies concerning the psychological adjustment of children with SCD.

The chronic nature, frequent hospitalizations, painful and sometimes disfiguring problems, and profuse number of children living with SCD make studies of the psychosocial needs of this population significant and relevant. The potential of the disease to constrict emotional well-being through overwhelming pain, separation from family and loved ones, and the helplessness of hospitalization make finding effective interventions essential. Finally, the conclusions of researchers has confirmed the importance of recognizing individual differences among subjects in studies addressing children hospitalized for SCD.
Summary

The literature review in this chapter presented empirical research, as well as qualitative case studies, regarding psychological issues impacting pediatric patients. Psychological adjustment specific to children with SCD was also reviewed, but generally did not address psychosocial issues of children hospitalized as a result of SCD symptoms or complications. LOC proved to be a primary factor in attempting to describe, measure, and understand the psychological issues of hospitalized children.

LOC may represent a relatively stable attribute. Importantly, however, research has demonstrated that perceptions of control can be acquired. In fact, if LOC was a consistent and innate trait, then behavioral evidence of change would disrupt the validity of the construct. However, researchers have argued that perceptions of control can be altered by life events or stressors, including illness and hospitalization. Inversely, reformation of external perceptions of control can reduce anxiety and increase emotional and physical well-being. Lefcourt, (1982) asserted that shifting the LOC of an individual “from an external to an internal position would seem to be a natural goal for psychologists whose aims are often to revive their patients’ flagging efforts in pursuit of satisfactions they have forsaken as hopeless” (p. 149).

The concept that LOC is malleable is important when synthesizing the data reviewed in this chapter. The literature review revealed two very important factors impacting the study of psychosocial concerns of children in hospitals: (a) children often respond to hospitalization and illness with diminished feelings of control, (b) children hospitalized for different reasons experience common psychological responses. These two empirically based assertions are congruent with the therapeutic contentions of the qualitative articles. Each is briefly reiterated here, with discussion of the link cognitive strategies in art therapy can provide between LOC and emotional responses to hospitalization.

First, perception of control was associated with positive adjustment and emotional well-being. Pediatric patients, however, were identified as a population with minimal opportunity to exercise control. The use of imagery in art therapy with this population can be used to enhance coping by increasing the number of choices available to patients within
a given situation (Nelson-Burford, 1985). Creativity and art making invite multiple opportunities for exercising individual control and problem-solving, through the making of independent decisions and choices. Additionally, art therapy provides patients with the unique opportunity to give form to feelings, allowing the experience of control and mastery over their emotions.

Secondly, the identification of psychological responses prevalent across diagnostic categories provides a foundation for addressing the psychosocial needs of children in hospitals, and cognitive approaches may be useful in addressing patients’ concerns. The fears and concerns of pediatric patients can be targeted for intervention within the psychological “safe place” established by the art therapist. Art therapy experiences can be designed to encourage patients to express emotional responses to (a) illness, (b) medical procedures, (c) body function, (d) separation, and (e) the hospital environment. The provision of art materials engenders the expressive communication of psychological responses to illness, hospitalization, and treatment of disease. Furthermore, the normalizing influence of art making and the production of positive imagery can promote relaxation to combat the stressors of hospitalization. Relaxation, in turn, can reduce anxiety and increase self-efficacy (Kleinknecht, 1991; Rosal, 1996). Finally, creative activities which encourage exploration and increased familiarity with the hospital environment may serve as forms of modified desensitization to internalize control for pediatric patients.

Internalizing appropriate perceptions of control and appropriate responses to stressors requires the processing of accurate information. The visual imagery created in art therapy can assist the art therapist in identifying patients’ cognitive understandings and misunderstandings of medical treatments they undergo, body image related to illness or medical intervention, and prospective outcomes of hospitalization. Misunderstandings and distortions regarding hospital experiences may then be addressed by the art therapist.

In conclusion, opportunities to experience control and make choices, express and process concerns, and internalize appropriate information and perceptions can decrease anxiety in hospitalized children. The hospital setting, however, provides few opportunities for children to make decisions, have choices, solve problems, express and master emotions, communicate understanding of treatments and outcomes, or explore the physical
environment without the threat of imminent intervention. The literature review provided information which informs the parameters and objectives of art therapy programming intended to reduce anxiety and internalize patients’ LOC.

Finally, within the reviewed literature was acknowledgement that absence of anxiety behaviors can serve as an indicator of perceived control. It follows, therefore, that a reduction of observed anxiety behaviors may indicate a shift in perception, or locus, of control. This directly informs the research design outlined in Chapter 4 by suggesting that the efficacy of art therapy in meeting the psychosocial needs of pediatric patients may be determined by its ability to reduce patient anxiety.
CHAPTER 3
METHODOLOGY

Each component of the art therapy research project with children in hospitals is delineated on following pages. The discussion begins with a reminder of the null hypotheses and the research question. The following sections clarify other aspects of the methodology.

Research Question and Hypothesis

The purpose of this study was to collect empirical data regarding the efficacy of art therapy with children in hospitals. The hypothesis for this study assumed that no changes would be revealed following art therapy intervention. Additionally, if changes were revealed following art therapy intervention, those changes would not be sustained over time. The researcher sought to collect data which would support or reject the research question, “Can an art therapy protocol, designed and implemented for children in hospitals, reduce anxiety behaviors in hospitalized pediatric patients?

Research Design

The effectiveness of art therapy to reduce pediatric patient’s anxiety was examined through single subject research methodology. As noted by Behling and Merves (1984), the single subject design was significant in its ability to: (a) validate the effectiveness of a treatment; (b) further the knowledge base of the helping professions; and (c) evaluate clinical practice. The single subject design described below was repeated with a total of 3
subjects in an effort to underscore and support the research findings through study replication.

**Single Case Design**

The research design of was comprised of two phases: (A) baseline, and (B) treatment. Behling and Merves (1984) used small boxes (□) to denote observations for baseline data, and X to represent an intervention; dots represent the observation of some activity (dependent variable). Figure 2.1 illustrates this design.

![Figure 3.1 The “A-B” Design.](image)

The short length of hospitalization was a primary consideration in the design of the research methodology. The A-B design was chosen for its flexibility and its applicability within the time constraints of the subjects’ hospital stays. The design was adapted to the specific conditions of inpatient hospitalization, including the brief duration of pediatric patient hospitalization which does not allow for extended baseline collections, prolonged intervention phases, or additional conditions or phases such as “A-B-A” or “A-B-A-B” designs.

Generally, A-B-A and A-B-A-B designs are implemented when a researcher wishes to confirm that a specific intervention was the cause of change in a target behavior. This is
particularly true in research which uses behavioral modification techniques. Within a behavioral approach, it is assumed that when an intervention ceases, targeted behaviors return to baseline levels; data collected after a behavioral intervention has ceased will depict shifts which allow the researcher to conclude that the intervention was the cause of change during phase B. However, the art therapy intervention within this study did not follow a strict behavioral modification approach. Art therapy interventions are hypothesized to affect changes in LOC. Thus, changes in mental processes are found. If an art therapy intervention were effective as hypothesized, new behaviors would be maintained after the termination of the intervention phase in the A-B design. Therefore, the A-B-A and A-B-A-B designs are not necessary, since therapeutic changes should not deteriorate when the intervention is withdrawn.

Participants

The hospital chosen for the study was located in the southeast United States. The hospital was one of two hospitals serving a city of approximately 150,000 people and its surrounding rural communities. The specific medical services available at the hospital dictated the diagnosis categories, and therefore, the duration of hospitalization of the patients it served. Generally, pediatric patients admitted to the hospital remained inpatient for only 2 to 3 days. Pediatric patients with diagnoses, such as leukemia, requiring extended hospitalization traveled to a larger teaching hospital within the state. These short duration of hospitalization for the subjects in this study impacted the design as described later in this chapter.

The age and diagnostic category chosen for convenience was specific to the pediatric population of a local hospital venue; the single subject research design was repeated with patients within the same age range (between 6 and 9 years of age), gender (female) and diagnosis (SCD). It was hoped that by focusing on one diagnostic category, age, and gender, positive results of the study would suggest efficacy within the larger population.

The first patient was 6 years-old. She had been diagnosed with SCD at 2 weeks of age. Her mother reported that she had suffered from a stroke as a baby as a result of the sickle shaped cells in her blood. The residual effect of the stroke was an irregular gait;
however, she was ambulatory despite the resulting gait changes, and did not require a leg brace. Subject 1 was admitted to the hospital for a routine monthly blood transfusion. The transfusion replaced her blood with non-sickled blood from a donor. This routine prophylactic procedure necessitated that the patient be admitted to the hospital once a month for two and a half days.

The second patient was 9 years-old. She arrived for her monthly transfusion on a weekend, and shared a hospital room with Subject 1. Subject 2 had been receiving monthly transfusions since she was 4. She was in second grade, and lived at home with her mother and four siblings. Her mother recalled that she was approximately 6 months-old when she was diagnosed with SCD. Although Subject 2 had suffered two mild strokes as a baby due to SCD, she had no residual physical problems.

Unlike Subjects 1 and 2, Subject 3 was admitted to the hospital for acute symptoms of SCD. The 9 year-old patient was born in Nigeria and had moved with her family to the United States just before her sixth birthday. She was in fourth grade, and was the youngest child in her family. Although this admission was her first during the year of the study, her father reported that she had been admitted to the hospital multiple times annually since her diagnosis with SCD at 1 year of age. On the occasion of this hospitalization, Subject 1 was suffering from terrible pain in her abdomen. Her physician had explained to the family that her bowels were not functioning properly in response to the acute SCD episode.

For inclusion in the study, each subject needed to be admitted to the hospital for at least 2 full days. Importantly, patients were studied individually; each patient observed constituted a study in which N=1. Behling and Merves (1984) argued that:

Basic to the purpose of N=1 is to find effective interventions, in order to change behaviors, processes, activities, or feelings, depending on the situation (p. 9).

Instrumentation

Instruments utilized included: (a) a survey detailing each patient’s history, (b) a schedule documenting observed behaviors related to anxiety, (c) the Children’s Hope Scale, and (d) the Children’s Health Locus of Control Scale. Additionally, recorded case notes were collected to reinforce or elucidate the quantitative data. The researcher, a
registered art therapist (ATR) and doctoral candidate in art therapy, was responsible for administering the instruments (with the exception of the Anxiety Behavior Schedule which was used by trained data collectors); and procuring detailed case notes during art therapy sessions as well as during subjects’ interactions within the pediatric unit.

The patient history survey. The first instrument, the patient history survey, was developed to document the medical history of the patients. Items on the instrument recorded basic personal and family information as well as educational and medical history (see Appendix D). Hospital personnel helped with the provision of some medical history information, while the patient’s family furnished other pertinent data.

The patient history addressed family income to acknowledge socioeconomic status (SES), a factor the literature review surmised could impact the psychological development and adjustment of subjects. Additional information regarding developmental level was procured by the item requesting each subject’s grade level in school. The items regarding each subject’s family and siblings were included to furnish the researcher with practical information. For example, the identification of family members prepared the researcher to include visiting family members in the art therapy interventions if they were present at the time of individual sessions.

The Anxiety Behavior Schedule. The second instrument, the Anxiety Behavior Schedule (ABS), allowed for the collection of anxiety-related data (see Appendix E). Two observable categories of behaviors, chosen for their applicability to the study population, were listed for reporting on the ABS. These behavioral manifestations had been documented as observable behaviors thought to be direct indicators of anxiety (Lader & Marks, 1971; Keable, 1989; Kleinknecht, 1991; Rowan & Eayers, 1987; Spielberger & Rickman, 1990). The first overt behavioral category noted on the observation schedule was fidgeting or restlessness. This included squirming, finger picking, rocking, foot shaking or shuffling, and shaking or tremor in hands. The second category of behaviors included avoidance behaviors. This category included evasive/protective maneuvers, lack of eye contact, clinging to family members or guardians, and vocalizations of distress (“I want to go home”).

Trained data collectors followed interval recording techniques to collect the ABS data. Four highly qualified individuals served as data collectors; each collector was a
skilled art therapist with graduate level training and clinical experience. Furthermore, one data collector was a doctoral student with two earned Master’s degrees (one in art therapy, one in social work), and another data collector had earned a Ph.D. The data collection checklist in Figure 3.2 was used in the training of each data collector. Following an initial explanation of the procedure, each of the collectors had an opportunity to practice using the ABS, and the researcher was readily available if at any time the collectors had a question about the procedure.

![Data Collection Checklist](image)

**Figure 3.2** Data Collection Checklist.

**The Children’s Hope Scale.** The third instrument was the six-item Children’s Hope Scale (CHS) (see Appendix F). Hope, the risk-resistant factor defined by the authors, is similar to constructs of locus of control and resiliency. Snyder et al. (1997) argued that the
stability of children’s hope makes the CHS an important tool for predicting outcomes of stressful life experiences. After initial development and testing of the scale, the authors administered the instrument to five additional samples of children: (a) a group of 48 boys and 43 girls (ages 8-17), with arthritis, sickle cell disease, and cancer; (b) 170 boys (ages 7-13) treated for attention-deficit/hyperactivity disorder (AD/HD); (c) 74 boys without AD/HD matched in ages with the previous group; (d) 70 boys and 73 girls (ages 8-16) previously treated for cancer; and (e) 154 boys and 168 girls (ages 8-16) in public schools in the mid-west of the United States. The authors (1997) published their findings of the scale’s internal item consistency and test-retest stability; they did not find significant gender, racial, or age differences in response to the items. In establishing construct validity, the authors found positive correlation between the children’s scores and the primary caregivers’ ratings of the children’s hope. Additionally, the authors found positive correlation with perceived competence and control, and negative correlation with depression.

Snyder et al. (1997) suggested that reliability and validity of suggest that the six-item instrument may be used to predict “psychosocial adjustment, pain, and medical adherence outcomes in acute and chronically ill children” (p. 418). Use of the instrument within this study was hoped to provide pertinent information in the analysis of the observable behavior data by indicating individual differences in subjects, particularly in regard to how they respond to the challenges of hospitalization and illness. The simple to use self-report scale was administered at the beginning of the intervention phase, before the patient participated in art therapy interventions.

The Children’s Health Locus of Control Scale. Finally, the Children’s Health Locus of Control Scale (CHLCS) was used (Parcel & Meyer, 1978). The instrument consisted of 20 statements that children were asked to respond to with Yes (agree) or No (disagree) (see Appendix G). The authors assumed that studies of children’s health behavior might be furthered by the instrument’s assistance in determining: (a) the relationship of health LOC to identifiable health behaviors, (b) the identification of experiences leading to the reinforcement of internal or external LOC, and (c) the effects of planned experiences on children’s health LOC (1978).
Goertzel and Goertzel (1991) examined Parcel and Meyer’s CHLCS (1978) by correlating scores on the CHLCS with self-concept and anxiety measures for children with chronic illness as opposed to healthy children. Their study included 38 children (ages 8-18) who received outpatient treatment for a primary diagnosis of cancer. The authors revealed that the reliability of the CHLCS with children with a serious chronic illness was somewhat satisfactory, but “not impressive” (p. 535). However, the authors found that individual items on the CHLCS did maintain correlation with positive self-concept and positive (non)anxiety with chronically ill subjects. The findings of the authors were presented in the literature review; the authors’ stressed their assertion that LOC and hope were closely related for children with chronic illness, and construct problems with the semantics of individual items for children with chronic illness, as opposed to healthy children.

Recognizing possible limitations of the instrument with children with chronic illness, the CHLCS was used in this study to provide pertinent information in the analysis of the observable behavior data by indicating individual differences in subjects LOC specific to the domain of health. The specific items which did demonstrate reliability with children with chronic illness were also considered to ascertain changes in internality or externality of LOC. The instrument was administered at the initiation of art therapy intervention (as a pre-test) and again following the termination of the intervention phase (as a post-test).

