SELF-CONCEPT DEVELOPMENT IN SCHOOL-AGED CHILDREN WITH CONGENITAL UPPER LIMB DIFFERENCES: A MIXED METHODS STUDY

by

Sally Ann Martens

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Final approval and acceptance of this dissertation is contingent upon the candidate’s submission of the final copies of the dissertation to the Graduate College.

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DEDICATION

I dedicate this dissertation to my children, Chase, Charlee, and Cain. I love you mostest today, tomorrow, and always.
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ABSTRACT

**Purpose:** The purpose of this mixed methods study was to explore self-concept development in school-aged children with congenital upper limb differences.

**Background:** Self-concept development has been shown to be a central point of reference for all further psychosocial development. Having a negative self-concept has a direct relationship on a child’s personality and over the course of their lifespan can influence academic and career success, peer interactions and relationships, generativity and life satisfaction and meaning.

**Research Design:** A convergent mixed methods design.

**Methods:** A purposive sample of nine children with congenital upper limb differences completed a 58-question survey. All participants then proceeded to collect photos and provide written descriptions each day over the course of one week, for a total of 63 photographs and 63 written descriptions. Data was merged for mixed methods integration and analysis to provide a rich description of self-concept development in school-aged children with congenital upper limb differences.

**Results:** The mean self-concept was 51.22 (±10.43). Mean domain scores were behavioral adjustment 52 (±8.19), freedom from anxiety 48.56 (±10.42), happiness and satisfaction 49.44 (±10.73), intellectual and school status 54.78 (±10.31), and social acceptance 49.89(±8.64). Five prominent themes arose from integrated results: emotions, sense of accomplishments, positive view of oneself and one’s physical body, hobbies, and a sense of connection. Children with CULD defined their self-concept through expressions of self-efficacy (20 photographs and written descriptions, self-image (four photographs and written descriptions), and social identity (39 photographs and written descriptions). Concordance and expansion existed within the results.
**Implications:** Results from this study created a more comprehensive description of self-concept, including an expanded understanding of the social identity of school-aged children with congenital upper limb difference. Future research studies are needed to explore the relationships between self-efficacy, self-image, and social identity, to create middle range theories and develop interventions aimed promoting healthy self-concept development. Additional research is needed to explore the long-term psychosocial effects of the changes in children’s social context secondary to growing up during the COVID pandemic.
CHAPTER 1: INTRODUCTION

Statements of Problem

Children with congenital upper limb differences are frequently challenged with negative social encounters as a result of having a physical difference (Hatzenbuehler et al., 2013). These negative social encounters can have an intense impact on a child’s psychosocial development and subsequently lead to the development of a negative self-concept (Hatzenbuehler et al., 2013). Having a negative self-concept has a direct relationship on the gradual evolution of a child’s personality (Mascall, 1986) and over the course of their lifespan can influence: school success, peer interactions, career selection, intimate relationships, middle adulthood generativity and overall life satisfaction (Jhangiani et al., 2014; Newman & Newman, 1979). Although, previous research has identified that children with congenital upper limb differences (CULD) are at increased risk for negatively affected psychosocial development (Hatzenbuehler et al., 2013; American Academy of Orthopaedic Surgeons [AAOS], 2020; Varni et al., 1992), there continues to be a gap in the literature examining self-concept development in school-aged children with congenital upper limb differences. Therefore, the purpose of this mixed methods study is to describe self-concept development in school-aged children with congenital upper limb differences.

Background and Significance

Congenital upper limb differences (CULD) are physical differences of the hand or upper extremity that are present at birth, and have the potential to impact both the appearance and the function of the child’s hand (AAOS, 2020). CULDs occur in 20 out of every 10,000 babies born, and are more prevalent in boys than girls (AAOS, 2020). Children with a CULD more are more likely to encounter negative social interactions and peer relationships as a direct
result of having a physical difference (Franzblau, 2015; Hatzenbuehler et al., 2013; Varni et al., 1992; Varni, 1989).

Peer relationships, defined as a chosen bidirectional social experience, interaction, or exchange, provide crucial opportunities to learn normal, adaptive modes of social conduct and social cognition, encourage moral development, and develop interpersonal skills (Parker et al., 2015). In early school aged years, children (ages 6 to 9 years old) typical exhibit an increased need for peer acceptance. During late school-aged years, children (ages 9 to 12 years) exhibit needs shifting from a desire for group approval to a need for a close, intimate bond with a same-sex peer (Parker et al., 2015). Also, during late school-aged years, relationships with peers are comprised of important characteristics such as: friendships, peer status, social exclusion, peer rejection and victimization (Martens, 2020).

Friendships during the school-aged years have been shown to provide developmental advantages such as support for children experiencing stressors (e.g., negative social experiences, behavioral and/or genetic risk factors, negative life events) and protection from peer victimization (Hodges et al., 1997). This is an important finding for children with CULD as they are at increased risk for developing psychological disorders such as depression, mood disorders, and anxiety (Achenbach, 2015; Varni et al., 1992; Varni, 1989). When a child is part of a reciprocated friendship, the relationship serves as a buffering agent against further negative peer experiences (Choukas-Bradley & Prinstein, 2014). For example, Brendgen et al. (2013) found that children who participated in a positively reciprocated friendship were noted to have a significant protective factor for depression and other mood disorders.
Peer status is becoming increasingly difficult to understand. Previously, peer status was often referred to as sociometric popularity; however, in more recent studies it is being defined as the degree to which a child is liked or disliked by their peers (Choukas-Bradley & Prinstein, 2014). Children seek membership into a peer group because acceptance into a group provides a sense of belonging and aids identity development (Newman & Newman, 2001). For example, children who are accepted into a peer group feel that there are many things to like rather than dislike about themselves, and this positive perception is generally present amongst all members of the group as a whole (Lewin et al., 1999). Conversely, when a group rejects a child, a general opinion has formed among members of the peer group that the child is undesirable or uninteresting (Lewin et al., 1999). Children are keenly concerned with and aware of their peer status as it has significant effects on friendships and social and mental development (Parker et al., 2015).

Social exclusion, commonly defined as the experience of being kept apart from others emotionally or physically, can have an adverse impact on emotional and social development (Williams, 2009). During the school-aged years, social exclusion has been shown to negatively affect emotions and psychological needs and has been noted to disrupt cognitive processes (Tobia, 2017). Social exclusion, especially when chronic or repeated contributes to the development of psychopathology such as anxiety and depression in children and young adolescents (Hamilton et al., 2016). Episodes of social exclusion including episodes of peer rejection, relational aggression and victimization that occur during the school-age years are linked to poor school performance and an increased risk of developing internalizing and externalizing behaviors (Ladd & Troop-Gordon, 2003). This was one reason for concern during
the recent COVID pandemic, as children were being socially excluded by the national health mandates which restricted their ability to go to school or participate in group activities.

Existing literature demonstrates that peer rejection correlates with increased risk for externalizing symptoms, heightened self-consciousness and declines in self-esteem (Lewin et al., 1999; Parker et al., 2015; Prinstein & Cillessen, 2003). As peer group leaders invite some individuals and exclude others, the rise of cliques in school-aged children contributes to the presence of biases and may intensify a child’s insecurities about their social position and acceptance (Adler & Adler, 1995). As a result, school-aged children expend a good deal of energy and thought during conversations with their close friends ruminating about their social status and guarding against rejection (Eder, 1985; Parker & Gottman, 1989).

School-aged children with disabilities experience more rejection than their peers without disabilities (Odom, 2005). Research has found that children with disabilities, including CULD, when compared to typically developing children, have fewer peer relationships and are less accepted than typically developing children of the same age (Guralnick et al., 1996; McConnell & Odom, 1999; Odom, 2005). As a result of being more frequently socially rejected, children with disabilities may miss opportunities to engage in rich and essential social learning experiences (Odom, 2005).

Victimization, also known as peer victimization, is defined as a pattern of aggressive acts, either physical or non-physical, that a child endures from their peers over a prolonged amount of time (Olweus, 2010). Peer victimization can be direct or indirect, overt, or covert. Children with certain characteristics, such as children with a physical difference or disability, are often targets of peer victimization (Bukowski & Adams, 2005; Olweus, 1978; Perry et al., 1988).
Unfortunately the occurrence of peer victimization continues to increase and it has become apparent that the developmental significance of this experience is not simple (Bukowski & Adams, 2005). The ways in which peer victimization affect a child seems to depend on the frequency, type and context in which it occurs (Parker et al., 2015).

Bullying is a prevalent form of victimization and children with disabilities are at increased risk of being bullied (Chatzitheochari et al., 2016; Olweus, 1978, 2010). In fact, children with disabilities were two to three times more likely to be bullied compared to their typically developing peers (Ervin, 2011). Research focused on the bullying of children with disabilities revealed increased reports of verbal abuse (e.g., name calling, mimicking, teasing), social exclusion, and physical aggression (Ervin, 2011; Rose et al., 2011). Consequently, children with disabilities who had been victims of bullying have more violent and aggressive behavior, hyperactivity, emotional disorders, and interpersonal/social difficulties (Chatzitheochari et al., 2016; Ervin, 2011).

**Psychosocial and Self-Concept Development**

Negative peer interactions have been shown to increase a child’s risk of developing psychological conditions (e.g., depression, anxiety, mood disorders), and negatively impacting their psychosocial development (Achenbach, 2015; Parker et al., 2015). Psychosocial development is a progressive process of human development that is affected by environmental factors and ultimately determines an individual’s psychosocial health (Erikson & Erikson, 1997). Psychosocial health is defined as a state of mental, emotional, social, and spiritual well-being (Hatzenbuehler et al., 2013). School aged children embark upon a crucial phase of psychosocial development in which they begin to form their self-concept (Parker et al., 2015). Self-concept
formation is an evolutionary process that culminates in a person’s internal sense of who they are (Martens, 2021; Parker et al., 2015).

Self-concept development has been shown to be the cornerstone for all further psychosocial development (Jhangiani et al., 2014; Mascall, 1986). Having a negative self-concept has a direct relationship on the gradual evolution of a child’s personality (Mascall, 1986) and over the course of their lifespan can influence: academic and career success, peer interactions and relationships, generativity, and life satisfaction and meaning (Jhangiani et al., 2014; Newman & Newman, 1979). Unfortunately, there is very limited research examining self-concept and psychosocial development in children with CULD. To assist children with CULD in developing positive self-concepts, it is critical to better understand the unique factors affecting their psychosocial development.

Worldview and Philosophical Perspectives

Constructionism

Constructionism (Crotty, 1998; Godfrey-Smith, 2003; Reed & Shearer, 2018) and complex systems science (CSS) (Capra & Luisi, 2014; Sturmberg, 2016) are the author’s epistemological and ontological perspectives and their application to the psychosocial development of children with CULD. Constructionism, also referred to as social constructionism, is a philosophical perspective that emerged from historicism during the post-positivist era (Godfrey-Smith, 2003). Constructionist’s hold an interpretive view which suggests that reality, meaning, and knowledge are constructed from social processes between people and their environment, and are developed and disseminated within a social context (Crotty, 1998; Reed & Shearer, 2018). Social context is defined as the direct or indirect influences of individual that are
in continual communication (Turner et al., 1994). Social context may include a person’s community, family, friends, peers and setting in which these interactions and relationships occur (Turner et al., 1994). Meanings and truths are constructed in a social manner that acknowledges historical and cultural influences, and this challenges the previously held positivistic belief of one stable truth (Crotty, 1998). Constructionism emphasizes the important role that the social context plays in person’s understanding of their environment and the creation of knowledge.

