Photographic Research Through a Child Life Lens

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Katelyn E. Schlosser
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This thesis titled

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by

KATELYN E. SCHLOSSER

has been approved for

the Department of Social and Public Health

and the College of Health Sciences and Professions by

Jenny Chabot

Associate Professor, Department of Social and Public Health

Randy Leite

Dean, College of Health Sciences and Professions
Abstract

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Director of Thesis: Jennifer Chabot

Hospitalization greatly impacts the daily lives and routines of children by altering their normal lifestyle and presenting the family system with new and significant stressors. Child life specialists and other medical professionals who work with hospitalized children can benefit from greater understanding of these children’s hospital experiences. By means of participatory photographs and related participant interviews, this study examined the experiences of children receiving hematology/oncology related services to gain a greater understanding of the impact of hospitalization on them.
Dedication

I dedicate this work to my family, friends, and faculty whose love and support helped me tremendously throughout this project. To the children and families I had the privilege of working with through this project, it has been an honor.
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Chapter 1: Introduction

Background Information

Hospitalization greatly impacts children’s daily lives and routines by altering their normal lifestyle and presenting their family system with new and significant stressors. Related to child development, the fears associated with unfamiliar settings and people, invasive medical procedures and treatments, loss of control, and children’s understanding of their illness directly affect the experience and behavior of hospitalized children (American Academy of Pediatrics, 1993; Gaynard et al., 1990; Wright, 1995). In addition, hospitalization directly impacts children’s cognitive, emotional, and physical development (Gaynard et al., 1990). Positive interactions with medical and nonmedical staff, procedural preparation, education, and the use of patient and family centered care and the presence of caregivers and peers can positively influence each patient’s unique hospital experience and help to guard against negative effects of hospitalization (Bell, Johnson, Desai, & McLeod, 2009; McCue, 2009; Thompson & Snow, 2009).

“Child life specialists facilitate coping and the adjustment of children and families by providing play experiences, presenting information about events and procedures, and establishing supportive relationships with children and parents to encourage family involvement in each child’s medical care” (American Academy of Pediatrics, 1993, p. 671). Child life specialists work with children and families in hospital and other healthcare settings to “promote effective coping through play, preparation, education, and self-expression activities” (Child Life Council, n.d., para. 2). Through coping, distraction, medical play, and other developmentally appropriate activities and expressive means,
child life specialists help children and their families better manage the stressors and effects of hospitalization (American Academy of Pediatrics, 1993; Child Life Council, n.d., para. 2; Goldberger, Mohl, & Thompson, 2009).

With an extensive background founded in child development, child life specialists strive to understand the psychosocial needs of children and, using play as a framework, interact with each child on their unique developmental level (American Academy of Pediatrics, 1993; Jessee & Gaynard, 2009). “Child life specialists psychologically prepare patients for health care procedures, provide emotional support, facilitate therapeutic play, and use knowledge of child and family development to enhance the children’s experience in health care settings” (Cole, Deiner, Wright, & Gaynard, 2011, p. 2). To aid in assessing how children cope with a medical condition, hospitalization, or new diagnosis, child life specialists use techniques such as observations of nonverbal communication, expressive arts, and medical play. These techniques offer children control in settings where, very often, their control has been taken away. In addition, expressive arts and medical play encourage mastery and the expression of children’s emotions, thoughts and perceptions about their current situation (American Academy of Pediatrics, 1993).

In a similar way, photography provides the opportunity for expression. It offers the photographer the chance to gain a sense of control over and mastery of the camera and empowers them to make choices (Fereday, MacDougall, Spizzo, Darbyshire, & Schiller, 2009). When used in research, participatory photography, photoelicitation, and other methods of photographic data collection help to provide insight into the minds of the participants from a first-person perspective. “Photoelicitation, or inserting a
photograph into a research interview, unlocks subjectivity, perspective, and emotion, surfaces information which might otherwise remain ‘invisible,’ hidden, or submerged, and encourages participants to see their communities, experience, and daily lives with fresh eyes” (Lorenz, 2011, p. 260). Literature also suggests that using photography offers a nonverbal outlet through which the participant can conceptualize their thoughts, feelings, and experiences into something real (Dyches, Cichella, Olsen, & Mandeleco, 2004). Of the current literature in nursing, children’s health care, and psychology that focuses on using photoelicitation to explore the perspectives of children, the most commonly explored topics include perspectives of children with developmental disabilities (Dyches et al., 2004), well children’s home life experiences (Jorgenson & Sullivan, 2010), and children with chronic and terminal illnesses (Fereday et al., 2009; Savedra et al., 1988). Yet, little research using participatory photography as a tool for better understanding the perspectives of hospitalized children has been conducted from a child life perspective.

Using participatory photography as a research tool, the goals of this study were to understand how hospitalized children, specifically those receiving hematology/oncology related services, experience hospitalization and to gain a greater insight into their perspectives. By means of participatory photographs and related participant interviews, this study enhances the current understanding of what children impacted by hospitalization find important. Through data collection and analysis, this study aimed to answer the following questions: What experiences, people, and things are important to hospitalized children? What meaning do hospitalized children give to the imagery they
create while in the hospital? What aspects of hospitalization prove significant to hospitalized children? Does hospitalization play a significant role in their photographs?

Do the children express an impact of hospitalization on their lives, relationships, or themselves? By pursuing the answers to these questions, this study provided a first person perspective into the life of the hospitalized child in the hopes of better meeting their emotional, physical, and cognitive needs while in the hospital setting.
Chapter 2: Review of Literature

Child Development and the Impact of Hospitalization and Chronic/Terminal Illness

Developmental theories and frameworks have helped us understand the way people work, where they come from, where they might be going, and how they got there. “Theories are our way of making sense of the world around us; theories guide us in our interactions with others, help us to analyze our observations and experiences and offer us solutions” (Turner, 2009, p. 23). In his theory of development, Erik Erikson viewed development as a constantly evolving continuum of stages, shaping individuals through interactions with the world around them (Turner, 2009). Based on a set of stages and developmental tasks, Erikson’s *Psychosocial Theory of Development* identifies the connection between a person’s emotional needs and the demands of their social environment and how that connection helps a person search for an identity and a role in life (Turner, 2009; Woolfolk, 2009). When working with infants, for example, it is important to detail their psychosocial need for trusting relationships with their caregivers. When that infant is hospitalized, the constant shifting of caregivers and potential for the absence of a main caregiver may lead that child to develop a sense of mistrust. Toddlers seek autonomy from their caregivers, trying to accomplish new tasks. Hospitalization can reduce that toddler’s freedom to master tasks on their own, creating the potential for that child to doubt their capabilities. As development continues, children’s cognitive processes begin to use magical thinking, make-believe play, and symbolic themes (Jessee & Gaynard, 2009). As hospitalized children in this stage of development begin to translate hospital experiences into symbols through their play, their magical thinking may
lead to misconceptions, resulting in fear and misunderstanding (Jessee & Gaynard, 2009; Turner, 2009). Therefore, explaining medical procedures to hospitalized children at this stage of development is especially important.

Adolescence is a particularly crucial time in children’s development as they begin to develop a sense of who they are, how others perceive them, and how they perceive peer relationships. When hospitalized, the adolescent’s peer relationships may be strained because he or she is forced to stay in the hospital for extended periods, missing school, important social events like prom and football games, and other normative life events. Adolescents also begin future-oriented thinking and question what their purpose is and where they see themselves going. Adolescents draw upon their motivations, past experiences, strengths, and weaknesses as they begin to form a self-identity (Woolfolk, 2009). For adolescents diagnosed with a chronic or terminal illness, hospitalization “separates the teen from normal group activities, disrupts future plans, and increases insecurities about appearance and self-worth” (Pearson, 2005, p. 14). Fears about the future and the ambiguity of what that future may hold pose a great threat to adolescent identity, leaving potential for the development of identity confusion.

When adolescents with a chronic or terminal illness are hospitalized, their privacy and independence are often compromised. They may feel as though no one thinks about their needs for personal time and space. “During this developmental stage, adolescents are becoming independent, autonomous persons, and communication with adults may be inhibited” (Hanna & Jacobs, 1993, p. 155). Developmentally, they are seeking opportunities to explore being independent and autonomous, but hospital settings and...
medical conditions put restraints on their developmental needs. By offering adolescents opportunities to actively participate in treatment protocols while honoring their need for privacy and confidentiality, trusting patient-staff relationships can begin to take shape (Pearson, 2005). It is crucial to respect adolescents’ need for privacy and independence by offering them choices and personal space as they develop their sense of identity. To further facilitate communication, it is crucial to offer them indirect verbal and creative outlets through which to express their thoughts and feelings. Whether through journaling, drawing, or photography, participating in the creative art process allows children and adolescents to explore their thoughts, feelings, fears, and dreams (Rollins, 2005).

Going beyond the social-emotional connection identified in Erikson’s *psychosocial theory of development*, Vygotsky focused on the influence that cultural context and previous experiences have on children’s reactions to new experiences. “The cultural context is considered to influence what children learn and how they learn it” (Turner, 2009, p. 27). Based on Vygotskian theory, each child has a context unique to him or her and comprised of different socio-cultural elements including cultural background, interactions with others (teachers, parents, siblings, medical professionals, etc.), previous hospital experiences, and past experiences the child has had. Children’s “thinking is described as reflecting the integration of where they are cognitively with the demands of the given context (immediate or cultural)” (Turner, 2009, p. 27). Being cognizant of children’s cultural contexts promote feelings of security, support, and comfort, all of which are elements crucial to facilitating positive, trusting relationships.
between medical staff and the children and families they serve (Ahmann & Rollins, 2005).

Chronically and terminally ill children spend most of their time dealing with their condition. Whether in a hospital, school, or home setting, children’s adjustments to a chronic or terminal condition impacts their perception of developmental tasks, such as mastery, competency, autonomy, identity, body image, and peer relationships (Hicks & Davitt, 2009). In order to fully understand the perceptions chronically ill children have of themselves, we must look at what self-concept is and how it is impacted. “Self-concept plays an influential role in constructing an understanding of reality and one’s place in it and in shaping individuals’ emotions, motivations, decisions, and actions within that perceived reality” (Icard & Nurius, 1996, p. 30). In their study of the self-concepts of adolescents (ages 9-14) with acute and chronic diseases, Gültekin and Baran (2007) explored factors influencing children’s self-concepts, including hospitalization length, developmentally appropriate medical teaching strategies, and acute versus chronic conditions. According to their findings, children facing long treatments tended to have lower self-concepts than children with more acute treatment regimens. Similarly, children who were undergoing surgical procedures or treatments that altered their appearances, such as chemotherapy, showed greater negative self-concepts, and those self-concepts were even lower if the children were not educated about the procedure at a developmentally appropriate level. These findings regarding surgery, education, and self-concept were thought to be due to the immense threat to the body that surgery imposes on children, the altering of their physical self, and their increased anxiety caused
by the medical professional’s failure to educate children on medical procedures (Gültekin & Baran, 2007). Being able to recognize threats against ill children’s self-perceptions allow us to take action to prevent negatively impacting their self-concept.

