A Retrospective Look at How Effectively Parents, Peers Without a Chronic Illness, and Other Adolescents With a Chronic Illness Impact the Self-Esteem and Body Image of Adolescents With a Chronic Illness

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This thesis titled
A Retrospective Look at How Effectively Parents, Peers Without a Chronic Illness, and
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Adolescents With a Chronic Illness

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Abstract

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A Retrospective Look at How Effectively Parents, Peers Without a Chronic Illness, and Other Adolescents With a Chronic Illness Impact the Self-Esteem and Body Image of Adolescents With a Chronic Illness

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Statement of the problem: The developmental task for adolescents to accept their body may be hindered by the diagnosis of a chronic illness. There is a lack of adequate support or resources to assist adolescents with a chronic illness in building a positive body image and self-esteem.

Methodology: A retrospective interview was conducted with three adults who were diagnosed with a chronic illness during or prior to adolescence. The interview consisted of body assessment questions and questions about their process of building self-esteem and a positive body image. There was also a Rosenberg’s Self-Esteem Scale for both their current self and adolescent self, completed prior to the interview.

Conclusion: Adolescents with a chronic illness benefit from parents, peers without a chronic illness, and other adolescents with a chronic illness, as long as those groups are supportive. The primary source of self-esteem and positive body image comes from body acceptance, which is facilitated through positive, supportive interactions with the aforementioned groups.
Dedication

Joan Jurich, thank you for bettering my research with your time, knowledge and wisdom. It was invaluable and greatly appreciated. You have made many great contributions in your life and I am glad you chose my thesis as one of those. You have left a positive impact on numerous people, including myself, and I am so grateful to have been able to work with you throughout my graduate school experience at Ohio University.
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Chapter 1: Introduction

Background Information

Each stage of life has developmental tasks associated with it; in order to be successful in a later stage, the preceding tasks must be achieved. One of the developmental tasks in adolescence is accepting one’s body (Seiffge-Krenke, Kiuru, & Nurmi, 2010). Acceptance means to acknowledge something without judgment or the desire to avoid or change it (Atkinson & Wade, 2012). With body acceptance, this would mean individuals acknowledge their chronic illness and the differences it may have caused to the body, but they do not wish to alter their body. If adolescents are experiencing high stress during this developmental period, the task of accepting their body may become more difficult to achieve (Seiffge-Krenke et al., 2010). Therefore, it is likely that adolescents who are dealing with the stress of a chronic illness may have difficulty accepting their body, potentially leading to a negative body image.

There are almost twice as many hospitalized children aged 4 and under than children ages 5-14 (Child Life Council [CLC], 2006). Because the majority of the population in pediatric hospitals is young children, child life activities tend to be aimed toward those younger children instead of adolescents. However, the CLC (2006) mentions that patients with chronic illnesses are now living well into their adolescence, meaning the prevalence of adolescents being hospitalized in a pediatric hospital for frequent and/or long-term stays has increased. Certified Child Life Specialists (CCLS) need to have programs aimed at adolescent patients with chronic illnesses who have frequent or long-term hospitalizations to address the developmental needs of adolescence.
Addressing developmental needs for adolescent patients includes facilitating peer interactions and promoting positive identity development. Those two areas are especially important because the patient’s ability to cope with hospitalization and diagnosis stressors is impacted by his or her body image, self-worth, and attitude toward the illness (Kaddoura, Cormier, & Leduc, 2013). Peer interactions and positive identity development may lead to better coping, ultimately decreasing hospitalization and diagnosis stressors.

Issues for adolescents pertaining to hospitalization include fear of losing their identity, concerns of body image, separation from family and peers, as well as a concern about their status in their peer group after hospitalization (Rollins, Bolig, & Mahan, 2005). Adolescents may respond to these fears with anxiety, withdrawal and depression. To combat those possible negative responses, Rollins et al. (2005) suggest addressing body image concerns, encouraging peer group activities within the hospital and facilitating peer visits.

Terms Defined

**Child life profession.** CCLSs are part of the psychosocial team in a pediatric hospital setting. One of their main goals is to minimize the adverse effects of the stress associated with hospitalization. CCLSs are educated in human growth and development and are able to predict how children may react to hospitalization (Kaddoura et al., 2013). With this education, CCLSs understand the possible reactions for each age group and can therefore try to prevent those negative reactions. They strive to decrease the stress of hospitalization by promoting optimal development by providing health education to the
patient and family, preparing the patient and family for medical procedures through play and developmentally appropriate communication, enhancing the patient’s coping skills, helping the patient express emotions about past or future events, and establishing a therapeutic relationship with the patient and the important people in the patient’s life (CLC, 2006).

**Chronic illness.** A chronic illness is defined as such when daily functioning is affected for more than 3 months a year, individuals are hospitalized for 1 month of the year, and/or when individuals require the use of an adaptive device (Muscari, 1998). Two decades ago, 10% of U.S. children were diagnosed with a chronic illness (Muscari, 1998) and as of 2016 the Office of Adolescent Health reported the rate to be 31% (U.S. Department of Health and Human Services). A few examples of chronic illnesses are: cystic fibrosis, asthma, diabetes, sickle cell anemia, cerebral palsy, and cognitive defects (Muscari, 1998). In 2006, the most prevalent juvenile chronic illnesses in the U.S. were asthma, obesity and cognitive delays (Lowry, 2010). The impacts of a chronic illness are most prominent during adolescence (Muscari, 1998). To combat these impacts, Muscari (1998) suggests fostering self-esteem by helping the adolescent set realistic goals, encouraging socialization with both healthy and ill peers, and joining support groups for those with the same chronic illness.

**Body image.** Body image is how one views oneself, which is determined by both present and past experiences with one’s body (Walker, 2009). Walker (2009) describes body image as developing from birth, so it is a continuous process of reintegrating new perceptions of one’s body. By early middle childhood, individuals have developed
concrete operational thinking and can therefore reflect on their experiences as well as understand other’s thoughts, which both play a part in the development of body image (Walker, 2009). Body image is developed through a “mirror viewing” process that Price (2009) described as the internalization of comments and life experiences that adolescents receive from peers in regards to their appearance or body’s abilities. To assess body image, one must consider the individual’s view of his or her appearance, his or her body competence, how others have reacted to his or her body, and the value he or she places on appearance (Biordi & Galon, 2013). With a chronic illness, these aspects such as appearance and body competence may change over time, so individuals must learn to adjust and adapt to body image fluctuations (Biordi & Galon, 2013).

**Self-Esteem.** Self-Esteem refers to the confidence one has in one’s self and abilities. Self-esteem is especially important during adolescence and when events outside of the adolescent’s control (such as the diagnosis of and hospitalization for a chronic illness) occur, he or she may become stressed. This stress is what can lead to a disturbance in body image and ultimately body dissatisfaction (Murray, Rieger, & Byrne, 2013). Self-esteem is already fragile during adolescence, but having a chronic illness makes maintaining self-esteem even more difficult (Preechawong et al., 2007). Hospitalization or dealing with a diagnosis and the physical differences it causes could be stressors that might make body acceptance difficult, leading to low self-esteem.

**Statement of the Problem**

The principal researcher observed underrepresentation of services and support for adolescents with a chronic illness in her Child Life practicum and volunteer experiences.
Due to this age group being sensitive to body image and self-esteem, with the added stress of hospitalization and/or a chronic illness, there is a distinct need for support. The following questions were posed in order to determine the most effective form of support for adolescents with a chronic illness: (a) who was the most helpful in fostering the participant’s self-esteem and body image during adolescence; (b) in what ways did the participant and the helpful person interact; (c) what is the relationship between body image and self-esteem for the participant; and, (d) how can the results of this study be transformed into better resources to be used in pediatric hospitals for adolescents with a chronic illness?