**Complex System Science**

Rooted in holism, complex system science (CSS) is a philosophical perspective that appreciates and explores the relationships and interdependencies between parts of an integrated whole (Capra & Luisi, 2014; Sturmberg, 2016). Complex adaptive systems (CAS) are nested systems from which constant interactions between different parts of the system influence one another and other systems, systemically (Sturmberg, 2016). A CAS has the following seven key characteristics: non-linearity, open to environment, self-organizing, emergence, patterns of interaction, adaptation and evolution, and co-evolution. (Chaffee & McNeill, 2007; Koithan et al., 2012; Sturmberg, 2016).

Non-linearity of a CAS implies that the system is sensitive to conditions, and that responses to stimuli can be varied and disproportional which may result in significant changes within the system (Chaffee & McNeill, 2007; Sturmberg, 2016). CAS are referred to as open to the environment, which suggests that the system continuously interacts with its environment. Self-organization refers to the parts of the CAS are in constant, complex interaction with each other which creates a balance of exploitation and exploration.
Growing from self-organization a key principle of CAS, emergence which refers to the development of new behaviors or properties of a CAS that are the result of the interconnectivity of a system’s parts that cannot be appreciated by a reductionistic perspective; therefore, suggesting that the whole is greater than the sums of its parts (Sturmberg, 2016). Patterns of interaction refer to the composite interactions between the parts of the CAS and suggest that different combinations of parts leads to the same outcomes and conversely, the same combination of parts may lead to alternative outcomes. Adaptation and evolution imply that changes involve the whole system and that new levels of homeostasis are achieved. Finally, co-evolution suggests with the emergence of new properties and behaviors, each part of the CAS has changed due to constant tension and balance (Chaffee & McNeill, 2007), and this may ultimately result in the parallel creation of a new nested sub-system (Sturmberg, 2016).

**Application to Psychosocial and Self-Concept Development**

By merging the two philosophical perspectives, constructionism and CSS, researchers can visualize human health and nursing practice through a holistic lens that appreciates the unique complexity of each human being. Researchers can visualize a child with a CULD as a complex adaptive system, with near constant interaction with their environment and other people. Through these interactions and exchanges children are constructing their realities and deriving meaning and knowledge from their unique social contexts. The knowledge gained from these exchanges directly impacts the psychosocial development of the growing child.

A child’s psychosocial development and self-concept are emergent properties, formed or created from their self-organizing and adaptive behaviors. Psychosocial health is constructed by each individual child and is grounded in their social context. A child with a CULD is
inextricably connected to an intricate web of relationships whose interaction with their social context leads to adaptive behaviors which in turn inspires the emergence of new properties, and ultimately informs systemwide change and learning, creating new knowledge and practices (Koithan et al., 2012; Sturmberg, 2016).

**Theoretical Framework**

The theory of self-concept development in childhood was created and served as the theoretical framework for this study and is displayed in Figure 1 below. The following sections will provide a brief summary the theory. The full paper titled “Theory of Self-Concept Development in Childhood” is available in Appendix A.

**Figure 1**

*Theory of Self-Concept Development in Childhood*

![Diagram of Self-Concept Development in Childhood](image)

(Martens, 2021)

**Theory of Self-Concept Development in Childhood**

Sim et al., 2014), self-concept is defined as an internal sense of who one is and is the result of triadic reciprocal determinism between social identity, self-efficacy, and self-image. The relationships among the three key concepts of self-concept are in constant flux and ever evolving. New definitions of these key concepts were created for use within nursing and are displayed in Table 1.

**Table 1**

*Summary of Concept Derivation*

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<tr>
<td><strong>Self-Concept</strong></td>
<td>An internal sense of who one is, and it is derived by the triadic reciprocal determinism of: social identity, self-efficacy and self-image (Martens, 2021).</td>
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<tr>
<td><strong>Social Identity</strong></td>
<td>The perception of one’s roles, involvement, and memberships in social groups (Abrams &amp; Hogg, 1990).</td>
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<tr>
<td><strong>Self-Image</strong></td>
<td>The summation of a person’s perceptions of themselves and their physical body (Bacchini &amp; Magliulo, 2003).</td>
</tr>
<tr>
<td><strong>Self-Efficacy</strong></td>
<td>The summation of a person’s feelings, emotions and opinions about their own abilities and talents (Bacchini &amp; Magliulo, 2003).</td>
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**Research Aims and Questions**

The following research aims, and questions will be addressed by the proposed study:

**Research Aim 1 (Quantitative)**

Describe self-concept scores of children with congenital hand differences using the Piers-Harris Children’s Self-Concept Scale, 3rd edition (PHCSCS).

1. What is the mean self-concept score of school-aged children with CULD?
2. What are the mean scores for each of the six domains:
   a. Behavioral adjustment?
   b. Freedom from anxiety?
c. Happiness and satisfaction?
d. Intellectual and school status?
e. Physical appearance and attributes?
f. Social acceptance?

**Research Aim 2 (Qualitative)**

Describe self-concept in school-aged children with a congenital upper limb difference using a modified photovoice methodology.

1. How do children with CULD describe their self-concepts?
2. Is having a limb difference a key component of a child’s self-concept?

**Research Aim 3 (Integration of Mixed Methods)**

Create a rich description of self-concept in children with CULD by merging quantitative and qualitative data sets.

1. What are the key categories and themes of self-concept identified by children with a CULD?

**Review of the Literature**

The following discussion provides a brief summary of the state of the science as derived from a scoping review entitled “Self-Concept Development in Children with Limb Differences: A Scoping Review” (Appendix B). The scoping review described the state of knowledge regarding the development of self-concept in children with limb differences, specifically:

1. How does having a limb difference affect a child’s self-concept?
2. How does having a limb difference affect the concepts of self-concept (self-efficacy, social identity, self-image)?
3. How does having a limb difference affect the concepts associated with self-concept (self-perception & self-esteem)?

4. What factors influence the development of self-concept in children with congenital limb differences?

5. Which research instruments are used to evaluate self-concept or one of its associated concepts?

Methods

This scoping review was performed using the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) extension for scoping reviews (Tricco, 2018) as a protocol. A comprehensive literature search was conducted using Embase, CINAHL, PsycINFO and PubMed databases between December 2020 to May 2021. The search strategy is detailed in the PRISMA 2020 flow diagram (Page et al., 2020) and can be found in Appendix B.

Protocol and Registration

The protocol was drafted using the Preferred Reporting Items for Systematic reviews and Meta-Analysis Protocols (PRISMA-P) (Tricco, 2018), which was revised by the reviewers after feedback from faculty members at the University of Arizona College of Nursing. The protocol and search strategy were then registered with and disseminated through the Open Science Framework on 11 April 2021 (https://osf.io/fvgx/?view_only=8c71fd6cfd2a43c79df15af1b1c240dd).

Search Results

The literature search yielded 87 results from which 11 duplications were removed, yielding a total of 76 articles. After screening titles and abstracts, 53 articles were excluded. The
remaining 23 full text articles were retrieved and assessed for inclusion. Of these, 14 articles were excluded for failing to meet inclusion criteria. The remaining nine articles met inclusion criteria and a detailed table displaying the characteristics of the included studies can be found in Appendix B.

Of the nine articles included in this review, seven described studies were performed in the United States (US). Five were published before 1997. Seven used self-report instruments, and five of these used four or more self-report instruments. Only two studies focused on evaluating self-concept, while the remaining seven studies focused on associated concepts of self-concept (i.e., self-perception, self-image, & self-esteem). All studies included both girls and boys less than 18 years of age with limb differences. Participants’ mean ages ranged from 10.3 to 16 years old.

Only two studies included the use of a comparison or control group in their study design. Of the nine articles: six were quantitative, cross-sectional, exploratory studies; one was a qualitative, phenomenological participant observation study; one was a quantitative, cross-sectional, descriptive study; and one was a qualitative, participatory action research study.

Correlating with the design types, seven studies utilized self-report measures (ranging from one to eight measures), and five used four or more self-report measures. While only two of the studies directly measured or focused on self-concept, the remaining articles focused on associated concepts such as self-esteem (4), social inclusion (2), and self-perception (1). Measures used to evaluate self-concept and associated concepts included: Self-Perception Profile for Children (SPPC), Social Support Scale for Children (SSSC), Family Environment Scale (FES), Children’s Hassles Scale (CHS), Children’s Depression Inventory (CDI), Degree of Limb...
Loss Scale (DLLS), Dyadic Adjustment Scale (DAS), State-Trait Anxiety Inventory for Children (STAIC), Beck’s Depression Inventory (BDI), Family Relationship Index (FRI), Functional Ability Measure (FAM), Loneliness Measure, DISABKIDS Chronic Generic Measure (DCGM-37), Piers–Harris Children’s Self-Concept Scale (PHCSCS).

Discussion

The gap in the existing knowledge examining how self-concept is affected when a child has a limb difference was highlighted when analyzing the search results. There were only two existing studies that focused primarily on evaluating the self-concept of children with limb differences. The first study, conducted in 2002 by Wijma et al., examined the nature and correlates of self-concept in children with obstetric brachial plexus palsy (BPP) (Wijma, 2002). Since BPP is typically the result of a trauma sustained during the birth process and may result in a life-long limb difference, this article met inclusion criteria. This study found that children with BPP have lower self-concept in athletic competence, but higher self-concept in scholastic competence and behavioral conduct (Wijma, 2002). Boys with BPP, when compared to boys without disabilities, have lower self-concept only in the domain of athletic competence, but girls with BPP score just as well or better in all domains of self-concept than girls without disabilities (Wijma, 2002).

These findings were reinforced by Andersson et al.’s (2011) study which explored self-concept and psychological well-being in children with hand and upper extremity differences using a quantitative exploratory approach. Overall self-concept scores showed that the hand difference group had positive self-concept scores which were equal to a comparison group of healthy children (Andersson et al., 2011). However, within the hand difference group, those with
mild differences had significantly lower scores than those children with more severe and visible limb differences. Their findings suggest that children with a more mild or minimally visible limb difference may be at greater risk for poor self-concept development.

While the existing literature was limited in examining overall self-concept development, the findings focused more on how a limb difference affected the concepts associated with self-concept such as: self-esteem, self-perception, and self-image. Varni et al. (1989) investigated self-esteem in 41 children with limb differences and found that low self-esteem was predictive of the development of depressive symptomology (Varni et al., 1989). Another study (Varni & Yoshio, 1991) investigating self-esteem development in 51 children with limb differences found that higher self-perception scores were statistically predictive of lower depressive and anxious symptoms and higher general self-esteem (Varni & Setoguchi, 1991). These studies suggest that in children with limb differences, low levels of self-esteem are associated with the development of anxiety and depressive symptomology.

Self-image was explored in a qualitative descriptive study conducted at a summer camp for children with limb differences (Indelicato et al., 2019). In this study, three themes related to self-image emerged: self-perception, camp participation, and coping (Indelicato et al., 2019). Ylimäinen et al. (2010) explored perceived physical appearance and health-related quality of life (HRQoL) in children with limb differences. Girls with longitudinal, bilateral, or lower limb differences reported significantly lower HRQoL than girls with other limb differences, and unexpected attention from peers and others negatively impacted perceived physical appearance and HRQoL (Ylimäinen et al., 2010). However, while investigating self-image, both studies noted a desire for connection with others as an overarching theme, thereby highlighting the
importance of the social context in a child’s development (Indelicato et al., 2019; Ylimäinen et al., 2010).