Qualitative data collection. In addition to the data collected from the above instrumentation, careful attention was given to the behavior, and patterns of behavior, demonstrated by the subjects during the art therapy sessions. Additionally, interactions of the subjects within the larger space of the pediatric unit were recorded, including contact with hospital staff and family members. The documentation of qualitative information was made by the researcher, who utilized ethnographic research techniques to collect, and analyze information.

Procedure

The baseline or “A” phase of the design began on the first day of each subject’s hospital admittance. Baseline observations by a trained recorder were made every 2 hours.
For example, if the first observation was made at 9:00am, the following ones were made at 11:00am, 1:00pm, 3:00pm, and 5:00pm. During these baseline observation periods, the target behaviors for anxiety were documented. Each observation lasted 10 minutes, and partial-interval sampling was used to gather the data; for each minute of the 10 minute observation, the observer watched the patient for the first 15 seconds (the “observation interval” period), then recorded whether or not either or both of the target behaviors were present (the “recording interval” period). If the behavior was present during the first 15 seconds of each minute, the “+” was circled on the ABS (see Appendix E). If the behavior did not occur, the “-” was be circled. The totals for each behavior were added together for each observational period.

After completion of the baseline period, an art therapy intervention was implemented. This began the treatment or “B” phase of the design. Each subject participated in three individual art therapy sessions during phase B. Art therapy interventions lasted 1 hour, with 2 hours between interventions. Data collection continued every 2 hours during the intervention phase of the study.

The simplicity and flexibility of the single subject design permitted delay in the initiation of baseline data collections. For example, the baseline data collection for the third subject did not begin until seven hours after her admission to the hospital. Although the delay was the result of delay in the researcher being called to the hospital, its result was actually helpful in determining that changes in the dependent variable resulted directly from the introduction of the intervention. If phase B had begun exactly ten hours after admittance for each subject, one could argue that time, not the intervention, was responsible for a decrease in observable anxiety behaviors.

**Treatment Protocol**

Following the baseline data collection phase, three art therapy interventions were conducted at regular intervals for each subject. During each of the interventions, the art therapist interacted directly with the patient. The sessions took place in the patient’s room or in the activity room. Sessions were 1 hour long, or as long as permitted by the child’s physical limitations and/or endurance. Individual art experiences were adapted as necessary for the special physical requirements of individual patients.
Discussion time was planned for each session. During the 1 hour sessions, the art therapist noted subjects’ verbalizations, behavior, and responses to the art making processes. Immediately following each session, subjects’ comments and responses to the art making process and the art therapy sessions were documented.

Three interventions were used during Phase B of the study. These interventions were: (1) the Environmental Collage (Appendix H), (2) the Elimi-Pain Game (Appendix I), and (3) the Before-During-and-After Drawing Series (Appendix J). The art therapy interventions were designed to facilitate knowledge acquisition regarding the diagnosis and treatment of SCD, enhance perceptions of control and opportunities for decision making, support expression of psychosocial needs regarding illness and hospitalization, and enhance accurate comprehension of treatment processes and outcomes.

One objective of the art therapy interventions was to increase perception of control. Therefore, addressing Thompson’s and Spacapan’s (1991) characteristics of successful control-enhancing interventions (delineated in Chapter 2) was significant for the treatment phase experiences. The characteristics identified by the authors were important elements of the art experiences planned for the patients. For example, simply making art materials available to pediatric patients met two of Thompson’s and Spacapan’s suggestions: (a) it provides numerous occasions to make minor decisions, and (b) it allows opportunities to engage in successful experiences.

Furthermore, the therapeutic interventions, in addition to soliciting nonverbal information regarding the accuracy of disease comprehension, incorporated educational and informational components which contributed to personal control. Pediatric patients gathered information and communicated their perceptions about their disease, its treatment, and the function of hospitalization through the process of making, collecting, and assembling images for the Environmental Collage (Appendix H), engaging in creative interaction in the Elimi-Pain Game (Appendix I), and portraying cognitive perceptions through visual images in the Before-During-and-After Drawing Series (Appendix J). The knowledge gained by the young patients informs self-responsibility, stress management, and mindfulness of control in everyday life. Furthermore, provision of age-appropriate, accurate information as well as opportunities for identification and expression of emotional responses to illness and hospitalization furnished patients with the tools and erudition
needed to participate in decision making. Armed with information and creative opportunities for expression, patients were reminded that even when they require hospitalization for their illness, they can experience a measure of control over their emotional responses to their circumstances, and they can participate in their health care and maintenance.

Finally, as part of the treatment protocol, when the art therapist initially entered the patient’s hospital room, she introduced herself and requested that the child participate in the art therapy experiences. At the conclusion of each session, the art therapist confirmed the time of the next session and remind the patient that she will be returning with another art experience. These simple gestures provide necessary occasions for control over at least one element of the patient’s schedule and visitors, which is another characteristic of control-enhancing interventions identified by Thompson and Spacapan (1991). An extensive therapeutic narrative is available in Appendix K.

Internal Validity

It was essential to be aware of, and attempt to prevent, threats to internal validity. In this study, threats to internal validity included: loss of subjects (mortality), testing threat, and history threat. Techniques were be implemented to alleviate some concern regarding threats to internal validity and to minimize the effect of these threats. These techniques include: standardization of the condition under which the study will occur, standardization of the procedures, and the securing of information on the subjects of the study (Fraenkel & Wallen, 1996).

Location, data collector characteristics, and implementation threats noted by Fraenkel and Wallen (1996) were significantly reduced through standardization of procedures implemented by trained collectors. Franklin, Allison, and Gorman (1996) discussed the importance of training data collectors to limit observer bias and maintain the validity of behavioral observations. Bloom, Fischer, and Orme (1999) emphasize practicing the observation process with the data collector as well as arranging trial observation sessions. The training of the data collectors for this study included covering each of the elements in the Data Collection Checklist recommended by Bloom, Fischer,
and Orme (1999) in Figure 3.2. In addition to the elements on the Data Collection Checklist, retraining was available as needed.

Data Analysis

Behling and Merves (1984) argued the benefits of reinforcing the visual inspection of graphed single data with statistical methods appropriate for the analysis of single subject research. The authors pointed out, however, that although statistical evidence may demonstrate important changes, it should augment, not replace visual inspection of graphed data. The method chosen for analysis of data gathered during this research was the relative frequency procedure. Statistical significance was determined at a 95% confidence level by consulting a probability distribution table.

Statistical significance at 95% allowed the researcher to conclude that changes evidenced in the intervention phase were the result of art therapy, not chance. Typical behavior, calculated using baseline observation data points, was identified on the visual display data and across each phase of data collection. The proportion of data points falling outside the parameters of this band of typical behavior during the intervention phase was used to calculate the significance of change. Data points located below the range of typical behavior represented desirable behavior change. Data points located above the range of typical behavior represented undesired behavioral change.

Limitations

The primary limitations of the design of this research resulted from the short duration of hospitalization for the individual pediatric patients at the hospital venue chosen for the study. In the case of subject 3, the study protocol was not completed when the patient was released prematurely. Additionally, each subject’s baseline behavior did not necessarily stabilize, as would be optimal before proceeding to the intervention phase. The authors argued that by recording the steady state, the therapist could locate the specific condition or occasion of the subject’s problem. For this research, the collection of the baseline data was initiated shortly after the initial hospitalization of the subjects, and it was the anxiety provoked by the occasion of hospitalization, the threatening environment of the hospital, and the medical treatment that was studied. Furthermore, the three art therapy
interventions will take place within 1 or 2 days; one art therapy session per day would have been an optimal schedule.

The hospital at which the study will took place was not set up for collection of behavioral observation data. There are not, for example, patient rooms with one way viewing windows. Therefore, the presence of the recorder in the subjects’ rooms, making notes in response to his observations, had the potential to impact on the very anxiety behaviors she was there to record. Therefore, the recorder will make her presence as unobtrusive as possible. For example, she generally stood across the room from the patient. If the subject occupied a shared hospital room, the recorder stayed on the side of the room occupied by the roommate during the observation period.

The reservations generally associated with the A-B design are: (a) changes might have occurred without the intervention, and (b) changes may be correlated with an event (Behling & Merves, 1984). Attempts to address and control for these limitations were made within the design of the study methodology. Delay of the baseline phase for the second and third subjects was helpful in concluding that changes were not simply a result of the amount of the passage of time.

Regarding the use of the CHLCS, Parcel and Meyer (1978) argued that stronger predictions of behavioral outcomes could be generalized when measurement of internal and external LOC within a specific category or context could be made. Although more applicable to children with SCD than a general LOC measure, the CHLCS was fundamentally concerned with health education and health motivation, rather than the experience of chronic, genetically transmitted diseases such as SCD. The context of current hospitalization, in addition to the immediate anxiety responses to the combined trauma of illness and hospitalization, were not directly addressed by the instrument. In fact, Goertzel and Goertzel (1991) found that the instrument achieved only modest to unsatisfactory reliability results when studied on pediatric cancer patients, as opposed to healthy populations of children. The authors did identify, however, specific items on the instrument which had strong correlations with self-concept and reduced levels of anxiety. Additionally, the instrument was comprised of items which purposefully address three distinct subscales: (a) internality, (b) powerful others, and (c) chance or luck. The results of the CHLCS, particularly responses to the specific questions with high correlation to
positive self-concept and reduced levels of anxiety, were considered in the analysis of all data collected on each subject.

Finally, for this study, only children with a diagnosis of sickle cell disease within a limited age range were considered. Therefore, replication of the study with additional disease or injury categories, and within different age ranges, is strongly encouraged. Additional implications of the study are presented in chapter 5.
The null hypothesis for this study alleged that an art therapy protocol, designed and implemented for children in hospitals, would not effect change in anxiety behaviors in children experiencing hospitalization and medical treatment. Furthermore, any resulting changes in quantity of observable behaviors would not be sustained over time. Two sets of data, quantitative and qualitative, were utilized in addressing the study hypothesis. Quantitative data was collected through the utilization of three instruments; the data collected on each is this chapter. Additionally, detailed qualitative information was recorded (see Appendix K); information from the qualitative narrative specific to the hypothesis is presented in this chapter.

**Quantitative Results**

**Anxiety Behavior Schedule**

Data collected on the Anxiety Behavior Schedule (ABS) for the first subject is graphed in Figure 4.1. Visual inspection of the graphed data suggests a slight reduction in anxiety upon initiation of Phase B. However, the anxiety experienced during Phase A was minimal, as was confirmed using the relative frequency procedure; analysis of the data revealed that the subject was not anxious enough during Phase A for any change in Phase B to be statistically significant.

ABS data for the second subject are presented in Figure 4.2. The hypothesis that the art therapy protocol could reduce anxiety in hospitalized pediatric patients was supported by the data on this subject. Visual inspection of the data depicts anxiety
reduction in Phase B. The relative frequency procedure confirmed reduction in anxiety resulted directly from art therapy. Significance was determined at the .05 level. This level of significance was confirmed for the follow-up period as well.

Figure 4.1. ABS data for Subject 1.

Figure 4.2. ABS Data for Subject 2
The ABS data on the third subject is presented in Figure 4.3. Only three observation periods were completed during Phase B, as the subject was released early from the hospital; the absence of at least one additional data point prohibited use of the probability distribution table during the relative frequency procedure. Therefore, the data on this subject was inconclusive. This was particularly disappointing given the promising results suggested by the initial data trend.

![Figure 4.3. ABS Data for Subject 3](image)

Data from the ABS demonstrated promising trends, but only the data from the second subject is valuable in addressing the hypothesis. For the second subject, the art therapy protocol was unquestionably effective in reducing anxiety. This is a very important certainty, but it is only true for one individual. This falls short of the research design’s objective to establish efficacy through replication. Additional subjects would be required to demonstrate a more definitive implication of art therapy’s ability to reduce anxiety for this population.

The Children’s Hope Scale

All of the subjects demonstrated high hope on the CHS. In addition to depicting subject’s total scores on the CHS, Figure 4.4 presents subjects’ categorical responses to
agency and pathway items. The CHS contains three items tapping agency thoughts, and three items designating pathway thoughts. The authors of the instrument (Snyder et al, 1997) distinguished between agency and pathway components of hope. Agency thoughts reflect perception of competence; pathway thoughts represent perception of control.

Subject 1 scored highest on the CHS. She answered all six items, agency and pathway, with the same response on the 6 option continuum, “All of the time.” Her high hope paralleled the minimal anxiety evidenced by the ABS data, corroborating the risk-resistant factor that the authors (Snyder et al, 1997) contended the CHS measures.

![Figure 4.4. Subjects’ scores on the CHS, reflecting agency and pathway components.](image)

Subject 2’s responses to the CHS indicted high hope, with narrowly higher competence than control. The score for subject 3 also indicated high hope, and like subject 1, the agency and pathway item categories received equal weight. This corroborates the assertion of Snyder et al. (1997) that the components are theoretically and empirically linked, and both components must be added to measure goal directed thinking.

The results of the CHS revealed two characteristics common to all 3 subjects: (a) all had high hope, and (b) all reported balanced agency and pathway components of hope. Also revealed was the negative correlation of the CHS scores to ABS baseline averages.
(see Figure 4.5). The subject with the highest CHS score had the lowest average number of anxiety behaviors during phase A of the ABS. The subject with the lowest CHS score had the highest average number of anxiety behaviors during phases A of the ABS.

Figure 4.5. Relationship between ABS Baseline Phase Data and CHS scores

The Children’s Health Locus of Control Scale

The items on the CHLCS address three subscales: a) Internality, (b) Externality or Powerful Others, and (c) Chance. The instrument was administered as a pre and post test to secure information which might elucidate ABS data. Figure 4.6 depicts each subject’s percentage of affirmative responses, for each subcategory of control identified in the CHLCS, for all items which were answered on the pre-test (Subject 3 did not answer four of the items on the CHLCS; this is discussed later). Figure 4.7 provides the same information for the CHLCS post-test.

As Figure 4.6 illustrates, all of the subjects demonstrated high internal LOC on the pre-test. All of the items tapping internal LOC to which subjects responded were answered affirmatively. Subject 1 and Subject 2 also responded to all of the external items affirmatively, while Subject 1 responded to 71% of the external items positively.
The pre-test indicated the subjects’ high internal and external perceptions of control. At the time of testing Subjects 2 and 3 believed that either they, or powerful others, controlled their health. Subject 1 demonstrated a more internal than external locus of control, responding affirmatively to 100% of the internality items, and 71% of the externality items. Responses to the chance items were more varied, however.
Subjects 1 and 2, who both demonstrated high internality and externality, each also responded to the chance items affirmatively at high percentages (100% and 80% respectively).

The results of the CHLCS post-test differed from the pre-test in one crucial respect. All of the subjects demonstrated a reduction in externality. Following the art interventions, all of the subjects demonstrated greater internal LOC than external LOC. This is particularly significant support for the art therapy interventions which were designed to enhance control.

Careful consideration was given to those items the authors (Goertzel & Goertzel, 1991) determined correlated with positive self-concept or positive (non)anxiety even for children with chronic illness. Figure 4.8 exhibits each of the items, and subjects’ responses to them.