**Hypothesis.** Adolescents with a chronic illness experience more isolation than their peers without a chronic illness and connecting them to social support is highly important (Nicholas et al., 2007). This isolation may contribute to negative body image and low self-esteem. The principal researcher believes further research in the area of self-esteem and body image in adolescents with a chronic illness will suggest that adolescents rely more on peers who can relate to their experience (meaning either that they have been hospitalized or share their chronic illness) for developing positive body image and self-esteem than on parents or friends from outside the hospital. Therefore, the principal researcher thinks the impact this research will have on CCLSs is that they will need to be educated regarding online support groups/networks and advocate for their use in pediatric hospitals. Once online networks are created and actively utilized, they will be an important resource to provide to adolescent patients.
This generation of adolescents is tech-savvy and understands how to use online resources (Nicholas et al., 2007). These networks can connect them to peers who share their experience, provide more education on their illness and provide a place in which the adolescent can safely compare themselves to similar peers, which are all protective factors against developing low self-esteem (Pinquart, 2012). The CCLS could update these networks with current realistic information on chronic illnesses using developmentally appropriate language, as well as monitor online chat rooms/discussion boards for appropriateness. The CCLS may also be able to use the chat rooms/discussion boards as a means of assessment and utilize that for intervention plans. For example, if an adolescent posts something nonfactual on the discussion board, the CCLS could converse with the adolescent about the post. The conversation would be to assess whether the misconception came from a need for accurate information or whether the post was coming from an expression of feelings. Then, based on whether it was a lack of knowledge or expression of feelings, the CCLS could provide education or a self-expressive activity and processing of emotions, respectively.

**Rationale for Present Study**

Adolescents face a critical crisis, figuring out and then accepting their identity, according to Erikson’s psychosocial theory (Svetnia, 2014). Those with a chronic illness are continuously going through bodily changes due to periods of exacerbation or remission of the symptoms their illness causes and this change causes a need to reintegrate their sense of self (Lubkin, 1998). This means adolescents with a chronic
illness are continually dealing with a changing body image, which impacts their sense of identity, making achievement of their psychosocial crisis difficult.

According to Lubkin (1998), there are four stages of structuring one’s body image, which are the impact, retreat, acknowledgment, and reconstruction stages. The impact stage is when individuals with a chronic illness focus their energy on the illness itself and not the effects it is having on their body (Lubkin, 1998). After the impact stage, they recognize their body has changed, but they have no remaining energy to address the issue and instead focus on building energy for any upcoming battles with the illness (Lubkin, 1998). According to Lubkin (1998), individuals in the retreat stage may also be in denial, leading to feelings ranging from apathy to joy. In the acknowledgment stage, individuals realize that their body image is no longer ideal and they face any losses that have occurred due to the illness (Lubkin, 1998). Lubkin (1998) states that this is a time when individuals may experience a need to be alone and that the reactions and responses of others are critical to them as they undergo the process of redefining their body image. During this time, individuals will need to discuss their chronic illness and the changes that have occurred to their body and body’s abilities (Lubkin, 1998). The final stage is reconstruction, which, according to Lubkin (1998), is when individuals readjust to their body, reorient themselves to social situations, and reintegrate their new body image into their life.

These stages of restructuring body image after a bodily change due to a chronic illness are important because they allow professionals to recognize what the patient is going through. It provides insight into when it could be appropriate for a CCLS, parent,
or peer to intervene and help in the process of that individual obtaining a positive body image. It is apparent that chronic illnesses cause changes in body image and that restructuring body image could have a negative or positive outcome, both likely affecting the individual’s self-esteem. The aim of this study is to maximize resources that will build the adolescent’s self-esteem and foster a positive body image during a time when the stresses of a chronic illness are so prominent.

This research provided the field of Child Life a better understanding of which group of people can most effectively improve the body image and self-esteem of adolescents with a chronic illness. Not only did we find which group tends to be most effective, but we also found what it is they do that makes them effective at improving the self-esteem and body image of adolescents with a chronic illness. The results could lead to:

1. Better CCLS-parental facilitation of activities that improve the adolescent’s body image and self-esteem and/or better education from the CCLS to the parent on how to do this.

2. A more effective partnering of hospital and school to provide more opportunities for healthy peer interaction and/or CCLS integration into schools to provide the peers without a chronic illness with accurate information about the chronic illness and how to interact with that peer.

3. The creation of or more use of online support groups for adolescents with similar chronic illnesses and/or more adolescent-specific group activities within pediatric hospitals.
Potential Limitations of Present Study

Limitations of this study lie in the design, such as the retrospective interviewing. The participants were required to be 18-28 years of age because adolescence is 12-18 years and memory editing in retrospection should be limited if the potentially oldest participant is only 10 years removed from the latest year of their adolescence. However, it should be noted that memory can be faulty, which is why a retrospective design is a limitation. Another limitation in the design is the self-reporting aspect. Because the participant is reporting, they could possibly report what they think the principal researcher wants to hear.

Those limitations cannot be controlled in this study, but even with them present, results from the study can still be valid for achieving the intended outcome of the research. Even if there is memory editing or faulty self-reporting, the participants will be able to describe which group (parent, healthy peer, or another adolescent with a chronic illness) they feel would have been most effective at improving their self-esteem and body image and why. This is important because the goal of this study was to improve the resources for adolescents with a chronic illness to enhance their self-esteem and body image. Having reports from individuals who have gone through that time and struggled with the stress and effects of a chronic illness on self-esteem and body image will be helpful in achieving that outcome.

Delimitations

Participants in this study must have been diagnosed by age 12 with a chronic illness, as defined previously. They must have been aware of their chronic illness
diagnosis during their adolescence, 12-18 years of age. During participation in the study, they must have been aged 18-28. The age range to participate was chosen in the hope of limiting memory editing due to the retrospective design of the study. The individuals who participated in the study were recruited from flyers passed out by the principal researcher, announcements made in classes at a university in the mid-west and electronic versions of the flyer posted to Child Life forums and social media sites.
Chapter 2: Review of Literature

This review focused on the three groups this research examined in terms of which were most efficient at improving the body image and self-esteem of adolescents with a chronic illness. Those groups are: parents of the adolescent with a chronic illness, peers without a chronic illness and other adolescents who also have a chronic illness. It also reviewed the theoretical lenses used to frame this research, Erikson’s psychosocial theory and Piaget’s cognitive theory.

Background on Child Life

The rationale for child life programs in the hospital is based on the observation of hospitalized pediatric patients. A negative emotional impact was observed due to the stress of the hospital and/or diagnosis. Developmental interruptions due to hospitalization and a loss or regression of self-esteem were also observed (Wojtasik & White, 2009). In 1979, the Association for the Care of Children’s Health (ACCH) drafted The Child Life Position Statement which contains the rationale for child life programs, the theories and philosophies that ground the field, the requirements for practicing as a CCLS and the essential components of a child life program (Wojtasik & White, 2009). Some of those components are opportunities for self-expression, maintaining family relationships, providing life experiences, and promoting the maintenance of self-esteem (Wojtasik & White, 2009).

The Child Life Position Statement was updated in 2006 by the American Academy of Pediatrics (AAP) and has most recently been updated in 2014 as the Policy Statement of Child Life Services of the AAP. The more recent statement acknowledges
that patients with chronic illnesses are living longer, so they face the challenge of transitioning out of the pediatric hospital to adult facilities for their care (Committee on Hospital Care [CHC] & CLC, 2014). CCLSs can facilitate this transition by educating patients and discussing what the patient may expect or fear, as well as their hopes and needs (CHC & CLC, 2014). AAP’s policy statement also suggests that activities allowing for maintenance of peer relationships and the establishment of new relationships are beneficial for adolescent patients. To accomplish the maintenance of prior and establishment of new relationships, the Policy Statement suggests activity rooms for adolescent patients and online support groups (CHC & CLC, 2014).

**Adolescent Stressors**

Adolescence is a time in which individuals need to adjust to bodily changes (Krayer, Ingledew, & Iphofen, 2008). This is a transition period and with stress during the transition, positive adjustment may be difficult to achieve. Adolescents have a need for privacy (Rollins et al., 2005). With the bodily changes they are trying to adjust to and the invasion of privacy that is to be expected during hospitalization, a hospital is a stressful environment for adolescents. Procedures that physically invade the body, hospital staff needing to enter into the privacy of adolescents’ hospital rooms, and the requirement to share private information to facilitate their healthcare can all add to this stressful transition period of adolescence.