The power of the social context reverberated through the search results as a significant moderating factor affecting the development of self-concept and its associated concepts in children with congenital limb differences. Social context has most recently been defined as encompassing the immediate physical surroundings, social relationships, and cultural milieus within which defined groups of people function and interact (Casper, 2001). Additionally, social contexts are dynamic and change over time in response to both internal and external forces. Varni (1989) led research endeavors that demonstrated the powerful effects of social context on a child’s psychosocial development. Early studies suggested that a lack of social support, family conflict and organization, marital discord, higher daily hassles, and micro stressors were significantly associated with low self-esteem and predictive of lower perceived physical appearance (Varni et al., 1989; Varni & Setoguchi, 1991, 1993). Varni and Setoguchi (1993) further investigated predictors of depression, anxiety, and self-esteem in children with congenital limb differences, and their results suggested that higher parental depression and anxiety predicted higher child depression and anxiety and lower self-esteem.

Studies led by Varni also found that psychological adjustment factors were significantly related to perceived parent, teacher, classmate, and friend social support (Varni et al., 1989; Varni & Setoguchi, 1991; Varni et al., 1992). These studies also concluded that higher classmate, parent, and teacher social support, peer acceptance, scholastic competence, and athletic competence were statistically predictive of higher perceived physical appearance and higher self-esteem (Varni et al., 1989; Varni & Setoguchi, 1991). Pasek and Janette (1996) evaluated
components of skill mastery and self-esteem in children with limb differences. Their findings suggested that skill mastery is an important component of a child’s positive self-efficacy and self-perception, and that evidence of preexisting self-esteem and perceived social support were as likely to produce positive effects as skill mastery (Pasek & Schkade, 1996), which further reinforces the importance of the social context on a child’s self-concept development.

Lastly, the measurement tools utilized to evaluate self-concept and associated constructs varied greatly. In total, 14 different measurement tools were utilized in the nine included studies. In those studies, seven studies utilized self-report measures, and the remaining two studies were qualitative designs that did not utilize measurement scales. In the seven studies that used measurement tools, five studies used four or more self-report measures in their designs. After reviewing the multitude of measures utilized, one measurement tool, the Piers-Harris Children’s Self-Concept Scale (PHCSCS) was the most comprehensive directly measuring self-concept. This measure not only provided overall self-concept scores, but also included scores in six associated domains of self-concept: behavior adjustment, freedom from anxiety, happiness and satisfaction, intellectual and school status, physical appearance and attributes, and social acceptance period.

**Summary and Conclusion**

In summary, the findings reflected in this scoping review demonstrate the effects of the social context on the psychosocial development of children with limb differences. Social contexts included peer, familial, and classmate interactions and relationships; and these directly affected the development of depressive symptomatology, anxiety, general self-esteem, self-perception, and self-concept. The effects of having a limb difference on a child’s self-concept
development is an area in need of future research. Existing research has shown that self-concept development is crucial in determining a child’s personality, and it can influence their academic success, peer interactions, career selection, intimate relationships, middle adulthood generativity, and later life satisfaction (Mascall, 1986; Newman & Newman, 1979). Since there are currently only two studies focusing on self-concept development during the school aged years of children with CULD, additional research is needed to improve our knowledge about self-concept and psychosocial development in this population. In the next chapter, the study methods will be presented.
CHAPTER 2: PRESENT STUDY

Chapter 2 presents the summary of the methods, results and conclusions of the present study:

3. Merge qualitative and qualitative data to create a rich description of self-concept in children with CULD.

This chapter expands upon results that are included in one of the three manuscripts appended to this dissertation, in addition to providing a summary of the approach, methods, results, discussion, and conclusion of the dissertation.

Manuscript Option for Dissertation

Prior to final dissertation defense, three manuscripts have been completed and are presented in Appendices A through C. The manuscripts include a theory paper (Appendix A), a state of the science paper (Appendix B), and a data-based results paper (Appendix C). Editorial review and expert input were provided by the dissertation committee chair and all committee members on all three manuscripts in preparation for journal submission.

Manuscript 1: Theory Paper

The first manuscript titled “Theory of Self-Concept Development in Childhood” (Appendix A) will be submitted to the Nursing Science Quarterly journal following final dissertation defense.
Manuscript 2: State of the Science Paper

The second manuscript is a scoping review titled, “Self-Concept Development in Children with Limb Differences: A Scoping Review” (Appendix B). This manuscript will be submitted to the *Journal of Creativity in Mental Health* following final dissertation defense.

Manuscript 3: Data-based Results Paper

The third manuscript is a data-based results paper titled “Self-Concept Development of Children with Congenital Upper Limb Difference: A Mixed Methods Study” (Appendix C). This manuscript will be submitted to the *Nursing Research* journal following final dissertation defense.

Study Methods

This study used a convergent mixed methods design measuring self-concept with the Piers-Harris Children’s Self-Concept Scale (PHCSCS) questionnaire and using a modified photovoice methodology, which is a photo-elicitation research method. The quantitative data included participant’s sociodemographic information collected via chart reviews, and PHCSCS scores which were obtained via interviewer administration. The qualitative data was comprised of photographs with written descriptions, and was electronically collected from the study supplied iPod Touches using Qualtrics\textsuperscript{\textregistered} (2020). The quantitative statistical results from the PHCSCS surveys were merged with the qualitative findings from the modified photovoice methodology for a more comprehensive understanding of self-concept development in children with CULD. A diagram of the mixed methods research study design is displayed in Figure 2.
Sample and Sampling

Nine school-age children with a CULD participated in the study. Inclusion criteria was children with a CULD difference between the ages of 6 to 12 years old. Children were excluded from participation in the study if they had: upper extremity differences acquired through trauma, cognitive or developmental disabilities and delays and/or syndrome. Similar mixed methods and photovoice studies in children had samples sizes ranging from 3 to 15 participants (Abma & Schrijver, 2020; Adams et al., 2017; Malka et al., 2018; Shannon, 2013); thus, a sample size of
10 participants was established. Enrollment and recruitment ceased when thematic saturation or a lack of new emerging themes (Green & Thorogood, 2004) was achieved with nine participants.

**Recruitment**

Participants were recruited from the outpatient hand and upper extremity clinic at Shriners Hospital for Children Northern California (SHCNC). SHCNC is a non-profit, pediatric medical center in Sacramento, California that provides highly specialized medical care and rehabilitation to children with congenital and complex medical needs. In 2020, SHCNC cared for over 24,000 pediatrics patients (Carpenter, 2021). Of those patients, 153 children were identified through chart reviews as having met inclusion criteria and nine participants were successfully enrolled.

**Data Collection**

**Quantitative Measures**

The sociodemographic information (e.g., gender, ethnicity, race, zip code, type of CULD, academic grade level, parental marital status, presence, & number of siblings) was collected through a comprehensive chart review. Using the autoscore form, the paper format of the PHCSCS was interviewer-administered in a quiet outpatient clinic exam room.

**Piers-Harris Children’s Self-Concept Scale (PHCSCS) 3rd Edition**

The PHCSCS is a brief self-report measure of self-concept in children between the ages of 6 to 22 years old. The measure consists of 58 descriptive statements, written at a first grade reading level, utilizing a ‘yes’ or ‘no’ answer format. (Piers & Harris, 2018). In addition to providing overall self-concept scores, the PHCSCS also provides scores for the following associated six domains: behavioral adjustment, freedom from anxiety, happiness and
satisfaction, intellectual and school status, physical appearance and attributes, and social acceptance. Raw scores were converted to T-scores (mean= 50, standard deviation 10) and percentage ranks. T-scores less than or equal to 29T is very low, 30T to 39T is low, 40T to 44T is low average, 45T to 55T average, 56T to 59T is high average, 60T to 69T is high, and equal to or greater than 70T is very high (Piers & Harris, 2018).

**Qualitative Measure**

After the quantitative data was collected, participating children began the photovoice methodology by engaging in a 15-minute training session. During the training session the following prompts: “What makes you, you” and “Who are you” were discussed at length and examples were provided. Participants were instructed on basic photography techniques and the iPod Touch’s camera functions were reviewed. Participants collected and submitted photographs with written descriptions via QualtricsXM (2020) directly to the Shriners Hospital for Children cloud storage Box (also referred to as the SHC Box). Participants submitted one photograph per day for the seven days following enrollment. As an incentive for study participation, the participants were able to keep the iPod Touches for personal use after the completion of the study.

**Modified Photovoice Methodology**

Photovoice is a visual research methodology which combines ethical photography and community participation to foster positive social and cultural change (Wang, 1997). This research study utilized a modified photovoice methodology to be appropriate for children, ensuring that the children were trained on the devices. Photo-documentation occurred as the participants collect photographs addressing the study prompts over the seven days following
enrollment. Photo-elicitation is traditionally a method where researchers present photographs for discussion with participants in a one-on-one interview or in small focus groups; neither was possible due the age of children and the COVID pandemic. For this modified approach for children, participants provided written descriptions with each photograph they submitted. This provided contextual meanings of each photograph and ensured that the participant’s “voice” was maintained throughout the remainder of the process. This approach was chosen to maintain children’s privacy and allow children to share personal information in a confidential manner.

Data Analysis

Quantitative Analysis

Descriptive statistical analysis was performed using STATA statistical software (StatCorp., 2021). Statistical analysis described the distribution (frequencies & percentages), central tendencies (mean) and dispersion (range & standard deviation) of the self-concept scores and the scores of the six domains (behavioral adjustment, freedom from anxiety, happiness & satisfaction, intellectual & school status, physical appearance & attributes, and social acceptance).

Qualitative Analysis

Qualitative data, including both photographs and captions were uploaded into NVivo (QSR International Pty Ltd., 2020) for data analysis. 63 Photographs and the accompanying 63 written descriptions were analyzed using a directed approach to content analysis which was guided by the theory of self-concept (Hsieh & Shannon, 2005). Analysis began by identifying key concepts as coding categories and then creating operational definitions for each category as
derived from the guiding theory. Next, the photographs and written descriptions were inductively coded by multiple members of the research team. Codes were then organized into subcategories and themes which were subsequently organized into the predetermined coding categories. No new data emerged during the analysis of the ninth participant’s data.

**Mixed Methods Integration and Analysis**

Mixed methods integration and analysis occurred once both the quantitative and qualitative data sets had been independently analyzed. The three key steps of mixed methods integration and analysis used for this study were integration data analysis procedures, representation of integration results, and interpretation of the integration (Creswell & Plano Clark, 2018). During this mixed methods data analysis, a joint display was created to show a side-by-side comparison of the quantitative, qualitative, and integrated findings. Points of concordance, discordance, and expansion provided additional rich insights into self-concept development of school-aged children with CULD.

**Rigor and Trustworthiness**

Rigor and trustworthiness are two key concepts that ensure the quality and credibility of a mixed methods research study. To ensure quantitative rigor in this research study, a review of psychometric properties of possible instruments was conducted while designing the research study. The PHCSCS was selected and used during this study due its acceptable psychometric properties (high inter scale correlations = .77 to .83, Cronbach’s $\alpha = .92$) (Flahive et al., 2015; Franklin Jr. et al., 1981). The PHCSCS included measures for response bias (RES) and inconsistent response (INC) for each completed survey. Each completed survey was well under the acceptable thresholds (RES < 0.7, INC < 0.7).
All four criteria of trustworthiness were included into the study design to ensure qualitative rigor in the proposed study (Lincoln & Guba, 1985). Credibility was maintained by having participants written descriptions for each photograph to ensure that their voices and meanings were maintained throughout data analysis. To ensure transferability, precise descriptions of the study’s participants, setting, and research procedures, contexts and assumptions were provided and discussed for future use (Trochim et al., 2016). Dependability was ensured by maintaining a detailed audit trail to promote accurate coding and reporting of results. Lastly, an audit trail as well as bracketing and reflexive journaling was employed to ensure confirmability.