<table>
<thead>
<tr>
<th>Item positively correlated with positive self-concept</th>
<th>Subject 1 Pre/Post</th>
<th>Subject 2 Pre/Post</th>
<th>Subject 3 Pre/Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can do many things to prevent accidents.</td>
<td>Yes/Yes</td>
<td>Yes/Yes</td>
<td>NA/NA</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Item negatively correlated with positive self-concept</th>
<th>Subject 1 Pre/Post</th>
<th>Subject 2 Pre/Post</th>
<th>Subject 3 Pre/Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other people must tell me what to do when I feel sick</td>
<td>No/No</td>
<td>Yes/No</td>
<td>Yes/No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Items positively correlated with positive (Non)Anxiety</th>
<th>Subject 1 Pre/Post</th>
<th>Subject 2 Pre/Post</th>
<th>Subject 3 Pre/Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can do many things to fight illness.</td>
<td>Yes/Yes</td>
<td>Yes/Yes</td>
<td>NA/NA</td>
</tr>
<tr>
<td>I can do many things to prevent accidents</td>
<td>Yes/Yes</td>
<td>Yes/Yes</td>
<td>NA/NA</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item negatively correlated with positive (Non)Anxiety</th>
<th>Subject 1 Pre/Post</th>
<th>Subject 2 Pre/Post</th>
<th>Subject 3 Pre/Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other people must tell me what to do when I feel sick</td>
<td>No/No</td>
<td>Yes/No</td>
<td>Yes/No</td>
</tr>
</tbody>
</table>

Figure 4.8. CHLCS items correlated with self-concept and (non)anxiety. The items Goertzel and Goertzel (1991) identified as correlated with feelings of self-concept and reduced anxiety are presented, with each subject’s pre and post test response.
All of the subjects responded affirmatively to each item positively correlated with either positive self-concept or positive (non)anxiety. Subjects 2 and 3 initially responded affirmatively to the item negatively correlated with both self-concept and (non)anxiety. Their responses on the post test, however, changed. On the post-test, Subjects 2 and 3 responded negatively to the negatively correlated item. This item, in fact, represented their change to a more internal locus of control. The correlation established by Goertzel and Goertzel (1991) for that particular item strengthened the argument that art therapy was effective in shifting locus of control to internal.

Subject 3 is the only subject that did not respond to all the items on the CHLCS instrument. She stated she could not understand, and therefore did not answer, the same four questions for the pre-test and post-test. The questions were: (a) “Bad luck makes people get sick,” (b) “I can do many things to fight illness,” (c) “Other people must tell me how to stay healthy,” and (d) “I can do many things to prevent accidents.” Her dilemma was the incongruity of these items with her experience of chronic illness, as explained in Chapter 2. For example, “Bad luck makes people get sick” does not make intuitive sense to an individual with a chronic medical condition. The individual may indeed feel unlucky to have the disease, but she has learned that there are specific biological or genetic components that cause the disease, not bad luck. Additionally, a chronically ill patient can do many things to avoid acute symptoms, but avoidance of disease crisis cannot be guaranteed. One may dress warmly in the winter and eat healthy foods, but still experience a SCD crisis. This argument can be made for all of the items subject 3 could not answer. Nonetheless, in scoring only for the items subject 3 did answer, change to greater internality that externality on the post-test was demonstrated.

Summary

Although the data from Subject 2 stands alone in demonstrating the efficacy of art therapy when the ABS outcomes are examined in isolation, the results of the CHLCS provide vital information in rejection of the null hypothesis. All of the subjects demonstrated greater internality following the interventions. This imparts critical backing for the theoretical argument that art therapy intervention can increase individuals’ internality of control.
Although, the ABS data for subject 3 was inconclusive, when subject 3’s outcomes are coupled with the results of her CHLCS, promising information emerges. The CHLCS post-test administered to subject 3 prior to her early release displayed a higher percentage of affirmative responses to internality items than to externality items, in contrast to her pre-test results. Although the ABS data set for phase B was incomplete, after two art therapy interventions, the underlying theoretical component of a shift in LOC had been achieved. With the results of all 3 subjects demonstrating the same trend in reduced externality upon the post-test administration of the CHLCS, powerful evidence for rejection of the null hypothesis is demonstrated.

Finally, the ABS follow-up data for Subject 2 provides evidence for the rejection of the secondary null hypothesis. Subject 2 sustained the changes that resulted from participation in the art therapy protocol. Therefore, the quantitative data provides evidence that (a) the art therapy protocol, designed for hospitalized pediatric patients, can reduce anxiety in patients hospitalized for medical treatment, and (b) the reduction in hospitalized children’s anxiety behaviors resulting from participation in the art therapy protocol is sustained over time.

**Qualitative Results**

The art therapy sessions took place in the activity room of the pediatric unit. The room was located at the end of one of the unit’s two corridors. All four walls of the room were skillfully painted with a continuous cheery outdoor mural. Each wall carried over the scene from the adjacent wall; for example, one wall started with a wooded landscape and picnic area that moved into a country fair, followed by a pond scene then a valley. Children’s furniture toys were pushed unsystematically against the walls to line the perimeter of the room. Nearly all of the plastic benches and tables were sized for 2 to 5 year-old children. Some were missing parts. A low activity table sat at the end of the room nearest to the door, and this area was tidied and prepared for art making.

None of the subjects resisted participation in the study, and all eagerly participated in the art making process. The subject’s responses to art therapy appeared to result from the nature of their hospitalization. The subjects who were admitted for
routine transfusions, as opposed to acute disease process, presented as relatively well-
defended in the pediatric unit; yet, given the psychological safe place of the art therapy session, they allowed their emotions to be exposed. As explained in additional detail in Appendix K, Subjects 1 and 2 were able to contain their psychosocial needs in the hospital despite their isolation from family and their age-appropriate fears of hospitalization. They managed their psychosocial needs by masking their emotions; they generally appeared cheerful and did not articulate fears or concerns to the hospital staff. However, in the psychologically supportive space of an art therapy session, the young patients grasped the opportunity to process their emotional and psychosocial experiences.

Although they were able to summon defenses that belied their psychological distresses in the psychosocial isolation of the hospital environment, when their emotions were brought to the surface as a result of artistic and creative exploration, they had difficulty in containing them. It was at that time, as opposed to the periods before the intervention phase and between art therapy sessions, that the anxiety levels of the young patients were exposed. Just as the art therapy interventions provided opportunities for self expression and learning, the reinforced knowledge that they would again soon have access to the safe place established as a parameter of art therapy sessions, and perhaps the unconditional positive regard provided by the art therapist, seemed to provide the psychological fortification they required to return to the realities of hospitalization. In fact, by her third art therapy session, Letecia was able to re-contain her insecurities simply by being told the art therapist would stop in her room to see her before leaving for the day.

The third subject, admitted to the hospital in SCD crisis, was not equipped with the defenses that the transfusion patients had mastered. Her anxiety was more overt. As explained in the qualitative narrative (Appendix K), the ABS data points representing no observable data points during her baseline were the result of powerful medications which resulted in near sleep, belying her emotional state. Unlike the subjects admitted for transfusions, Subject 3 was constantly attended by at least one of her family members. Also unlike the other 2 subjects, she became increasingly at ease within the art therapy sessions, and did not need time to regroup before returning to her room. Her affect became calm and playful during art therapy sessions. Her eye contact increased, as did
her verbal communication; she asked questions and responded to questions, and the volume of her voice grew to a more appropriate conversational level.

Despite the differences in the progression of art therapy sessions, all three subjects shared a common behavior. Each subject solicited information regarding the exact time and place where the following session would take place, and then asked the art therapist to repeat this information when she returned to her room. This knowledge was particularly meaningful to the subjects, and provided an important measure of control.

The protocol for this study included three art therapy interventions. The interventions were designed to increase the internality of subjects’ LOC by familiarizing them with the hospital environment, providing opportunities for control and expression, and addressing established cognitive structures regarding their treatment and medical condition. The subjects’ responses to these interventions are noted in the following paragraphs, and is also reported in detail in Appendix K.

The Environmental Collage

The subject matter photographed by the patients for the Environmental Collage was similar, as was the order in which they photographed the elements and people within the hospital environment. The subjects all photographed non-staff individuals who were in their rooms (family members or roommates) before moving out of their rooms to photograph the nurses at the nurses station. The subjects also included photographs of themselves. None of the subjects photographed the medical equipment used in their care; therefore, the provision of direct information regarding treatment was circumvented.

The arrangement of the photographs in each subject’s collage was similar; each was linear and arranged horizontally on the paper. The subjects used the time of the first session to discover the role of the art therapist and the “rules” of interaction. This trial engagement with art therapy was facilitated by the nature of collage and the inclusion of photographic imagery introduced art therapy as non-threatening; subjects’ art skills were not challenged, and closed directives were avoided. By the end of each subjects’ first art therapy session, the parameters of art therapy as a “safe place” and the role of the art therapist as the person in the hospital who addressed psychosocial needs was internalized by each of the subjects. For subject 1 in particular, liberation from carefully guarded
defenses was accompanied by a temporary amplification of emotional vulnerability. The incongruous data point during the intervention phase of the ABS mark this transition from highly defended to psychologically supported. The therapeutic narrative in Appendix K addressed this change.

The Environment Collage intervention provided occasions for subjects to make more than creative choices. It permitted the subjects to act out control over the hospital environment; subjects were given unique opportunities to give verbal orders to their caregivers, fellow patients, or family members. The opportunities for perceived control seemed to be the most important benefit of the environmental collage intervention.

The Elimi-Pain Game

The Elimi-Pain Game was the strongest intervention for the provision of accurate and appropriate information to the subjects. In addition to the game’s drawing tasks and abstract representation of pain tasks, the game cards asked direct questions about SCD treatment, symptoms, and prophylactic initiatives. Each subject gained empowering information about their disease, and steps they could take to prevent SCD crisis.

The researcher had an interesting opportunity to observe the assimilation of new information by one of the subjects. As reported in the Appendix K, the researcher escorted Subject 1 to her room following the Elimi-Pain Game. Upon reaching her room, Subject 1 stated she felt dizzy and required help to get into bed. The art therapist asked if she had eaten that day. Subject 1 explained that she didn’t eat breakfast, nor did she like the lunch that was served, so she had only eaten potato chips. Recalling a game card from the Elimi-Pain game, Letecia recalled that to stay healthy, she should eat nutritious foods. With that recollection she asked the art therapist if she would find something good for her to eat.

The Before-During-and-After Drawing Series

The Before-During-and-After Drawing Series was the least effective intervention of the protocol. The intervention would have better served pediatric patients hospitalized with acute, rather than chronic, conditions. Unfortunately, it was not implemented with subject 3, the only subject in the study who was hospitalized in SCD crisis, as she was
released early. Subjects 1 and 2 had copious experiences with the routine of being admitted and released from the hospital, so they were familiar with the procedure. They had learned that the routine transfusions did not impact their body function or self-concept during the interim between monthly hospitalizations.

Although not an ideal intervention for children hospitalized for routine procedures, the Before-During-and-After drawing directive did provide valuable indicators of the subjects’ developmental levels. For example, six year-old Subject 1 created images representative of the early stages of preschematic art skill development. Anderson (1992) reported that by about 6 years of age, children generally include detail in their renderings, even if objects are not drawn to scale. Anderson also suggested that beginning at approximately 5 years of age, “children…who fail to include items from their surroundings, or who rather consistently draw stereotypic images” (1992, p. 104) may have intellectual, emotional, or physical problems. The developmental concerns prompted by the figure drawings for the Before-During-and-After intervention were also indicated by the tree drawings with which Subject 1 struggled during free drawing time, following completion of her environmental collage (see details in Appendix K).

Given the developmental impediments depicted in Figure 1’s drawings (and to a lesser extent by the simplified stick figures produced by Subject 2), the drawing directive itself may have been exigent. The required abstract thinking regarding time may be particularly problematic for the 6 year-old Subject 1. This will be an important consideration for practice for this, and comparable populations.

Summary

The results of the qualitative data, paralleling the findings of the quantitative data, support the rejection of the null hypothesis. The art therapy interventions, particularly the Environmental Collage and the Elimi-Pain Game, provided experiences which were open-ended, offered valuable occasions to exercise control, and granted opportunities to explore, express, and process emotional responses to hospitalization, SCD treatment, isolation, loss of control, and other distressing events. The qualitative reports indicate that the subjects, given opportunities to process psychological material and gain age-
appropriate, accurate information, were able to regulate their emotional responses to the hospital environment and demonstrate decreased anxiety.

The qualitative data also supports rejection of the secondary null hypothesis. Study of Subject 2, who was readmitted to the hospital for subsequent hospitalization, demonstrated sustained behavioral changes upon the subsequent hospitalization. In fact, immediately upon finding the researcher in the hospital during the subsequent hospitalization, she initiated the processing of anguish encountered both inside and outside the hospital environment in the time since she had engaged in art therapy. Subject 1 identified the researcher/art therapist as what seemed to be the only channel available to her in the hospital, and both verbal and visual processed psychologically demanding material. This parallels the quantitative data and rejects the study’s null hypothesis, that art therapy intervention would not sustain positive outcomes.

Synopsis of the Results

The art therapy protocol was conclusively effective in reducing anxiety for the second subject. This was a critical outcome; unfortunately, a trend could not be established given the early release of subject 3, and the relative psychological well-being of subject 1. Additional subjects are required to demonstrate a more definitive inference of art therapy’s ability to reduce anxiety for this population.

The results of the CHS revealed two characteristics common to the 3 subjects: (a) all had high hope, and (b) all reported comparable propensity for agency and pathway thinking. Finally, a comparison of the subjects’ scores on the CHS revealed a negative correlation with the ABS baseline phase averages. The highest CHS score translated to the lowest average number of anxiety behaviors reported for phase A on the ABS. Conversely, the lowest CHS score translated to the highest average number of anxiety behaviors reported for phase A on the ABS.

The results of the CHLCS post-test differed from the pre-test in one very important respect. All of the subjects demonstrated a reduction in externality. This is particularly significant support for the art therapy interventions which were designed to enhance control. Following the art interventions, all of the subjects demonstrated greater
internal LOC than external LOC. The qualitative information presented in this chapter, as well as in Appendix K, also provided information which prompted the rejection of the null hypothesis.
CHAPTER 5

CONCLUSION

This research study sought to answer the question, “Can an art therapy protocol, designed and implemented for children in hospitals, reduce anxiety behaviors in hospitalized pediatric patients?” The null hypothesis, that art therapy protocol would improve the psychological well-being of children experiencing hospitalization and medical treatment by decreasing their anxiety was disproved. Furthermore, the secondary hypothesis, that any demonstrated changes in observable anxiety behaviors would be sustained should a patient be readmitted to the hospital, was also disproved.

Reduction in Anxiety Behavior

The results reported in chapter 4 support the rejection of the null hypothesis in two very important ways. First, the ABS data on Subject 2 definitively confirmed reduction in anxiety due to art therapy intervention. Second, every one of the subjects demonstrated reduced externality following art therapy intervention. This supersedes the inconclusive outcome of Subject 3’s ABS data, resulting from her early release.

Even though the ABS data did not develop as anticipated, the conclusive trend in efficacy sought through repetition of the research design was realized in the LOC shifts of the subjects. Even with the ABS data set for phase B incomplete, the researcher found that after two art therapy interventions, the underlying theoretical component of the research had been achieved. Greater internality resulted from art therapy interventions.

The CHS findings indirectly supported the rejection of the null hypothesis. The data from the instrument behaved as it should, given the construct of hope and its
relationship to LOC. The CHS scores identified a negative correlation with (non)anxiety, which reinforced validity of ABS data. The instrument’s demonstrated value as a predictive tool is presented later in this chapter.

**Sustained Change**

The theoretical position of the researcher purported that any change in observable anxiety behaviors would not be sustained should a patient be readmitted to the hospital. The opportunity to collect follow-up ABS data for Subject 2 on a subsequent hospitalization provided the data to reject this hypothesis. Eight months after participating in the study protocol, Subject 2 sustained a significant reduction in anxiety behavior. Therefore, the reduction in anxiety behaviors resulting from the art therapy interventions was sustained and was documented through follow-up data collection upon Subject 2’s subsequent readmission to the hospital.