Understanding the correlation between self-concept and chronic illness, we are able to deconstruct the inner workings of chronically ill adolescents’ self-perception. One very vulnerable aspect of adolescents’ self-concept is body image. During this stage in their development, adolescents face changes in their body fat, height, weight distribution, and hormones, all of which, when combined with a physical illness or condition, can cause immense challenges and threats to that child’s self-perception. Yet, there are intervention steps that can be taken to help promote positive self-concepts and decrease the negative impact of chronic illness on adolescents’ self-perception. In her research, Walker (2009) discusses psychoeducational programs to teach children about their condition, treatment, and the expectations of their illness. These programs focus on advocating for children to describing the fears, discomfort, and strangeness they may be feeling, the use of mind-body meditation techniques to help reduce stress within the children, and offering group therapy to promote social adjustment to their condition. These coping techniques can be and are currently used in hospital settings to aid in the adolescent’s construction of positive self-perceptions.

Békési’s (2011) found that creating an internal locus of control for children with chronic illness promotes a sense of independence and power over their condition. The conflict of feeling restricted by parents’ rules while still having to depend on them for emotional and physical support, challenges chronically ill children’s sense of autonomy,
and threatens to lower their self-esteem and self-perception (Békési et al., 2011). When working with hospitalized chronically-ill children, it is important to focus on understanding their quality of life perceptions and self-perceptions. By understanding these perceptions, hospital staff can develop better strategies for helping them face the obstacles and challenges of hospitalization and chronic or terminal illness while offering children developmentally appropriate autonomy. “Coping with the stress of having a chronic illness, understanding the disease itself, as well as dealing with its possible outcomes and long-term sequelae, and being involved in the tough course of decision making, reinforces the early maturation of these (diabetic) children and may be connected to enhanced level of autonomy” (Békési et al., 2011, p. 7).

The Foundation of Child Life Services

Understanding the positive correlation between frequent hospitalizations, medical procedures, and stressors caused by hospitalization and delayed psychosocial development, it is crucial for professionals working with chronically ill children to be well versed in child development. With a strong foundation in children’s development and knowledge of developmental and psychosocial theory, Child Life Services provide child and family centered care to children and families facing hospitalization, chronic and terminal illness, bereavement, and other stressful life events (Child Life Council, n.d.; Wojtasik & White, 2009, p. 3).

Understanding children’s universal language of play, Certified Child Life Specialists (CCLS) use play to help hospitalized children express themselves in developmentally appropriate ways, master challenging tasks and events, cope with
stressors of hospitalization and illness, and experience a sense of comfort during hospitalization (American Academy of Pediatrics, 1993; Jessee & Gaynard, 2009).

“When children are able to effectively cope with stressful transactions encountered in the hospital, they experience a sense of mastery or competence that can generalize to other potentially stressful situations” (Gaynard et al., 1990, p. 17).

CCLSs understand children’s development and its role in understanding the way children perceive their environment, how to fulfill their psychosocial needs, and where they are developmentally. Through play, children create symbolic representations to express their views, relationships with others, and feelings such as fear, hope, anxiety, and loneliness (Jessee & Gaynard, 2009). Observing and interacting with children at play, CCLSs use play as a tool to better understand the children’s images of their experiences and relationships. (Jessee & Gaynard, 2009). Incorporating tools and materials typically used with children while in the hospital into typical play activities, commonly referred to as medical play, can “allow (children) to approach a threatening situation with greater understanding and develop a sense of mastery over it” (American Academy of Pediatrics, 2009).

CCLSs recognize that each child is part of a large and expansive system of interactions and environments. Using the systems theories comprised of family systems and ecological theory, CCLSs focus on providing child and family centered care. Based on family systems theory, the family acts as a “socializing agent,” offering support, education, and comfort to a child (Turner, 2009, p. 31). Each member of the family contributes to the functionality of the family as a system. Due to the interaction and
connection among the system members, who is in the family system is unique to each family. This may include the more traditional definition of the nuclear family but also may include members such as grandparents, stepparents and siblings, aunts, uncles, and nonbiologically related members. Understanding key elements of family systems theory, CCLSs “recognize and understand that events, such as the diagnosis of illness or the traumatic injury of a child, impact the whole family,” therefore, “interventions focus not only on supporting the family’s ability to cope within the healthcare system, but (to) also transition smoothly back into life outside the protective walls of the healthcare environment” (Turner, 2009, p. 32). Family systems theory reinforces and solidifies the importance of promoting and advocating for child and family centered care within and beyond the hospital setting.

Not only does the child make up part of the family system, but he or she also plays a key role in the systems surrounding the family, as noted in Bronfenbrenner’s (1979) ecological theory. Ecological theory is based on the understanding that three systems, microsystem, mesosystem, and exosystem, layer on top of one another, surrounding and impacting the individual person at the center. For example, a hospitalized child forms the center of the system. The first system that surrounds the child is the microsystem, comprised of settings within which the child immediately develops (family, home, child care, school, hospital, etc.). Within the microsystem, the child has direct, one-to-one relationships with those making up the settings (child to parent, child to child care provider, child to doctor, etc.) (Turner, 2009).
The next layer, the mesosystem, is comprised of interactions and relationships between and among microsystems. These interactions indirectly impact the child (school to parent, parent to doctor/hospital, etc.) Finally, the exosystem is comprised of, “those systems separate from the individual but which have an effect on the microsystems containing the developing child, for example, the parent’s workplace, financial institution, or local pharmacy” (Turner, 2009, p. 33). Based on Bronfenbrenner’s ecological theory, CCLs work to better understand and identify the interrelationships among all the systems impacting a child and advocate for collaboration within, among, and between the systems in an effort to provide the best possible family and child centered care.

**Photography as a Means for Understanding the Child’s Perspectives**

Adolescents and children can use photography to explore their surroundings, interactions, and perspectives, permitting others to glimpse into their personal experiences, interactions, and interpretations. Hanna and Jacobs (1993) used photography as a means of data collection to explore how adolescents with cancer perceived the meaning of health. Understanding that, “during this developmental stage, adolescents are becoming independent, autonomous persons, and communication with adults may be inhibited” (1993, p. 155), Hanna and Jacobs (1993) explored if photographic data collections facilitated the adolescent participant’s responses to the researcher’s questions.

Consisting of adolescents diagnosed with cancer who were attending a weekend retreat, participants were asked to write their description of a time they experienced health. Next, given a polaroid camera, researchers asked participants “to take pictures of
situations of health” (1993, p. 159). After three weeks, interviews of the participants were conducted to understand how the images taken described health and how the camera did or did not help describe health.

In the data analysis, Hanna and Jacobs (1993) found that participants did not complete the written portion of the study to describe health but did use the camera to visually capture their perceptions of health. Participants indicated that using the camera was fun and that they “had given considerable thought to what health meant before they took pictures” (1993, p. 160). Showing that photography was a positive method to encourage communication with adolescents with cancer, these findings “may be used to facilitate adolescents’ and parents’ development of a better self-understanding and improvement of health behaviors” (1993, p. 162). During interviews, many themes among the descriptive expressions of the photographs emerged including growing and living (e.g., pictures of newly planted trees, big trees), being active and having abilities (e.g., sports equipment, people playing, schoolbooks), and having feelings and a future (e.g., pictures of significant others, future jobs.) In their discussion, Hanna and Jacobs (1993) found that using photography in research with adolescents with cancer facilitated communication and offered the participants an enjoyable experience. From these findings, health care professionals, parents, and peers gain an understanding of how adolescents diagnosed with cancer perceive health and how photography facilitates communication with adolescents. It has been said “that to care for an adolescent effectively during hospitalization, it is essential to understand how hospitalization is experienced” (Savedra & Highley, 1988, pp. 219-220).
Using symbolic interactionism to ground her doctoral research, Close (2005, 2007) explored the “lived experiences of children and adults with long-term conditions in context of their relationships with family carers and healthcare professionals” (Close, 2007, p. 29). Close gave child participants a disposable, single-use camera and asked them to take pictures of “whatever was important in their lives which they would then discuss at the next interview” (Close, 2007, p. 31). As the children described their photographs, four different types of photographs emerged: special events, ordinary places, people who were special to the child, and pictures of the child. Using this approach, Close was able to see how the children expressed their feelings and emotions regarding relationships, self-perception, and environment.

Close stated, “the communicative and structural characteristics of photography can be compared to those of verbal language” (2007, p. 33). In her research, Close approached the data as a “visual language,” using the “meanings (semantics), interpretation (pragmatics), and sense of order (syntax)” that comprise verbal speech and language (2007, p. 33). Through the participant interviews, Close found the children ordered their images in a narrative fashion and made interpretations about their world by assigning meaning to the images they captured. “The implicit and explicit set of interpretations involved in ordering the photographs led to deep and fruitful data about flexibility, reflexivity, self-image, and adapting to disability in the wider world” (2007, p. 34). Howard (2000) reinforced Close’s linking of language to the chronically ill child’s photographic interpretations of their life experiences.
According to Howard (2000), language links cognitive and interactive realms and plays a key role in the development of meanings through interaction with the outside world. “Analyses of media portrayals acknowledge how language works together with nonverbal expressions and interactional contexts as part of the interactive construction of identities” (Howard, 2000, p. 373). In other words, personal identity is negotiated, constructed, and communicated through language by means of interaction and media. Based on these findings, we can predict that in a hospital setting, photography can act as nonverbal communication for chronically ill children. By giving the children free reign over a camera, they are able to express their thoughts, interactions, and feelings through visual imagery expressing their views and perceptions.

The Theory of Symbolic Interactionism in Relation to Photography

To understand the ill child’s perspective and use of photography to explore the development of their self-perception, the findings and support of symbolic interactionism will be used in this study. According to this theory, connections between symbols and interactions help individuals decode the world around them, shaping their behaviors and the active roles they play within that reality (LaRossa & Reitzes, 1993). In order to understand this theory’s relationship to self-perception/self-concept development, it is important to break it down to two main aspects: symbols and interaction.

As early as birth, individuals are exposed to sights, sounds, smells, and touches that infants are unable to fully interpret. Yet, we begin to associate certain sounds, sights, touches, and smells with different meanings that help us code certain interactions. For example, when a baby hears a high-pitched voice, a smiling, happy face of a primary
group member (e.g., a family member or caregiver) usually follows. Through this interaction, a baby begins to interpret these messages being sent and, though not fully aware of their meaning, develops an awareness of others around him or her. Based on an individual’s awareness of others and their perception of him or her, a self-concept develops with a need for the support and approval of these others, a concept termed by Charles Horton Cooley as the looking glass self (LaRossa & Reitzes, 1993). It is through interaction and self-development that, “individuals translate their feelings toward primary group members into more abstract symbols and ideals and also translate their concrete experiences into norms and values” (LaRossa & Reitzes, 1993, p. 138). Cooley’s concept links the human sentiments, such as self-esteem, to our interpretation of the way in which others see us, judge us, and treat us through socially constructed means; yet these interpretations only have significance once the individual is able to objectify themselves through language.

“With names and labels (language), we are able to step outside of our selves as subjects and see our selves as others do (reflexive role-taking)—that is as objects. We become conscious of our selves (reflective self-consciousness) and separate our selves from others” (Lindesmith, Strauss, & Denzin, 1988, p. 45, as cited in Musolf, 1996, p. 305). As we see our selves as objects, we also see our selves as symbols interacting with other symbols, resulting in symbolic interactions, allowing us to self-objectify and self-develop though those interactions (Musolf, 1996). Applying this concept to children’s development and the impact that chronic illness can have on that development, we understand the important connection of language, interaction and self-perception
development. As a chronically ill child is surrounded by language that depicts them as different from children without a chronic illness, that language in combination with their interaction with medical professionals begins to create a self-concept of being an “ill child.” Through those interactions, chronically ill children begin to perceive themselves through the eyes of others around them, in turn, developing a “sick child” identity.