**Data Management**

All data collected for the study was stored in the secure, password protected SHC box. According to Shriners Hospital for Children policy, all data collected for the study will be maintained securely the SHC Box for five years following the completion of the study.

**Results**

**Participant Sociodemographics**

Table 2 displays a summary of the participant’s sociodemographic information. Of the nine participants, 56% were female. Participant’s ages ranged from 8 years to 12 years old, with a mean age of 9.8 (±1.45) years old. Some 11% of participants were in the 2nd grade, 33% in the 3rd grade, 11% in the 4th grade, 33% in the 5th grade and 11% in the 6th grade. Additionally, 33% of the participants reported their race as White, 22% Asian, 22% Other, 11% American Indian or Alaska Native, and 11% Black or African American. And 56% of participants reported their ethnicity as Not Hispanic or Latino. Additionally, 89% of the participants reported their
parents as married and living together, while 11% were not married/living separately. All participants reported having siblings, with 11% having one sibling, 44% had two siblings, 33% had three siblings and 11% had four siblings.

Table 2

Descriptive Statistics of the Nine Participants (N = 9)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number (%)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td>9.8 (±1.5)</td>
</tr>
<tr>
<td>8</td>
<td>2 (22%)</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>2 (22%)</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5 (56%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4 (44%)</td>
<td></td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2 (22%)</td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2 (22%)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Hispanic or Latino</td>
<td>4 (44%)</td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>5 (56%)</td>
<td></td>
</tr>
<tr>
<td><strong>Grade Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>3rd</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td>4th</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>5th</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td>6th</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td><strong>Parents Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married Living Together</td>
<td>8 (89%)</td>
<td></td>
</tr>
<tr>
<td>Not Married Living Separately</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td><strong>Number of Siblings</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>4 (44%)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td><strong>State ADI Score</strong></td>
<td>7.89 (±1.6)</td>
<td></td>
</tr>
<tr>
<td><strong>National ADI Score</strong></td>
<td>33.11 (±18.3)</td>
<td></td>
</tr>
</tbody>
</table>
Utilizing the five-digit zip code from the participant’s home address, socioeconomical status (SES) was determined using the Area of Deprivation Index (ADI). The ADI allows for ranking of neighborhoods by socioeconomic disadvantage for a region of interest, both locally and nationally, and includes the following domains: income, education, employment, and housing quality (University of Wisconsin, 2019). ADI scores are ranked on a scale of 1 to 100 nationally and 1 to 10 locally or statewide. Scores of ‘1’ reflected communities that experience the least deprivation comparatively. State ADI scores ranged from 5 to 10, with a mean of 7.89 (± 1.62). National ADI scores ranged from 14 to 74, with a mean of 33.1 (±18.27).

Aim 1 Results (Quantitative)

**What is the Mean Self-Concept and Six Domain Scores of School-Aged Children with CULD?**

The mean scores, standard deviations, percentile ranges and the minimum and maximum range for self-concept and the six domains are displayed in Table 3. The mean self-concept score of school-aged children with CULD was 51.22 (±10.43). The mean scores for the six domains were: behavioral adjustment 52 (±8.19), freedom from anxiety 48.56 (±10.42), happiness and satisfaction 49.44 (±10.73), intellectual and school status 54.78 (±10.31), and social acceptance 49.89 (±8.64).

**Table 3**

**Summary of the PHCSCS Scores**

<table>
<thead>
<tr>
<th>Scales</th>
<th>Mean (Standard Deviation)</th>
<th>Percentile Range</th>
<th>Min to Max Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Concept</td>
<td>51.22 (±10.43)</td>
<td>29-71%</td>
<td>32-66</td>
</tr>
<tr>
<td>Behavioral Adjustment</td>
<td>52 (±8.19)</td>
<td>29-71%</td>
<td>35-58</td>
</tr>
<tr>
<td>Freedom from Anxiety</td>
<td>48.56 (±10.42)</td>
<td>29-71%</td>
<td>32-58</td>
</tr>
<tr>
<td>Happiness and Satisfaction</td>
<td>49.44 (±10.73)</td>
<td>29-71%</td>
<td>26-57</td>
</tr>
<tr>
<td>Intellectual and School Status</td>
<td>54.78 (±7.77)</td>
<td>29-71%</td>
<td>41-61</td>
</tr>
<tr>
<td>Physical Appearance and Attributes</td>
<td>52.78 (±10.31)</td>
<td>29-71%</td>
<td>26-57</td>
</tr>
<tr>
<td>Social Acceptance</td>
<td>49.89 (±8.64)</td>
<td>29-71%</td>
<td>34-60</td>
</tr>
</tbody>
</table>
Aim 2 Results (Qualitative)

*How do Children with CULD Describe Their Self-Concepts?*

Children with CULD defined their self-concept through expressions of self-efficacy, self-image, and social identity. As displayed in Figure 3, the following five prominent themes of self-concept development arose from the photographs and written descriptions: emotions, sense of accomplishment, positive view of oneself and one’s physical body, hobbies, and sense of connection.

**Figure 3**

*Thematic Map of Self-Concept Development*

Emotions were discussed in five of the participating children’s written descriptions of 11 of their photographs. The children’s likes, hobbies and dislikes were reported in relationship to the pursuit of a positive emotion. Participating children did not write about negative emotions, nor did they provide images of people, places, objects etc., that provoked the feeling of a negative emotions. Emotions were exclusively discussed from a positive perspective.
A sense of accomplishment was described by eight of the participating children in 11 photographs and written descriptions. Children photographed their artistic creations and scholastic achievements. Accompanying their photographs, participating children provided positive written descriptions of their accomplishments.

Of the nine participants, two children expressed characteristics of a positive self-image. Children described positive views of their overall selves in two photographs and two written descriptions. Positive views of their physical bodies were also described in two photographs and their written descriptions.

The next prominent theme of self-concept described by participating children was hobbies. Eight participating children described their social identity by sharing their hobbies. Hobbies which included art, reading, music, being in nature, technology and videogaming were described in 23 photographs and their written descriptions.

The fifth theme, sense of connection was described by all nine of the participating children in 22 photographs and written descriptions. Sense of connection was described by participating children through their relationships with their family member, friends, and pets. A sense of connection through friendships was reported by three participating children. Six children reported a sense of human connection through photographs and descriptions of family members, particularly their parents and siblings. A sense of connection was also described by six children as they shared photographs of their pets. Most children shared photographs of their dogs however, a one participant shared a photograph of her bearded dragon. Children described their relationships with their pets, their pet’s habits and how playing and interacting with their pets made them feel a positive sense of connection.
Is Having a Limb Difference a Key Component of a Child’s Self-Concept?

Children did not identify having a limb difference as a key component of their self-concept. Limb differences were not photographed nor addressed in the written descriptions by any of the participating children.

Aim 3 Results (Integration of Mixed Methods)

What are the Key Categories and Themes of Self-Concept Identified by Children with a CULD?

The mixed methods integration and analysis was based on the guiding theoretical framework; therefore, the guiding concepts (also known as categories) included self-efficacy, self-image, and social identity. Five themes were identified during qualitative data analysis and included: emotions, sense of accomplishment, positive view of oneself and one’s physical body, sense of connection and hobbies. Concordance and expansion provided additional clarification regarding the theoretical relationships between guiding concepts and themes. Table 4 presents the joint display of the quantitative, qualitative, and mixed methods integration results.

Results from both the qualitative and quantitative data endorsed concordance within the concept of self-efficacy. Children with CULD acknowledged occasional decreases in their moods or emotional state, but primarily report maintaining an overall positive emotional state. Children with CULD also more often engaged in activities that promoted positive emotions and provoked a sense of accomplished. Integrated results also found that school-aged children with CULD have positive perceptions of their academic performances and overall life appraisals.
### Table 4

**Joint Display for Mixed Methods Meta-inferences**

| Concepts                | Qualitative Results                                                                                                                                                                                                 | Quantitative Results                                                                                                                                                                                                 | Mixed Methods Meta-inferences                                                                                                                                                                                                 |
|-------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| **Self-Efficacy**       | **Emotions:**  
The pursuits of positive emotions influenced children’s likes, dislikes, hobbies, and connections. Emotions were exclusively discussed from a positive perspective.  
**Sense of accomplishment:**  
Children demonstrated a sense of accomplishment by sharing and providing positive descriptions of their artistic creations and scholastic achievements. | Evaluated themselves as well behaved but acknowledged a few difficulties with their conduct.  
Reported mostly positive emotional states, but acknowledged a few difficulties related to their moods.  
Reported both positive and negative appraisals of their overall life experiences, however the positive outnumbered the negative appraisals.  
Evaluated themselves as performing acceptably well in the academic setting. | Concordance.  
Both the qualitative and quantitative results endorse that children with CULD maintain a primarily positive emotional state and engage in activities to promote positive emotions.  
Additionally, both sets of results suggest that children with CULD have positive perceptions of their academic performances and overall life appraisals. |
| **Self-Image**          | **Positive perception of oneself and one’s physical body:**  
Self-reflections of the children’s overall selves, appearances and physical characteristics were discussed in an exclusively positive perspective.  
Limb differences were not included in the children’s self-reflections and evaluations of their physical bodies. | Reported both positive and negative perceptions of their appearance and physical characteristics, however the positive outnumbered the negative reports. | Concordance.  
Although self-image was least references concept, both the qualitative and quantitative results suggest that children with CULD possess overall positive self-reflections of their overall selves and their physical bodies.  
Limb differences were not found to be a key component of a children’s self-image. |
| **Social Identity**     | **Sense of connection:**  
Children expressed a sense of connection through the positive descriptions of their relationships with their community, friends, family members, and pets.  
**Hobbies:**  
By describing their interests and preferred activities, children enthusiastically shared their hobbies, which included: art, music, physical activities/sports, reading/literature, technology and videogaming. | Reported an overall satisfaction with their social functioning, while acknowledging occasionally difficulties with peer interactions. | Expansion.  
A more comprehensive understanding of the social context of school-aged children with CULD was revealed.  
Community, family members, friends and pets serve as important sources of connection.  
Hobbies serve as a key source of social identity for children with CULD. Findings suggest that hobbies may serve as pathway for a sense of connection and may also influence a child’s emotions and sense of achievement. |
Results from both the qualitative and quantitative data endorsed concordance within the concept of self-image. Although self-image was the least referenced concept, results suggested that children with CULD possessed overall positive self-reflections of their overall selves and their physical bodies. Limb differences were not found to be a key component of the children’s self-image.

Qualitative results offered expansion within the concept of social identity by revealing children’s extended social context. Combined with community and pets, family members and friends served as important sources of connection for children with CULD, and a rich description of their social context from the children’s perspectives. Nearly all (n=8) of the participating children shared photos of their pets and described the relationships with their pets as making them happy. Children also talked about their families making them feel safe and happy, with siblings being the most referenced family members. Activities and hobbies with siblings evoked positive emotions from participants. For example, an 8-year-old female wrote the following:

“Today I went to the fair. I got to hang out with my older brother and his friends. I got to go on some rides with my friends from school.”

This child engaged in her community with her brother and their friends, highlighting the importance of her social context.