**Correlations with Previous Research**

The use of the CHLCS revealed two specific issues. Each was addressed in the literature and correlated previous findings. The first was encountered during the administration of the instrument; the second presented itself during the analysis of the data.

During the pre-test administration of the CHLCS with Subject 3, the patient stated on four occasions, that she could not respond to an item. Goertzel and Goertzel (1991) encountered this problem as well. The authors (1991), who studied LOC in children with cancer, addressed the problematic nature of instrument items designed to predict healthy children’s responses to health obstacles used with children with life-altering illness. The authors wrote:

For healthy children illness is an inconvenience, not a threat to life. They are free to respond to the locus of control items more casually and based on memories of illness rather than with the impact of current daily experience of illness as a threat. (p. 539)
The authors were concerned that some health LOC questions belied pediatric patient’s experience of illness.

A child who is asked to agree or disagree with statements such as, ‘I can only do what my doctor tells me to do about my health’ or ‘the best way to keep from getting sick is to have regular medical checkups’ (Thompson, Butcher, & Berenson, 1987, p. 84) may be torn if he believes that it is a good thing to have checkups and follow the doctor’s advice, but that these are not the only nor necessarily the best things to do. (p. 539)

The second issue was a paradox that presented itself during analysis of the subjects’ responses to internal LOC and external LOC items. Responses that Subject 2, Subject 3, and to a lesser degree Subject 1, provided for the CHLCS items demonstrated both high external LOC and high internal LOC. Even when externality was reduced following art therapy interventions, the subjects still attributed control to powerful others on items tapping externality. Initially, the art therapist was concerned that the subjects’ large percentage of affirmative responses to CHLCS items reflected developmental or language difficulties. However, reflection on a theory presented by Goertzel and Goertzel (1991) contributed an alternative perspective on the patients’ seemingly ambiguous LOC. Cognizant of the connection between hope and locus of control in children undergoing treatment for life threatening illness, the authors concluded that for the pediatric patients they studied, hope was “very important to the process of dealing with illness” (p. 407). They examined the link between hope and control, and proposed that whether young patients with chronic illness believed their disease was controlled by their physicians, parents, themselves, or all of these, was not as important as believing that it was controllable.

The issue of hopefulness and decreased helplessness is very important to pediatric cancer patients. This is a primary issue…It may not matter so much whether a control is internal or external but whether the child believes that the disease can be controlled…Hope can come from believing that either the patient and/or powerful others are in control of the illness. (p. 539)

The sustained changes in anxiety behavior demonstrated by Amber during a subsequent hospitalization also offered a correlation to previous research. Thompson and
Spacapan (1991), examined perceptions of control on vulnerable populations. The authors identified positive outcomes associated with the effects of a sense of control, and presented themes for further development. They also revealed a particularly useful application of perception of LOC which parallels the data on Subject 2. The authors argued that ameliorative effects of control are residual, extending beyond the immediate situation over which an individual perceives control. The results of the data collected on the second subject corroborate their assertion that one of the benefits of advancing perception of control is the residual advantage it affords. Furthermore, the application of art therapy practice advocated in the literature (Crowl, 1980; Prager, 1995; Rode, 1995; Russell, 1995; Viscardi, 1994) helped to promote the change necessary to sustain desired outcomes.

Finally, the relationship of high hope and high LOC demonstrated by subjects’ responses on the CHS and CHLCS finds correlation in the literature. Thompson and Spacapan, (1991) found that personal characteristics impact feelings of control. The relationship of the stable characteristic of hope to LOC strengthens the application of the CHS as a predictive tool.

**Implications for Future Practice**

The process of qualitative and quantitative data collection and the patterns revealed during the art therapy interventions, as well as in the larger pediatric unit, revealed important considerations for future medical art therapy practice with hospitalized pediatric patients. The implications for future practice included (a) the provision of time and place information for subsequent art therapy sessions, (b) the inclusion of group art therapy in the pediatric units, (c) implications for the presence/absence of family support for the patient(s), and (d) responsiveness to individual differences among pediatric patients. These implications are discussed, with examples, in the following paragraphs; their impact on programming and policy follow.

One simple suggestion for art therapy with this population was introduced in the literature review and reiterated in this study. The importance of providing patients with detailed and precise information regarding the ensuing art therapy session was paramount. The subjects in this study requested this information at the end of the session, and again
when they were returned to their rooms. This simple, straightforward provision of information afforded the means of psychological fortification required by the transfusion patients to leave the supportive art therapy environment, and provided comfort and support to the subject admitted in SCD crisis.

On two occasions during the intervention phase protocol, subjects invited third parties to participate in the Elimi-Pain Game. Subject 2 invited her young roommate; Subject 3 invited her brother. In both cases, the sessions were not interrupted by the participation of unexpected others. In fact, the art therapist should be flexible in planning interventions and sessions to allow for the inclusion of parents, siblings, and other patients. The therapist may even decide to organize group art therapy sessions which children from the unit are invited to attend, or sessions that incorporate family members who are in the hospital to participate in their children’s care. Even art therapy sessions intended to take place one-on-one at a patient’s bedside may need a back-up plan which incorporates or acknowledges the presence or participation of a parent.

During this small study, only the subject who was admitted for treatment of SCD crisis maintained the presence of family members. The subjects who were admitted for routine procedures were not accompanied around the clock; conversely, one subject’s family visited for approximately one and a half hours. The other patient had no visitors during the course of her weekend at the hospital. If a larger pattern was established, it would behoove the art therapist to plan for familial participation when patients were admitted for treatment of acute conditions, and also plan to address the particular psychosocial needs of children without immediate familial support.

The researcher noted, in the results of the qualitative component of the study in chapter 4 and in the qualitative narrative in Appendix K, that there were decisive differences in the responses of patients to art therapy based on the nature of their admission. One patient was admitted for acute care for SCD crisis; two were had pre-scheduled admissions for routine transfusion. The results of the Before-During-and-After Drawing Series were also discussed in terms of crisis or routine admission. Certainly, these differences suggest that art therapists working with hospital patients consider different objectives for individual patients, based upon patients’ individual familiarity levels with hospitalization as well as medical treatment.
Another individual differences issue impacting practice implications presented during art therapy sessions. The drawings of the first and second subjects demonstrated probable developmental difficulties encountered by the patients. The researcher could not conclude whether the resulting deficiencies were the result of socioeconomic factors (which were shared by the first two subjects), or the result of living with a chronic and life-altering illness (missing school, weakness or fatigue, etc.). Nonetheless, the art therapist working in this setting should address the likelihood that children with chronic illness may experience developmental difficulties. For example, it became apparent that the youngest of the three subjects in this study may not have been able to form complete cognitions for the abstractions of time essential to the final intervention (the Before-During-and-After Drawing Series). Alternative instructions, interventions, or vocabulary may be useful in working with individual patients.

The implications for practice discussed in this section carry important implications for hospital programming and policy. Most importantly, the results of the study established a decisive trend in the efficacy of art therapy in addressing the psychosocial needs of pediatric patients; specifically, the participation of subjects in the art therapy intervention protocol resulted in a reduction of anxiety behavior and an increase in internal LOC. Therefore, the primary implication is that art therapy be made available to pediatric patients. Consequently, secondary considerations would be necessary. For example, if a hospital initiated the availability of art therapy for its patients, physical space would be required to conduct art therapy, particularly, if family or group art therapy were initiated. The activity room described in this study would accommodate a small group, but not a large group or open studio.

Additionally, upon the initiation of a hospital art therapy program, a referral system involving families, nurses, and other hospital staff, could be implemented; the art therapist might also utilize an instrument such as the Children’s Hope Scale to identify appropriate participants. If artists in residence or volunteers were part of a hospital’s arts in medicine program, supervision by a trained art therapist would be crucial in the planning of interventions to meet individual patient’s psychosocial needs, address individual differences, and tackle ethical issues that would arise.
Implications for Further Research

Implications for Future Research Subjects/Populations

The results of this study hold important implications for further research. The most obvious is continuation of the study protocol with subjects meeting the criteria for this study. Through repetition of results, definitive trends in efficacy may be recognized for this population. Having a minimum of 2 additional subjects, with baseline data revealing sufficient anxiety, complete the study protocol would be ideal.

The study design could be also be implemented with different ages, gender, or diagnostic categories of pediatric patients. It would be particularly interesting to reproduce the study with patients hospitalized for longer durations; the design of baseline and intervention data collection intervals could be extended. For example, subjects’ duration of hospitalization would necessarily be lengthier in an oncology unit. What are the characteristics or graphic qualities of drawings created by children with life threatening illness? What effect does major surgery (for example, an emergency appendectomy) have on the body image of pediatric patients? This may tap into the value of the Before-During- and-After Drawing Series with acute care pediatric patients.

One important consideration for researchers is differentiation between subjects hospitalized for acute disease processes or accidents, and those hospitalized for routine treatment. The distinction between transfusion admission and SCD crisis admissions was not made in the design of this study; had it been, a problem such a Subject 1 not exhibiting sufficient anxiety may have been avoided. Furthermore, if the researcher chose to work with patients with chronic medical conditions, the research might be implemented with outpatient groups, rather than in the hospital setting. If so, evidence of psychological well-being or LOC could be correlated with compliance to medical or pharmaceutical regimes. Other important research questions resulted from the collection of qualitative data. For example, what percent of the duration of hospitalization are patients admitted for acute care accompanied by supportive family? What percent of their time in the hospital do patients admitted for pre-scheduled, routine treatment spend unaccompanied by family?

Finally, the results of the study and its original impetus point to an important implication for future research. Given the limited art therapy or arts in medicine
programming currently in place in hospitals, a research design could be implemented which would compare the psychological well-being of patients in hospitals with therapeutic arts programming as opposed to the psychological well-being of patients in hospitals without such programming. Anxiety, adherence to medical treatment regimes, pain behaviors or self-reports of pain, might be measured as indicators of psychosocial health. Given the information gathered during this study, a researcher might ask: How much time alone do pediatric patients spend in hospitals with arts and medicine programs versus hospitals without arts in medicine programs? How does this effect psychological well-being? Furthermore, the differences between arts and medicine programs facilitated by artists and volunteers and clinically based arts medicine programs could be examined.

Implications for Future Research Interventions

The art therapy interventions may need to be changed or altered to apply the research design to patients in other categories of medical diagnosis. The Elimi-Pain game is specific to children with SCD, and would not be appropriate for other populations. The substitution of game cards specialized for other medical conditions, however, would be a relatively simple solution to this problem. Additionally, the Before-During-and-After Drawing Series is more appropriate for patients hospitalized for acute medical conditions than for patients hospitalized regularly for routine treatment. Including an instrument to identify the development or cognitive level of patients with chronic illness would address the study findings that two of the three subjects rendered drawings inconsistent with their chronological age. Furthermore, a schedule developed for a longitudinal study could track the number of school days missed by pediatric patients who are hospitalized on a regular basis for prophylactic treatment.

Implications for Future Research Instrumentation

Data results also hold implications for instrumentation used in future research. For example, the CHLCS was designed to measure health LOC in healthy children; an instrument measuring health LOC specific to patients with chronic illness may diminish problems such as those encountered with items on the CHLCS. Such an instrument could still focus on the narrow construct of health LOC, but would not present the ambiguities of
the current CHLCS. Researchers may wish to employ instrumentation to examine differences between global and situational hope.

The results of the CHS supported the predictive value of the instrument’s measurement of hope, as contended by its authors (Snyder et al, 1997). Of importance was the CHS data’s correlational relationship with ABS and CHLCS data. Researchers may consider the predictive value of hope in regard to treatment goals for art therapy, as well as medical treatment goals. The instrument might also be used in the study selection process, to identify patients requiring additional nurturance and education to advance their hopeful thinking.

Conclusion

The data collected during the course of this research study support the rejection of the null hypotheses. The quantitative data demonstrated that the externality of LOC could be decreased through participation in an art therapy protocol. The qualitative data also confirmed that the art therapy protocol resulted in the reduction of anxiety behaviors; furthermore, it was verified that the reduction in anxiety behaviors resulting from art therapy intervention was sustained over time. The qualitative data supported the rejection of the null hypotheses. Evidence of the therapeutic nature of the art making was substantiated through careful observations of the art therapy sessions. Specific instances were identified in which the art therapy (a) educated subjects about sickle cell disease, (b) introduced patients to elements of the hospital environment, (c) engaged patients in normalizing activity, (d) addressed cognitive perceptions of medical treatment, (e) provided one-on-one support from a trained, perceptive adult, (f) provided occasions for patients to generate personal choices, (g) offered opportunities for verbal and symbolic communication, and (h) encouraged patients’ active interaction with the hospital environs. The art therapy experiences were open-ended and provided opportunities to explore, express, and process emotional responses to hospitalization, SCD treatment, isolation, loss of control, and other distressing events.

The execution of art therapy research designs with quantitative, as well as qualitative data collection, may prove vital in cultivating the recognition of the field within
the constructs of psychological and medical paradigms. Research based programming may also promote the value of multimodal communication, symbol systems, creativity, and cognitive restructuring as integral to mental health services. Finally, evidence of the benefits of art therapy may lead to expanded opportunities for individuals to receive art therapy treatment whether undergoing medical regimes in hospitals or experiencing other psychologically challenging life events.
Although the authors did not address hospitalization as a specific possible stressor, feelings of “being different,” including being physically different, were addressed.
APPENDIX A

ARTS IN MEDICINE PROGRAMS
Table A.1. Hospitals with arts in medicine programming.