Adolescence is also a time to develop a personal and social identity (Krayer et al., 2008). Peers serve many purposes during adolescence, one of which being a point of comparison against which adolescents evaluate themselves (Krayer et al., 2008). This
evaluation contributes to the development of identity. Adolescents with a chronic illness may choose a healthy peer as their target of comparison and compare an attribute on which they are impaired, resulting in a negative appraisal of him or herself. These evaluations based on comparisons are central to body image development (Krayer et al., 2008).

In the hospital, adolescents face many stressors due to their developmental stage, which as previously shown includes the importance of peers and one’s body. Some other hospital stressors include separation from group activities, isolation from peers and insecurities about their appearance (Rollins et al., 2005). Connections and relationships are important to adolescents, but the hospital is not always conducive to these important aspects of adolescence (Nicholas et al., 2007). Adolescents also experience stress due to having a lack of control and loss of independence during hospitalization (Rollins et al., 2005). Having opportunities for age-appropriate play that contributes to mastery and achievement would help lessen specific stressors (Olson, 2010). Olson (2010) suggested that video games are an age-appropriate activity that can be used to promote mastery and achievement. In addition, research has shown that playing video games leads to adolescents having less loneliness, more feelings of friendship, and an outlet for emotions (Olson, 2010).

**Adolescents with a Chronic Illness**

Adolescents who have a chronic illness may have visible differences and/or limited competencies in both academics and physical activities, which may lead them to have a negative body image and low self-esteem. Golan, Hagay, and Tamir (2014) found
that for adolescents with higher self-esteem, appearance had less of an influence on self-worth and that those with higher self-esteem also find more positive qualities within themselves. Self-worth and finding positive qualities about oneself may be difficult for adolescents with a chronic illness, so it is important to encourage the development of positive self-esteem in these adolescents.

Other research has suggested that accepting (adapting and tolerating) the diagnosis greatly influences the well-being of individuals with a chronic illness (Casier et al., 2013). Casier et al. (2013) described acceptance as “the strength to focus on what is pleasurable in life despite being ill” (p. 1347). Without acceptance, having a chronic illness can be a risk factor for developing depression, problem behaviors, and impairments in academic, physical, and social functioning. With acceptance, individuals with a chronic illness can have more positive outcomes, such as less anxiety, disability, and depression and better social, emotional, and physical functioning (Casier et al., 2013).

Adolescence and Self-Esteem

In general, there are a few factors that can affect the reporting of self-esteem. The first is age. Adolescents tend to report lower self-esteem than children do because individuals do not start comparing themselves to others until adolescence (Pinquart, 2012). Pinquart (2012) also mentioned that children in middle childhood tend to overestimate their abilities, and a major source of self-esteem is competence in abilities. Since adolescents have a clearer view of their abilities, if they lack certain abilities, this could contribute to a lower report in self-esteem. A second factor in self-esteem reporting
is gender. Males tend to have higher self-esteem than females because women are typically dissatisfied with their body and base a majority of their self-esteem on their appearance (Pinquart, 2012). Another major influence on how adolescents report their self-esteem is what Pinquart referred to as a “self-protective process” (2012). This occurs when adolescents have a desired competence that differs from their actual competence, and they become uncertain about how to respond (Pinquart, 2012). An example of this could be adolescents who have the desire to be a great long-distance runner. To protect their self-esteem, these adolescents may tell themselves that their body is competent in running, when in fact, their muscles could fatigue easily or their lungs may not have the capacity to run long distances. When it comes time to report on their self-esteem, adolescents have to choose whether to report based on a self-protective view of their body or on the realistic view of their body’s capabilities. Adolescents reporting their self-esteem may also under-report issues with their self-esteem due to wanting to give a socially acceptable answer (Pinquart, 2012).

The CLC (2006) stated the importance of involving adolescent patients in activities that promote self-esteem. Sources of self-esteem can be parental and peer acceptance, perceived competence in physical and academic activities, and physical appearance, which is the most important factor in self-worth during adolescence (Pinquart, 2012). One study found that pediatric cancer patients who had a positive perception of their physical appearance had the outcome of higher self-esteem (Walker, 2009). Therefore, adolescents who do not have that positive perception of their body are at a higher risk for low self-esteem.
Adolescence and Body Image

According to Pinquart (2013), body image is the attitude and perception one has of their body and having a negative body image can lead to depression, anxiety, low self-esteem and insufficient self-care. Adolescents who have a chronic illness are impacted in multiple ways, including an impact on their degree of socialization, psychological well-being and body image (Johnson, Ravert, & Everton, 2001). Walker (2009) stated that a chronic illness that causes a physical change could have a prominent effect on body image. More negative effects on body image are expected to be found if adolescents have multiple aspects of their physical appearance affected by the chronic illness, they have experienced more bullying or teasing due to their physical appearance, and/or they do not have effective coping strategies in place (Pinquart, 2013). Individuals with a negative body image may display nonverbal clues, such as: hiding parts of their body, needing an excessive amount of reassurance from others, exaggerating their behaviors when in pain and having regressive behaviors (Walker, 2009). A few other signs that may indicate a negative body image include difficulty sleeping or nightmares, social or emotional withdrawal, and aggression (Walker, 2009).

Parents Fostering Self-Esteem and Body Image

Family functioning plays a role in how adolescents cope with hospitalization and their diagnosis (Preechawong et al., 2007). Preechawong et al. (2007) found that patients with a cohesive family were better able to actively cope with their situation. Family functionality being cohesive means that the members of the family are able to relate well to each other, they follow accepted routines, and they are fulfilling all the necessary roles
and tasks associated with those roles (Preechawong et al., 2007). In one study, it was found that self-esteem was strongly predicted by family functioning, and that less satisfaction with family relationships predicted lower self-esteem (Preechawong et al., 2007).

Parental perceptions and comparison of oneself to friends and family is related to self-worth, which affects self-image (Golan et al., 2014). It was found that adolescents are more likely to achieve developmental tasks, such as accepting their body, when their parents have an authoritative parenting style and support their adolescent’s autonomy (Seiffge-Krenke et al., 2010). Child life professionals aim to continually support natural family roles during hospitalization. A philosophy of Child Life is that families provide the most supportive relationships because they are the ongoing caregivers; the family knows the patient best; the roles of the family are familiar to the patient; and, typically, the family is committed to the best interests of the child (Gaynard et al., 1998).

**Peers Without a Chronic Illness Fostering Self-Esteem and Body Image**

The approval and support from peers is especially important to the process of accepting oneself and one’s body (Price, 2009). In order for individuals to have a successful life, according to Price (2009), they must trust and like their own body. If adolescents view their body as problematic or feel like they cannot control their body, which is often the case with individuals who have a chronic illness, they may start to isolate themselves from peers and social situations (Price, 2009). Adolescence is a time when physical appearance is starting to become a focus and thus peers may react negatively to someone whose chronic illness has visible effects that make them less
physically attractive (Pinquart, 2013). This means it is important to foster peer relationships that are accepting and nonjudgmental.