**Discussion**

By using mixed methods, this research explored and created a rich description of self-concept development in children with CULD. Children with CULD reported positive self-concepts that fell within the average category for PHCSCS scores and are reflective of having a healthy and balanced self-evaluation (Piers & Harris, 2018). These findings aligned with others
(Andersson, 2011) that children with hand differences had overall self-concept scores equal to a comparison group of children without hand differences.

The Piers-Harris Children’s Self-Concept Scale (PHCSCS) survey was an effective tool for measuring self-concept scores in children with CULD. The survey provided illuminating insights into self-concept by providing scores in six associated domains of self-concept. All surveys were completed less than 10 minutes and the participant burden was minimal. The survey scoring also provided measures of inconsistent responding index and response bias which ensured rigor in data collection.

Concordance of the integrated results revealed that children with CULD described their self-concept in terms of their self-efficacy, self-image and social identity. When referring to their self-efficacy, children described a primarily positive emotional state. To promote positive emotions, children with CULD engaged in activities and maintained supportive relationships with peers and their family members. Children described relationships with their parents and siblings as making them feel happy and safe. Supportive relationships within the family unit of a child with a CULD has been shown to encourage positive emotions, increase a child’s sense of self-efficacy, and decrease the likelihood of developing depressive symptomology in adolescents and adulthood. (Varni et al., 1989; Varni & Setoguchi, 1991)

Children also described creating art as making them feel happy and being a means for expressing emotions. The pursuit of activities or hobbies that provoked positive emotions were frequently related to the children’s sense of accomplishment. School-aged children with CULD described their artistic creations and scholastic accomplishments from a positive perspective. These findings align with Pasek and Schkade (1996) who reported perceived skill mastery as
promoting a sense of accomplishment and increasing the child’s self-esteem levels. Additionally, children with CULD who report high levels of perceived academic accomplishment have been shown to have high levels of self-efficacy and positive overall self-concepts (Wijma, 2002). In concordance with existing literature, the results of this study further highlight self-efficacy as an important component of self-concept during the school-aged years for children with CULD. However, the results of this study provided innovative insights into how children describe self-efficacy. Emotions and a sense of accomplishment not only contribute to a child’s self-efficacy, but they are also important themes utilized by children when describing their self-concepts.

Although self-image was the least referenced concept by participating children, concordance of the qualitative and quantitative results suggested that children with CULD possess overall positive self-reflections of their overall selves and their physical bodies. An important finding from the qualitative literature was that children did not photograph or describe their limb differences, which suggests that they are not a key component of the children’s self-image. This finding correlates with findings from a recent photovoice project by Indelicato et al. (2019) in which the children’s physical differences were not described as a key point of their self-image. Perhaps, children with a CULD have unconsciously accepted their physical differences since it was present at birth, and as they have grown they have continued to embrace their physical bodies.

Expansion about social identity provided by the qualitative results offered a more comprehensive understanding of children’s social identity. School-aged children with CULD reported hobbies and a sense of connection as important aspects of their social identities. Findings suggested hobbies may serve as pathway for a sense of connection and may also
influence a child’s emotions and sense of achievement. Hobbies described by the participants included: art, exploring nature music, reading and literature, technology and videogaming. A majority of the hobbies described were being engaged in a solitary manner; however, the context of the pandemic influenced the ability to engage with peers. When referring to technology and videogaming, children often used these hobbies to engage with family, friends, and peers. Technology and videogaming has become an important platform for providing children with a sense of connection through digital connectivity. For children with CULD, digital connectivity provides a means for inclusivity into their social context.

Digital connectivity has been increasingly important the past three years as children’s social context has significantly changed as a result of living through the Covid pandemic. In person access to peers has been significantly limited and children’s typical day has been changed as a result of the pandemic. School-aged children have been immersed in online learning, and social engagement with peers has occurred primarily through means of digital connectivity. Other forms of peer engagement such as sports and organized activities were limited or cancelled due to national health mandates. The pandemic-imposed social restrictions interrupted new friendships opportunities (Hallett, 2021) for school-aged children with CULD.

Quarantine and shelter-in-place mandates significantly shifted children’s daily schedules, and instead of being in a classroom setting with their peers a majority of the week, children were at home with their families. This shift in social context was reflected in the study’s findings as children with CULD more often described relationships with their parents, siblings and pets as opposed to relationships with their peers. Relationships with family members have provided school-aged children with a critical boost in their sense of connection during the pandemic.
Previous research has shown that children who report increased feelings of connection with their family members are less likely to develop depressive symptomology (Schacter & Margolin, 2019).

Results of this study reveal effects that the COVID pandemic has imposed on children’s social context; however, the long-term effects of the pandemic have yet to be determined. The lack of children with CULD reporting friends is an interesting finding, as developmentally during the school-aged years children are typically exhibiting an increased need for peer acceptance including a need for a close, intimate bond with a same-sex peer (Parker et al., 2015). The discordance of the results from this study and prior research merits further exploration of the social context in which this study was conducted.

Despite the changes in children’s social context, school-aged children with CULD continued to describe their self-concept through the triadic determinism of self-efficacy, self-image and social identity; thereby supporting the guiding theoretical framework, the theory of true-belonging. Themes identified by the participating children crossed over between the concepts within self-concept. For example, hobbies which are part of social identity can provide a means for a child to feel a sense of accomplishment. As stated previously, a sense of accomplishment has been shown to increase a child’s self-efficacy which subsequently has been shown to positively affect the child’s self-image (Indelicato et al., 2019). Therefore, to reflect the fluidity of the self-efficacy, self-image, and social identity the model has been updated to reflect areas of overlap and convergence. This is displayed in Figure 4 below.
Study Strengths

This study successfully used a mixed method design to gain a more comprehensive understanding of self-concept development in children with CULD. School-aged children with CULD successfully and enthusiastically engaged in a modified photovoice methodology during which they shared intimate aspects of their self-concept with the research team. Such rich data would not have been obtained using other research methodological approaches. Thematic saturation was reached during the qualitative data analysis by the ninth participant, participants included in this study came from very diverse racial, ethnic, and socioeconomic backgrounds.

The use and revision of the theory provided a developmentally appropriate theoretical framework for the study. The framework approached psychosocial development from a constructionism inspired complex system science worldview perspective which allowed for children’s descriptions of their self-concept to be embraced, and subsequently led to the expansion of our knowledge regarding their social identities.
Study Limitations

The participant’s age ranges was the first limitation noted. The proposed age range was 6 to 12 years of age; however, the minimum age of the included participants was 8. Of the remaining potential participants, children 6 or 7 years of age with a CULD were not available for participation in the study.

The second limitation of the study was that this study was conducted during the Covid pandemic, which has altered their social context. The change in day-to-day activities has the potential to impact the findings of this study. Had this study been completed prior to the Covid pandemic or if it is repeated after the pandemic restrictions have fully lifted, results may differ significantly. The full implications of living through the Covid pandemic on the development of children cannot yet be appreciated or fully understood.

A third limitation of this study was that no data was collected on the ways in which participants typically interacted with their peers. This study did not examine children’s preferred platform (in person, chat, facetime, social media, etc.) for peer interaction, or how often they engaged with peers daily. Future inquiry about peer interactions should also include the methods (in person, phone, tablet or computer) used and how often the children interacted with their peers both pre- and post-COVID.

Implications for Nursing Practice

Nursing is uniquely situated to identify children that may be at risk for poor psychosocial health and refer these children and their families to essential social supports. Based on the results of this study, nursing can encourage children to participate in hobbies, and other activities that create a sense of accomplishment or connection such as engaging in the community or pet
ownership. Incorporating the results from this study into nursing practice may help promote healthy psychosocial development including developing a positive self-concept for children with CULD.

**Implications for Future Research**

Additional longitudinal research is needed to identify areas of psychosocial development that have been most significantly impacted by the pandemic to better understand the needs that children may have as they progress into adulthood.

By further researching and exploring self-concept development in all children, not only children with congenital limb differences, the theory will continue to evolve and will offer a formidable foundation from which to visual self-concept development. The theory may inspire the creation of additional middle range theories that will improve our knowledge and understanding of psychosocial development and its long-term consequences. The creation of these theories will inspire future researchers to create interventions aimed at promoting healthy self-concept development and improving children’s overall psychosocial well-being.

**Conclusion**

The completion of this mixed methods study led to the creation of a rich description of self-concept development in school-aged children with CULD. Expansion of the results facilitated the revision of the guiding theoretical framework and illuminated important aspects of the children’s social context from a first-person perspective. Additional studies are needed to understand self-concept and its associated concepts more fully to develop interventions for improving children’s psychosocial development and well-being.
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APPENDIX A: MANUSCRIPT #1 –
THEORY OF SELF-CONCEPT DEVELOPMENT IN CHILDHOOD
(SUBMITTING TO Nursing Science Quarterly)
Theory of Self-Concept Development in Childhood

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Abstract

Development of self-concept in childhood has been shown to have significant effects on lifelong generativity and life satisfaction. However, definitions of self-concept are varied, and an understanding of the relationships among the concepts comprising self-concept remains elusive. To bridge this theoretical gap, a theory of self-concept was developed. Derived from a constructionism inspired complex system science worldview, the theory of self-concept provides a theoretical foundation for self-concept development in childhood. This novel theory provides a theoretical foundation for future scholars to pursue the creation of middle range theories informing nursing practice and research to promote healthy psychosocial development in childhood.

**Key Words:** self-concept, self-acceptance, true belonging, constructionism, complex system science, grand theory, mental health, psychosocial development.
Introduction

The U.S. Department of Health and Human Services (USDHHS) recognizes the importance of childhood as a critical phase of growth and development by creating objectives aimed at improving children’s health, safety, and well-being within the Healthy People 2030 initiative (Office Disease Prevention and Health Promotion, 2021). Due to rising childhood mental health concerns, the USDHHS promotes the importance of safe, stable, and supportive relationships as crucial for children’s psychosocial development (Office Disease Prevention and Health Promotion, 2021). Psychosocial development is a progression of human development affected by environmental factors and ultimately determines an individual’s psychosocial health (Erikson & Erikson, 1997). Psychosocial health is defined as a state of mental, emotional, social, and spiritual well-being (Hatzenbuehler et al., 2013).

Developmentally during the school-aged years, when children are between the ages 6 to 12 years old, they navigate a critical period of intense psychosocial development in which they are beginning to form their self-concept (Parker et al., 2015). Self-concept is defined as an internal sense of who one is (Martens, 2021). Self-concept has a direct relationship on the gradual evolution of a child’s personality (Mascall, 1986) and over the course of the lifespan can influence school success, peer interactions, career selection, intimate relationships, middle adulthood generativity and overall life satisfaction (Jhangiani et al., 2014; Newman & Newman, 1979).

Early research in the field of psychosocial development found a significant and positive correlation between self-acceptance and self-concept (Shepard, 1978). Additional studies found that a child’s self-acceptance was driven by their self-concept and provided them with a positive
outlook which increased their emotional regulation, resilience, and their willingness to experience life and grow (Bernard, 2013; Bernard & Pires, 2006). Iorga et al. (2016) found that a person’s self-concept as well as their self-image were affected by their level of self-efficacy. While previous research has demonstrated the association between self-acceptance, self-concept, self-image, and self-efficacy (Bernard, 2013; Bernard & Pires, 2006; Iorga et al., 2016; Shepard, 1978), there continues to be a gap in our knowledge about how these concepts are intertwined.

Currently a universal definition for self-concept is lacking therefore the theory of self-concept was developed. The theory was created through two stages. The first stage consisted of establishing the nursing philosophical foundation from which the constructs were viewed. The second stage used concept derivation and statement derivation to create definitions and document relationships amongst the key concepts and constructs. Derived from a constructionism inspired complex system science worldview, the theory of self-concept development in childhood explores the relationships between self-concept, social identity, self-efficacy and self-image. This paper will discuss the theory’s philosophical foundations as well as providing definitions and relationships amongst the included constructs.