<table>
<thead>
<tr>
<th>Institution/Hospital</th>
<th>Location</th>
<th>Art Therapy Provided</th>
<th>Art in the Environment Only</th>
<th>Artists in Residence or Volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stanford Medical Center</td>
<td>Los Angeles, CA</td>
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<tr>
<td>Scripps Hospital</td>
<td>San Diego, CA</td>
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<tr>
<td>UCSF Comprehensive Cancer Center</td>
<td>San Francisco, CA</td>
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<tr>
<td>University of California Davis Medical Center</td>
<td>Sacramento, CA</td>
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<tr>
<td>Lee Memorial Health System</td>
<td>Ft. Meyers, FL</td>
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<tr>
<td>Shands Teaching Hospital</td>
<td>Gainesville, FL</td>
<td></td>
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</tr>
<tr>
<td>Northeast State Hospital &amp; St. Catherine’s Hospital</td>
<td>Jacksonville, FL</td>
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<tr>
<td>Wolfson Children’s Hospital (contracted through Art with a Hearth for Children)</td>
<td>Jacksonville Beach, FL</td>
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<tr>
<td>Florida Hospital</td>
<td>Orlando, FL</td>
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<tr>
<td>Orlando Regional Medical Center</td>
<td>Orlando, FL</td>
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<tr>
<td>University of Miami</td>
<td>Miami, FL</td>
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<tr>
<td>Bay Pines VA Medical Center</td>
<td>St. Petersburg, FL</td>
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</tr>
<tr>
<td>Jackson Children’s Hospital</td>
<td>Miami, Florida</td>
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<tr>
<td>Tallahassee Memorial Hospital</td>
<td>Tallahassee, FL</td>
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<tr>
<td>H. Lee Moffitt Cancer Center &amp; Research Institute</td>
<td>Tampa, FL</td>
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<tr>
<td>Intracoastal Health Foundation/St. Mary’s Medical Center</td>
<td>West Palm Beach, FL</td>
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<tr>
<td>Mass General Hospital</td>
<td>Boston, MA</td>
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<tr>
<td>Rush Children’s Hospital (through Snow City Arts Foundation)</td>
<td>Chicago, IL</td>
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<tr>
<td>University of Iowa’s Hospital and Clinics</td>
<td>Iowa City, Iowa</td>
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<tr>
<td>Duke University Health System</td>
<td>Durham, NC</td>
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<tr>
<td>Brenner Children’s Hospital (through Arts for Life)</td>
<td>Winston-Salem, NC</td>
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<tr>
<td>Forsythe Medical Center</td>
<td>Winston-Salem, NC</td>
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<tr>
<td>North Carolina Baptist Hospitals</td>
<td>Winston-Salem, NC</td>
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<tr>
<td>Sunnyview Rehabilitation Hospital</td>
<td>Schenectady, NY</td>
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<tr>
<td>The Cleveland Clinic</td>
<td>Cleveland, OH</td>
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<tr>
<td>St. Charles Medical Center</td>
<td>Bend, OR</td>
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<tr>
<td>Eva Memorial Hospital</td>
<td>Chattanooga, TN</td>
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<tr>
<td>Vanderbilt Medical Center</td>
<td>Nashville, TN</td>
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<td></td>
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</tr>
<tr>
<td>University of Virginia Health System</td>
<td>Charlottesville, VA</td>
<td></td>
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</tr>
<tr>
<td>Medical College of Virginia</td>
<td>Richmond, VA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The Lombardi Cancer Center</td>
<td>Washington, DC</td>
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<td></td>
</tr>
</tbody>
</table>
APPENDIX B

PEDIATRIC MEDICAL ART THERAPY ARTICLES
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Article Title</th>
<th>Client/ Population</th>
<th>Successful Art Experiences</th>
<th>Ineffectual Art Experiences</th>
<th>Overriding Function(s) of Art Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crowl, M.</td>
<td><em>Case study: The Basic Process of Art Therapy as demonstrated by efforts to allay a child’s fear of surgery</em></td>
<td>A 9 year-old male pediatric patient in an inpatient psychiatric center hospitalized for hernia surgery</td>
<td>After the client spontaneously drew himself and included his “hernia,” the art therapist prompted him to graphically represent what was “going to happen to the hernia” (p. 49). Following the child’s response to that directive, the art therapist asked the child “Now, where is the hernia?” The child created a graphic response, and then spontaneously drew a picture of himself after the operation.</td>
<td>No examples provided</td>
<td>Expression and mastery of inner emotions</td>
</tr>
<tr>
<td>Epping, J., and Wilmuth, M.</td>
<td><em>Art therapy in the rehabilitation of adolescents with spinal cord injuries</em></td>
<td>A 13 year-old female pediatric patient in a rehabilitation unit of a large hospital, admitted with quadriplegia</td>
<td>The only directive noted was request for the patient to draw (with an adaptive device) a self portrait. The therapist also encouraged the patient to draw herself with a full body as opposed to a stick figure.</td>
<td>No examples provided</td>
<td>Feelings expressed and projected in drawings, allowing the processing of unconscious material</td>
</tr>
<tr>
<td>Geraghty, B.</td>
<td><em>Art therapy with a Native Alaskan girl on a pediatric ward</em></td>
<td>A 10 year-old female pediatric patient in a hospital in Alaska</td>
<td>Prompting of neutral pictures or pictures with positive meaning, followed by support for graphic expression of more difficult or negative associations.</td>
<td>No examples provided</td>
<td>Expression and communication of emotions through graphic representation and projection</td>
</tr>
<tr>
<td>Prager, A.</td>
<td><em>The art therapist’s role in working with hospitalized children</em></td>
<td>Four case studies: (1) a 5 year-old male patient with a kidney tumor which had spread to his lungs, (2) an 8 year-old male patient with an acute case of coup, (3) an 11 year-old male with multiple impairments, and (4) a 15 year-old female patient with gas gangrene</td>
<td>No directives were given to the patients. However different types of art media, or choices of art media, were available at different sessions.</td>
<td>Ineffective art experiences were provided</td>
<td>Availability of expressive outlet through art media</td>
</tr>
<tr>
<td>Author</td>
<td>Title</td>
<td>Type</td>
<td>Description</td>
<td>Examples</td>
<td>Summary</td>
</tr>
<tr>
<td>--------</td>
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<td>---------</td>
</tr>
<tr>
<td>Russell, J.</td>
<td><em>Art therapy on a hospital burn unit: A step towards healing and recovery</em></td>
<td>Two case studies</td>
<td>Two case studies on hospitalized pediatric burn patients: (1) an 8 year-old female, and (2) a 4 1/2 year-old female.</td>
<td>The children were not given directives; however, they were provided with different types of art media, or choices of art media. Additionally, the art therapist recommended specific media based on the patient’s previous enjoyment of that media.</td>
<td>No examples provided</td>
</tr>
<tr>
<td>Viscardi, N.</td>
<td><em>Art Therapy as a Support Group for Adolescents with Muscular Dystrophy</em></td>
<td>Not a case study</td>
<td>Not a case study. General discussion of an art therapy group for adolescents with MS in a state-supported educational facility.</td>
<td>The group participants choose the materials they wanted to use and made decisions as a group about how they would proceed. One activity described was a clay family sculpture.</td>
<td>No examples provided</td>
</tr>
</tbody>
</table>
APPENDIX C

CLINICAL MANIFESTATIONS
OF SICKLE CELL DISEASE (SCD)
Table A.3. Clinical Manifestations of Sickle Cell Disease (SCD)

| **Anemia** | Since sickled cells only last between 10-20 days in the bloodstream, the bone marrow cannot replace the cells fast enough. This results in the blood being chronically short of red blood cells, causing fatigue, paleness, and shortness of breath. |
| **Hand-Foot Syndrome** | Occurring more commonly in adults than children, blocked small blood vessels in the extremities causes pain, swelling, and fever. |
| **Pain** | Pain may occur in any joint or organ, wherever and whenever sickled cells block oxygen flow. |
| **Stroke, Paralysis, or Death** | When sickle cell clots occur in the brain, they may lead to stroke, paralysis or even death if oxygen flow is not restored to the brain tissue. |
| **Eye Complications and Blindness** | The retina of the eye is the thin film responsible for receiving and processing visual information. Tiny sensors in the retina convert light into electrical information for the brain. When the retina does not get enough oxygen due to blockage, it can deteriorate and may cause blindness. |
| **Jaundice** | The rapid breakdown of red blood cells can result in a yellowing of the skin and eyes. |
| **Delayed Growth** | The shortage of red blood cells to the long bones, spinal column, and hips may cause delayed or halted growth in children and a slight build in adults. Structural damage to the hips may require a prosthesis. Damage to the spinal column may cause compression and severe pain. |
| **Delayed Puberty** | The shortage of red blood cells may cause delayed sexual maturity or underdeveloped sexual organs. |
| **Ulcers** | A sickle cell clot in the skin can cause ulceration of the skin. |
| **Infections** | Sickled blood cells can cause damage to the spleen. Since the spleen destroys bacteria in the blood, children and adults are with SCD are vulnerable to infections and have great difficulty fighting off infections once they are established. This is the number one killer of babies with SCD: fatal infections have developed in infants as young as 3 months old. For this reason, young children (between 3 months and 5 years of age) frequently receive oral penicillin to protect against infection. |
| **Enlarged Spleen** | In children, the spleen may become enlarged, trapping blood inside and resulting in shock or death. |
| **Acute Chest Syndrome** | Similar to pneumonia, this life-threatening complication results from infection or trapped sickle cells within the lungs. |
APPENDIX D

PATIENT HISTORY FORM
# Patient History

## Personal Information

<table>
<thead>
<tr>
<th>Patient’s ID Number:</th>
<th>Age:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highest grade of school completed:</td>
<td>Date of Birth:</td>
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</table>

## Medical Information

<table>
<thead>
<tr>
<th>Age at diagnosis with Sickle Cell Disease:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Symptoms of Sickle Cell Disease:</td>
</tr>
<tr>
<td></td>
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<td></td>
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<tr>
<td>Has the patient been hospitalized before? If so, please list approximate dates and symptoms:</td>
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</tbody>
</table>

## Family Data

<table>
<thead>
<tr>
<th>With whom does the patient live? (please include siblings and other relatives):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do other members of the family or household have sickle cell disease?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Est. Annual Household Income (please check one):</td>
</tr>
<tr>
<td>☐ Less than $15,000</td>
</tr>
<tr>
<td>☐ $30,000 to $40,000</td>
</tr>
</tbody>
</table>

---

**Figure A.1.** Patient History Form
APPENDIX E

THE ANXIETY BEHAVIOR SCHEDULE
Anxiety Behavior Schedule

Patient ID #: ___________________________ Recorder’s Name: ___________________________

Behaviors to be observed:

A. Fidgeting or Restlessness. This may include squirming, finger picking, rocking, foot
shaking or shuffling, and shaking or tremor in hands.

B. Avoidance behaviors. This may include evasive/protective maneuvers, lack of eye
contact, clinging to family or guardian, and vocalizations
of distress (“I want to go home”).

Date: ___________________________
Observation Duration: ________________

<table>
<thead>
<tr>
<th>Interval</th>
<th>Observation Time Period</th>
<th>Behavior</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Total</th>
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Figure A.2. Anxiety Behavior Schedule (ABS)
APPENDIX F

THE CHILDREN’S HOPE SCALE (CHS)
The Children’s Hope Scale
(or “Questions About Your Goals”)

Directions: The six sentences below, describe how children think about themselves and how they do things in general. Read each sentence carefully. For each sentence, please think about how you are in most situations. Place a check inside the circle that describes you the best. For example, place a check (√) in the circle (◯) above “none of the time,” if this describes you. Or, if you are this way “All of the time,” check this circle. Please answer every question by putting a check in one of the circles. There are no right or wrong answers.

1. I think I am doing pretty well.

   - None of the time
   - A little of the time
   - Some of the time
   - A lot of the time
   - Most of the time
   - All of the time

2. I can think of many ways to get the things in life that are most important to me.

   - None of the time
   - A little of the time
   - Some of the time
   - A lot of the time
   - Most of the time
   - All of the time

3. I am doing just as well as other kids my age.

   - None of the time
   - A little of the time
   - Some of the time
   - A lot of the time
   - Most of the time
   - All of the time

4. When I have a problem, I can come up with lots of ways to solve it.

   - None of the time
   - A little of the time
   - Some of the time
   - A lot of the time
   - Most of the time
   - All of the time

5. I think the things I have done in the past will help me in the future.

   - None of the time
   - A little of the time
   - Some of the time
   - A lot of the time
   - Most of the time
   - All of the time

6. Even when others want to quit, I know that I can find ways to solve the problem.

   - None of the time
   - A little of the time
   - Some of the time
   - A lot of the time
   - Most of the time
   - All of the time

Notes: When administered to children, this scales is not labeled “The Children’s Hope Scale,” but is called “Questions About Your Goals.” The total Children’s Hope Scale score is achieved by adding responses to the six items, with “None of the time” =1; “A little of the time” =2; “Some of the time” =3; “A lot of the time” =4; “Most of the time” =5; and “All of the time” =6. The three odd-numbered items tap agency, and the three even-numbered items make up pathways.

Figure A.3. The Children’s Hope Scale (CHS)
APPENDIX G

THE CHILDREN’S HEALTH LOCUS OF CONTRL SCALE (CHLCS)
<table>
<thead>
<tr>
<th>The Children’s Health Locus of Control Scale (CHLC)</th>
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<tr>
<td>1. Good health comes from being lucky.</td>
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<td>2. I can do things to keep from getting sick.</td>
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<td>3. Bad luck makes people get sick.</td>
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<td>4. I can only do what the doctor tells me to do.</td>
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<td>5. If I get sick, it is because getting sick just happens.</td>
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<td>6. People who never get sick are just plain lucky.</td>
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<td>7. My mother must tell me how to keep me from getting sick.</td>
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<td>8. Only a doctor or a nurse keeps me from getting sick.</td>
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<tr>
<td>9. When I am sick I can do things to get better.</td>
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<tr>
<td>10. If I get hurt it is because accidents just happen.</td>
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<tr>
<td>11. I can do many things to fight illness.</td>
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<tr>
<td>12. Only the dentist can take care of my teeth.</td>
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<tr>
<td>13. Other people must tell me how to stay healthy.</td>
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<td>14. I always go to the nurse right away if I get hurt at school.</td>
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<tr>
<td>15. The teacher must tell me how to keep me from having accidents at school.</td>
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<tr>
<td>16. I can make many choices about my health.</td>
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<tr>
<td>17. Other people must tell me what to do when I feel sick.</td>
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<tr>
<td>18. Whenever I feel sick I go to see the school nurse right away.</td>
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<tr>
<td>19. There are things I can do to have healthy teeth.</td>
</tr>
<tr>
<td>20. I can do many things to prevent accidents.</td>
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Figure A.4. The Children’s Health Locus of Control Scale (CHLCS)
APPENDIX H

THE ENVIRONMENTAL COLLAGE
Environmental Photo Collage

Materials:  
Polaroid instant camera  
Polaroid film  
Paper  
Glue sticks  
Magazines  
Hospital brochures  
Scissors  
Markers

Population:  Hospitalized pediatric patients

Number of Sessions:  One

Concept:  The Environmental Photo Collage is designed to allow pediatric patients to explore the hospital environment, identify emotions associated with hospitalization, redefine cognitive conceptualizations, and create a visual image of the environment.

Approaches/Skills

Production:  
1. Patient will learn basic principles of photographing with a Polaroid camera (distance, use of flash, etc.).
2. Patient will use the camera as a tool for recording the environment and the individuals in the hospital environment.
3. Patient will use scissors to cut photos and images and words from magazine and hospital brochures, and use glue to adhere images to paper surfaces.
4. Patient may use makers to complete the collages.

Objectives:  
1. Patient will explore the hospital environment, and will use the camera to photograph the hospital environment and individuals who will participate in his or her care.
2. Images or words from magazines, hospital literature or brochures, or journals will be cut out for use in the collage.
3. Patient will complete a collage using photographs, cut-outs, and markers.

Procedures:  
1. The art experience will be introduced to the patient
2. The Polaroid camera and basic photographic principles will be introduced. The camera may be demonstrated.
3. The child will be escorted to medically pre-approved destinations of his or her choice in the hospital. This may require adaptive measures (for example, the use of a wheelchair).
4. Photographs will be made of hospital personnel or and the hospital environment.
5. Images from magazines, journals, and hospital brochures will be selected by the patient.
6. The patient will assemble the images on the paper and adhere them with the glue stick.
7. The collages and the art process will be discussed/explored.
8. The child will store the completed artwork in a pre-designated portfolio, and will assist with the clean-up of the art materials.

**Expressive Outcome Possibilities:**

1. Patients may become more comfortable and comfortable with the treatment of their disease and the hospital environment.
2. Patient may develop rapport with the therapist and recognize the therapist’s role as liaison, information provider, and advocate.
3. Patient’s competency in responding to the stresses of illness and hospitalization may be improved.
4. The experience may validate the child’s inner experience
5. Patient may create symbols or abstractions in their visual imagery
6. The child may develop an understanding of the relationship between herself the hospital environment, and the treatment of SCD.
7. Patient will have opportunity to make choices and decisions which may increase perceptions of control.

**Vocabulary:** Photographs, Polaroid camera, collage, environment, flash, etc.
APPENDIX I

THE ELIMI-PAIN GAME
Elimi-Pain: A Therapeutic Art Game
for Children and Adolescents with SCD

Materials:  Elimi-pain game board and game pieces
            Markers

Population:  Pediatric patients hospitalized with SCD

Number of Sessions:  One

Concept:  The patient will utilize creative verbal and non-verbal expression to increase self-awareness about their illness and themselves. Patients will be introduced (or reintroduced) to appropriate information regarding the diagnosis, treatment, and health maintenance of SCD; they will engage in creative activities which reinforces both the medical information and their personal identities.