Stemming from Cooley’s looking glass self-concept and the direct links between interaction and self-concept, Howard (2000, relying on Charmaz, 1995) wrote that when individuals face serious illness, “Processes of bodily assessments and subsequent identity tradeoffs sum to a surrendering to an identity as ill” (Howard, 2000, pp. 379-380). Through this research, we are able to see the direct connection between symbolic interaction and the ill identity by the immense struggles that individuals face through labeling their identity and interactions, which create an ill identity and alter their goals and self-perception, based on this identity.

When considering symbolic interactionism, it is important to also recognize how the child’s perception of self and the impact that illness and hospitalization have on that perception shape that child’s sense of identity in a major way. Massie (1984) explained, “Having a chronic illness’ is sometimes an elusive concept because one’s illness becomes melded into one’s identity. To ask what I would be like without hemophilia is an impossible question, like asking who Abraham Lincoln would have been if he had been a midget. Clearly, there is a me distinct from hemophilia, yet it is hard to say where the boundaries to that me are” (Massie, 1984, p. 17). I am interested in seeing how this identity may be interpreted through the hospitalized child’s use of photography.
Chapter 3: Methodology

Participants

Though the study was open to children ages 7 to 18, the five active participants enrolled in the study ranged in age from 14 to 18 years of age. Using a preparticipation survey (see Appendix A), the participants specified their age, race/ethnicity, and how frequently they have used a digital camera (see Appendices B through E for participant survey responses). The participants consisted of two females and three males (see Appendix C). Three participants identified their race/ethnicity as African American, two participants identified as White/Caucasian, and one identified as Asian (see Appendix D). Finally, using a 5 point Likert-based rating scale, the participants recorded how frequently they used a digital camera prior to participating. One participant recorded never using a digital camera prior to their participation in the study, two participants recorded using a digital camera occasionally (11 to 20 times), and two participants recorded using a digital camera very frequently (31 + times) (see Appendix E).

Participant Recruitment and Research Methods

This research study was designed to be easily integrated into the pediatric hospital setting and to work flexibly around the needs and wants of the participants and their medical staff. The CCLS covering the hematology/oncology units provided the researcher with a list of potential participants who met the study inclusion criteria. The researcher then met with the qualifying individuals using direct person to person solicitation and introduced herself and explained the research study. The participants met with the researcher a total of two times, once to introduce him or her to the study, obtain
consent/assent forms, explain the camera equipment, and be taught a short lesson about
photography and a second time to share three to four images with the researcher and be interviewed about the photographs. Interested potential participants received a copy of an adolescent assent form (see Appendix F) or an informed consent form (see Appendix G), and the guardians received a parental informed consent form (see Appendix H) and photo release form (see Appendix I) reviewed and approved by the hospital, the institutional review board of the university affiliated with the hospital and the Ohio University institutional review board. The researcher explained the forms to the potential participants and guardians and answered any questions they had. After giving the potential participants and their guardians time to privately review and discuss the research study and consent/assent forms, the researcher returned to answer any additional questions. If the potential participant was interested in participating in the study and their parent/guardian approved of their participation, the researcher attained the signed and witnessed consent/assent and photo release forms.

The researcher gave copies of the signed assent/consent forms to the participant and/or the parent/guardian of each participant. The researcher administered a short survey to the participants (see Appendix A), which asked for demographic information, age, gender, race/ethnicity and their previous experience using a digital camera. Next, the participants were given a Kodak Easyshare digital camera and memory card. The researcher asked participants if he or she had ever used a camera similar to the one given and the researcher demonstrated various functions of the camera (e.g., how to power the camera on and off, take a photograph, turn the flash option on and off, recharge the
battery, view previous photos taken, and apply different effects such as black and white or sepia tone to images) The researcher also told participants that the camera he or she was using was a gift to them for participating in the study and that he or she was to keep it after the study was complete. Participants were informed that he or she could quit the study at any time he or she wished, that there would be no consequence for quitting and that he or she would still keep the camera that they were given to use if he or she chose to drop out of the study. The researcher instructed participants to take pictures of anything the participants would like while in the hospital but asked participants to refrain from taking pictures of other patients. The participants were also instructed to ask permission of hospital staff, such as nurses, volunteers, doctors, or anyone who might work for the hospital, before taking pictures of or with the staff members.

After participants were asked again if they had any questions about the camera or the research study, the participants were then given the option to view a printed PowerPoint presentation (see Appendix J) that explained various elements of photography (e.g., composition, repetition, light, mood, and the rule of thirds). Participants could choose not to take part in the photography lesson. The participants were then asked what time during the next day would be best for him or her to share their photos with the researcher and the second meeting was scheduled.

During the following day, the researcher met with participants for a second time to review the participant’s favorite three to four images. The researcher conducted a short interview while the participant shared the images he or she took. An outline of the interview questions can be found at Appendix K. The researcher recorded the interview
using a handheld, audio-recording device. After the interview was complete, participants received prints of their three or four chosen images and the researcher reiterated that the participants were to keep the camera and memory card that they used during the study.

**Location**

The study took place in the inpatient hematology/oncology unit and outpatient hematology/oncology clinic within a large, freestanding children’s hospital in the Midwestern United States. Participants took photos from within their hospital or treatment room, the unit, and other areas throughout the hospital.

**Protection of Participant Identity**

To protect participant identity and confidentiality, interviews were deidentified by the researcher during transcription and all audio-recorded interviews were erased after transcription. Participant photographs and surveys, obtained by the researcher, were de-identified to protect participant confidentiality.

**Approach to Analysis**

Once interview responses were transcribed, deidentified and matched with the associating photographs, the researcher analyzed the transcriptions and photos looking for common, preliminary themes of hospitalization across the participants’ data. A full chart of participant responses and image descriptions can be found in Appendix L. Next, the researcher collaborated with a professional colleague who is also a CCLS. During this collaboration, the researcher reviewed the transcripts and photographs for a second time while sharing the preliminary themes of hospitalization, images, and transcriptions with her collaborating colleague. Here, the researcher and collaborator discussed and solidified
the preliminary themes of hospitalization across participant data and compiled additional themes. Finally, the researcher organized the themes of hospitalization identified during her independent and collaborative analysis, narrowing the scope to four major themes of hospitalization shared across the participant data.
Chapter 4: Findings

Introduction to Findings

While analyzing participant images and interview responses, many common themes began to emerge across the data. This chapter will highlight four themes of hospitalization identified during data analysis: significance of family, medical/nonmedical staff presence, objects representing emotions, and the participant’s reflection on the impact of the hospital experience. The following chapter recounts the participants stories shared during the interviews regarding the three to four chosen images participants wished to share. To enhance the reader’s understanding of the participant’s responses, some images taken by participants will be displayed in this chapter as well. Though the images in this publication are black and white, the participants chose to take the majority of the photographs in full color, with the exception of two images where the participants chose to alter the camera’s settings to create black and white or sepia (a yellowed, vintage hue) toned images. The participant altered images will be identified in the subsequent chapter. A full chart of participants and image descriptions can be found in Appendix L.

Theme One: Significance of Family

Throughout the analysis of the participants’ images, a common theme of the significant role the participants’ family plays in their life and hospital experience emerged. Of the five enrolled participants, three of the five chose to share images of their family members or of an object that reminded them of a family member. Participant two chose to share two photographs she took highlighting her family. The first photo she
shared was a photo of her father. He appeared seated in a chair in the participant’s room. From the appearance of his hands and posture, he seemed to be throwing his hands back in a playful manner. Smiling as she described the photo, participant two said she loved this photo because her dad is very cool and silly and the photo was funny. “It makes me feel good, it put a smile on my face, it makes me laugh.” The second image related to family that participant two shared showed her mother petting a pet therapy dog that came to visit the participant in her room. “I like it because the dog look(s) like Scooby-Doo and my mom . . . she just brightens my day when I’m here and I just love her so much, that’s why I chose this picture.”

Participant four chose to share a photo he took of his mom and dad. When asked why he chose to share this photo, he said, “‘Cause they’ve been with me since this started and are still with me right now . . . like no matter how bad things got.” When asked what this photograph makes him think about, the participant began to shed tears saying, “Everything pretty much . . . *silent pause* . . . I’m glad that they’re here.” Giving the participant the choice to move on to another picture or continue talking about this image, he said, “I’m just kinda thankful that they put up with me through all this. I’m really glad.” These two participants chose to and were able to take photographs of their family members while in the hospital setting, but not all participants chose to photograph members of their family. Participant five chose to share a photo he took of a building from the view out of his hospital room window (see Figure 1). The participant altered the image color from full color to sepia tone. When asked to describe the photograph, he said that he took the photo while he was talking to his friend about how old they thought the
building in the picture was. He spoke about how the building was “historical” and that it brings a lot to the community because women have their babies there. When asked what feelings or emotions the participant had when looking at the photo, the participant smiled and replied, “my sister was born there.”

Figure 1. Photograph taken from perspective of participant's hospital room window. Participant altered image color to appear grey/orange color, giving it a vintage look.

**Theme Two: Medical/Nonmedical Staff Presence**

Four of the five participants chose to showcase medical/nonmedical staff in their images. Six of the 18 total images taken and selected by the participants in the study showed medical/nonmedical staff presence in three different ways:

1. The staff member alone;
2. The staff member with the participant; and,

3. An object from the staff member given to the participant.

Throughout their interview responses, participants chose to highlight certain elements about the hospital staff and characteristics of their interactions with the staff members. Of the four photographs participant five chose to share, three of the images selected featured medical and nonmedical staff members.

The first image participant five chose to talk about was of his doctor smiling in a white lab coat in front of a curtain used to divide the shared patient room. When looking at this photo, the participant laughed saying, “It makes me feel happy . . . because he’s (the doctor is) happy . . . it makes me feel like he enjoys his job.”

*Figure 2.* Photograph taken by participant of hospital staff member playing piano.
The second photo participant five chose showed a woman, “the library person, who organizes and runs the library” standing in a decorated desk cubical and waving at the camera. When asked what this photograph makes him think of he replied, “how sweet she is . . . I feel like she’s always there for people, to help people out . . . mmhm She recommended me some good movies and books and you know, she’s always there to help people out.” When describing the person in the next photo (see Figure 2), the participant described the woman playing piano as his “friend.” From the image, the woman appears to be wearing a stethoscope and white lab coat, and therefore, a part of the medical staff. When asked what feelings this photo elicits, the participant replied, “how good she can play . . . She says she’s been playing piano ever since she was in second grade, and she says she’s 24 now.”

Participant four chose to share an image that he asked his parent to take of him and his nurse. “‘Cause like, without all the nurses here, I really wouldn’t be here now either. I’m kinda thankful that they’re here also, and I know it’s not the best working with me because I don’t really do a lot of things, you know it’s good that they, that they’re here too.” When asked what this photo made him think about, he replied, “that people actually help out other people; that they actually care about you.” Similar to participant four, participant three also chose to share a photo of himself with a staff member. Based on how close the subjects are in the image and the angle at which the photo was taken, the participant took the photo himself by turning the camera around and snapping the picture of himself wearing a T-shirt with the words, “This is my Super Hero Shirt” written on it and a staff member. “This is my social worker and me . . . she’s just an
awesome social worker, I always hangout with her when I’m here. She’s awesome.” As
the participant reflected on what this photo makes him think about, he said, “basically
just havin’ a good time.”