METHODS AND INITIAL THEORETICAL CONCEPTS

Phase 1: Philosophical Worldview

The creation of the theory of self-concept is based in a constructionism inspired complex system science worldview of human health and well-being. Constructionism, also referred to as social constructionism, is a philosophical perspective that emerged from historicism during the post-positivist era (Godfrey-Smith, 2003). Constructionist's hold an interpretive view which suggests that reality, meaning, and knowledge are constructed from social processes between
people and their environment, and are developed and disseminated within a social context (Crotty, 1998; Reed & Shearer, 2018). From a constructionism perspective, social context which includes social, historical and cultural factors, is crucial to knowledge development. Knowledge is built through shared meanings (Reed & Shearer, 2018) and meanings and truths are constructed in a social manner acknowledging historical and cultural influences, (Crotty, 1998). Constructionism emphasizes the key role that the social context plays in person’s understanding of their environment and the creation of knowledge. For children, the knowledge gained from exchanges with their social context directly influences psychosocial development and well-being (Erikson & Erikson, 1997).

Complex system science is a philosophical perspective that appreciates and explores the relationships and interdependencies between parts of an integrated whole (Capra & Luisi, 2014; Sturmberg, 2016). Complex adaptive systems are nested systems from which constant interactions between different parts of the system influence one another and other systems, systemically (Sturmberg, 2016). A complex adaptive system has the following seven key characteristics: non-linearity, open to environment, self-organizing, emergence, patterns of interaction, adaptation and evolution, and co-evolution (Chaffee & McNeill, 2007; Koithan et al., 2012; Sturmberg, 2016). A human being is a complex adaptive system composed of multiple interactive parts (biological, psychological/emotional, social and cognitive in nature) which are intricately integrated and in-separable (Parse, 1992; Sturmberg, 2016). As a complex adaptive system, a human and their environments are in continuous, dynamic, and open interaction; these exchanges not only affect but also define health and well-being (Parse, 1992; Sturmberg, 2016).
A Constructionism Inspired Complex Systems Science View of Human Health and Nursing Practice

Constructionism and complex system science are merged to allow for visualizing human health and nursing practice through a holistic lens that appreciates the unique complexity of each human being. In contrast to the historical definition of health as the absence of disease (Capra & Luisi, 2014), a constructionism inspired complex system science worldview enables philosophers and researchers to appreciate that an individual’s definition of health is biological, psychological, social, and cognitive well-being as constructed by their social context. Using a constructionism inspired complex system science approach to nursing practice, practice is defined as an individualized person-centered, evidence-based practice with emphasis on the person’s health, healing, wellness, and/or growth with mind–body–spirit integration and synchrony (Erickson et al., 2013), enables nurses to appreciate social contexts, while also acknowledging the relevance of biological, psychological, social, and cognitive factors that influence human health as they apply nursing knowledge.

The constructionism inspired complex system science worldview can be applied to the key concepts of psychosocial development in children, to inform the philosophical foundation, provide context, and clarification of meanings to enable nursing researchers to practice, discover and focus the researcher’s lens. Applying a constructionism inspired complex system science worldview enables nurses to visualize a child as a complex adaptive system, as children are constructing their realities and deriving meaning and knowledge from their unique social contexts. Psychosocial health is constructed by each individual child and is grounded in their social context. The constructionism inspired complex system science worldview enables nurses
to appreciate that a child is inextricably connected to an intricate web of relationships whose interaction with their social context leads to adaptive behaviors which in turn inspires the emergence of new properties, and ultimately informs systemwide change and learning, creating new knowledge and practices (Sturmberg, 2016; Koithan, Bell, Niemeyer & Pincus, 2012).

**Phase 2: Derivation Strategies**

Nursing frameworks focusing on self-concept development in childhood are non-existent; therefore, multiple frameworks focusing on psychosocial development were borrowed from the social sciences (Abrams & Hogg, 1990; Angelou, 1973; Bacchini & Magliulo, 2003; Bernard, 2013; Brown, 2021; Hayes & Strosahl, 2004; Markus & Nurius, 1986; O’Donohue, 2004; Shepard, 1978; Sim et al., 2014) with Bandura’s (1986, 2001) social cognitive theory being the premier choice. Bandura integrates behaviorist and cognitivist educational theories to explain, analyze and understand the complex nature of social learning. Social learning is learning of certain behavioral patterns that are causing social recognition or social disdain (Bandura, 1986). The social cognitive theory suggests that through dynamic, multidirectional interactions with their environment and other people, humans generate knowledge or rules that then influence their psychosocial development. Although the social cognitive theory addresses the complex nature of an individual’s environment, under further evaluation it lacked internal consistency with the desired concept at the heart of the inquiry, namely, self-concept.

To overcome this theoretical chasm, the need to create a new theory self-concept arose. The theory of self-concept was developed by expanding upon and logically combining
existing knowledge through the use of concept and statement derivation strategies (Walker & Avant, 2019).

**Concept Derivation**

The strategy of concept derivation entails redefining a concept from a parent field of study resulting in the creation of a new concept within a new field (Walker & Avant, 2019). The strategy involves examining the literature in closely related fields of study for definitions of concepts, selecting a set of concepts from the closely related field of study, and redefining the concepts in term of the topic of interest (Walker & Avant, 2019). To define self-concept for use within nursing, the strategy of concept derivation was used to examine this concept in existing sociology and psychology literature (Table 1).

Table 1. *Summary of concept derivation.*

<table>
<thead>
<tr>
<th>Concept</th>
<th>Evolved Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Concept</td>
<td>An internal sense of who one is, and it is derived by the triadic reciprocal determinism of: social identity, self-efficacy and self-image (Martens, 2021).</td>
</tr>
<tr>
<td>Social Identity</td>
<td>The perception of one’s roles, involvement, and memberships in social groups (Abrams &amp; Hogg, 1990; Martens, 2021).</td>
</tr>
<tr>
<td>Self-Image</td>
<td>The summation of a person’s perceptions of themselves and their physical body (Bacchini &amp; Magliulo, 2003; Martens, 2021).</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>The summation of the emotions, feelings and opinions a person holds about their own abilities and talents (Bacchini &amp; Magliulo, 2003; Martens, 2021).</td>
</tr>
</tbody>
</table>

**Self-Concept**

Early psychology and sociology philosophers suggest that self-concept formation begins with the process of knowing, but is more than the knower and the known (Hattie, 1992). The knower gains knowledge about themselves through self-appraisals (Hattie, 1992), and self-knowledge has been suggested to be at the heart of self-concept. Markus and Nurius (1986)
define self-concept as a complex and dynamic array of shifting self-knowledge. Rosenberg (1979) defines self-concept as the summation of a person’s thoughts and feelings, having reference to oneself as an object.

Self-concept is fluid and shifting, with meaning derived from a person’s unique traits, relationships and current social memberships; therefore, suggesting that social identity shapes one’s working self-concept (Sim et al., 2014). The content of the working self-concept depends on what self-conceptions a person has formed in response to a given experience, event, or situation within their social context (Markus and Nurius (1986).

The novel self-concept is defined as an internal sense of who one is, and comprised of one’s social identity, self-efficacy, and self-image (Figure 1). Social identity is the perception of one’s roles, involvement, and memberships in social groups (Abrams & Hogg, 1990). Self-image is the summation of a person’s perceptions of themselves and their physical body (Bacchini & Magliulo, 2003). Lastly, self-efficacy is the summation of the opinions a person holds about their own abilities and talents (Bacchini & Magliulo, 2003). Formulation of one’s self-concept is related to a person’s ability to accept themselves.

Statement Derivation

The strategy of statement derivation is utilized when developing a statement or set of statements about the concepts (Walker & Avant, 2019). Self-concept is a fluid sense of oneself that is influenced by a person’s self-image, self-efficacy, and social roles (Figure 1). Social identity incorporates social roles (examples: family, friends, school, relationships, teammates etc.), spiritual affiliations and community engagements. Traits derived from a child’s social identity, directly influences their self-efficacy and self-image (Sim et al., 2014). Children’s level...
of self-efficacy has been shown to significantly affect their performance in daily activities; for example, children who have having high self-efficacy levels are more confident, can rally more and are more successful which strengthens their self-image and their self-concept (Magdalena, 2015). Self-image has also been found to play a central role in constituting the nucleus of the scheme of self-concept (Bacchini & Magliulo, 2003). Bacchini and Magliulo (2003) highlighted the importance of the relationship between self-efficacy and the self-image. Their findings suggested that the relationship between self-efficacy and the self-image was primarily positive, however at times it was extremely tenuous or absent, and due to the complex nature of this relationship the need for future multimethod and multidimensional research studies was highlighted (Bacchini & Magliulo, 2003).

Drawing from existing research, self-concept comprises social identity, self-efficacy, and self-image, based on triadic reciprocal determinism. The relationships among these three concepts are in constant flux and ever evolving. As a person’s social context changes, their self-concept also shifts slightly, and this adaptation is commonly referred to as a working self-concept or working self. However, our sense of self, our inner most self-concept is evolutionary and serves as the foundation for our working self.
Discussion

The theory of self-concept sets forth a foundation from which healthcare practitioners, researchers and philosophers can appreciate the complex relationships between the three concepts social identity, self-efficacy, self-image, within the larger concept of self-concept in children. A child’s social identity, self-efficacy and self-image are in a constant, dynamic and evolutionary relationship, working together to create a child’s self-concept (Martens, 2021). Although self-concept formation begins and is most formidable in childhood, one’s self-concept evolves into a more concrete construct in adulthood (Erikson & Erikson, 1997; Parker & Gottman, 1989; Parker et al., 2015).

The theory of self-concept also provides definitions of key concepts of psychosocial development in childhood for use within nursing and other health related disciplines. By creating an organized and congruent language of psychosocial development, philosophers across the health related disciplines can work together to sustain and build knowledge through
the creation of useful and meaningful middle range theories for studying this phenomena in
care of childhood (Reed & Shearer, 2018). Based on existing literature in the fields of psychology
and sociology(Abrams & Hogg, 1990; Angelou, 1973; Bacchini & Magliulo, 2003; Bernard,
2013; Brown, 2021; Hayes & Strosahl, 2004; Markus & Nurius, 1986; Martens, 2021;
O’Donohue, 2004; Shepard, 1978; Sim et al., 2014), a definition for use within the health
sciences of self-concept emphasizes the importance of the triadic determinism of the
following three concepts: self-identity, self-efficacy and self-image. Exploring the complex
relationship between these concepts is crucial to gaining a more comprehensive understanding
of self-concept development in children.

As our understanding and knowledge of psychosocial development in childhood
continues to develop, research focused on the concepts compromising self-concept (self-
identity, self-efficacy, and self-image), will expose sensitive areas of development where
interventions could facilitate positive changes and promote healthy development. For
example, in early childhood, family and parental figures are the primary members of a child’s
social group. However, as a child enters middle and late childhood and into adolescence also
known as the school-aged years, peer groups become the key focus of a child’s social group
(Parker et al., 2015). Peer groups are a key variable affecting a child’s social identity;
therefore, interventions aimed at promoting positive peer relationships have the potential to
positively impact a child’s social identity.