Approaches/Skills
Production: 1. Patients will visually represent their pain.
            2. Patients will respond to drawing tasks requested by the cards in the “Back to the Drawing Board” deck.

Objectives: 1. Patients will have an opportunity to engage a non-threatening outlet for the expression of pain as well as the stresses associated with SCD and hospitalization.
            2. Patients will have an opportunity to build a trusting and empathetic relationship with the therapist and healthcare providers.
            3. Patients will have an opportunity to build coping skills through the use of educational components of the game, distraction from the hospital environment, and a sense of control over their disease, their environment, and their emotional responses.
            4. Patients will have an opportunity to engage in a normalizing and enjoyable activity which provides a measure of control.
            5. Patients will learn about the disease that effects their bodies.
            6. Patients will learn information regarding health care maintenance of SCD.

Procedures:
The object of the game is to unlock the center box and “release the pains.” The first player to successfully open the lock wins the game. The “rules” are as follows:
            1. The game will be introduced to the patient(s).
            2. Players choose a game piece and decorate it.
            3. Players draw a picture describing their pain. The drawing may be abstract or realistic. Prompts may include questions such as: (a) What color is the pain? (b) Where is the pain? (c) If you could see the pain, what would
it look like?
4. Completed pictures are placed in the box at the center of the game board.
5. After players have placed pictures inside the box, it is closed and locked.
6. The first player rolls the dice and moves her game piece the corresponding number of spaces on the game board.
7. If a player lands on a pink square, she picks a card from the “Give a Shout-Out” deck and completes the task on the back.
8. If a player lands on a green square, she picks a “Back to the Drawing Board” deck and completes the task on the back.
9. If a player lands on a blue square with a key on it, she picks a key from the key bag. After choosing the key, she attempts to open the lock on the box at the center of the game board. If the lock opens, then the “pains are released” and that player wins the game. If the key does not successfully open the lock, it is the next player’s turn.
10. If a player lands on a “SCD Trivia” square, a trivia question regarding SCD is asked from the SCD Trivia deck. If the player correctly answers the question, she is rewarded by getting to pick a key from the key bag and an attempt to open the locked box.

Expressive Outcome Possibilities:
1. Patients may become more comfortable and comfortable with the treatment of their disease and the hospital environment.
2. Patients may develop rapport with the therapist and recognize the therapist’s role as an information provider and advocate.
3. Patient’s competency in responding to the stresses of illness and hospitalization may be improved.
4. The experience may validate the child’s inner experiences.
5. Patients may create symbols or abstractions in their visual imagery (representing pain, for example) which enhances non-verbal communication.
6. Patients may develop an understanding of the relationship between themselves and SCD.
7. Patients will have opportunity to make informed choices and decisions which may increase perceptions of control.
8. Patients may apply the information they have internalized regarding the maintenance of SCD to healthcare practices outside the hospital environment.

Vocabulary: game piece, game-board, pain, key bag, trivia, abstract

Related Readings/References:
APPENDIX J

THE “BEFORE-DURING-AND-AFTER” DRAWING SERIES
Before, During, and After Drawing Series

Materials: White drawing paper
           Colored pencils or markers

Population: Hospitalized pediatric patients

Number of Sessions: One

Concepts: The purpose of this activity is to allow the patient to: (1) explore emotions such as fear, pain, and body image, (2) express and neutralize perceptions about forthcoming medical procedures, (3) communicate misunderstandings regarding treatment outcomes, and (4) imagine positive outcomes of hospitalization.

Approaches/Skills
Production: The patient will draw three images in white drawing paper using colored pencils or markers.

Objective: The patient will complete three images

Procedures:
1. The child will be asked to create a drawing of him/herself prior to entering the hospital.
2. The child will be asked to create a drawing of him/herself during the hospital stay; this may include specific medical procedures.
3. The child will be asked to create a drawing of him/herself after medical treatment (or after leaving the hospital).
4. The art therapist and patient will discuss the drawings, and information or stories provided about the drawings will be written by the patient, or dictation will be taken by the art therapist.
5. The child will store the completed artwork in a pre-designated portfolio, and will assist with the clean-up of the art materials.

Expressive Outcome Possibilities:
1. The patient will explore perceptions about medical problems and procedures.
2. The patient may express misunderstandings or incomplete understandings of his or her illness, treatments, or expected hospital outcomes.
3. The art therapist can serve to provide accurate, age appropriate information regarding the patient’s illness, treatment, or expected hospital outcomes.
4. The patient can use imagination and creativity to explore possible outcomes of the hospital stay.
5. The patient’s inner experiences can be validated and reinforced.
6. Patient will have opportunity to make choices and decisions which may increase perceptions of control.
**Vocabulary:** before, during, after, surgery, etc.

**Related Readings/Resources:**
APPENDIX K

THE THERAPEUTIC NARRATIVE
The text of this appendix is comprised of qualitative narratives presented on each of the subjects. Each narrative will be followed by discussion of the data collected during observations of each subject as well as the results of the Children’s Hope Scale (CHS) and information derived from the Children’s Medical Locus of Control Scale (CHLCS). The pseudonym for the first subject is Letecia. The second patient is called Amber. The third and final patient, admitted to the hospital for acute symptoms of sickle cell disease, is referred to as Mandika.

Letecia

Narrative on Letecia

Letecia (pseudonym) was a 6 year-old girl enrolled in kindergarten at a local public school. She lived with her mother and five siblings. Her three sisters were 11, 9 and 7 years of age. Her younger brothers were 3 years-old and 5 months-old. Although some of Letecia’s siblings carried the genetic trait for sickle cell, none had the disease. The family income was $545 per month, or $6,540 per year.

Letecia was diagnosed with SCD at 2 weeks of age. Her mother reported that Letecia had suffered from a stroke as a baby as a result of the sickle shaped cells in her blood. The residual effect of the stroke was an irregular gait. Letecia was ambulatory despite the resulting changes in her gait, and did not require a leg brace.

Almost immediately upon the initiation of the data collection it became evident that developmentally appropriate attention had not been given to the first subject following her admission to the hospital. On the evening of Letecia’s admission, well after the hospital’s dinner time, Letecia had not touched her food. Her meal of poached fish, lima beans, and rice remained on her tray, covered and cold. Children in neighboring rooms had remnants of hamburgers, potatoes, and fruit on their trays. Clearly this was not a meal she had been helped to request from the menu, still tucked under the napkin on the tray. Thompson and Spacapan (1991) argued that providing individuals with options to make minor decisions (such as what they would like to eat) could enhance perceptions of control and lead to
positive outcomes. In this case, Letecia’s only choice was not to eat the food she had not been given an opportunity to select.

Letecia voiced her discontent, stating she was hungry. She asked the researcher, whose role was unknown to her at that time, if she would find her something to eat. The researcher spoke with personnel at the nurses’ station, and asked how she could get a simple sandwich or burger for the young patient. The researcher was given a voucher and instructed that she could get an appropriate child’s meal in the cafeteria on the hospital’s first floor. Returning with Letecia’s meal, the researcher found the young patient to be quite demanding. For example, Letecia demanded to have ketchup on her burger, and insisted that the researcher open the packet. She also wanted her milk opened, and the tray table, on wheels, positioned very specifically near the bed. The researcher stated that she would be happy to help, but Letecia needed to remember to use a more polite tone and manner in her requests. Letecia nodded and restated her requests using “please” and “thank you.” Before leaving, the researcher helped Letecia make menu choices for the following day’s meals while Letecia repeated several times that she wanted to see the researcher the following day. The researcher reasoned that Letecia’s demands were attempts to exercise some measure of control.

The intervention phase began with Letecia creating an Environmental Collage. The use of the instant camera was explained to Letecia, and her portrait was made to show her how the film developed. Although she had never used a Polaroid camera, she was eager to experiment with taking making her own instant images. She began by taking a photograph of her hospital roommate eating breakfast. She quickly moved out to the corridor, her medication pole in tow, where she encountered a person dressed in a large character outfit from a local chain restaurant. The character and the restaurant’s manager were visiting the pediatric unit to give small gifts to the young patients for the December holidays. After choosing gifts offered to her by the visitors, she asked to have her photograph taken with the restaurant mascot for her photo collage. At the nurses station, she photographed several members of the staff and asked to have her photograph taken with others. Letecia’s final photograph was of her with several nurses posing in front of the unit’s Christmas tree.

The collage was assembled in the pediatric unit’s activity room. The room, at the end of one of the unit’s two corridors, is painted on all four walls with a cheery outdoor
mural with a pond scene, a country fair, and a wooded landscape. Children’s toys lined the perimeter of the room, and a low activity table sat at one end of the narrow room. Letecia sat at the table where a large sheet of white drawing paper, markers, construction paper, scissors, and a glue stick were available for collage work. Letecia didn’t know where to begin, so the concept of a collage was explained in several ways. After looking through the materials, Letecia began gluing the photos to the large sheet of drawing paper. She began with a photograph of one of the nurses, and below glued the photo of herself that was taken during her lesson on how to use the Polaroid camera. Four more photographs were added from right to left, top to bottom. The first was of a teenage patient hospitalized on the unit. Next, a photo of another nurse was added, followed by the photograph of Letecia’s roommate, and then a nursing aid. Finally, Letecia glued the photograph of herself with the restaurant mascot to the right of the other photographs. Letecia used the markers to draw boxes around four of the photos and then added her version of her name (she repeated the first letter of her name multiple times, as she did not know the rest of the letters) to the image in several places.

Stating that she was satisfied with the collage, Letecia began to display behavioral indicators of anxiety that were not present as she had worked on the collage. She would not make eye contact, became restless, and used a whining tone of voice. She abruptly requested more drawing paper to draw a tree. Letecia was gently reminded of the time frame for the remainder of the session, before being given a fresh sheet of paper for free drawing. On the fresh sheet of paper, Letecia drew two organic shapes that she called trees. She was unhappy with the trees and became increasingly frustrated (see Figure A.5). Insisting on a second sheet of fresh paper, she drew several letters and more shapes to represent trees. Still discontent with her trees, she became tearful. She resisted redirection or assistance and became increasingly agitated as the time allotted for the session came to a close, yet she did not want to leave the activity room; she did not even want to stand. However, when she was again reassured and reminded that the art therapist would return in 2 hours to introduce another activity, she stopped crying. She quietly returned to her room with the art therapist and asked again when the therapist would return. Then she said she was very hungry and asked for something to eat.
Figure A.5. Letecia’s “Trees”

Two hours later, the activity room was once again the setting for an art therapy intervention, the Elimi-Pain Game (Bailey, 2002). As the game was being introduced to Letecia, a young boy entered the activity room with a teenaged hospital volunteer. Paul (pseudonym), who was 8 years old, was also a patient and explained that he was in the hospital because he had sickle cell disease. Letecia asked him to join us in playing the game. The game began with each of the players decorating a small wooden game piece shaped like a human figure. Letecia waited for the art therapist to begin decorating her piece before she worked on her own piece. This established a pattern of the art therapist drawing a feature on her piece, and Letecia drawing it on hers. This continued for the eyes, nose, mouth, hair, and clothes.

The next step was for each of the players to represent their pain on laminated body cards (Figure A.6). Letecia colored the torso and arms of her figure red; the upper legs were colored burnt-orange, and the lower legs and feet were colored brown. She said that she did not have specific areas of pain in her body, but that she felt “just not good” all over her body.
After the figures were placed in the box and the box secured with the small lock, the game began. The players understood that the object of the game was to find the key and unlock the box to release all the players’ pain. During the game, Letecia drew a card with the question, “What can you do to avoid getting sick from sickle cell disease?” A discussion followed in which the children talked about things that they could do to stay healthy, such as dressing warmly in cold weather and drinking plenty of fluids. In fact, Letecia had many questions about specific things she could do to keep from experiencing the symptoms of her disease; she asked Paul about his responses, and would then confirm with the art therapist that his answers were accurate. At one point during the game the art therapist landed on a space and had to draw from the deck of cards. The task was to draw something for each of the other players. Paul said he wanted the art therapist to draw ice cream for him. Obligingly, an ice cream cone was drawn and he happily accepted it. Letecia insisted on ice cream as well, and was explicit in the toppings to include, such as whip cream and a cherry, and no bananas. Presented with her drawing, she was adamant that she wanted the one Paul had. Paul was happy to trade with her, and the demand appeared to be based upon Letecia’s need to assert control rather than upon a preference for one drawing over another.
During the game, Letecia responded to other cards with congruent application of self-control. For example, she drew a card that read “Draw something that makes you angry.” After a long pause, she drew a straight line approximately an inch and a half long. She would not verbalize regarding the mark she had made, and ignored Paul’s requests that she tell him what it was that she drew. Letecia enjoyed her momentary control over Paul and refused to answer to his polite pleadings to for her to talk about her drawing; she held the paper away from him and smiled while shaking her head. Later, a discussion ensued when the art therapist drew a card which read, “Draw something you don’t like in the hospital.” Both children exclaimed “Shots!” The art therapist drew a syringe and needle. The children were laughing in agreement that this was something not to like in the hospital when Letecia quieted and abruptly stated, “I don’t hate needles,” with flat affect. Initially, Letecia’s change in tone and affect when she made this statement seemed unexpected. However, during her weekend of treatment, Letecia demonstrated a pattern of masking emotions and fears related to hospitalization; it was fitting that the direct discussion of needle aversion was her signal to revert back to her coping pattern.

After some time, Letecia landed on a space with a key icon, and picked from the pouch the key which fit the lock. As she opened the box, she and Paul burst in to applause at the release of the pain. It was interesting to contemplate, given Letecia’s age and need for control, what her emotional response might have been if she had not been the player to “win” the key that opened the box.

The art therapist walked the children back to their rooms upon completion of the game and the session. Letecia stated she felt dizzy and was visibly unstable on her feet. She required help to get into her bed. A nurse came into the room as the art therapist helped Letecia settle into bed. After telling the nurse that Letecia was feeling dizzy, the art therapist asked Letecia what she had had to eat that day. Letecia explained that she didn’t eat breakfast, nor did she like the lunch that was served, so she had only eaten potato chips. Recalling a question from the Elimi-Pain game, Letecia stated that Paul had told her that to stay healthy, she should eat nutritious foods. Nodding, she requested the art therapist find her something good to eat.

For the final art therapy session in the intervention phase of the research, Letecia created a Before, During, and After (Before admittance to the hospital, During her
weekend stay in the hospital, and After leaving the hospital) series of drawings (see Figure A.7). She rotated the paper as she progressed through the series. The schemata for her figure in each of the three drawings was nearly identical. The “Before” drawing was made with a black marker, the “During” drawing was made with a pink marker, and the “After” drawing was made with a red marker. The primary differences in the three figures can be seen in the details of the faces. Although both the “Before” and “During” drawings have strait lines representing the mouth in what appears to be a serious expression, the “During” figure is the only one of the three for which Letecia drew wide open circles for eyes; the resulting expression looks to the viewer like surprise or fear. Finally, the “After” figure is the only one of the three figures to have an upturned mouth, indicating a smile. Although Letecia finished her drawings well before the end of the hour allotted for the third and final session, she indicated that she was ready to return to her room. The session began at 6:00pm, and Letecia’s behavior indicated she was tired. She stated, however, that she was only done with her artwork if the art therapist would remember to stop in her room to say goodbye to her before leaving for the day. The art therapist assured her she would do so, and did.