![Balloon](image)

*Figure 3. Photograph taken by participant of balloon given to her by a nurse.*

Participant two chose to share a photo she took of a heart-shaped balloon that
read, “Get Well Soon” (see Figure 3). “I like this picture. I took this picture because one
of my favorite nurses gave it to me, and every time I get sick or my birthday come
around, she give me something’ like a balloon.” Smiling, participant two continued
saying, “I like it because it’s a heart and I like the colors in it and when I look at it, it
makes me feel happy.” Though this photograph does not picture the staff member, the actions of that staff member are evident in the image taken by participant two.

**Theme Three: Objects Symbolizing Feelings, Memories, or Meaning**

Eight of the 18 images taken by the participants did not contain people, but rather were photographs of objects. All five participants took at least one photograph of an object that they related to feelings, memories, or meaning during their interviews about the images. As previously discussed, participant two related a balloon given to her by a nurse (see Figure 3) to feelings of happiness and participant five (see Figure 1) who associated a building seen from his hospital room to memories of his sister being born.

*Figure 4. Photograph taken by participant of bell in hematology/oncology clinic.*
Participant three chose to share two images of objects. Before even being asked about the photograph, participant three eagerly showed me a picture of a bell on a wall and said, “This I would like to be ringing this bell because that’s when you are completely done with cancer” (see Figure 4). In the outpatient hematology/oncology clinic, this bell is posted in the hall for all patients, medical staff and guests to view as they walk to treatment rooms, staff offices, and other areas in the clinic. When asked what feelings this photo gave him, he became very serious and replied, “It makes me want to fight harder to get to that.” Patient three shared another photograph of a blood pressure machine in a clinic treatment room (see Figure 5). When asked what the photo was of, he said “the blood pressure machine . . . it’s my least favorite part of this. I don’t know what it is, I always get huge bruises on my arm from it.” When asked what this picture makes him think about, participant three smirked and said, “pain.”

*Figure 5.* Photograph taken by participant of a blood pressure machine.
At first glance, the image participant four chose to share (Figure 6) resembles a solar depiction of the sun or an abstract painting of some sort. “I took a picture of egg drop soup . . . it kinda looked like vomit,” he said laughing about the image he spoke of. When asked why he chose to take this photo, participant four looked down and paused before saying, “Cause it was the first food I got to eat in, um, for two days.” Participant four continued conversation saying that the soup tasted “Amazing!” Describing his feelings when he looks at the photo, participant four released a sigh as he says, “Relief . . . I finally got to eat.” When asked to reflect on what this photo makes him think about, participant four replied, thoughtfully smiling, “that like even if you have to wait a while, it was worth it, it was good . . . (silent then laughs) egg drop soup doesn’t really look good on camera.”

Figure 6. Photograph taken by participant of egg drop soup.
All three images participant one chose to share focused on objects and did not showcase any people in the images. Throughout the interview, participant one answered questions in a very direct way without much explanation beyond her original descriptions and feelings. She described her first image (see Figure 7) as, “a nook cover and it’s like airplanes but I made it black and white [in the photograph] instead of it being pink and orange and white.” Here the participant altered the camera settings from color to black and white. She stated that she took the picture because she thought it was cool.

The second image participant one chose to share looked abstract; an unidentifiable red swirled string across grey looking fabric (see Figure 8). “It’s chemo on my leg” patient one explained. She took the photo “because it’s bright, it’s bright red.” When looking at the photograph, she thinks of “getting chemo . . . I don’t know (participant laughs).”
The final image participant one shared during her interview was of “my bracelet on my ankle, yeah my friendship bracelet on my ankle” (see Figure 9). Participant one stated that she took the photograph because her friend made her that bracelet and it’s pretty and she thought it (the picture of the bracelet) would be nice. When asked if this picture makes her think about anything or have any feelings, participant one responded in a very serious tone, “I think about my friend. I haven’t seen her, I don’t see her very much.” Participant one chose not share any additional images.
Figure 8. Photograph taken by participant of chemotherapy tube on participant's leg.

Figure 9. Photograph taken by participant of friendship bracelet on participant's ankle.
Theme Four: Self-Reflection/Impact of the Hospital Experience

Participant two chose to share an image taken of her as she sat on her bed in her hospital room with the pet therapy dog. She smiled as she described the photograph, reflecting on herself saying, “I like it because I look pretty in this picture, even on my sick day, and I like it because the dog, he was very friendly. And he just let me touch him and I really don’t like big dogs because I’m scared of them but this one I wasn’t scared of. He was well trained and everything.”

In participant four’s earlier response to the image of him with his nurse, he reflected on his existence and his abilities when he said, “‘Cause like, without all the nurses here, I really wouldn’t be here now either. I’m kinda thankful that they’re here also, and I know it’s not the best working with me because I don’t really do a lot of things, you know it’s good that they, that they’re here too.” Through his interactions with the nursing staff, participant four reflected on his hospital experience and the effects of hospitalization. In addition, the photograph he shared of his parents provided an opportunity for participant four to reflect on his hospital experience, “they’ve been with me since this started and are still with me right now . . . like no matter how bad things got.”

In her interpretation of her image of the chemo tube lying on her leg (see Figure 8) participant one reflects on her hospital experience, “I’m getting chemo.” Participant three reflected similarly on his hospital experiences through his photographs, specifically when describing the bell (see Figure 4) “ I would like to be ringing this bell because that’s when you are completely done with cancer . . . it makes me want to fight harder to
get to that.” Participant three also shared an image of himself laying on his back on the exam table in the outpatient hematology/oncology clinic exam room. He is wearing a t-shirt that reads, “This Is My Superhero Shirt.” He chose this photo “because it used to be every two weeks I’d be laying there getting my port accessed.” He also said that participating in this photographic research study, “I realize that it’s really not as bad as it seems . . . sometimes . . . it just, I don’t really know how to explain it.” He appeared at a loss for words when trying to further describe these feelings about his experience.
Chapter 5: Discussion

While compiling the themes that emerged during data analysis of participant photographs and interview responses, similarities and differences across participant data began to stand out.

Analysis of Themes: Medical and Nonmedical Staff Presence

The first theme uniting similarities among participants’ data is that of medical/nonmedical staff presence. Four out of the five participants chose to share their experiences with hospital staff, either medical or nonmedical, signifying the important impact that medical staff play in children’s hospital experiences. The many different ways participants chose to convey the importance of staff presence during their hospital experience shows how diverse the interactions among staff and patients can be. Children and adolescents derive different meaning from similar patient staff interaction and this can differ from patient to patient making each child’s hospital experience unique to that child and family. Participant photos and interview responses highlight the impact of the medical/nonmedical staff members by the important role of their interactions, relationship building, and their feelings of thankfulness for the presence of those staff members. Though all of these participants interacted with medical and nonmedical staff, the participants differed in the unique ways they portrayed their interactions and the role those interactions played in each participant’s development.

At the start of his interview, participant five highlighted that his motivation for signing up for this study was, “because I want to become a forensic photographer and I want to further my experience in photography.” Participant five chose to photograph staff
members for three of his four images. He was not present in the images with the staff, but rather, he had the staff members pose for a picture during their interaction with the participant. Participant five’s descriptions focused on his perspective of each individual staff member; how that staff member appears to affect others around them. As discussed earlier, “Self-concept plays an influential role in constructing an understanding of reality and one’s place in it and in shaping individuals’ emotions, motivations, decisions, and actions within that perceived reality” (Icard & Nurius, 1996, p. 30). Based on developmental theory, children in later adolescence begin to develop more reflective thought processes, enabling them to think in more abstract ways.

Participant five matches this developmental description as he reflects on his experiences with the library staff member saying, “I think of how sweet she is . . . she’s always there for people, to help people out.” He also uses abstract thought when describing the image taken of his smiling doctor. When asked how the picture makes him feel or what it makes him think about he said it, “makes me feel happy because he (the doctor) is happy . . . makes me feel like he enjoys his job.” Here, participant five internalizes the interaction with his doctor and comes to an abstract concept connecting the doctor’s demeanor with the happiness and value placed on the job the doctor is doing. He observed that the doctor looked happy and inferred that the doctor also enjoyed his job.

When describing how he felt when he looks at the photo of the staff member playing piano, participant five (age 18) said, “how good she can play . . . she said she has been playing since she was in second grade and she’s 24 now.” Due to the nature of his
inpatient hospital experience, the doctor, library staff member, and other medical staff member may be considered members of patient five’s “primary group” (LaRossa & Reitzes, 1993, p. 138). Based on his images and interview responses, it is possible that participant five’s interactions with this primary group impacted his self-development in reference to his self-concept, specifically his future oriented thinking about his occupation and desire to become a forensic photographer. Each photograph participant five took of staff was taken from an “outside” perspective and his feelings focused on the competencies and attributes of each individual in association with their occupation (happy in their job, helping people, being good at piano). As the oldest participant in the study, participant five is placing an emphasis on occupations, admiring the attributes and competencies of these medical professionals. These may also serve as personal goals for participant five to achieve in his future career and as questions for him to answer about his future; how can he be happy in his job like his doctor seems to be in his job, how can he help people like the library staff member, what is he good at like the staff member who is good at piano?

Participant two (age 15) highlighted staff presence, not by having a picture of the staff member, but rather by taking a picture of something that a staff member gave to her as a gift (see Figure 3). When describing the photograph, participant two said, “I took this picture because one of my favorite nurses gave it to me and every time I get sick or my birthday come around, she give me somethin’ like a balloon, and I like it because it’s a heart and I like the colors in it and when I look at it, it makes me feel happy.”
There can be a grey area that the patient/staff relationship can fall into if the staff member begins to take on a friendship role with their patient. This can happen when a staff member begins to give their patient gifts for occasions such as birthdays and holidays. Participant two describes how “every time I get sick or my birthday come around,” her favorite nurse “gives me somethin’ like a balloon . . . when I look at it, it makes me feel happy.” This presents two important concepts to consider when working with hospitalized children: promoting the child’s sense of normalcy while in the hospital by recognizing important life markers in their lifespan (birthday, prom, graduation, etc.) and maintaining professional boundaries between patients and staff members.

From her interview response, it is apparent that participant two feels special, cared for, and appreciated because her nurse gave her a gift on her birthday and when she is in the hospital on other days. By recognizing participant two’s birthday, her nurse helped promote feelings of normalcy and took an active role in honoring this normative life event. These are important messages to send to hospitalized children because often times they may feel that they are a burden to those who care for them, feel that they don’t matter, and also normative life events, like birthdays, can often be overlooked.