According to the theory of self-concept, the developmental evolution of a child’s
social identity has the potential to impact self-efficacy and self-image, and vice versa;
however, research has not yet studied the association between these three concepts
congruently. In theory, it may be proposed that a child who experiences positive peer relationships, develops a positive social identity which then consequently promotes positive self-image and self-efficacy. This would in turn lead to the development of a positive self-concept thereby promoting the continued psychosocial developmental progression towards self-acceptance. The opposite scenario may also be proposed: a child who experiences negative or poor peer relationships, develops a negative social identity which then consequently promotes negative self-image and self-efficacy. Ultimately this child would develop a negative or poor self-concept and would be unable to progress towards self-acceptance.

However, psychosocial development is not generally linear in progression but rather in constant flux, shifting and evolving with each new life experience and interaction. Using this perspective, it could be proposed that a child who has experienced poor or negative peer relationships may still be able to develop a positive self-concept if they possess a positive self-image and self-efficacy. Our knowledge has yet to appreciate the dynamic reciprocal relationship between these concepts, and by better understanding the relationships between the social identity, self-image and self-efficacy, interventions can be developed and tested to promote and support positive self-concept development. The theory of self-concept could serve as a theoretical framework for future studies aimed at improving our understanding of the relationships between social identity, self-image, and self-efficacy, as well as intervention-based studies focused on promoting positive self-concept development in childhood.

Additionally, as researchers use the theory of self-concept to expose sensitive areas of psychosocial development, these areas may serve as targeted areas of psychosocial assessment
in clinical practice. As previously mentioned, peer groups become a key focus of a child’s social identity in the school aged years, therefore, evaluation of a child’s peer relationships during this developmental period may serve as an indicator of social identity and self-concept development. Self-concept development has been shown to be the cornerstone for all further psychosocial development, such as personality, academic and professional success, and life satisfaction and generativity (Jhangiani et al., 2014; Mascall, 1986). Developing a negative self-concept has been associated with an life-long increased risk for developing anxiety, depression and lower the optimism, self-esteem and self-efficacy (Ledrich & Gana, 2012).

It is imperative that practice include routine and developmentally appropriate assessments of psychosocial development in childhood. By including routine assessments, health care providers will be able to identity children at risk for negative self-concept development and poor psychosocial well-being and facilitate early access to the mental health and social support services that are needed. Early intervention during childhood is key to promoting life-long psychosocial well-being.

**CONCLUSION**

Derived from a constructionism inspired complex system science worldview, the theory of self-concept was created using concept and statement derivation strategies to reveal relationships amongst the key concepts and constructs of psychosocial developmental in childhood. The theory of self-concept provides definitions of social-identity, self-image, self-efficacy, and self-concept for use within health-related disciplines. The theory of self-concept may be used by researchers, philosophers, and health care practitioners as a framework from which to visualize the psychosocial development of self-concept in childhood. Future studies are
needed to further evaluate these relationships and develop middle range theories focused on the psychosocial development of children.
References


APPENDIX B: MANUSCRIPT #2 –

SELF-CONCEPT DEVELOPMENT IN CHILDREN WITH LIMB DIFFERENCES: A SCOPING REVIEW

(SUBMITTING TO The Journal of Creativity in Mental Health)
Self-Concept Development in Children with Limb Differences: A Scoping Review

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Keywords: children, children with disabilities, self-concept, limb differences, psychosocial development
Self-Concept Development in Children with Limb Differences: A Scoping Review

ABSTRACT

Background

Having a visible physical difference, such as a limb difference, can have a significant impact on a child’s psychosocial development, as children with limb differences may experience negative psychosocial sequelae. Such experiences can have detrimental health consequences; however, the impact these situations have on a child’s self-concept has not yet been explored.

Objective

The aim of this scoping review was to investigate the findings of literature pertaining to self-concept of children with limb differences.

Methods

Literature searches were conducted in Embase, CINAHL, PsycINFO and PubMed databases. Articles written in English within the last 50 years (1971-2021) that focused on children under age 18 years with limb differences were included in the search. Data collected included: authors, year of publication, study location, study design, participant and comparison group characteristics, measures used, measurement timing, data collection, and findings.

Results

Nine articles met the inclusion criteria and were included in this review. Seven articles used self-report instruments, and five of these used four or more self-report instruments. Only two studies focused on evaluating self-concept, while the remaining seven studies focused on associated constructs of self-concept (i.e., self-perception and self-esteem). These studies found
that the social environment directly impacted the development of depression, anxiety, self-esteem, self-perception and self-concept.

**Conclusion**

The social environment appears to have a moderating effect on the psychosocial development of children with limb differences, but literature examining the effects of having a limb difference on the development of self-concept is sparse. This review demonstrated a need for a gold standard instrument with which to assess self-concept.

**Clinical Relevance**

Level II: Scoping review of Level-II studies
**BACKGROUND**

Children with limb differences, which are physical differences of the hand, arm, foot or leg, are at increased risk for developing psychological disorders such as depression, mood disorders, and anxiety [1-3]. Limb differences may be congenital (present at birth) or acquired (often referred to as amputation), and they may affect both the appearance and function of a child’s extremity [4]. Children with limb differences often report facing negative peer reactions including social stigma and exclusion as a result of their physical difference [5]. Negative encounters such as these may impact a child’s psychosocial well-being (state of mental, emotional, social, and spiritual well-being [5]), and psychosocial development (progression of human development that can be impacted by environmental factors, and that ultimately determines life satisfaction, meaning and purpose [6]).

From age 6 to 18 years of age, children navigate a critical phase of psychosocial development focused on establishing a self-concept [6,7]. Self-concept is influenced by the reciprocal relationship of three constructs: 1) social identity (perception of one’s involvement and memberships in social groups), 2) self-efficacy (opinions about one’s ability to exert control over one's own motivation, behavior, and social environment), and 3) self-image (perception of oneself as an individual and of one’s physical body)[8,9]. Self-concept has been associated with and related to other constructs of psychosocial development such as self-esteem (one’s overall feelings about the qualities within their self-concept) and self-perception (view of one’s overall self) [1,8]. Therefore, appreciation of the connection between these psychosocial constructs further demonstrates the importance of self-concept development. Having a negative self-concept impacts the child’s personality and can influence their school performance, peer
interactions, career selection, intimate relationships, middle adulthood generativity (regard for and ability to care for other generations), and life satisfaction [7,11]. The aim of this scoping review was to describe the state of knowledge regarding the development of self-concept in children with limb differences, specifically:

- How does having a limb difference affect a child’s self-concept?
- How does having a limb difference affect the constructs of self-concept (self-efficacy, social identity, self-image)?
- How does having a limb difference affect the constructs associated with self-concept (self-perception and self-esteem)?
- What factors influence the development of self-concept in children with congenital limb differences?
- Which research instruments are used to evaluate self-concept or one of its associated constructs?

**METHODS**

**Search Strategy**

This scoping review was performed using the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) Extension for Scoping Reviews [11] as a protocol. We conducted a comprehensive literature search in Embase, CINAHL, PsycINFO and PubMed databases between December 2020 to May 2021. Suggested similar articles yielded through the database searches and reference lists from searched articles were also considered for eligibility. The search strategy included the following MESH headings:
Filters applied to the searches included articles written within the last 50 years, from 1972 to current, full text, published in English and including children (0-12 years old) and adolescents (13-18 years old).

**Inclusion and Exclusion Criteria for Study Selection**

Inclusion and exclusion criteria are displayed in Table 1. All types of methodological approaches, quantitative, qualitative, and mixed methods studies were included in order to ensure all related articles were comprehensively reviewed. Articles that examined self-concept or one of its associated constructs, such as self-esteem or self-perception, were also included. Articles that were editorial or commentary literature and those for which the focused population involved children with developmental delays, cognitive impairments, or syndromes were excluded.

**Charting Data**

The first selection of articles for review was based on a screening of titles and abstracts conducted by the primary author. The second screening entailed a review of the full text from either member of the review team, and each article was reviewed by two team members to ensure the article met the inclusion criteria. In the event of a disagreement regarding inclusion during the second article screening, a third team member was available to review the article in
question. The data collected from each selected article reflected the aim and research questions and included: authors, year of publication, study location, study design, participant and comparison group characteristics, measures used, measurement timing, data collection, and results. Data was collected using a customized Google™ form, and the two reviewers independently extracted the data. The primary reviewer uploaded responses into an Excel™ document; the two reviewers reviewed this document during monthly team meetings. A formal quality assessment or appraisal of the risk of bias of articles was not conducted as this is not required by scoping review methodology [11].

**Protocol and Registration**

Our protocol was drafted using the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols (PRISMA-P) [11], which was revised by the reviewers after feedback from faculty members at the University of Arizona College of Nursing. The protocol and search strategy were then registered with and disseminated through the Open Science Framework on 11 April 2021 (https://osf.io/fvgyx/?view_only=8c71fd6cfd2a43c79df115af1b1c240dd).

**RESULTS**

**Search Results**

Our literature search yielded 87 results from which 11 duplications were removed, yielding a total of 76 articles. After screening titles and abstracts, 53 articles were excluded. The remaining 23 full text articles were retrieved and assessed for inclusion. Of these, 14 articles were excluded for the reasons displayed in Table 2. The remaining 9 articles met inclusion criteria. The search strategy is detailed in the PRISMA Flow Diagram [12] displayed in Figure 1.
The location, design, number, and characteristics of participants and control group if used, data collection including measures and timing of measures, and results for the 9 included studies are displayed in Table 3.

Of the 9 articles included in this review, 7 described studies performed in the United States. Five were published before 1997. Seven used self-report instruments, and 5 of these used 4 or more self-report instruments. Only 2 studies focused on evaluating self-concept, while the remaining 7 studies focused on associated domains of self-concept (i.e., self-perception, self-image and self-esteem). All studies included both girls and boys less than 18 years of age with limb differences. Participants’ mean ages ranged from 10.3 to 16 years old. Only 2 studies included the use of a comparison or control group in their study design.

Of the 9 included articles: 6 were quantitative, cross-sectional, exploratory studies; 1 was a qualitative, phenomenological participant observation study; 1 was a quantitative, cross-sectional, descriptive study; and 1 was a qualitative, participatory action research study.

Correlating with the design types, 7 studies utilized self-report measures (ranging from 1 to 8 measures), and 5 used 4 or more self-report measures (Table 3). While only 2 of the studies directly measured or focused on self-concept, the remaining articles focused on associated variables such as self-esteem (4), social inclusion (2), and self-perception (1). Measures used to evaluate self-concept and associated constructs included:

- Self-Perception Profile for Children (SPPC)
- Social Support Scale for Children (SSSC)
- Family Environment Scale (FES)
- Children’s Hassles Scale (CHS)
• Children’s Depression Inventory (CDI)
• Degree of Limb Loss Scale (DLLS)
• Dyadic Adjustment Scale (DAS)
• State-Trait Anxiety Inventory for Children (STAIC)
• Beck’s Depression Inventory (BDI)
• Family Relationship Index (FRI)
• Functional Ability Measure (FAM)
• Loneliness Measure
• DISABKIDS Chronic Generic Measure (DCGM-37)
• Piers–Harris Children’s Self-Concept Scale (PHCSCS).