Positive outcomes such as less aggression, better control of illness, and more emotional stability have been linked to positive peer relationships between children who do not have a diagnosis and children with a chronic illness (McCarroll, Lindsey, McKinnon-Lewis, Chambers, & Frabutt, 2009). However, a study found that children with a chronic illness were more anxious in social situations than children who do not have a chronic illness. It also found that children with a chronic illness were at risk for having difficulties with relationships with peers without a chronic illness (McCarroll et al., 2009). McCarroll et al. (2009) suggested that these difficulties might arise due to the individual’s chronic illness impacting the way they feel about themselves, such as feeling like they do not fit in with their peers without a chronic illness. Essentially, if adolescents with a chronic illness have low self-esteem, this influences their behavior and leaves them vulnerable to relational difficulties. It is also important that adolescents with a chronic illness may be physically limited in the interactions they are able to have with peers without a chronic illness depending on their health status and restrictions associated with it (McCarroll et. al, 2009). Therefore, even if adolescents with a chronic illness do want to interact with their peers without a chronic illness and they would otherwise not have difficulties in relationships, their lifestyle may not allow for healthy peer relationships to develop.
Adolescents with a Chronic Illness Fostering Self-Esteem and Body Image

It is important for adolescents to feel that they are like their friends in areas such as clothing, physical appearance, physical abilities, and academic abilities to name a few (Preechawong et al., 2007). This likeness makes them more comfortable because adolescents are always comparing themselves to their peers and making judgments (Preechawong et al., 2007). If their friends are like them, they will be less likely to judge themselves harshly or negatively. According to Preechawong et al. (2007), feeling different has an effect on adolescents’ self-esteem. Hospitalization and treatment causes changes, which alter adolescents’ perception of themselves (Preechawong et al., 2007). However, if their friend is another adolescent with a chronic illness, they will likely be going through similar experiences, putting the adolescent back in that likeness comfort.

In a study about adolescents who were hospitalized with a cancer diagnosis, adolescents listed their concerns associated with their life stage. Amongst many concerns were “…isolation from peers, delayed social development, negative body image, [and] absence from education, work and the community…” (Barling, Stevens, & Davies, 2014, p. 151). Because of their diagnosis, they were scared they would be isolated and rejected, which is a valid fear because Johnson et al. (2001) reported that frequent hospitalizations, doctor visits and being excluded from activities for health-related reasons can all lead to peer isolation for adolescents with chronic illnesses. These adolescent patients expressed that support from other adolescents with cancer was more important than support from family or other healthy friends (Barling et al., 2014).
Many chronic patients continue to go to a pediatric hospital through adolescence and young adulthood simply because this facility has all of the patient’s background information. However, being an adolescent in a hospital full of younger children is isolating, just as much as it is for an adolescent to go to an adult outpatient facility and be surrounded by adults (Barling et al., 2014). This isolation and rejection that adolescent patients feel could lead to low self-esteem and according to the adolescents in this study, they want support from peers their age who are going through the same hardships. Pinquart (2012) stated that comparing oneself to other peers with chronic illnesses rather than peers without a chronic illness has been shown to be a protective process for adolescents with chronic illnesses against developing low self-esteem. Pinquart (2012) also suggested the following to promote self-esteem and try to prevent body dissatisfaction in adolescents: providing realistic information about the illness, enhancing social competence, promoting positive peer relationships, and reframing the stressors.

**Gap in Research**

In reviewing the literature, the principal researcher never found a study that compared to one another the groups (parents, peers without a chronic illness, peers with a chronic illness) that were working at improving adolescent’s self-esteem and body image. There are individual studies done on each group, as seen in the literature review, but no studies were found that compared the aspects of each group to determine what makes a certain group more effective at improving the self-esteem and body image of adolescents with a chronic illness. This study hoped to fill in that gap by having participants who
have experienced each group’s efforts speak about why one group was more effective than the others.

**Theoretical Lens**

**Psychosocial.** Erikson defined adolescence as ages 12-18 (Rollins et al., 2005). Erikson’s psychosocial theory identified eight stages that characterize an individual’s development from infancy to old age (Svetnia, 2014). He proposed that each stage presents the individual with a crisis that is due to an internal conflict (Svetnia, 2014). The crisis for adolescence is Identity vs. Identity Crisis. To mature psychosocially, the individual must resolve the crisis (Svetnia, 2014).

In adolescence, to be considered successful in psychosocial development, one must achieve identity, in which self-esteem is essential (Preechawong et al., 2007). One’s body and its capabilities are integral in self-esteem and identity formation (Walker, 2009). Therefore, it can be presumed that if one’s bodily capabilities are limited or one’s body image is negative due to a chronic illness, self-esteem could be low, which would lead to difficulty in achieving identity. Not being able to achieve a positive identity in adolescence means the adolescent’s development will be hindered. Child Life programs encourage normal development and the achievement of tasks associated with normal development (Wojtasik & White, 2009).

**Cognitive.** Piaget’s cognitive theory labels adolescence as a time of formal operational thinking, which means they can imagine the past, present, and future and figure out logically what might occur based on varying multiple factors (Rollins et al., 2005). This suggests that adolescents with a chronic illness can look into the future and
imagine what their life may become and what it could be like if they never were diagnosed with a chronic illness. Because adolescents have logic and the ability to consider the impact of multiple situational factors on their trajectory, adolescents with a chronic illness may not always see the best future for themselves. Their prognosis along with their body’s abilities could come into play, which could be depressing for an adolescent with a chronic illness, leading them to potentially dislike their body and have a negative body image. However, they also have the ability to look into the past and see what has and has not worked for them. This ability could allow adolescents with a chronic illness to see how they have developed their strengths, what makes them feel better about themselves, and apply those to their current situation. Encouraging adolescents to use this skill of self-observation may increase a sense of choice and control, which could lead to them feeling more competent in managing their lives.
Chapter 3: Methodology and Research Design

This research was designed as a retrospective study collecting qualitative data through semi-structured interviews. The objectives of this research were:

1. Discover which group of people (parents, peers without a chronic illness or adolescents who also have a chronic illness) are best able to facilitate the positive body image and self-esteem of adolescents with a chronic illness
2. Discover what methods each group used and how those methods led to positive body image and self-esteem in adolescents with a chronic illness
3. Utilize the findings to provide new or more resources for adolescents with a chronic illness in pediatric hospitals that would help foster their positive body image and self-esteem

Upon notice that an individual wanted to participate, the principal researcher set up an interview time with the potential participant and sent the participant the Rosenberg Self-Esteem Scale (see Appendix A; Rosenberg, 1989). There were two identical copies sent to the participant: one to be done based on how the participant currently felt and one to be done retrospectively based on how they felt in adolescence. This scale was created in 1965 by Dr. Rosenberg and has correlations ranging from .82-.88 in test-retests (Rosenberg, 1989). The scores can range from 0-30 and the potential participant must have scored between 15-25 to meet the criteria of currently having normal self-esteem (Rosenberg, 1989). Low self-esteem is anything under 15. The participants e-mailed the completed scales back to the principal researcher who then scored them sometime before the interview. Based on the scores for current self-esteem, a slightly different interview
guide was used for participants with low self-esteem. As part of the interview, the participants answered questions from a body image assessment (see Appendix A). Participants were then interviewed (see Appendix A) about their experiences with self-esteem during adolescence. All the interviews took place on the phone and were recorded and later transcribed by the principal researcher.

**Participants and Participant Recruitment**

**Inclusion criteria.** For individuals to be included as a participant in this study, they needed to meet all of the following criteria: be diagnosed with a chronic illness as defined previously, currently fall into the age range of 18-28, and have been diagnosed by age 12. The participants had to be diagnosed with the chronic illness by age 12 because this is the start of adolescence, which is when individuals start to compare their bodies to other (Pinquart, 2012). Being diagnosed by the start of adolescence would also give the individuals time to deal with body image and self-esteem issues as adolescents, allowing them to meaningfully report on their experiences with peers without a chronic illness, peers with a chronic illness, and parents during their adolescence. The age range for participants was set at 18-28 because it was a retrospective study and the principal researcher believed 10 years removed from the end of adolescence was an appropriate amount of time to remember the events and recall what instances led to the development of positive body image and self-esteem. Participants must have been diagnosed with a chronic illness because this is an integral variable in the study, due to effects on body image and self-esteem. Having a chronic illness may impact the body’s capabilities,
which could lead to an issue with competence for adolescents, which is a major influencer on body image and self-esteem.