Patient-staff boundaries are important to maintain but at times can be difficult to define. Some psychosocial disciplines have ethical principles that prohibit the individual staff member from giving personal gifts to patients. For example, the ethical principles and guidelines for child life professionals, set by the Child Life Council, prohibit a child life specialist giving a personally purchased gift to a patient. One way that child life professionals honor this boundary and ethical principle while still celebrating the
normative life events of their patients, such as birthdays, would be by throwing a birthday party one day a month to celebrate all patients who have a birthday that month. From participant two’s response, it is obvious that receiving a gift and the recognition of important life events enriched her hospital experience. From a child life perspective, it is interesting to note that this action was also out of step from child life boundaries. It is important to explore how to celebrate the life and normative events in a child’s life without violating these professional boundaries. When a patient is given a gift on behalf of an individual staff member, the patient/staff boundaries are blurred. Patients may begin to associate this staff member with feelings of friendship and form attachments that lead to wanting to reciprocate the actions (i.e., giving the nurse a gift for her birthday, etc.) A professional relationship and a friendship possess different boundaries and expectations. If a staff member gives a patient a gift “every time I get sick” (participant two), a patient may begin to expect gifts whenever they come to the hospital or see that staff member. In addition, these actions can affect the perception other patients and families have of the hospital experience. Patients in the room across the hall may see a nurse bring gifts to one patient but then they never receive a gift themselves. These patients may feel that they are not getting the same treatment, either personal or professional, as this other patient or do not have a “good relationship” with that staff member because of this. They may begin to feel as though they need to do something special in order to receive a gift or be treated like the patient who got a gift.

Participant four (age 15) chose to have his parent take a picture of him standing next to his hospital bed with his nurse. When participant four describes the photo, he
reflects on his hospital experience and the fact that because of his condition, “I know it’s not the best working with me because I don’t really do a lot of things . . . .” Often times, children in hematology/oncology must be placed in isolation due to treatment protocol. Participant four’s response demonstrates a high level of self-awareness and empathy for those working with him in the hospital. He is thankful for their presence and, despite feelings of limitation caused by his medical condition, treatment protocol and hospitalization, he understands “that people actually help out other people . . . that they actually care about you.” Though he does not detail the specifics about his interactions with his nurse, participant four implies that his experience in the hospital has been challenging, but his nursing staff has stayed with him and supported him despite these challenges. Participant four expresses his awareness of the impact his condition and hospitalization has himself as well as the staff members.

During this period of psychosocial development, adolescents are concerned with perspectives of others and how they appear to those they interact with (Turner, 2009, p. 30). After sharing this photo, participant four was asked what he enjoyed about the Snapshot Photography program, “It was fun taking pictures and participating in, I’m glad I could help out.” By “helping out” with the research study, participant four exemplifies developmentally appropriate cognitive moral development for an adolescent his age (15 years old). Participant four places an emphasis on his relationship with his nurses and the impact they have had on him and replicates these feelings by “helping out” with the research study. By recognizing the limitations placed on him by his condition and hospitalization, participant four is aware that “I don’t do really do a lot of things,” but by
participating in this project, he is able not only to give back, gaining a sense of altruism, but also can feel accomplished because though he might not be able to “do a lot of things,” he could take pictures and help out. Taking part in the research study, participant four feels accomplished and altruistic.

School achievement and extracurricular activities outside of the classroom environment help to promote this developmentally appropriate expression of altruism and accomplishment. As child life professionals, it is important to understand how hospitalization threatens the adolescent’s need to exercise their feelings altruism. Recognizing how medical and nonmedical professionals can provide hospitalized adolescent’s opportunities to practice these skills they would typically develop in their classroom environment but now cannot due to hospitalization is important to positive adolescent development. Adolescents begin to consider the feelings of other and how he or she impacts those around them during this time of development. One way to help promote adolescent’s developmental desire to act altruistically while promoting positive cognitive moral development is to provide opportunities for the patients to give back and take an active role in creating something. Promoting programs where the child patients lead a group activity in the activity center or host a hospital wide radio show once a week can give an adolescent an opportunity to feel that they are making an impact on those around them in a positive way.

Analysis of Themes: Significance of Family

The second major theme among three of the five participants’ images and interview responses focuses on the significance of family and family presence. Family
members offer a sense of security and familiarity that hospitalization and illness can compromise and threaten. When children are put into an unfamiliar environment during hospitalization, it is important to help them feel comfortable by bringing elements from home into the room and advocating for parental and sibling presence to help promote feelings of normalcy and comfort. When children are accustomed to the hospital setting because of frequent visits to clinic or more long term stays on inpatient units, the children may be familiar with the setting but support from parents and siblings are still crucial to helping that child maintain a sense of normalcy and support.

Family presence can also provide a sense of familiarity and offers hope and security. Child life specialists work to promote patient and family centered care and communicate the understanding of the family as a system. Advocating for parental presence during procedures, child life specialists focus on collaboration between medical staff and parents. When parents are present during procedures, children and adolescents gain a sense of comfort and security, which reduces their anxiety and increases procedural compliance. In addition, allowing parents to play an active role in the child’s health care enables parents to regain their role as parent, which is often taken away by medical restrictions and requirements. This empowerment leads to an increase in parental advocacy and a decrease in their anxiety because the parents gain knowledge and understanding of their child’s medical condition and treatment. In turn, children and adolescent’s anxiety decreases as they observe their parent’s anxiety decrease. Parental support played a crucial role in participant four’s images and responses as he describes the feelings of support and constant presence his parents provided him during his stay in
the hospital. He emphasizes how “they’ve been with me since this started and are still with me right now . . . like no matter how bad things got.” From this statement, it appears that participant four’s hospital experience goes beyond this day in the hospital, his words create the feeling that he has been on a journey caused by his medical condition, but he did not have to face that journey alone. He is thankful for the presence and companionship his parent’s provided by being there for him, “no matter how bad things got.” Frequent or extended hospitalizations can frustrate children and families, rearrange their definition of normal, and change the dynamics of their family system. Participant four empathizes with the struggles and trials his parents have gone through with him during his medical journey, explaining, “I’m glad they’re here (begins to cry).”

The significance of family and their constant presence is also connected to the participant’s self-reflection and the impact of hospitalization. The statement, “they’ve been with me since this started and are still with me right now . . . like no matter how bad things got” alludes to participant four’s reflection of his hospital experience. During an interaction with participant four and his family, his father took a photograph of the researcher and participant four talking and posing together. He said that he has been documenting his son’s journey throughout his illness. Participant four’s father is a witness for his son, an advocate who offers his presence and support throughout his son’s medical journey. By photographing his son’s medical journey, participant four’s father is placing value on his son’s life and life experience. This can help to enhance participant four’s sense of self and purpose by his father intentionally documenting his son’s experience. This impact is evident when participant four says that he will probably keep
taking pictures after participating in the research program because, “you can like keep track of everything that goes by, you know, like I took the picture of the first food I ate in a couple days, things like that.”

When speaking with participant four and his parents before the interview, his father shared that participant four was eagerly looking forward to being able to see his siblings again whom he was not able to see for an extended period of time due to being confined to isolation due to his condition. Hospitalization affects the entire family system and the immense emotional response shown by participant four highlights the importance of maintaining normalcy for the patient by advocating for parental and family presence in the hospital setting whenever possible. Parental presence helps the children feel like they are not alone in their medical journey; they have someone there to be their witness, to be their support, and to be a constant in an environment when things are ever changing and their control has been taken away from them.

Children and adolescents are keyed in to the feelings and emotions of parents. When a parent is anxious, a child can sense their anxiety and may begin to become anxious themselves. If a parent is relaxed and comfortable in a setting, a child will often begin to relax their body as well and their own feelings of comfort will increase. Before beginning the interview, participant two seemed comfortable but not fully at ease. She smiled when speaking and responded politely, but there was some sense of discomfort or hesitance being communicated. When she began describing the photographs of her dad acting silly, throwing his hands up in the air and making a funny face, the demeanor of participant two (age 15) changed, making her smile, laugh, and “feel good.” Acting “cool
and silly” and “funny,” her father offered a different atmosphere than that of by her
hospital room. As she analyzed the photo of her father expressing his emotions, letting
loose and acting silly, participant two also relaxed and laughed as she described the
remaining images during her interview. This continued when she described the picture of
her mom. She sighed, smiled at her mom who was in the room, looked at the picture
saying, “she just brightens up my day when I’m here, and I just love her so much.”
Similarly, participant two’s mother also offers a sense of refreshment for the participant
during her hospital stay. As deduced from earlier in the interview, participant two has had
previous experiences in the hospital environment. It is apparent that having her mom and
dad present with her during her hospital visits lifts her spirits and offers a sense of love,
comfort, and support crucial to promoting a positive hospital experience.

**Analysis of Themes: Significant Objects**

Children create meaning and symbols out of many objects they encounter in the
hospital setting. Based on the previously mentioned theory of symbolic interactionism,
human beings decode the world around him or her using meaning derived from symbols
and interactions. Objects in the hospital setting can have a different meaning for every
individual based on previous experiences and interactions with that object and, therefore,
may act as a symbol of different interpretation. Often times, child life specialists
associate a comparative object or experience with a medical instrument or procedure to
help a child relate and understand this new experience. For example, if a child is learning
what it means to have their blood pressure taken and they want to know what it might
feel like, a child life specialist or other medical/nonmedical staff member may say that
other children have said it feels like your arm is getting a hug. Often times, a hug is considered a positive interaction, something that you receive from someone you love and trust. Yet, not all children or adults associate a hug with a positive feeling, specifically if the individual had been sexually abused or harmed by someone who wanted to “hug” them. It is important to understand how different medical tools and procedures feel to children and adolescents in order to prepare children for said medical tools and procedures. Participant three (age 15) shared a photo of the blood pressure machine (see Figure 5) and associated it with “pain” because “I always get huge bruises on my arm from it.” Knowing and understanding participant three’s interpretation of the blood pressure machine can help expand how future medical and nonmedical professionals understand how a child might experience getting their blood pressure taken. Blood pressure and vital check-ups may appear to be routine and noninvasive procedures to professionals who encounter them every day, but for children who fear the “pain” associated with the procedure, getting their blood pressure checked can be an ever looming and threatening stressor. Participant three’s insight into his experience with the blood pressure machine helps to enhance how medical professionals might better prepare other children for having their blood pressure taken and how it might appear to them. Because of participant three’s experience, he now associates blood pressure machines with pain and bruising. Understanding the meaning children in hospital settings give objects increases awareness and sensitivity to the diverse associations and interpretations children have of different tools and procedures.
In a similar way, children may make meaning out of objects in the hospital setting that can motivate and inspire him or her as they face their personal hospital experiences. The bell hanging in the hematology/oncology outpatient clinic symbolized a goal for participant three to reach: ringing the bell because he is “completely done with cancer” (see Figure 4). His determination to “fight harder to get to that” shows the immense meaning this bell holds for him and other patients in the clinic. Offering children chronic and terminal illness a symbol of hope heightens their motivation and suggests that they have the ability to take control of how their medical condition will impact them. When participant three looks at the bell, he thinks about “fighting harder to get to that,” this can be accomplished.

Children facing chronic illness must change their life to accommodate for their medical needs. Their life may seem like it is no longer in their control but, rather are being controlled by their condition. By placing this bell in the hematology/oncology clinic, the hospital staff offers children the opportunity to feel a sense of control over their something and give them a goal to aspire to. They are able to look to the future, consider the possibilities and aspire to achieve their goals. Feelings of incompetence and self-doubt can be combated by promoting goal setting, offering feelings of motivation to overcome obstacles and maintaining a sense of hope. This bell acted as a motivating factor for participant three and in turn, emphasizes the significance and importance of his fight to be “completely done with cancer.” Though the bell is a well-known symbol in the clinic for those to ring when they no longer have cancer, participant three derived his own meaning from the bell. This is important for medical and nonmedical professionals to
gain a greater understanding regarding the importance of meaning and messages objects in the hospital represent to the patients they serve. Participant three used the bell as a motivator, something that makes him think about his future and work to make cancer absent from that future. This tactile object offers a light the end of the tunnel with the idea, “I have the power to take action to beat this.” That bell represents the end, the win, the fight against cancer that has been won and that they have beat it themselves.