![Figure A.7. Letecia’s “Before-During-and-After” Drawing.](image-url)
Amber

Narrative on Amber

Amber (pseudonym) arrived for her monthly transfusion on Saturday, and she shared a hospital room with Letecia. She was 9 years-old, in second grade, and lived at home with her mother and four siblings. Amber’s sisters were 6, 10, and 13 years of age. Her brother was 11 years-old. Amber’s mother identified their total family income as less than $15,000 annually.

Amber’s mother recalled that Amber was approximately 6 months-old when she was diagnosed with SCD. Amber had suffered from two strokes as a result of the sickle-shaped blood cells. She had been receiving monthly transfusions since she was 4.

On the morning that the interventions with Amber were to begin, the researcher entered her room at the time previously arranged. The researcher spoke quietly as Amber stirred from sleep. A nursing assistant entered the room, turned on some lights, and spoke to both girls to wake them. Amber opened her eyes and greeted the art therapist, who noticed her bedding was very wet, including around the port when the IV line entered her body through an incision. Amber whispered to the researcher that sometimes she had accidents at night, especially in the hospital when the IV pole constantly dripped fluids into her body and it was difficult to make it to the bathroom. Concerned that urine would be problematic near the opening around Amber’s port, the researcher quietly suggested to the staff member that she would be happy to help get Amber to the bathroom to wash and dress. The nursing assistant immediately approached Amber and reprimanded her for “wetting the bed.” She blurted “5 year-olds wet the bed, not 9 year-olds” before the researcher could redirect her. This exchange demonstrated the frustrations articulated by Jellinek and Herzog (1990) who were concerned with hospital staff’s lack of training and general information on the developmental and psychological care of young hospital patients.

As with Letecia, the first art therapy intervention with Amber was the Environmental Photo Collage. Amber asked the art therapist to show her how to use the Polaroid camera by taking a photograph of her in her hospital bed. Feeling ready to explore the unit with the camera, Amber decided to leave her hospital room to look for
subjects for her photographs. She stated that she wanted to find her favorite nurse to photograph. Moving up the hall to the nurses station, Amber stopped to photograph a paper snowflake decoration hanging from the ceiling. At the nurses station, she photographed four nurses and nurses aids individually, and then asked the nurses to gather for a photograph with her in front of the Christmas tree. Two of the nurses were called away briefly to help other patients, so Amber asked the art therapist to photograph her with the two that remained. She liked the photograph of the three of them, but decided she really wanted to wait for the other nurses to return so she could be in a photograph with all of them together. The nurses returned a few minutes later and Amber arranged everyone in front of the tree for the photograph, making sure that her medication pole was not blocking anyone.

Amber had seen Letecia’s finished photo collage the day before, so she was eager to go to the activity room to create her own collage. She immediately began arranging the photographs on her paper, and when she was pleased with the arrangement, she glued them in place. When she finished gluing, she wrote “This is my poster” at the bottom of the paper. Next, she used markers to fill in areas of her poster, including coloring around each of the photographs. When time for the first session was winding down, she asked for assistance in completing the pattern she had established on the borders of the photos. The art therapist obliged and Amber provided specific instructions on where to color with each of the two markers. Amber was very pleased with the completed collage and asked if she could bring it to the nurses station to show everyone. She also wanted to know exactly when the art therapist would work with her again, and advised the art therapist where to look for her when it was time, listing the nurses’ station, her room, and the bathroom in her room as places she might be found. She also stated that she could work on the next project right away. The art therapist told her what time the following session would be, and also told her that they would play a game called “Elimi-Pain.” Amber nodded in agreement and asked the art therapist if she would walk with her back to her room.

About an hour later, Amber approached the art therapist to let her know that she had invited her roommate, Letecia, to play the game with them during the next session, and she wanted to make sure this was alright. The arrangement of the girls as roommates had gone well initially; the girls sat on one another’s beds and shared snacks and small toys
they had brought from home. Although the television in the room played constantly, there were no activities planned.

By the time the art therapist found the girls for the second session, Amber was expressing frustration with her young roommate who, she stated, had been “bugging me for hours.” After several hours of the shared room arrangement, Amber, who was nearly 3 years older than Letecia, became overwhelmed with the task of sharing space with her young roommate. She admitted to the art therapist that she probably should not have asked Letecia to join her for her second art therapy session. She reasoned, however, that she would play the game with Letecia since the art therapist would be readily available, and she would have the art therapist to herself for the third session.

Once again, the game began with the players decorating their game pieces. Amber used the markers to create a dress for her piece and added curly black hair and facial features. She said that her game piece looked like her mother, and that her mother would look pretty in the dress she colored on the piece. Next, the body outline on the laminated card was introduced with the concept of illustrating one’s pain. Amber indicated that she felt no obvious physical discomfort at that time, but then quietly looked at her roommate and grinned before coloring the top of the figure’s head bright red.

Once again, players rolled the dice to move around the board, and answered questions and completed drawing tasks for the opportunity to draw a key to try to open the box and release all the players’ pain. Several questions were repeated from previous day. Again too, the questions and tasks on the cards prompted conversations among the players, particularly regarding proactive health care issues surrounding sickle cell disease. These questions were new to Amber, who articulated her knowledge about avoiding sickle cell crisis and learned additional practical information regarding the disease and its treatment; the cards also presented the opportunity for Letecia to review the information introduced to her the previous day.

Each time a player had an opportunity to pick a key out of the pouch and attempt to open the lock, Amber would clap with excitement. Finally, with just two keys left in the pouch, Amber earned a chance to choose a key. Her key fit the lock and she opened the lock on the box containing each player’s pain and discomfort. She sang “I released the pain” as the box opened. Letecia was not as pleased with Amber’s success, and she
articulated that she wanted to have been the one to find the key and release the pain. Amber, assuming the role of the older and more mature roommate, tried to ignore Letecia’s pouting and stated simply, “Maybe next time you will get the key.” After leaving the room however, she sought one-on-one reassurance from the art therapist. She asked the art therapist when they would work together next, and asserted that next time it would be just herself and the art therapist; she would not ask Letecia to participate.

Even if the two girls were the same age, living in the same room for the weekend without intervention and intermittent supervision would have been difficult. The girls did not feel particularly ill, and were completely ambulatory, as long as they moved their IV poles with them when they walked. They had access to a library of sorts, but the computers were not turned on. The library had an ample selection of books, but Letecia had not yet learned to read. The play room, beautifully decorated with hand-painted murals, was at the far end of one wing of the pediatric unit with toys that were generally for children younger than Letecia and Amber, and many were missing parts. Amber’s family visited once over the weekend. All of these factors added up to many hours of unstructured time for the girls who eagerly participated in the art interventions planned by the researcher.

The art therapy intervention planned for the third and final session with Amber was the Before, During, and After Drawing Series. Amber chose to use three separate sheets of paper for the series of drawings. In the first, she drew herself with her four siblings and her mother. The stick figures in the drawing were all grounded on the bottom of the page, and the relative heights of the family members was reasonably accurate. Although Amber employed a simple schema for the human body, gender was differentiated through hairstyle; the females in the series each had long hair swept to the right. The figure which Amber identified as herself in the “Before” drawing had arms which were significantly longer than those of the other figures. Amber drew herself first, on the left edge of the paper, and all four of her siblings separated her from her mother. She drew a door to her left, which she stated was the entrance to the hospital, and she stood closer to the door than to her nearest family member.

In the second drawing, Amber drew herself during her weekend stay at the hospital. Once again, she drew herself first, a stick figure on the left edge of the paper. To her right,
she created a detailed drawing of the intravenous (IV) medication pole which was attached to her body through a tube entering her chest just below her left shoulder. This element can be seen in the portion of Ambers drawing detailed in Figure A.8. Unlike the stick figures in the series of drawings, the IV pole was notable for meticulous attention to detail. It included legs and wheels, the computer medication monitor with buttons, the bag of intravenous fluids and the arms on which bags of medications were hung, the tube draped between the pole and Amber, and the site where the tube entered her body. To the right of the IV pole Amber drew three stick figure nurses, identified by their first initials.

Figure A.8. Detail from Amber’s “During” Drawing.

In the third and final drawing of the series, the “After” drawing, Amber once again used stick figures, this time to represent just herself and her mother (Figure A.9). The two figures are holding hands and carrying Amber’s belongings home in a bag. On her body, Amber drew the port where her medication had been delivered over the course of the weekend. This time, no tubes were attached, and she no longer had the IV pole. Unlike the two previous drawings, the relative size of the figures were not to scale; Amber drew
herself taller than her mother, and for the first time, she drew herself in the center of the paper.

Figure A.9. Detail from Amber’s “After” Drawing.

Amber recalled that the art therapist had stated that they would have three sessions together. As the third session came to a close, she verbalized her concern about not seeing the art therapist again. She was able to calm herself by reasoning through self-talk that her mother would arrive to take her home later that evening. However, she did ask, as Letecia had, that the art therapist stop in her room to say goodbye before leaving.

Amber’s Subsequent Hospitalization

The art therapist had an opportunity to follow-up with Amber on a subsequent hospitalization. Amber had been readmitted to the hospital for another scheduled transfusion. Amber saw the art therapist on the Friday night of her admission and asked if they would be able to make art together again on the following day. The art therapist responded that they would, indeed, make art together. Amber said she was glad because
she had to tell the art therapist something. Plans were made to work together the following morning, but Amber asked if the art therapist would let her get started by providing paper and markers for her to use that night.

The next morning, art therapist found Amber as arranged, and immediately Amber launched into a terribly distressing story. Amber explained that during one of her scheduled transfusion weekends, her younger cousin had been riding her bicycle at her home. He was hit by a car and died. Amber described how her mother had come to the hospital to tell her what had happened, and how she had cried in her hospital room. She described the funeral, the coffin, the individuals crying at the cemetery, and the newspaper report on the accident.

![Figure A.10. Amber’s drawing, “My Cousin’s Funeral.”](image)

Amber explained to the art therapist that she wanted to draw a picture of the funeral. Using the borrowed materials, she had already started by making a baseline of green grass. On the baseline, she added a large brown rectangle on the far left of the paper. It was the coffin, she explained. To the right of the coffin, she drew two amoebic figures identified vaguely as uncles or cousins, left a blank space to draw herself, and then continued drawing a car with the people who had arrived in the car, including her mother, her aunt, and the driver on the right edge of the paper, all drawn as stick figures. At that
point in the drawing she stopped, and asked if the art therapist could help her draw herself. She didn’t want to draw herself as a stick figure, she said, but she didn’t know how to draw a body. Notably, the graphic treatment of the other individuals attending the funeral as stick figures or amoebic shapes was not problematic for Amber; however, it was important that she portray herself accurately and with dimension. In addition to telling a story, through her artwork Amber sought to communicate her unique emotional needs to the single individual available to witness and support her psychological responses and needs. Certainly, Amber’s experience of the traumatic event and feelings of loss were exceptional within the circle of her family community. Not only was Amber isolated from her family at the time of the accident due to her hospitalization, but the bike her cousin was riding when he was hit by a car and sustained fatal injuries belonged to her.

Responding to Amber’s request for assistance in portraying herself, the art therapist used a separate piece of paper to modeled how ovals and “hotdog” shapes could be used in drawing the human form. Amber simultaneously drew the shapes on her paper to create her body shape. Then she created details such a ears, hair, and facial features. As she added a line of tears down each of her cheeks (see details in Figure A.11), she told the art therapist how sad it was to be at the funeral and to know the body of her cousin was in the box. She said that everyone at the funeral cried too. When Amber completed the image of herself, she sat quietly and looked at her finished drawing. After some time, she looked up at the art therapist and asked if she could keep the drawing. She then asked if she could draw with the art therapist later in the day too.

Figure A.11. Detail from Amber’s drawing, “My Cousin’s Funeral.”
Amber worked with the art therapist again that afternoon. Satisfied with the completed drawing of her cousin’s funeral, she stated that she would like to draw something different. Amber’s interest in developing her renderings of the human form prompted the art therapist to suggest they work together on drawing a person. Amber eagerly agreed and announced that she wanted to draw a picture of her mother to give to her when she was released from the hospital the following day. This time, the art therapist did not illustrate the modeled shapes that comprise the human body. Rather, the art therapist helped Amber practice the forms by moving her arms in front of her. Amber then repeated the arm movements using a pencil on paper. She “dressed” the figure using markers, and colored over the penciled shapes that made up the body. With minimal verbal prompting, she added elaborate details to create the face and hair. Without prompting, she added an appropriate hue to the skin of the figure’s face, arms, and hands, then used scissors to cut the paper from around the figure. Amber expressed amazement that she had created the image all by herself, and eagerly rushed to the nurses station to exhibit her artwork (Figure A.12).

Figure A.12. Amber’s portrait of her mother.
Mandika

Narrative on Mandika

Nearly 9 months after her initial participation in the study protocol, Mandika (pseudonym) was admitted for acute symptoms of SCD. Nine year-old Mandika was born in Nigeria and had moved with her family to the United States just before her sixth birthday. The fourth grader was the youngest child in her family. Both of her parents carried the sickle cell trait, and both of her siblings had SCD. However, her 13 year-old brother had never experienced severe symptoms of the disease, and her 17 year-old sister experienced some complications, but none as severe or frequent as Mandika had experienced.

Mandika’s father reported that although all three children were of short stature attributed to SCD, Mandika was the only one who had severe symptoms which necessitated repeated hospitalization. Although this August admission was her first during the year of the study, her father recalled that she had been admitted to the hospital multiple times annually since her diagnosis at 1 year of age. On this occasion, Mandika was suffering from terrible pain in her abdomen. Her physician had explained to the family that her bowels were not functioning properly in response to the acute SCD episode.

The interview with Mandika’s father to collect a patient history revealed three important distinctions from the patient histories of the first 2 subjects. The most important and obvious difference was that unlike the first 2 subjects, Mandika’s hospitalization was due to an acute SCD crises; Letecia and Amber were hospitalized for pre-scheduled prophylactic transfusions. Second, Mandika’s family unit included two parents who resided in the same home. Third, her family income was in the $20,000 to $30,000 range, while parents of both other subjects reported incomes of under $15,000.

The intervention phase for Mandika began on the afternoon of her second day in the hospital. The art therapist arrived in Mandika’s hospital room to obtain her consent for participation in the study and the art therapy interventions. The young patient’s father had stayed with her since her admission, and had slept in her room in the second hospital bed. Mandika’s brother had arrived earlier in the morning and had been entertaining his sister with short walks in the hospital corridor, video taped movies in the family’s native
language, books, and small toys. The art therapist noted that on their walks in the corridor, the pair stopped short of the nurses station, and didn’t travel far from the doorway to Mandika’s room. With the arrival of the art therapist, the brother and father turned their attention to the boy’s mathematics homework.

Mandika smiled shyly and nodded when the art therapist explained the creation of an Environmental Collage. Dressed in her blue hospital gown and bright yellow flip flops, she took several bites of Chinese food that her mother had delivered before waving goodbye to her father and brother to begin exploring the pediatric unit with a Polaroid camera in tow. She quietly voiced a request to visit the nurses station to photograph the nurses on duty. After taking several photographs of the nurses, Mandika headed back to her room to photograph her father, who was engaged in tutoring her brother. She continued on to the activity room, stopping twice to pose for photographs of herself next to the child friendly characters painted on the lower walls of the unit.

Settled in the activity room to assemble her collage, Mandika thoughtfully arranged her photographs on her paper. She removed them, maintaining the order she selected, then began gluing them one at a time to the large sheet of paper. After gluing six of the images, she stopped and asked the art therapist to take a picture of her working on the collage. Then she asked if she could photograph the art therapist. These images were added to the collage after Mandika extended her paper by gluing colored construction paper to each end of her artwork. As she worked, she became increasingly interactive with the art therapist; she made repeated eye contact, asked questions, and shared information about her school and friends; additionally, the volume of her voice increased. Mandika’s finished piece was a long rectangular poster that she voiced her pleasure in creating. Smiling, she asked if the therapist would push her IV pole so her hands were free to carry the artwork to her room to show her father. In her room, Mandika asked when she could work with the art therapist again.