**Participant recruitment.** Individuals were recruited for this study by handing out flyers (see Appendix B) in classes, which included the inclusion criteria, the thesis statement, and the principal researcher’s contact information. The principal researcher posted the same flyer as an electronic version onto social media sites, such as Facebook, Twitter, and Instagram (see Appendix B). The principal researcher also posted the inclusion criteria and thesis statement of this research on the Child Life Council’s student forum (see Appendix B). This was done in hopes that a Child Life student either fit the criteria for inclusion or that they would know an individual who fit and could pass the information along.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age (years)</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Olivia</td>
<td>Female</td>
<td>21</td>
<td>Type-1 diabetes</td>
</tr>
<tr>
<td>Taylor</td>
<td>Female</td>
<td>28</td>
<td>Quadriplegic spastic cerebral palsy &amp; asthma</td>
</tr>
<tr>
<td>Victor</td>
<td>Male</td>
<td>24</td>
<td>Cerebral palsy</td>
</tr>
</tbody>
</table>


Informed Consent Process

Subjects were recruited based on a voluntary agreement to participate in the study. After agreeing to participate, the subjects were e-mailed the purpose of the study as well as the informed consent form. They were reminded that participation at any point in the study was voluntary, and then they confirmed their reading, knowledge, and agreement via e-mail to complete the consent form (see Appendix C) to continue on in the study. After they read the informed consent form with plenty of time, the principal researcher encouraged any questions of clarification. The participants were informed that during the interview, the principal researcher would use a digital voice recorder, which would be kept in a locked cabinet in a locked office after the interview, along with the interview transcription, to ensure confidentiality.

To assure the participants of their confidentiality, the following was explained to them:

The participants will be recorded using the principal researcher’s personal digital recorder, which will be kept in a locked cabinet in a locked office when not in use. Once the recording is uploaded to software that will help in transcription and the transcription is completed and reviewed, the audio recording will be deleted from the digital recorder. The software will be on the principal researcher’s personal laptop, which is password protected. Only the principal researcher will have access to the recorder, audio recording, and laptop with the transcriptions. The transcriptions of interviews will use a pseudonym to ensure confidentiality. Transcriptions were created using
Dragon Speak software on the principal researcher’s personal computer. Those files on the computer and in the software were deleted after research completion.

The principal researcher made an Excel chart marking who had read and agreed to the electronic consent forms and the participants had access to their consent forms from the e-mail attachment. Before the interview was started, the principal researcher reminded the subjects that they could stop the interview at any time and that they were not required to answer every question if they did not want to because their participation was entirely voluntary.

**Procedure and Approach to Analysis**

**Interview procedure.** Interviews were conducted by the principal researcher in a private room and recorded by a digital recorder. Before starting the interview, the informed consent process was completed via e-mail, since all interviews were via the phone, and the participant was reminded s/he are going to be recorded and that participation was voluntary. The principal researcher conducted the interview with a semi-structured interview guide (see Appendix A) and the interview length depended on how in-depth the participant answers were, but averaged 10-15 minutes. Immediately after the interview, the principal researcher e-mailed the participant the debriefing text (see Appendix D) and a thank-you for participating. Later, the digital recording of the interview was transcribed for analysis electronically. Based on the responses in the interviews, the transcriptions were coded. The principal researcher looked at which group (parent, healthy peer, adolescent with a chronic illness) the participants responded as
having had a beneficial/effective impact on their self-esteem and body image, how the participants currently talked about their bodies and self-esteem, what hurt their self-esteem and body image during adolescence, and what was helpful to building their self-esteem and body image.
Chapter 4: Results

This chapter will use pseudonyms to discuss the participants. The results are derived from the self-esteem scales the participants filled out for both their current self-esteem and a retrospective view of their adolescent self-esteem as well as the information obtained during interviews. All of these data were coded into major themes.

Rosenberg Self-Esteem Scales

Olivia, age 21, has Type-1 diabetes. For her current self-esteem, she scored 27/30, which indicates high self-esteem. The retrospective scoring of her adolescent self-esteem was 25/30, which indicates she still had normal self-esteem on the high end, although it was slightly lower than it is now.

Victor, age 24, has cerebral palsy. For his current self-esteem, he scored 25/30, which indicates normal self-esteem on the high end. The retrospective scoring of his adolescent self-esteem was 17/30, which indicates normal self-esteem on the low end.

Taylor, age 28, has two chronic illnesses: asthma and spastic quadriplegic cerebral palsy. For her current self-esteem, she scored 10/30, which indicates low self-esteem. The retrospective scoring of her adolescent self-esteem was 2/30, which indicates very low self-esteem.
All of the participants had current scores that indicate higher self-esteem currently than the self-esteem they had during adolescence. Taylor, who had the lowest self-esteem during adolescence, still had the lowest score out of the participants. Taylor and Victor both had an increase of 8 points in their self-esteem scores since adolescence, although Taylor has had ten years for this increase, while Victor has only had 6 years since the end of adolescence. Olivia only had an increase of 2 points in her self-esteem score since adolescence. However, she has had the shortest amount of time to improve her self-esteem, being that she was only 3 years out from the end of adolescence. She also had and still has normal-high self-esteem. The potential reasons for the rises in self-esteem were discussed in the interviews.

**Common Themes**

**Physical indication of illness.** From pairing the self-esteem results with the body image portion of the interviews, a theme appeared. This theme is that with an increased physical indication of an illness, there was more reported issues with body image.
Olivia’s only indication of her Type-1 diabetes is a blood glucose monitor that she can hide under clothes. She had the highest scores for self-esteem and body image as well as the lowest indication of an illness out of the participants. Victor had the second highest self-esteem and body image scores and his only indications of having cerebral palsy are a slight limp and one hand being weaker. He stated in his interview that most people do not notice these symptoms and do not recognize that he has cerebral palsy until he tells them. Taylor, by far, had the lowest scores for both body image and self-esteem and she also had the most physical indications of having spastic quadriplegic cerebral palsy. She uses a wheelchair and also has spasticity in all four limbs. Taylor also experienced the most hospitalization for her chronic illness and stated that the constant focus on her weight and body along with being poked and prodded was damaging to her body image and self-esteem. This invasion of privacy and focus on the body was previously mentioned in the section on adolescent stressors.

**Societal perception.** A second theme that came from the interviews is that the public’s misunderstandings or negative stereotypes that they have toward chronic illnesses hinders the self-esteem and body image of adolescents who have those diagnoses. For Victor, his peers in school did not understand the emotional side of his illness. He said one of the most harmful parts of adolescence in regards to his body image and self-esteem was peers calling him names like “chicken arm” and mocking the physical effects of his cerebral palsy. Victor himself also had confusion surrounding his illness, which caused some of his negative emotions about his body. Taylor mentioned that others view her as incapable of pursuing her desired career as a CCLS. They have a
misunderstanding of her capabilities as well as a negative stereotype of people who use a wheelchair. Taylor said this negative stereotype and having a misunderstanding of her abilities contributed to her low self-esteem and dislike of her body. Olivia was also affected by the negative stereotypes her peers and the general public have of Type-1 diabetes. She said most people think her illness is caused by poor diet and lack of exercise, when that is not the case. She has been empowered by the opportunity to provide education to others on Type-1 diabetes.

**Self-change desires.** Another contributing factor to lower self-esteem that came as a third theme from the interviews was that the more things the participant wanted to change about their body, the lower their self-esteem score was in relation to the other participants. Taylor scored 27/30 on her current self-esteem and when asked about the overall view she had of her body, she stated that she had a positive view. She also answered that she would make no changes to her body. Victor scored a 25/30 on his current self-esteem and said that he accepts his body, although he does recognize that things in life could be easier if he did not have cerebral palsy. Olivia scored a 10/30 on her current self-esteem and stated that she only has a little acceptance of her body due to her “not great” view of her body. She stated that she wishes she could be smaller and stronger, have less focus put on her body, and be more helpful to those who help her with daily tasks.