Egg drop soup represented the end of participant four’s (age 14) long awaited meal after two days of not being allowed to eat due to medical reasons. He was “relieved” to eat it, even though he said it looked like vomit on camera. Similar to participant three who wanted to fight harder to be cancer free and ring the bell, participant four fought through feelings of hunger until he was medically allowed to eat again. Looking at the picture of the soup made him think about how even though he had to wait a while, the wait was worth it. The feeling he got after accomplishing this task, “relief . . . I finally got to eat.” Though the two day fast was a medical requirement, participant four used it as an opportunity to accomplish a task. Once he accomplished this task, he was allowed to eat. He worked hard and, “even though you have to wait, it was worth it.”

**Analysis of Themes: Reflection on Self or Hospital Experience**

Collectively analyzing participant five’s images and transcript, a theme emerges highlighting various medical and nonmedical staff members. With a focus on their attributes and strengths, participant five looked at how each individual he photographed excelled at what they did. His doctor looked happy, signifying his pleasure in his current
profession, the librarian staff member was always helping others out, and the medical staff member playing piano could play very well. Looking at each person’s occupation, participant five reflects on how each person’s presence impacts him. Perhaps interacting with individuals who appear to be proficient in their job influences participant five’s response about his reason for signing up for the research study, “because I want to become a forensic photographer and I want to further my experience in photography.”

During adolescence, individuals begin to use future oriented thinking and begin to perspective take on their future (i.e., school, work, family, relationships). As medical and nonmedical professionals, it is important to understand the importance of developing this future oriented thinking and gaining a greater awareness of how our relationships and interactions with adolescents can potentially influence their perspectives on this topic. The role of hospital staff members in the daily life of a hospitalized child is immense; therefore gaining this insight can help improve those interactions and possibly offer opportunities for the adolescents to do some beginning career exploration while in the hospital setting. Often this type of future-oriented, career focused learning experiences occur in the classroom setting. Yet, for children facing frequent and extended hospitalizations, they may miss out on this crucial part of their future oriented thinking and self-exploration. By seeing the important role that this plays in adolescent development, programs for hospitalized adolescents that offer career exploration may be very beneficial. For example, special events could be organized throughout the month where one or two individuals from various professions might come to a unit and offer an interactive activity teaching the children about their profession. This may offer children
and adolescents the opportunity to learn about new professions, experiences they might be missing in school because they are hospitalized, and begin to see how their talents and interests might come together into a profession.

Throughout development, children progress toward being independent, autonomous individuals. This is specifically important during adolescence when a need for control, choice, self-expression, and independent activities increase. When a child is hospitalized, their daily routine and opportunity to make independent choices, including decisions about their care, when they eat, when they get a procedure done, when they get to see their friends; become dictated and predetermined by someone else. This can lead to developmental setbacks and possible regression to previous developmental levels.

Throughout the interview responses and participant photos, the participants used words and phrases to depict why they chose to take a picture, what that picture makes them feel, and other thoughts that they had about the picture. These feelings often revealed reflections of their hospital experience. Even the simplest response to a question sheds light on how children experience the hospital setting. When describing what the photo of chemotherapy on her leg (see Figure 8) makes participant one (age 14) think about, “I’m getting chemo . . . I don’t know (participant laughs).” She is nonchalant, almost like getting chemotherapy is nothing new, it is typical. Chemotherapy treatments to participant one are routine, they are habitual, and therefore nothing new to her. When children face chronic and terminal illness, their lives take on a “new normal.” Instead of getting up every day, going to school and going through the motions of her typically
developing 15 year-old peers, participant one now adds chemotherapy treatments to her routine.

Noting the purposeful photo taken including only the chemotherapy tube on her leg, participant one seems intentional about what she chose to include in her photograph. She could have chosen to take a picture of herself sitting on the treatment table with the chemotherapy treatment attached, allowing the viewer to see the whole scene. Yet, participant one chose to zoom in only on the colored chemo treatment flowing through the tube that was draped across her pant leg, she did not allow the viewer to see the entire picture, the whole experience. Perhaps participant one views her treatment as an object, something that she does but it does not define her. It is simply something she is doing right now and it is separate from who she is. She chose to share this part of her hospital experience in an abstract photograph and did not wish to share any more details about the image except that she took the picture because the chemo and tubing was bright red.

Similarly, participant three’s image of himself on the treatment table made him reflect on when he gets his port accessed and how it used to be every two weeks. From his response we learn that there has been some type of change in when he gets his port accessed, it has either gotten shorter or longer in between accesses, but either way participant three intentionally shared this experience with the researcher. There is intentionality behind each image participants chose to share. The images make up a story; they are part of an experience, their unique experience that no one else has shared in the same way they have. When a picture is taken, it freezes something in time and space and allows it to be unchanged. The images of the participant’s hospital experiences document
a time and place where that child was and communicates where he or she has been and he
or she is going. Participant three is working toward ringing that bell, fighting harder to
get to that. That bell is the light at the end of the tunnel, the goal at hand. His experience
up to that point has all been to achieve that goal to ring the bell when he is “done with
cancer.” Participant four waited and it was worth it to wait because tasting his egg drop
soup after not being able to eat for two days was a relief. He is thankful that his parents
and nurses have been there for him through everything, even though he knows he is not
always the easiest to work with. He is self-aware and knows how much his
hospitalization has affected his family. He is caring, he wants to help others and give
back the compassion that he feels others have shown him during his hospitalization. The
journey of each participant is communicated in their photos and offers a first-person
perspective of the life of a hospitalized child. Each child’s journey, each child’s story,
each uniquely shared.

Implications

As child life professionals, the results of this research and data analysis offer great
insight into the experience of the hospitalized child. Through the continuous advocacy of
parental presence in a child’s hospital experience, child life specialists and other medical
and nonmedical professionals can work to continue to better meet the needs of child
patients and their families. It is important to share these findings across disciplines to
promote a widespread understanding of the importance of patient and family centered
care. Teaching future generations of medical and nonmedical professionals how to adapt
the hospital setting in a way to normalize the experience for children and families will
increase the quality of hospital experiences for the patients, their families, and also for the staff members who work with them. Helping children and families gain a sense of control over the hospital environment helps reduce their feelings of being overwhelmed and restricted by the hospitalization. For many children and their families, hematology/oncology related services become a “new normal.” Going to the hospital for a procedure or treatment may now be as frequent an event as going to the grocery store. Understanding the perspectives of children in this “new normal” can provide a window through which to view their most basic human needs and guide medical and nonmedical professionals to improving interactions and patient care to meet those needs.
References


Springfield, IL: Charles C Thomas Publisher, Ltd.

Springfield, IL: Charles C Thomas Publisher, Ltd.


Springfield, IL: Charles C Thomas Publisher, Ltd.

Appendix A: Preparticipation Survey

Snapshot Pre-Participation Survey

1. Age: ______
2. Gender:
   Boy ______ Girl ______
3. Race/ Ethnicity:
   White/ Caucasian ______ Black/ African American ______ Asian ______ Middle Eastern ______
   Hispanic ______ Bi-Racial ______ Other: ________________________________
4. Have you used a digital camera before?
   Yes ______ No ______
5. How many times have you used a digital camera?
   Never ______
   Rarely (1 to 10 times) ______
   Occasionally (11 to 20 times) ______
   Frequently (21 to 30 times) ______
   Very Frequently (31+ times) ______
## Appendix B: Participant Breakdown

<table>
<thead>
<tr>
<th></th>
<th>Participant One</th>
<th>Participant Two</th>
<th>Participant Three</th>
<th>Participant Four</th>
<th>Participant Five</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
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<td>15</td>
<td>15</td>
<td>15</td>
<td>18</td>
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<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
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<td>Black/African American</td>
<td>White/Caucasian</td>
<td>Asian</td>
<td>Black/African American</td>
</tr>
<tr>
<td><strong>Pervious Camera Use</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Frequency of camera use</strong></td>
<td>Very Frequently (31+ times)</td>
<td>Occasionally (11 to 20 times)</td>
<td>Occasionally (11 to 20 times)</td>
<td>Very Frequently (31+ times)</td>
<td>Never</td>
</tr>
</tbody>
</table>
Appendix C: Gender Breakdown
Appendix D: Race/Ethnicity

![Graph showing race/ethnicity categories: Black/African American, Asian, Caucasian]
Appendix E: Frequency of Camera Use

- Never (0)
- Rarely (1-10)
- Occasionally (11-20)
- Frequently (21-30)
- Very Frequently (31+)

Chart showing frequency of camera use with categories from 'Never' to 'Very Frequently'.
Appendix F: Adolescent Assent Form (Ages 13-17)

SNAPSHOT! Photography Project and Research Study: Adolescent Assent Form

[Behavioral] Documentation of Adolescent Assent Form
(Ages 13-17)

Title: SNAPSHOT! Photography Program and Research Study

Study Investigator: Katelyn Schlosser

Why am I here?
This is a research study. Only people who choose to take part are included in research studies. You are being asked to take part in this study because you are a [Hospital Name] patient receiving hematology or oncology treatment and are between the ages of 7 and 18. Please take time to make your decision. Talk to your family about it and be sure to ask questions about anything you don’t understand.

Why are they doing this study?
This study is being done to find out about what children and teens receiving hematology/ oncology services take pictures of to learn more about how you look at things, people, places, and activities.

What will happen to me?
If you decide you want to be in my study, you will take pictures during your day. You can take pictures at the hospital, at home, or anywhere you go. I will ask you questions about your pictures. You can tell me what is in the picture, where you were, and why you took it. You can share anything you would like about the pictures you take.

How long will I be in the study?
You will meet with me two times while you are in the study; once to meet me and learn about the camera and a second time to show me the photos you took.

Will the study help me?
You may benefit from being in this study because you will learn about photography, experience using a camera, be able to take photographs of your life and share those photographs with others. Information gained from this study may help other people in the future by helping others understand more about the lives of children receiving hematology and oncology services.

Will anything bad happen to me?
You might not want to talk about every picture that you take, and it is OK for you not to talk about any pictures that you don’t want to.

Will I get paid to be in the study?
For taking part in this research study, you will receive a digital camera and memory card that you will use during the study and will keep after the study. You will also keep the digital copies of all of your photos and receive printed copies of your favorite three to four photos.

Do my parents or guardians know about this? (If applicable)
This study information has been given to your parents/guardian and they said that you could be in it.
SNAPSHOT! Photography Project and Research Study: Adolescent Assent Form

You can talk this over with them before you decide.

**What about confidentiality?**
Every reasonable effort will be made to keep your medical records or your information confidential. But we do have to let some people look at your study records and maybe your hospital records.

We will keep your records private unless we are required by law to share any information. The law says we have to tell someone if you might hurt yourself or someone else. The study doctor can use the study results as long as you cannot be identified.