Two hours later, Mandika was ready and waiting when the art therapist arrived for the second intervention. The art therapist had explained that they would play a game, and this information must have been shared with her brother, as he prompted her to ask if it was a game that he could play too. Minutes later, in the activity room, the three sat down to play the Elimi-Pain game.
The players began the Elimi-Pain game by decorating their wooden game pieces. Mandika chose a “female” piece and made large eyes with long eyelashes on the face of the figure. Realizing that the eyes were so large that she had limited room for additional facial features, she turned the piece over and simplified her design; she made dots for the eyes and nose and drew a wide, smiling mouth. For the figure’s skirt, she choose a bright pink marker. Next, the players portrayed their pain on laminated cards. Mandika choose the bright pink marker to color the stomach area of the figure outlined on the card. With a brown marker, she filled in the figure’s entire right arm. With the laminated cards representing players’ pain securely locked in the box, the game began.

On her first turn, Mandika drew a “Give a Shout Out” card that directed her to “Describe something that you are missing because you are in the hospital.” She responded quickly, stating, “My friends.” On another turn, Mandika drew a card that directed her to “Draw a picture of something you don’t like in the hospital.” She thought for a moment and then drew a simple stick figure with an IV pole. She pointed to the pole and said, “That’s what I don’t like in the hospital.” When the art therapist drew card that directed her to “Ask the patient a question,” she asked Mandika if there was anything good about the hospital. Her brother blurted out “room service!” and they both laughed. When they had finished giggling, the art therapist redirected Mandika to think of something on her own that was positive about the hospital. Mandika responded, “room service, playing games, and feeling better!” After each player had had several turns, Mandika landed on a space with a key icon; she picked the key which opened the locked box and released the pain. The players cheered as the box was opened.

Mandika and her brother waned to play the game again. There was sufficient time left in the session, so the art therapist agreed. On her first turn, the art therapist drew a SCD Trivia card that asked the players what could been done to avoid a sickle cell pain crisis. Mandika wasn’t sure which of the answer choices was correct, but her brother helped her decide that the correct answers were “eat healthy foods” and “dress warm in cold weather.” The players also discussed the importance of drinking plenty of water. Another card drawn during the game asked the players which of four possible responses was not a warning sign for a sickle cell problem. Mandika correctly ruled out “a toothache” as a warning sign for sickle cell crisis. After each player had rolled the dice
several times, Mandika’s brother landed on a “Back to the Drawing Board” space and drew a card that directed him to pick a key. This time, he picked the key that successfully opened the box and released the pain.

Following the Elimi-Pain game session, the art therapist walked the children back to their room. Immediately thereafter, the data collector conducted the second observation of the intervention phase. The data collector then met the art therapist in the waiting room and explained that during the time she had been observing, Mandika’s mother explained to the young patient that she was going to ask the physician to release her that night, rather than waiting until the following afternoon as the had doctor resolved was necessary. This information was confirmed by a nurse, who added that she expected the doctor to arrive in approximately 1 hour; however, the nurse was not certain if the doctor would agree to release the patient early.

When the doctor arrived, the subject’s mother conversed with him while the art therapist waited to learn if the patient would be released before the completion of the study protocol. When the doctor left, the nurse confirmed that he had agreed to release the patient but did insist that Mandika receive one more pain treatment. The pain medication would take approximately 40 minutes to administer through Mandika’s IV. Quick calculation revealed that Mandika would be released before the third intervention phase observation, so the art therapist instructed the data collector to conduct the observation 30 minutes earlier than scheduled. The subject’s early release meant that the research design would not be completed; the intervention phase would not include the final art therapy session nor two of the five Phase B observations.

Summary

The information obtained through both qualitative and quantitative techniques was valuable in discerning the efficacy of art therapy in the reduction of anxiety behaviors of hospitalized children. The study uncovered logical outcomes as well as unexpected patterns of behavior specific to the categories of the study participants (routine versus crisis admission); furthermore, the art therapist’s observations before, during, and after the intervention phases of the study reinforced the finding that art therapy served as a
normalizing, age appropriate, non-verbal method of addressing psychosocial issues relevant to pediatric patients.

Interesting distinctions emerged between the subjects hospitalized for transfusions and the subject hospitalized in sickle cell crisis. First, as the data confirmed, the patients hospitalized for transfusions presented with fewer anxiety behaviors than the patient hospitalized for acute symptoms. This seems logical given the transfusion patients’ regular hospitalizations and their familiarity with the routine of treatment, as well as their acquaintance with the hospital staff.

The second distinction, however, was not anticipated. The art therapy sessions progressed differently for the transfusion patients than for the acute care patient. The subjects hospitalized for transfusions exhibited increased agitation during the individual interventions, while Mandika, hospitalized in sickle cell crisis, became more relaxed upon the initiation of the intervention phase. Mandika’s affect became calm and playful during art therapy sessions. Her eye contact increased, as did her verbal communication; she asked questions and responded to questions, and the volume of her voice grew to a more appropriate conversational level. Analogous to the subjects hospitalized for transfusions, however, at the end of the first session, she did solicit the exact time and place where the following session would take place, and then asked the art therapist to repeat this information when she returned to her room; this characteristic of interaction with the art therapist that was shared by all 3 subjects.

Conversely, the patients hospitalized for transfusions presented as composed and relaxed upon the initiation of the art therapy sessions; yet, as each individual session progressed, the girls became increasingly apprehensive and uneasy about the ending of the session. For Letecia, this response was most evident in the first session, which ended with tears. In the first half of the twentieth century, pervading policies within hospitals endorsed the separation of mothers and children during a child’s stay in the hospital. Hospital administrators reasoned that because staff reported children crying inconsolably after visits from their mothers, the presence of mothers was contraindicated for pediatric patients’ well-being (Spence, 1946). It was believed that if pediatric patients appeared more upset or anxious following the departure of their parents then when isolated from parents, it followed that parents were the cause of the distress and should not be permitted
to visit their children. This line of thinking was introduced in the literature review, and its untenable conclusions were widely refuted (Bergman and Freud, 1965; Geist, 1965; Petrillo and Sanger, 1972; Plank, 1962; and Vernon, Foley, Sipowicz and Schilman, 1965).

Lack of attention to the psychosocial concerns of well-defended hospitalized pediatric patients does not, in fact, translate to an absence of problematic psychological material. The researcher discovered patterns similar to those noted by opponents of parental visitation during and following art therapy interventions with the subjects in the study whose parents did not stay with their hospitalized children. Much like the dynamics of the child/mother relationships in the early part of the twentieth century, study subjects hospitalized with little or no access to their mothers demonstrated more emotional behaviors during and immediately following art therapy sessions than when there was no outlet for the expression or processing of psychological material. Similarly, although the subjects were able to summon defenses that belied their psychological distresses in the psychosocial isolation of the hospital environment, when their emotions were brought to the surface as a result of artistic and creative exploration, they had difficulty in containing them. It was at that time, as opposed to the periods before the intervention phase and between art therapy sessions, that the anxiety levels of the young patients were exposed. Just as the art therapy interventions provided opportunities for self expression and learning, the reinforced knowledge that they would again soon have access to the safe place established as a parameter of art therapy sessions, and perhaps the unconditional positive regard provided by the art therapist, seemed to provide the psychological fortification they required to return to the realities of hospitalization. In fact, by her third art therapy session, Letecia was able to re-contain her insecurities simply by being told the art therapist would stop in her room to see her before leaving for the day.

The qualitative data collected over the course of the subjects’ hospitalization revealed that a lack of overt anxiety behaviors did not translate to an absence of psychosocial needs. Without qualitative consideration, the patterns of transitioning to an environment psychosocial support would not have been exposed. The patients had inadequate occasions to process psychological material prior to the introduction of art therapy.
Evidence of the normalizing experience of art making was substantiated through the qualitative narratives of the art therapy sessions. The subjects were eager to create using the various art media, were familiar with the selected art materials, and did not require instruction on their use (with the exception of the Polaroid camera). The qualitative findings identified specific instances in which art therapy sessions served to: educate subjects about sickle cell disease; introduce patients to elements of the hospital environment; engage patients in normalizing activity; address cognitive perceptions of medical treatment; provide one-on-one support from a trained, perceptive adult; provide occasions for patients to generate personal choices; grant opportunities for verbal and symbolic communication; and encourage young patients’ active interaction with the hospital environs.

The art experiences were designed and chosen for their applicability and suitability across developmental levels, and the subjects fully participated in each of them. Importantly, the “art part” served multiple purposes. For example, for all 3 of the subjects, the instant camera served as a fun and non-threatening new tool with which to explore the hospital environment. Of course, the Environmental Collage, along with the Polaroid camera, was purposely selected for the powerful experiences made available to the patients. Letecia and Amber were hospitalized for scheduled monthly transfusions; they were already familiar with the nursing staff as well as the equipment and procedures which were elements of their treatment. Mandika, however, identified the nurses by the color of their hair or the playful patterns on their scrubs. Yet, for all of the subjects, perhaps the most poignant effect of using the camera was the control bestowed upon its operators. The patients were able to select, direct, and pose the subjects of their photographs. As most of the subjects of the photographs were nurses and nursing aides, this ironic role reversal allowed the young patients to “give orders” to the adults responsible for their care. This was coupled with the plethora of choices afforded the subjects in each of the art therapy interventions.

Art therapy’s normalizing and therapeutic influences were particularly significant given the environment in which the children spent their weekends. This was most clearly demonstrated by Amber, who processed anxiety and anguish encountered both inside and outside the hospital environment. With the art therapist, she initiated both verbal and
visual processing of psychologically demanding material in what seemed to be the only channel available to the children in the hospital. Observations revealed hospital worker’s fundamental lack of training and limited general knowledge regarding the developmental and psychological care of the young patients in their care. In the absence of a subject’s primary caregiver, there were no apparent individual(s) responsible for subjects’ nutritional concerns or choices, reactions to isolation, occupation of down time, or processing of hospital related emotions. Furthermore, the offensive and unprofessional remark regarding one subject’s wet bed demonstrated obvious omission of basic psychosocial instruction for pediatric support staff. Unlike the observed interactions between the subjects and hospital support staff, the art experiences were open-ended and provided opportunities to explore, express, and process emotional responses to hospitalization, SCD treatment, isolation, loss of control, and other distressing events.
APPENDIX L

APPROVAL MEMORANDUM FROM THE
FLORIDA STATE UNIVERSITY HUMAN SUBJECTS COMMITTEE
The forms that you submitted to this office in regard to the use of human subjects in the proposal referenced above have been reviewed by the Human Subjects Committee at its meeting on November 13, 2002. Your project was approved by the Committee.

The Human Subjects Committee has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval does not replace any departmental or other approvals which may be required.

If the project has not been completed by November 12, 2003, you must request renewed approval for continuation of the project.

You are advised that any change in protocol in this project must be approved by resubmission of the project to the Committee for approval. Also, the principal investigator must promptly report, in writing, any unexpected problems causing risks to research subjects or others.

By copy of this memorandum, the chairman of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department, and should review protocols of such investigations as often as needed to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Protection from Research Risks. The Assurance Number is IRB00000446.

APPLICATION NO: 32 572
Cr: M Rossal
APPENDIX M

PARENTAL INFORMED CONSENT FORM
Parental Informed Consent Form

As the parent/guardian of ________, I consent to my child’s participation in the research project “Art Therapy with Children Hospitalized with Sickle Cell Disease.”

This research is being conducted by Gaelynn P. Wolf Bordonaro, a doctoral student at the Florida State University. The purpose of the research is to study the effects of art therapy intervention on the anxiety experienced by children who are hospitalized with acuile symptoms of sickle cell disease (SCD). As a participant in the study, my child will participate in an artmaking experiences facilitated by the researcher.

I understand that I will be asked to provide information on my child’s medical history as it pertains to SCD. I authorize the hospital staff to provide information regarding my child’s history of SCD. My child will also respond to questions which address her reactions to hospitalization.

I understand that there are multiple benefits to allowing my child to participate in the study. First, she may experience less anxiety associated with being in the hospital and being treated for SCD. Second, she may increase her understanding about sickle cell disease. Third, my child’s participation in the study will provide valuable information about meeting the emotional needs of children in hospitals.

I understand that there is a possibility that talking about, making art about, and learning about SCD may carry a minimal risk that my child could experiencing anxiety. The researcher is a trained and experienced art therapist who will be available to process emotions with my child, should she experience any discomfort.

My child’s identity will be safeguarded. She will be given a pseudonym, and her real name will not be used. Additionally, photographs of her artwork may be taken, but no photographs will be taken of my child herself. Confidentiality will be maintained throughout the study to the extent allowed by law.

My child’s participation is totally voluntary and she may stop participation or withdraw consent at any time without prejudice or penalty. I have been given the right to ask questions about the study, and have the researcher respond to my inquiries. The results of the study will be available upon its completion through the Florida State University library.

I may contact the Florida State University Institutional Review Board at (850) 644-8533. The researcher is available if I have questions regarding the study. Her contact information is:

Gaelynn P. Wolf Bordonaro
Florida State University Art Therapy Program
123 Milton C. Shechter Hall
Tallahassee, Florida 32306
Email: gwpb@fsu.edu
Phone: (850) 644-4615

I have read and understand this consent form.

Signature of Parent/Guardian ___________________________ Date __________
APPENDIX N

CHILD ASSENT SCRIPT
Child Assent Script
For 8 to 10 year-old children hospitalized with Sickle Cell Disease

Good morning. My name is Gaelynn and I am an art therapist. I would like to make art with you today as part of a study I am doing. Your parents (or guardian/family) have said it is fine for us to make art together if you would like to (sic). It is also okay if you don’t want to.

As well as making art together, I would like to ask you some questions. It is okay if you are not sure about the answers. You can just try your best. If you don’t want to answer the questions or make art we can stop at anytime. No one will be upset and you won’t be in trouble.

Would you like to help me by answering some questions and making art?

*If the response is affirmative, the researcher will continue:* Great, we can start here in your room and work for about an hour. Then I will come back again at ________ and we will work together again. Are you ready to begin?

*If the response is negative, the researcher will thank the patient and excuse herself from the room.*


Bailey, J.K., (2002). *Art therapy and its effectiveness in increasing the understanding and expression of chronic pain in patients with sickle cell disease.* Unpublished manuscript, Florida State University, Tallahassee.


Gaelynn P. Wolf Bordonaro studied fine arts and specialized in photography at the University of Central Florida (UCF), earning her BA in 1989. She earned a Master’s Degree in 1997, and a Ph.D. in 2003, through the art therapy program at Florida State University (FSU). In 1999, she served as an Ambassdorial Scholar for Rotary International in Melbourne, Australia.

In addition to her medical art therapy work with hospitalized pediatric patients, the author has provided art therapy services through mobile immunization clinics in Melbourne, Australia. Her other areas of clinical specialization are the outcome of ongoing work with special populations in public school settings, where she has worked with children with mild to profound mental and developmental disabilities, Autism, emotional and attachment disorders, learning disabilities, and physical disabilities.

The author has served as a faculty member of the Expressive Therapies Program at the University of Louisville in Kentucky, a visiting lecturer in the art therapy program at La Trobe University in Australia, an adjunct faculty member at Tallahassee Community College in Florida, and has taught graduate courses in art therapy at Florida State University in Tallahassee. She has presented nationally and internationally on the use of art therapy with special populations, the role of photography in art therapy and special education settings, and geriatric art therapy.