**Importance of similar peers.** The fourth theme pulled from the interviews is that being around others who share their chronic illness or have a similar chronic illness is helpful. All the participants mentioned beneficial interactions and support coming from a
peer who also had a chronic illness. Victor grew up with siblings who also had cerebral palsy. He said being around them helped him see that his body could potentially have been more affected by this chronic illness both physically and cognitively. Watching his siblings adjust helped him make adjustments in his own life. Olivia attended multiple camps for children with diabetes growing up. She said this helped her interact with others like her and helped her understand her illness, which is why she is empowered to educate others now. Taylor attended a high school group for youth with a chronic illness. She said it was helpful to be able to share stories with people who could truly understand and relate to what she was dealing with at that time.

**Importance of parents and peers without a chronic illness.** In relation to the fourth theme, the participants also stated that the other groups the researcher asked about (parents and peers without a chronic illness) were also helpful in building their self-esteem and body image in a positive way. Two of the three mentioned that their mother was an important role model. Although mothers specifically were mentioned, in a broader context, any caregiver could take this role. Mothers were most likely being mentioned because the mother was the nurturing, supportive role in these participants’ lives. Olivia and Victor said their mothers taught them acceptance of their bodies. Olivia said her mother told her that everyone is different, which taught her that comparison is useless. This encouragement led Olivia to accept herself as she is. Victor said his mother’s leadership and respect toward him as a person has helped him feel good about himself. He also mentioned that both his parents gave him wisdom to defy the odds and continue on the path he is pursuing.
One participant specifically mentioned a peer who did not have a chronic illness being particularly beneficial in building up her self-esteem and body image. Taylor said she did not have many friends during adolescence, but the one she did have did not have any diagnosis. This friend was open to learning about Taylor’s chronic illness and was a supportive listener. Taylor said this supportive and understanding friendship during high school was very valuable in building her self-esteem. This friend was not displaying sympathy, but rather empathy, which is an important distinction. Sympathy recognizes another’s suffering, but empathy places oneself in that other’s situation and feels their feelings. Empathy is more personal, and usually more appreciated, as demonstrated here with Taylor appreciating her friend’s sense of understanding her situation without living it.
Chapter 5: Discussion

Implications for the Field of Child Life

The pediatric hospital setting can be an isolating environment for an adolescent (Barling et al., 2014). Adolescents with chronic illnesses who are experiencing changes in their body are already at risk for low self-esteem if they have a negative body image, but this isolation they feel is an added stressor that could lead to lower self-esteem if not addressed. Child Life is concerned with patients who range in age from early infancy to late adolescence. However, it is easy for an adolescent patient in a pediatric hospital to feel like they do not belong when younger children and activities for those children dominate. The aim of this research was to identify resources for adolescents to combat that feeling of isolation.

Empowerment in educating. The first suggestion drawn from this study is that adolescents who have a chronic illness should be empowered to educate others about their illnesses and bodies. This is drawn from two areas of the interviews. One, Olivia had success in accepting her body and herself and stated that educating others helped in this process of acceptance. Two, Victor mentioned that the confusion he had about his illness was a cause of negative body image and low self-esteem during adolescence. Therefore, proper education was related to a participant who had the highest self-esteem and body image in the study and confusion from perhaps a lack of education was related to a participant who stated this caused a negative impact on self-esteem and body image.

Education is a central role of child life. The patient should be informed about how his or her illness affects his or her body and the patient should be able to teach others
about that. All of the participants had experienced a hospitalization relating to their chronic illness, but none of them reported being visited by or receiving services from a CCLS. This could be because Child Life is still a young, growing profession. There may not have been a CCLS present at the hospital these participants were being treated. Where child life is not present, social work or nurses could also fill this role of education. Empowerment through education could be a primary goal for any of the staff on the adolescent’s medical journey. Through learning about their body and how their chronic illness currently affects and may affect them in the future, adolescents may be able to start integrating this illness into their identity in a positive way. Through education, they may also learn what capabilities their body has rather than focusing on limitations, which could also contribute to positive body image and boost their self-esteem.

**Importance of body acceptance.** Another implication of this study is that the way an adolescent’s body looks is a very important factor in self-esteem and body image, so acceptance of one’s body must come before an improvement in body image and self-esteem. This implication comes from the first theme, which was the correlation between physical indication of an illness and their self-esteem score. Because Taylor viewed being what she described as heavy and weak as unacceptable to herself, her body image and self-esteem scores were low. Because Olivia accepted her blood glucose monitor as a part of herself that makes her unique and understood that all bodies are different, her body image and self-esteem scores were high.

Therefore, it is important that the people who are in adolescents’ lives and who help them build self-esteem and create a positive body image should encourage the
adolescents to embrace what makes them different, whatever that may be. If adolescents view their bodies with positive words like “unique” or “special” instead of negative words like “weird” or “ugly,” they will build their body image positively. It was previously discussed that body image is formed through comparison during adolescence (Krayer et al., 2008). Instead of an adolescent with a chronic illness comparing their body to an adolescent who is healthy and seeing the differences as negative, there needs to be a shift in thinking. The thought should instead be like what Victor and Olivia talked about, which is that all bodies are different and what makes you unique is good.

**Findings from the Research Questions**

The first research question was: Who was the most helpful in fostering the participant’s self-esteem and body image during adolescence? All but one of the participants mentioned each of the groups being looked at as helpful in fostering their self-esteem. Parents, namely mothers, were discussed as being good role models for building self-esteem and positive body image. All three participants had a friend with a chronic illness or attended a support group for adolescents with chronic illnesses during adolescence and they all noted the benefit of having interactions with someone who could understand what they were going through. The participants also said it was important to have peers who were healthy as friends, as long as those friends were supportive.

The second research question asked: In what ways did the participant and the helpful person interact? Whether it was a parent, healthy friend, or a peer who also had a chronic illness who the participant said was the primary help to building up their self-esteem and body image, all of the participants said these people were understanding and
supportive. Support to the participants meant someone who was willing to listen to their struggles, someone who praised their strengths, who encouraged them to pursue their dreams, and accepted them as they are. Leading by example, while also respecting any limitations the participants may have had were also helpful qualities from those who were helping to facilitate their self-esteem and body image during adolescence.

The third research question was: What is the relationship between body image and self-esteem for the participant? Once the participants accepted their bodies as they were, their self-esteem rose. Those with higher self-esteem scores were able to list positive qualities about their bodies and had little they wanted to change about how their body looked or the abilities their body had. As important as parents, peers without a chronic illness, and other adolescents with a chronic illness all are in facilitating the self-esteem and body image of adolescents with a chronic illness, it is necessary to note that these are helping factors—not the source of—one’s self-esteem and body image. The primary factor when determining self-esteem and body image is how the adolescent perceives himself and how the adolescent feels about his body. Therefore, it is still incumbent for adolescents with a chronic illness to hear the praise, accept the support, incorporate others’ positive views into their body image, and ultimately recognize, understand, and embrace their body and its capabilities. This process of understanding and embracing is what will build their self-esteem and body image.

The final research question was: How can the results of this study be transformed into better resources to be used in pediatric hospitals for adolescents with a chronic illness? There needs to be an emphasis on empowering patients to educate others. Child
Life programming may implement resources for experienced and educated adolescents to teach newly diagnosed adolescents who share their chronic illness. This would be a way to empower the adolescent with educating others, as well as build a peer relationship. This peer relationship is important in adolescence, specifically in the hospital where the adolescents might otherwise feel isolated from peers. The connection to another adolescent with their diagnosis would also help by giving the newly diagnosed adolescent with a similar peer to compare their body to, which may help foster their body image.

This education could be paired with body positive language and shifting the focus from negatives and disabilities to positives and abilities. The principal researcher plans to create a PowerPoint presentation with the data collected from this research in order to present as an in-service for CCLSs in terms of how to talk with adolescents who have a chronic illness about their bodies and how to connect them to peers in a beneficial way.

**Limitations**

The main limitation in this study was that there was a time constraint on collecting data. This time constraint led to two other limits of the study:

1. Interviews had to be done retrospectively because there was no time to go through the IRB process of interviewing minors.
2. There were only three participants, but with more time to do recruitment, there may have been more participants.