The following information must be released reported to the appropriate authorities if at any time during the study there is concern that:
- child abuse or elder abuse has possibly occurred,
- you disclose illegal criminal activities, illegal substance abuse or violence

**What if I have any questions?**
For questions about the study please call Katelyn Schloesser at [PI Phone Number]. If you have questions or concerns about your rights as a research participant, the Chair of the Human Investigation Committee can be contacted at [HIC Phone Number]

**Do I have to be in the study?**
You don’t have to be in this study if you don’t want to or you can stop being in the study at any time. Please discuss your decision with your parents and researcher. No one will be angry if you decide to stop being in the study.
SNAPSHOT! Photography Project and Research Study: Adolescent Assent Form

AGREEMENT TO BE IN THE STUDY

Your signature below means that you have read the above information about the study and have had a chance to ask questions to help you understand what you will do in this study. Your signature also means that you have been told that you can change your mind later and withdraw if you want to. By signing this assent form you are not giving up any of your legal rights. You will be given a copy of this form.

Signature of Participant (12 yrs & older) ___________________________ Date __________

Printed name of Participant (12 yrs & older) ___________________________

Signature of Witness (When applicable) ___________________________ Date __________

Printed Name of Witness ___________________________

Signature of Person who explained the form ___________________________ Date __________

Printed Name of Person who explained form ___________________________

** Use when participant has had consent form read to them (i.e., illiterate, legally blind, translated into foreign language).
Appendix G: Informed Consent Form (Age 18)

SNAPSHOT! Photography Research Study: Behavioral Research Informed Consent

Behavioral Research Informed Consent
Title of Study: SNAPSHOT! Photography Research Study

Principal Investigator (PI): Katelyn Schlosser
[Name of Hospital]
Child Life Services
[Hospital Address 1]
[Hospital Address 2]
[Hospital Phone Number]

Funding Source: Pending grant funding from [Hospital Foundation]

Purpose
You are being asked to be in a research study of pediatric patients in inpatient and outpatient hematlogy/oncology areas and how they view their experiences and surroundings both in and out of the hospital setting using photography because you are a patient receiving hematlogy/oncology services at [Name of Hospital]. This study is being conducted at [Name of Hospital]. The estimated number of study participants to be enrolled at [Name of Hospital] is about 10. Please read this form and ask any questions you may have before agreeing to be in the study.

In this research study, we would like to see how pediatric patients receiving hematology/oncology treatments see people, places, things, and experiences in and out of the hospital. This will help us understand their needs and experiences. We will also look at how we can use photography as a coping strategy for patients.

Study Procedures
If you agree to take part in this research study, you will be asked to take photographs of your life throughout your day. You will be given short lessons about photography and learn how to use a digital camera.

You and the researcher will schedule two meetings based on your treatment schedule/hospital schedule. Each meeting’s duration time may be based on how you are feeling and your interests, but can last a maximum of 1 hour. During the first meeting, after attaining consent and assent forms from you, the researcher will teach a short photography lesson covering topics such as what makes a photograph, how a photograph is taken, and how to use a point and shoot digital camera. Next, you will receive a digital camera and the researcher will teach you how to use it. The researcher will then discuss the goals of the program. You will not be given mandatory rules or outlines for what you should photograph during your project participation. The researcher will suggest that you take photos of what you want to express, show, or find interesting, scary, fun, etc. The researcher will ask that you do not take pictures of or with other patients. If you wish to
SNAPSHOT! Photography Research Study: Behavioral Research Informed Consent

take photos of your doctor, nurse, or other people that work at [Name of Hospital], you must ask their permission first. This session may last up to 1 hour based on your interest.

During the next meeting, you and the researcher will look at all the photographs you took. The researcher will ask you to choose three or four images to talk about during an interview.

The interviews will be audio recorded by the researcher, Katelyn Schlosser, for data collection and analysis. Prints of the three or four chosen images will be made for ease in discussion, viewing, and verification for audio transcription. The tapes and transcriptions will be stored separately and kept secure in a locked cabinet in the Child Life office at [Name of Hospital] to protect participant’s identity. It is anticipated that the transcription will be completed within a three-month period.

After the interview is over, the researcher will give you printed copies of the three to four images you shared with them. This session will last a maximum of 1 hour.

Benefits

The possible benefits to you for taking part in this research study are that this study and program offers a tool you can use for self-expression and creative thinking. You will learn about photography and how to use a point and shoot camera.

This study is also important to Child Life Services. By seeing how school-age and teenage patients receiving hematolgy/oncology services view their surroundings, interactions, and experiences in and out of the hospital setting, health care professionals will be able to better understand how to adjust the hospital setting and make suggestions for adjustments at home. We will be able to see how children view their hospital and home experiences and learn about their stressors and positive ways to help them cope.

Risks

By taking part in this study, you may experience the following risks: You may not be comfortable meeting one on one with the researcher during the program, in which case, your parent would be able to attend the program. If you are not comfortable sharing your thoughts about the photographs taken, you will not be asked to share. There is a possible loss of confidentiality because you will be taking photographs that may identify yourself or others.

The following information must be released/ reported to the appropriate authorities if at any time during the study there is concern that:
  o child abuse or elder abuse has possibly occurred,
  o you disclose illegal criminal activities, illegal substance abuse or violence
SNAPSHOT! Photography Research Study: Behavioral Research Informed Consent

Study Costs

- Participation in this study will be of no cost to you.

Compensation

You will not be paid for taking part in this study. You will receive a point and shoot camera to use throughout the project and keep after participating in addition to printed images of your three or four favorite photos and a memory card containing the digital images you took during participation.

Research Related Injuries

In the event that this research related activity results in an injury, treatment will be made available including first aid, emergency treatment, and follow-up care as needed. Care for such will be billed in the ordinary manner to you or your insurance company. No reimbursement, compensation, or free medical care is offered by [University Affiliated with Hospital], [Hospital Medical Center], or [Name of Hospital]. If you think that you have suffered a research related injury, contact the PI right away at [PI Phone Number].

Confidentiality

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Institutional Review Board (IRB) at [University Affiliated with Hospital], or federal agencies with appropriate regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records.

When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity.

If photographs, videos, or audiotape recordings of you will be used for research or educational purposes, your identity will be protected or disguised. Your study information will be kept confidential by the researcher’s use of pseudonyms (made-up names) when the research is published. In addition, images used in the publication of the research that may disclose the identity of individuals (faces, addresses, license plate numbers) can be blurred to protect confidentiality and privacy and will only be used if you and your parent choose to sign a photo consent form.

Your answers will be recorded on an audio tape. The tape will be locked in a cabinet in the [Name of Hospital] Child Life Office until the study is done. The answers on the audio tape will be typed out on paper. Nothing that identifies you will be included. You will be given a
SNAPSHOT! Photography Research Study: Behavioral Research Informed Consent

made-up name so your identity will be unknown. There will not be a list that connects your name with the made-up name. After the study is done, the audio tape will be erased.

Voluntary Participation/Withdrawal

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you decide to take part in the study you can later change your mind and withdraw from the study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with [University Affiliated with Hospital] or its affiliates, or other services you are entitled to receive.

The PI may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study.

Questions

If you have any questions about this study now or in the future, you may contact Katelyn Schlosser or one of her research team members at the following phone number [PI Phone Number]. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at [IRB Chair Phone Number]. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call [Additional Phone Number] to ask questions or voice concerns or complaints.
SNAPSHOT! Photography Research Study: Behavioral Research Informed Consent

Consent to Participate in a Research Study

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

________________________________________
Signature of participant / legally authorized representative

____________________
Date

____________________
Printed name of participant / legally authorized representative

____________________
Time

____________________
Signature of witness**

____________________
Date

____________________
Printed of witness**

____________________
Time

____________________
Signature of person obtaining consent

____________________
Date

____________________
Printed name of person obtaining consent

____________________
Time

Submission/Revision Date: 15 July 2012
Protocol Version #: 1
Page 5 of 5
Participant’s Initials
Appendix H: Parental Informed Consent Form

SNAPSHOT! Photography Research Study: Parental Permission/Research Informed Consent

Parental Permission/Research Informed Consent
Title of Study: SNAPSHOT! Photography Research Study

Principal Investigator (PI): Katelyn Schlosser
[Name of Hospital]
Child Life Services
[Hospital Address 1]
[Hospital Address 2]
[Hospital Phone Number]

Funding Source: Pending grant funding from [Hospital Foundation]

Purpose

You are being asked to allow your child to be in a research study of pediatric patients in inpatient and outpatient hematology/oncology areas and how they view their experiences and surroundings both in and out of the hospital setting using photography because he/she is a patient receiving hematology/oncology services at [Name of Hospital]. This study is being conducted at [Name of Hospital]. The estimated number of study participants to be enrolled at [Name of Hospital] is about 10. Please read this form and ask any questions you may have before agreeing to be in the study.

In this research study, we would like to see, through the eyes and photography of children and teens who are hospitalized, how they see the world around them, their interactions, and experiences to help health care professionals understand the needs of pediatric patients in inpatient and outpatient hematology/oncology areas. How photography could be used as a coping strategy for these patients will also be looked at.

Study Procedures

If you, your child agree to take part in this research study, he/she will be asked to take photographs of their life throughout their day. They will be given short lessons about photography and learn how to use a digital camera.

Your child and the researcher will schedule two meetings based on their treatment schedule/hospital schedule. Each meeting’s duration time may vary and will be dictated by the participants based on how they are feeling and their interests, but it can last a maximum of 1 hour. During the first meeting, after obtaining consent and assent forms from you and your child, the researcher will teach a short photography lesson covering topics such as what makes a photograph, how a photograph is taken, and how to use a point and shoot digital camera. Next, your child will receive a digital camera and the researcher will teach him how to use it. The researcher will then discuss the goals of the program. The researcher will suggest that they take photos of what they want to express, show, or find interesting, scary, fun, etc. They will not be given mandatory rules or outlines.

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Parent/Guardian Initials
SNAPSHOT! Photography Research Study: Parental Permission/Research Informed Consent

for what they should photograph during their project participation with the exception of the following. The researchers will ask that your child not take pictures of or with other patients. If you child wishes to take photos of their doctor, nurse, or other [Name of Hospital] employees, they must ask their permission first. This session may last up to 1 hour based on the interest of the child.

During the next meeting, your child and the researcher will look at all the photographs your child took. The researcher will ask your child to choose three to four images to talk about during an interview.

The interviews will be audio recorded by the researchers, Katey Schlosser, for data collection and analysis. Prints of the three to four chosen images will be made for ease in discussion, viewing, and verification for audio transcription. The tapes and transcriptions will be stored separately and kept secure in a locked cabinet in the Child Life office at [Name of Hospital] to protect participant’s identity. It is anticipated that the transcription will be completed within a three-month period.

After the interview is over, your child will receive prints of their three to four chosen images and digital copies of their images on the camera’s memory card. This session will last a maximum of 1 hour.

Benefits

The possible benefits to your child for taking part in this research study are that this study and program offers a tool your child can use for self-expression and creative thinking. Your child will learn about photography and how to use a point and shoot camera.

This study is also important to Child Life Services. By seeing how school-age and teenage patients receiving hematology/oncology services view their surroundings, interactions, and experiences in and out of the hospital setting, health care professionals will be able to better understand how to adjust the hospital setting and make suggestions for adjustments at home. We will be able to see how children view their hospital and home experiences and learn about their stressors and positive ways to help them cope.

Risks

By taking part in this study, your child may experience the following risks: Your child may not be comfortable meeting one on one with the researcher during the program, in which case, you would be able to attend the program. If your child is not comfortable sharing his or her thoughts about the photographs taken, your child will not be asked to share. There is a possible loss of confidentiality because your child will be taking photographs that may identify themselves or others.