More participants would have allowed for more generalizations that could be applied to a broader audience. However, even with these limitations, the principal researcher was still able to draw important conclusions and find major themes from the
three interviews. Although the retrospective aspect is listed as a limitation due to potential memory issues, the principal researcher believes having adults adds to the study. This element allowed data such as how much the self-esteem scores have changed and it allowed the participants to reflect on and share who they saw contribute to their self-esteem and body image. Whereas, if the principal researcher had interviewed adolescents, they may not have had the clarity to look around them and see who was having an impact on their self-esteem and body image.

Another limitation, which is a result of only having three participants, is that there is not a variety of chronic illnesses represented in the data. There was Type-1 diabetes and two different types of cerebral palsy. The principal researcher believes a variety of chronic illnesses would have provided more distinctions to explore in the first theme. These distinctions could have provided insight into specific issues for certain diagnoses. It also could have shown whether there are more camps and support groups available for certain diagnoses over others.

**Further Research**

The principal researcher believes this is an important area of study and plans to collect similar data in the future. This will be done in hopes of recruiting more individuals with a variety of chronic illnesses. Camps and support groups for adolescents with a chronic illness seem to be effective in building the self-esteem and body image of adolescents with a chronic illness. Because adolescents already have fewer resources than children, the principal researcher wonders if certain groups of adolescents become even more isolated from resources when they do not have a “popular” chronic illness and their
specific diagnosis is not represented in these camps and support groups. Further research may lead to a discovery that this trend to only have resources for big, popular diagnoses is true. From there, more camps or support groups could be developed for those less represented diagnoses.

Another area of further research is to determine the specific attributes of those who facilitate the self-esteem and body image of adolescents with a chronic illness. Parents and healthy friends were shown to be good facilitators of self-esteem and body image for our participants. However, not all parents and friends who do not have a chronic illness are as understanding and supportive, perhaps due to a lack of education. If research is done regarding good facilitators’ knowledge, attitude, and actions, a manual could be developed. This manual could be utilized in support groups in high schools that mix peers with and without a chronic illness to educate them and encourage them to support and befriend adolescents who have a chronic illness. Because not everything can be generalized and every individual has unique struggles, it would be most beneficial and appropriate to listen to the adolescent himself, but the manual could be a starting place with tips and suggestions as a general guide to becoming more knowledgeable and accepting. The manual could be used in a similar way for parents who want to better understand how to interact with their adolescent who has a chronic illness, much like other parenting books.

The primary goal of further research would be to create more or improve upon current supports that are available to adolescents with a chronic illness. These supports would ideally be available at home, in the hospital, at school, and in leisure areas.
Adolescence is already a stressful time without adding a chronic illness to the mix of stressors. Self-esteem and body image are main areas of focus and are vital to future life stages. The principal researcher intends for further research in this area to lead to improvements for the general population of adolescents in the area of self-esteem and body image, but specifically for adolescents with a chronic illness. Improvements will come from knowledge in what helps and what hinders self-esteem and body image for adolescents with a chronic illness and a better understanding of how self-esteem and body image are experienced by this group.
References


Murray, K., Rieger, E., & Byrne, D. (2013). A longitudinal investigation of the mediating role of self-esteem and body importance in the relationship between stress and


Appendix A: Instruments

Rosenberg Self-Esteem Scale

Read the following 10 statements and evaluate yourself as you usually think of yourself. Then, write in a rating of how you respond to the statement about yourself. The ratings are as follows:
0- Strongly Disagree, 1- Disagree, 2- Agree, 3- Strongly Agree
The researcher will then score each, as some ratings need to be reversed.

<table>
<thead>
<tr>
<th>Statements</th>
<th>Rating</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel that I am a person of worth, at last on an equal plane with others</td>
<td></td>
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<tr>
<td>2. I feel that I have a number of good qualities</td>
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<tr>
<td>3. All in all, I am inclined to feel that I am a failure</td>
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<tr>
<td>4. I am able to do things as well as most other people</td>
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<tr>
<td>5. I feel I do not have much to be proud of</td>
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<tr>
<td>6. I take a positive attitude toward myself</td>
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<td>7. On the whole, I am satisfied with myself</td>
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<td></td>
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<tr>
<td>8. I wish I could have more respect for myself</td>
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<td></td>
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<tr>
<td>9. I certainly feel useless at times</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. At times, I think I am no good at all</td>
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</table>
Scores are calculated as follows:
For items 1, 2, 4, 6, & 7:
Strongly agree = 3, agree = 2, disagree = 1, strongly disagree = 0
For items 3, 5, 8, 9, & 10 (the score is reversed in valence):
Strongly agree = 0, agree = 1, disagree = 2, strongly disagree = 3
The scale ranges from 0-30. Scores between 15 and 25 are within normal range; scores below 15 suggest low self-esteem.

Body Image Assessment


The following questions are adapted from the above citation.

1. How would you describe your appearance?
2. How do you feel about your appearance?
3. How do others react to your appearance?
4. How do you feel about those reactions?
5. How well do you feel your body is able to do tasks as compared to others?
6. Have you experienced any stereotypes or negative reactions from others associated with your body? If so, explain.
7. Overall, with both your appearance and your body’s abilities, do you feel a sense of acceptance of your body or do you wish you could change certain aspects?
   a. If you feel acceptance, what do you think led you to this feeling of acceptance?
   b. If you wish you could change certain aspects of your body, which would you like to change and why?
Interview Guide (for normal-high self-esteem scoring participants)

The following questions will be asked to participants between the ages of 18-28 who are diagnosed with a chronic illness. Although participants will currently be adults at the time of the interview, the questions will ask them to recall issues pertaining to their chronic illness during their adolescence. Participants will be recruited mainly from the Mid-west since that is where the principal researcher is located and interviews are to be recorded.

1. Describe the view you had of your body during adolescence (ages 12-18)
   a. In what ways did that view changed throughout your adolescence?
   b. What do you think caused your body image to change?
2. How did you feel about yourself during that time?
3. Before someone helped improve your self-esteem and body image in adolescence, what would you say was the emotion you felt most often? How did you feel most often after you had positive self-esteem and body image?
4. What is your diagnosis?
5. Were you hospitalized for your chronic illness during adolescence? If so, how often and for how long each time?
6. What resources were offered during your hospitalizations to help you build your self-esteem and body image?
7. Who do you remember helping build your self-esteem and/or body image?
8. What did they do that improve your self-esteem and/or body image?

Interview Guide (for low self-esteem scoring participants)

1. Describe the view you had of your body during adolescence (ages 12-18)
   a. In what ways did that view changed throughout your adolescence?
   b. What do you think caused your body image to change?
2. How did you feel about yourself during that time?
3. What was your most common emotion during adolescence before you started doing things to attempt to improve your body image and self-esteem? How (if any) have your emotions changed?
4. What is your diagnosis?
5. Were you hospitalized for your chronic illness during adolescence? If so, how often and for how long each time?
6. What resources were offered during your hospitalizations in regards to building your self-esteem and body image?
7. Who do you remember trying to help build your self-esteem and/or body image?
8. What did they do to attempt to improve your self-esteem and/or body image?
9. Who do you think would have worked better for you? Or what could that person done differently to more effectively improve your self-esteem and/or body image?
10. In what ways does your chronic illness or body image impact your self-esteem currently?
Appendix B: Recruitment Tools

Child Life Student Forum Post

Hello,
My name is Juli Johnson and I am seeking a Master’s degree in Child & Family Studies with a concentration in Child Life at Ohio University. In fulfillment of that degree, I am working on a thesis. This post is seeking participants for my thesis research and lists the inclusion requirements, what participation will include, and contact information.
Participants must be 18-28 years of age, be diagnosed with a chronic illness by age 12, and understand/speak English. A chronic illness is defined as such when the individual’s daily functioning is affected for more than three months a year, they are hospitalized for one month a year and/or they require the use of an adaptive device (Muscari, 1998).
My thesis research is on the self-esteem and body image of adolescents with a chronic illness. The study is looking to discover the effects that certain social influences have on the self-esteem and body image of adolescents with a chronic illness. The social groups whose influences are being asked about are: parents of the adolescent with a chronic illness, peers without a chronic illness, and other adolescents with a chronic illness.
The research is being done as a retrospective study. It will include an interview (on body image, self-esteem, social influences, and their chronic illness) and the participant filling out a self-esteem scale.
If you fit the inclusion criteria listed above and are interested in participating in this study (or if you have questions and want more information), please contact the principal researcher Juli Johnson at jj679814@ohio.edu or (937) 903-6357.
Also, if you know someone you think may be interested and fits the inclusion criteria, please forward this information on to them.
Thank you for your consideration,
Juli Johnson
Flyer (hard copy and electronic copy for Facebook and Instagram)

This version of the flyer will be the hard copy that is passed out in classes and the electronic copy that is posted on Facebook. A screen shot will be taken to turn it into a photo that can be posted on Instagram and as an attachment on Twitter. The 140-character tweet with the photo attachment will say “Thesis on chronic illness and self-esteem and body image issues during adolescence…interested in participating? See photo for more info”.

Research Participants Needed
Topic: Adults with a Chronic Illness: Influences on Self-Esteem & Body Image During Adolescence
Aim of Study: To determine the effects that certain social influences have on the self-esteem and body image of adolescents with a chronic illness. The social groups whose influences are being looked at are: parents of the adolescent with a chronic illness, peers without a chronic illness, and other adolescents with a chronic illness.
Participation Requirements:
~ Currently aged 18-28
~ Diagnosed with a chronic illness by age 12 (the individual’s daily functioning is affected for more than three months a year, they are hospitalized for one month a year and/or they require the use of an adaptive device (Muscari, 1998))
~ Speaks & understands English
Study Includes:
~ Interview about self-esteem and body image during adolescence (in-person or Skype/phone)
~ Filling out a Self-esteem scale for now and your adolescence
For More Information: Contact researcher Juli Johnson at jj679814@ohio.edu or (937) 903-6357 or her advisor Jenny Chabot at Chabot@ohio.edu.
Appendix C: Informed Consent

Ohio University Adult Consent Form Without Signature

Title of Research:
Adults With A Chronic Illness Reflect on Adolescence: What Social Influences Impacted Their Body Image & Self-Esteem

Researcher: Juli Johnson

You are being asked to participate in research. For you to be able to decide whether or not you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, please write your consent via e-mail confirming that you understand what this form explains and that you are willing to volunteer as a participant in this study. This will allow your participation in this study. You will be able to download and save this document for your records.

Explanation of Study

This study is being done to find out the effects important social influences have on the body image and self-esteem of adolescents with a chronic illness. The social groups the research will ask you questions about are your parents (or primary caregivers), healthy friends, and other adolescents with a chronic illness. The research will find what ways each group attempted to improve your body image and self-esteem during adolescence.

If you agree to participate, you will first be asked to complete a Rosenberg Self-Esteem Scale. This scale will have you say whether you strongly disagree-strongly agree with 10 statements about how you think about yourself. After you fill that scale out, you will then be asked to answer questions about your adolescence. Those questions will be about who helped you work on your self-esteem and body image, how their help led to an increase in self-esteem and positive body image, and which resources you thought were the most helpful. You will also be asked specific questions about your body image and self-esteem during adolescence and how those are different currently. You will also be asked a couple questions pertaining specifically to your chronic illness. This interview will be audio-recorded. The recordings and transcripts will be stored in a locked drawer in a locked University office. Only the researcher will have access to the recordings and the transcriptions of the interview. The transcriptions will be on the researcher’s personal password protected computer. The recording will be destroyed after the transcription is...
complete and the transcription will be deleted at the conclusion of the study in the summer of 2016.

You should not participate in this study if you cannot understand/speak English, you are not currently diagnosed with a chronic illness, you were not diagnosed by age 12, or you are not currently in the age range of 18-28.

Your participation in the study will last approximately half an hour to an hour. The length of the study depends on how much you say when you answer questions in the interview, how long it takes you to fill out the Self-Esteem Scale, and whether or not you want to take a break.

Risks and Discomforts

No risks are anticipated in this study. You may experience some discomfort in answering questions in the interview. Issues about negative body image and low self-esteem can be difficult to remember and talk about.

Benefits

This study is important to society because it will provide knowledge on the effects social influences can have on body image and self-esteem. This study will hopefully provide information on both negative and positive influences in order to further educate readers of the study on how their actions and words can impact others.

Individually, you may benefit by reflecting on how far you have come in your self-esteem and body image. It could be beneficial to reflect on what support and resources helped you on the course to positive body image and self-esteem. Or if you are still struggling with self-esteem and body image, this experience may help you feel validated by having your story appreciated and valued. You may also feel good in knowing that your story will be in a study that is hoping to improve the life of others like you. Those others are adolescents who also have a chronic illness and are struggling with body image and self-esteem issues.

Confidentiality and Records

Your study information will be kept confidential by keeping everything in a locked drawer in a locked office or saved to a password protected document on the principal researcher’s personal computer. You will be assigned a pseudonym so that your name will not be on any of the research material, such as the Self-Esteem Scale and the Interview. Forms with identifying information, such as the signed consent form, will be in a separate locked drawer than the locked drawer containing forms with the pseudonyms. Once the study is over, all documents will be shredded and all files will be deleted from the computer.
Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with:

* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
* Representatives of Ohio University (OU), including the Institutional Review Board, a committee that oversees the research at OU;

**Contact Information**

If you have any questions regarding this study, please contact the investigator Juli Johnson, jj679814@ohio.edu, (937) 903-6357 or the advisor Jenny Chabot, Chabot@ohio.edu, (740) 593-2871.

If you have any questions regarding your rights as a research participant, please contact Dr. Chris Hayhow, Director of Research Compliance, Ohio University, (740)593-0664 or hayhow@ohio.edu.

By agreeing to participate in this study, you are agreeing that:

- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered;
- you have been informed of potential risks and they have been explained to your satisfaction;
- you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study;
- you are 18 years of age or older;
- your participation in this research is completely voluntary;
- you may leave the study at any time; if you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

Version Date: [05/14/15]
Appendix D: Debriefing Text

Thank you for your time and participation in this study.

The goal of this study is to determine the impact of social influences that parents, peers without a chronic illness, and other adolescents with a chronic illness have on the self-esteem and body image of individuals with a chronic illness during adolescence. It is utilizing first-hand, retrospective accounts of individuals with a chronic illness who have improved their self-esteem and body image since adolescence. The aim of the study is to provide first-hand information on what influences impact the self-esteem and body image in order to enhance knowledge in society in general and more specifically in pediatric hospitals. With this knowledge, social groups will be more equipped to effectively improve the self-esteem and body image of adolescents (ages 12-18) with a chronic illness.

The interview process may have brought up emotional memories for you in reflecting on a time when your self-esteem and body image was lower. While it is valid to be experiencing those emotions, it is important to recognize how far you have come and focus on your strengths and the positives in your life now. However, if you feel you need more help processing your emotions, please utilize the counseling services below.

Ohio University Counseling and Psychological Services

Location: Third floor of Hudson Health Center, located on North Green
Hours: 8:00am-5:00pm, Monday-Friday
Drop-in hours being 9:45 am to 3:15 pm, Monday through Friday.
Contact Information: Phone: (740) 593-1616, Fax: (740) 593-0091

If you are trying to reach a counselor during an emergency or want to talk to someone immediately, please call CPS (740) 593-1616 or OUPD (740) 593-1911 at any time.

Tri-County Mental Health & Counseling

Location: 90 Hospital Drive, Athens Ohio 45701
Contact Information: 740-592-3091

If you have any questions or concerns, you are welcome to contact me, Juli Johnson, by email at jj679814@ohio.edu or by phone at (937) 903-6357, or my researcher advisor Dr. Jenny Chabot by email at chabot@ohio.edu or by phone at (740) 593-2871. If you have any questions regarding your rights as a research participant, please contact Chris Hayhow, Director of Research Compliance, Ohio University, at hayhow@ohio.edu or by phone at (740) 597-1267.