The following information must be released/reported to the appropriate authorities if at any time during the study there is concern that:
- child abuse or elder abuse has possibly occurred,
- you/your child disclose illegal criminal activities, illegal substance abuse or violence

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Parent/Guardian Initials
There may also be risks involved from taking part in this study that are not known to researchers at this time.

Study Costs

Participation in this study will be of no cost to you.

Compensation

You or your child will not be paid for taking part in this study. Your child will receive a point and shoot camera that they will use throughout the project and may keep after participating in addition to printed images of their three to four favorite photos and a memory card containing the digital images your child took during participation.

Research Related Injuries

In the event that this research related activity results in an injury, treatment will be made available including first aid, emergency treatment, and follow-up care as needed. Care for such will be billed in the ordinary manner to you or your insurance company. No reimbursement, compensation, or free medical care is offered by [University Affiliated with Hospital], [Hospital Medical Center], or [Name of Hospital]. If you think that your child has suffered a research related injury, contact the PI right away at [PI Phone Number].

Confidentiality

All information collected about your child during the course of this study will be kept confidential to the extent permitted by law. Your child will be identified in the research records by a code name or number. Information that identifies your child personally will not be released without your written permission. However, the study sponsor, the Institutional Review Board (IRB) at [University Affiliated with Hospital], or federal agencies with appropriate regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records.

When the results of this research are published or discussed in conferences, no information will be included that would reveal your child’s identity. If photographs, videos, or audiotape recordings of your child are being used for research or educational purposes, your child’s identity will be protected or disguised. Your child’s study information will be kept confidential by the researcher’s use of pseudonyms (made-up names) when the research is published. In addition, images used in the publication of the research that may disclose the identity of individuals (faces, addresses, license plate numbers) can be blurred to protect confidentiality and privacy and will only be used if you choose to sign a photo consent form.
Your child’s answers will be recorded on an audio tape. The tape will be locked in a cabinet in the [Name of Hospital] Child Life Office until the study is done. The answers on the audio tape will be typed out on paper. Nothing that identifies your child will be included. Your child will be given a made-up name so their identity will be unknown. There will not be a list that connects your child’s name with the made-up name. After the study is done, the audio tape will be erased.

Voluntary Participation/Withdrawal

Taking part in this study is voluntary. You have the right to choose not to allow your child to take part in this study. If you decide to allow your child to take part in the study you can later change your mind and withdraw from the study. You and/or your child are free to only answer questions that you want to answer. You are free to withdraw your child from participation in this study at any time. Your decisions will not change any present or future relationship with [University Affiliated with Hospital] or its affiliates, or other services you or your child are entitled to receive.

The PI may stop your child’s participation in this study without your consent. If your child has any side effects that are very serious or if your child becomes ill during the course of the research study your child may have to drop out, even if you would like to continue. The PI will make the decision and let you know if it is not possible for your child to continue. The decision that is made is to protect your child’s health and safety, or because it is part of the research plan that people who develop certain conditions do or do not follow the instructions from the study doctor may not continue to participate.

Questions: If you have any questions about this study now or in the future, you may contact Katelyn Schlosser or one of her research team members at the following phone number [PI Phone Number]. If you have questions or concerns about you or your child’s rights as a research participant, the Chair of the Institutional Review Board can be contacted at [IRB Chair Phone Number]. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call [Additional Contact Phone Number] to ask questions or voice concerns or complaints.
**Consent to Participate in a Research Study:**
To voluntarily agree to have your child take part in this study, you must sign on the line below. If you choose to have your child take part in this study, you may withdraw them at any time. You are not giving up any of your or your child’s legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Date of Birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Signature of Parent/Legally Authorized Guardian</td>
<td>Date</td>
</tr>
<tr>
<td>Printed Name of Parent Authorized Guardian</td>
<td>Time</td>
</tr>
<tr>
<td>Signature of Witness (When applicable)</td>
<td>Date</td>
</tr>
<tr>
<td>Printed Name of Witness</td>
<td>Time</td>
</tr>
<tr>
<td>Oral Assent (children age 7-12) obtained by</td>
<td>Date</td>
</tr>
<tr>
<td>Signature of Person Obtaining Consent</td>
<td>Date</td>
</tr>
<tr>
<td>Printed Name of Person Obtaining Consent</td>
<td>Time</td>
</tr>
</tbody>
</table>

Submission/Revision Date: 15 July 2012
Protocol Version #: 1

Parent/Guardian Initials
Appendix I: Photographic/Publicity Release Form

PHOTOGRAPHIC/PUBLICITY RELEASE FORM

Date:     Time:     Purpose:

Patient Name (PLEASE PRINT): ____________________________ Date of Birth: ____________

Address: ____________________________ City: ____________________________ State: ____________ ZIP: ____________ Telephone: ____________

Consent and permission is hereby granted to ____________________________ its agents and employees and to any person, firm or organization that ____________________________ may designate or authorize to take photographs, pictures or motion pictures of me or any parts of my body. I further consent to the use of my likeness and voice in electronic or communication transmission including but not limited to film, videotape, internet, advertising or other forms of recording for the use in the production of materials by, for, or about ____________________________ and its activities.

This consent also includes the use of my name and pertinent data about me and/or my medical condition when used in conjunction with the production and release of information about ____________________________ activities.

I hereby authorize ____________________________ its agents and employees and any person, firm or organization that ____________________________ may designate or authorize to use such information and photographs, pictures or motion pictures with or without my name and biographical data concerning me, modified or retouched, for any and all of the following purposes for a period of five years from the date indicated above: NOTE: The signer may strike-out and initial any of the purposes below not desired.

  ________ News release  ________ Newspaper interview  ________ Television/radio news interview
  ________ Television commercial  ________ Radio commercial  ________ Billboards
  ________ Brochures  ________ Direct mail  ________ Release to other electronic communication
  ________ Fund raising and publicity  ________ Educational, Instructional or activities
  ________ Other

Further, I hereby waive and forego any right, entitlement or claim I might otherwise have to any compensation, fees or benefit by reason of any appearance or publication in any communication media (including reproductions or reprints) in accordance with the above. I specifically release ____________________________ its agents and employees and any person, firm or organization that ____________________________ may designate or authorize, from any liability or other obligation arising out of the use of such information and/or photography as I have herein authorized or from the use of any materials furnished by me in conjunction therewith.

I understand that I may request the cessation of the production of the recordings, film or other images of me and that I may revoke this Authorization at any time by notifying, in writing, Public Relations & Marketing, at ____________________________. If I choose to revoke this Authorization, I understand that my revocation will not affect any actions before receiving my revocation.

Patient signature: ____________________________ Parent/Guardian/Representative signature: ____________________________

Witness: ____________________________ Employee: ____________________________ Hospital/Clinic/Facility: ____________________________

8L-1372 (9/91)

NOT A PERMANENT PART OF THE MEDICAL RECORD
Appendix J: Preparticipation Photography PowerPoint Lesson

SNAPSHOTI Photography Program and Research Study
Lesson: What Is Photography?

What Makes a Photograph
Subject Lighting Composition

Subject:
Who, What, Where, When, Why?

Subject:
What happens when the light
behind an object in a photograph
is brighter than the light falling
on the object.

Silhouette:
What the eye of the
camera is open longer;
moving objects appear
blurred.

Soft Light: Light that shine
more evenly across the
object. This decreases
sharper shadows and
looks less
dramatic.

Hard Light: Light that shine
less evenly across the
object. This creates darker,
dramatic shadows.
Point of Interest

Position:
Point of focus is within a frame, drawing attention to the object you want to show off.

Contrast:
One object stands out from the background or other objects in the photograph.

Composition

Repetition:
Objects or background make a pattern in the picture. One thing could be multiplied many times over.

Depth of Field:
One object in the picture is in focus while the rest is blurry. This is also called selective focus.

Rule of Thirds

Divide the picture in thirds vertically and horizontally. Try putting your main subject in one place where the lines make a plus sign (+) to make the subject a terms off center and draws attention to it.

“Chimp-ing”

Word “To Chimp”
To look at the photos, you look right after you take it. Sometimes making “ooh ooh, ah ah shhh” noises similar to a chimpanzee when excited about the photo you took.

Now You’re Ready!

Get your camera and take some photos!
Appendix K: Post-Participation Participant Interview Script

Snapshot Photography Program and Research Project
Post-Participation Interview Questions

1. Age
2. Why did you sign up for the Snapshot Program?
3. Have you taken photographs before enrolling in Snapshot?
4. What do you like to take photographs of?
5. Which four (4) photographs would you like to talk about today?
6. Which photo, of the four you chose, is your favorite?
7. Please describe this photo for me.
8. Where were you when you took this photo?
9. Why is this photo your favorite?
10. What feelings do you have when you look at this photo?
11. What does this photo make you think about?

The following questions will be asked for the next three (3) photographs.
12. Please pick the next photo you would like to talk about.
13. Please describe this photo for me.
14. Why did you choose this photo?
15. Where were you when you took this photo?
16. What feelings do you have when you look at this photo?
17. What does this photo make you think about?

Additional questions
18. What was your favorite part about the Snapshot Photography Program?
19. What did you learn from this program?
20. Do you think that you will keep taking photographs?
## Appendix L: Image Descriptions Matched to Participants

<table>
<thead>
<tr>
<th>Image</th>
<th>Participant One</th>
<th>Participant Two</th>
<th>Participant Three</th>
<th>Participant Four</th>
<th>Participant Five</th>
</tr>
</thead>
<tbody>
<tr>
<td>Image 1</td>
<td>Participant one’s nook cover. Participant altered color to be black and white. (Figure 4.7)</td>
<td>Participant two’s father seated in participant’s room. His hands are up, making a silly face. Taken from participant’s bed.</td>
<td>Bell in the outpatient hematology/oncology clinic. (Figure 4.4)</td>
<td>Egg drop soup in bowl. Taken from a downward angle by participant. (Figure 4.6)</td>
<td>Participant’s doctor smiling; taken from participant’s view from hospital bed</td>
</tr>
<tr>
<td>Image 2</td>
<td>Participant one’s chemotherapy treatment tube across her leg. (Figure 4.8)</td>
<td>Balloon given to participant by her favorite nurse. Taken in participant’s hospital room. (Figure 4.3)</td>
<td>Participant three and his social worker, taken by participant by turning the camera around</td>
<td>Participant four’s parents seated in his hospital room. Taken from patient’s perspective from bed.</td>
<td>Library staff member smiling; taken from perspective of patient on the outside of the library desk</td>
</tr>
<tr>
<td>Image 3</td>
<td>Friendship bracelet on participant one’s ankle. (Figure 4.9)</td>
<td>Participant’s mother with pet therapy dog.</td>
<td>The blood pressure machine in a clinic treatment room. (Figure 4.5)</td>
<td>Participant four and his nurse in the participant’s room. Taken by participant’s parent.</td>
<td>Side view of medical staff member playing piano in the hospital chapel; taken from participant’s perspective</td>
</tr>
<tr>
<td>Image 4</td>
<td>Participant sitting in bed with the pet therapy dog. Photo taken by parent.</td>
<td>Participant three on the exam table in a clinic treatment room. Taken by participant by turning the camera around.</td>
<td></td>
<td></td>
<td>View of historical looking building, taken from perspective of participant’s hospital room window. Participant altered color to sepia tone (Figure 4.1)</td>
</tr>
</tbody>
</table>