**DISCUSSION**

The gap in the existing knowledge examining how self-concept is affected when a child has a limb difference was highlighted when analyzing the search results. There were only two existing studies that focused primarily on evaluating the self-concept of children with limb differences. The first study, conducted in 2002 by Wijma et al., examined the nature and correlates of self-concept in children with obstetric brachial plexus palsy (BPP) [16]. Since BPP is typically the result of a trauma sustained during the birth process and may result in a life-long limb difference, this article met inclusion criteria. This study found that children with BPP have lower self-concept in athletic competence, but higher self-concept in scholastic competence and behavioral conduct [16]. Boys with BPP, when compared to boys without disabilities, have lower self-concept only in the domain of athletic competence, but girls with BPP score just as well or better in all domains of self-concept than girls without disabilities [16].
These findings were reinforced by Andersson et al.’s study which explored self-concept and psychological well-being in children with hand and upper extremity differences using a quantitative exploratory approach [18]. Overall self-concept scores showed that the hand difference group had positive self-concept scores which were equal to a comparison group of healthy children [18]. However, within the hand difference group, those with mild differences had significantly lower scores than those children with more severe and visible limb differences [18]. Their findings suggest that children with a more mild or minimally visible limb difference may be at greater risk for poor self-concept development.

While the existing literature was limited in examining overall self-concept development, the findings focused more on how a limb difference affected the constructs associated with self-concept such as: self-esteem, self-perception, and self-image. Varni et al. investigated self-esteem in 41 children with limb differences and found that low self-esteem was predictive of the development of depressive symptomology [2]. Another study by Varni & Yoshio investigated self-esteem development in 51 children with limb differences and concluded that higher self-perception scores were statistically predictive of lower depressive and anxious symptoms and higher general self-esteem [13]. These studies suggest that, in children with limb differences, low levels of self-esteem are associated with the development of anxiety and depressive symptomology.

Another construct of self-concept, self-image, was explored in a qualitative descriptive study conducted at a summer camp for children with limb differences by Indelicato et al. In this study, three themes related to self-image emerged: self-perception, camp participation, and coping [19]. Ylimäinen et al. explored perceived physical appearance and health-related quality
of life (HRQoL) in children with limb differences. Girls with longitudinal, bilateral, or lower limb differences reported significantly lower HRQoL than girls with other limb differences, and unexpected attention from peers and others negatively impacted perceived physical appearance and HRQoL [17]. However, while investigating self-image, both studies noted a desire for connection with others as an overarching theme, thereby highlighting the importance of the social environment on a child’s development [17, 19].

The power of the social environment reverberated through the search results as a significant moderating factor affecting the development of self-concept and its associated constructs in children with congenital limb differences. The social environment has most recently been defined as encompassing the immediate physical surroundings, social relationships, and cultural milieus within which defined groups of people function and interact [36]. Additionally, social environments are dynamic and change over time in response to both internal and external forces [36]. Varni led research endeavors that demonstrated the powerful effects of the social environment on a child’s psychosocial development. Early studies led by Varni suggested that lack of social support, family conflict and organization, marital discord, higher daily hassles and micro stressors were significantly associated with low self-esteem and predictive of lower perceived physical appearance [2,13, 14]. Varni & Setoguchi further investigated predictors of depression, anxiety, and self-esteem in children with congenital limb differences, and their results suggested that higher parental depression and anxiety predicted higher child depression and anxiety and lower self-esteem [14].

Varni’s studies also found that psychological adjustment factors were significantly related to perceived parent, teacher, classmate, and friend social support [2,3,13]. These studies
also concluded that higher classmate, parent, and teacher social support, peer acceptance, scholastic competence, and athletic competence were statistically predictive of higher perceived physical appearance and higher self-esteem [2,13]. Another study by Pasek & Janette evaluated components of skill mastery and self-esteem in children with limb differences [15]. Findings suggested that skill mastery is an important component of a child’s positive self-efficacy and self-perception, and that evidence of preexisting self-esteem and perceived social support were as likely to produce positive effects as skill mastery [15], which further reinforces the importance of the social environment on a child’s self-concept development.

Lastly, it is important to note that the measurement tools utilized to evaluate self-concept and associated constructs varied greatly. In total, 14 different measurement tools were utilized in the 9 included studies. In those studies, 7 studies utilized self-report measures, and the remaining 2 studies were qualitative designs that did not utilize measurement scales. In the 7 studies that used measurement tools, 5 studies used 4 or more self-report measures in their designs. For example, studies conducted by Varni utilized 6 to 8 different self-report tools per participant, which carries the potential of increased participant burden and may make interpretation of data across multiple studies more difficult. The variability in preferred measurement tool application by different authors made it challenging to laterally compare and contrast findings.

The Self-Perception Profile for Children (SPPC) is a 36-item survey designed to assess a child’s perceptions of their self-concept in the following six different domains: scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct, and global self-worth [37]. The SPPC was found to have robust internal reliability ($\alpha=.83-.95$); however, inter-domain correlations ranged from weak to strong ($\rho=.05-.85$) [37]. While the
survey demonstrates promising psychometric properties, validating studies have been focused on small sample sizes of children with chronic illnesses. Further testing is needed to continue to validate the SPPC. The second measure, the Social Support Scale for Children (SSSC), is a 24 item survey that is utilized to assess a child’s perception of social support through the examination of the following 4 domains: parent, teacher, classmate, and friend [38]. Internal consistency of the SSSC was acceptable across all domains ($\alpha= .72\text{-.81}$) [38]. Although this measure has been well validated for use in pediatrics, the measure itself does not directly assess self-concept.

The Family Environment Scale (FES) is a 90-item survey that is utilized to assess the following domains of the family environment: cohesion, expressiveness, conflict, independence, achievement, intellectual-cultural, active-recreational, moral-religious, organization, and control [39]. After significant testing, the FES has been found to have low internal consistency for the FES domain scores ranging from .64 to .83 [39- 42]. Originally the FES was designed with an emphasis on construct breadth rather than on internal consistency; therefore, the FES continues to undergo revisions to improve its psychometrics properties [39]. The next measure, the Children’s Hassles Scale (CHS) is a survey consisting of 25 situational experiences also known as hassles. The CHS requires a child to indicate if each hassle occurred within the past month and rate how each hassle made them feel [43]. Prior research has found adequate internal consistency for CHS ($\alpha= 0.87$) [43,44].

The Children’s Depression Inventory (CDI) is a 27-item survey that is used to assess the severity of depressive symptoms in children and adolescents. The CDI has been validated for use with children from 8 to 17 years old, and it has demonstrated adequate internal consistency for
the CDI, ranging between \( \alpha \) 0.83 and 0.94 [43,45]. The Beck’s Depression Inventory (BDI) was another measure used to assess depressive symptoms in children. The BDI is a 21-item, self-report survey that is utilized to assess the characteristics and symptoms of depression in children [46]. The BDI was also found to have adequate psychometric properties, with a high internal consistency \( \alpha = 0.9 \) and retest reliability ranging from 0.73 to 0.96 [46].

The State-Trait Anxiety Inventory for Children (STAIC) is a 40-item self-report measure used to assess a child’s type and degree of anxiety. The STAIC was found to have adequate psychometric properties, which include an internal consistency \( \alpha \) that ranged from .86 to .95, a test-retest reliability coefficient ranging from .65 to .89, and adequate studies demonstrating the construct and concurrent validity of the measure [47,48]. The Loneliness Measure was utilized by studies to assess loneliness and social dissatisfaction, using a 16-item self-report survey [49]. The Loneliness Measure has also been found to have adequate internal consistency \( \alpha = 0.90 \) and internal reliability (split-half correlation between forms = .83; Spearman-Brown reliability coefficient = .91; Guttman split-half reliability coefficient = .91)[49].

The Dyadic Adjustment Scale (DAS) is a 30-item survey that is used to assess relationship satisfaction, intimacy, affective expression, and the degree of agreement regarding matter of importance within the relationship. Studies included in this review utilized the DAS to assess parental marital status of children. Prior research has found the DAS to have adequate convergent validity and internal consistency \( \alpha = .80 \) [50]. The Family Relationship Index (FRI) is a 12-item survey that is utilized to assess the overall quality of the family environment, family cohesion, expressiveness, and conflict. Early testing established acceptable validity of the
FRI survey (p < .05) when correlated with similar and well tested measures; however, there has been very limited reliability and validity testing of the FRI since initial evaluation [51].

The Degree of Limb Loss Scale (DLLS) is an observational scale used by providers for reporting the level of limb amputation. The DLLS was developed at UCLA as part of the Child Amputee Prosthetics Project [3,13]. The Functional Ability Measure (FAM) was initially designed to be used in addition to the Functional Independence Measure (FIM), which is a measure of 18 items used by clinicians to assess deficits in activities of daily living in patients with progressive, fixed, or reversible neurological or musculoskeletal conditions [52]. The FAM is a 12-item tool used by clinicians to assess cognitive, behavioral, communication, and community functioning capabilities, and it is not recommended as a stand-alone measure [52]. Lastly, the DISABKIDS Chronic Generic Measure (DCGM-37) is a 37-item Likert scale survey that is used to assess the health-related quality of life for children with a chronic condition or disease. CGM-37 was found to have adequate internal consistency (α > .70) and moderate to high correlations (0.65-0.81) between the mental and emotional sub-scales [53].

After reviewing the multitude of measures utilized, one measurement tool, the Piers-Harris Children’s Self-Concept Scale (PHCSCS) stood out as being the most comprehensive choice and the only tool that directly measured self-concept. This measure not only provided overall self-concept scores, but also included scores in 6 associated constructs of self-concept: behavior adjustment, freedom from anxiety, happiness and satisfaction, intellectual and school status, physical appearance and attributes, and social acceptance period. Previous studies found the PHCSCS to have convergent and discriminant validity relative to the other variables included in the scale, high inter scale correlations (.77 to .83), and a comparatively high degree of internal
consistency (Cronbach’s alpha= .92) [34, 35]. By utilizing the PHCSCS in future studies, researchers would be able to explore not only self-concept but also its associated constructs without adding increased burden to the participants.

**Limitations**

The results from this scoping review should serve to guide future research studies. Theses scoping review results are only up to date as of May 2021. Additionally, the studies included in this review world were all conducted in high income countries. Currently there are no available studies examining how having a limb difference affects self-concept in children from low-income countries. Lastly, the studies included in this scoping review were conducted over relatively short time frames, typically 2 years or less. To date, there have not yet been any longitudinal studies examining self-concept development in children with a limb difference.

**Conclusion and Future Research**

In conclusion, the effect of having a limb difference on a child’s self-concept development is an area in need of future research. Existing research has shown that self-concept development is crucial in determining a child’s personality, and it can influence their academic success, peer interactions, career selection, intimate relationships, middle adulthood generativity, and later life satisfaction [7,11]. Since there are currently only two studies focusing on this phenomenon, more research, including longitudinal studies, would improve our knowledge and enable clinicians to provide more effective support and intervention for children throughout their development.

The findings reflected in this review demonstrate the effects of the social environment on the psychosocial development of children with limb differences. The social environments
included peer, familial, and classmate interactions and relationships; and these directly impacted the development of depressive symptomatology, anxiety, general self-esteem, self-perception, and self-concept. Healthcare providers caring for children with limb differences should include psychosocial evaluations into their patient encounters in everyday practice to identify children that may be at risk for poor psychosocial development.

Future studies should focus on the developmental period of middle childhood to adolescence, between the ages of 8 and 17, as this is a crucial period for self-concept development [6,7]. Future studies should also examine the different aspects of children’s social environment and the impact of these factors on self-concept in children with limb differences, as previous research has demonstrated that social environment may help determine one’s personality, influence one’s academic success, and affect peer interactions, relationships, career selection, adulthood generativity, and later life satisfaction. The knowledge gained from future research studies will improve our understanding and enable us to provide more effective psychosocial support for children with limb differences throughout their development.
References


APPENDIX A

Figure 1

PRISMA 2020 flow diagram literature search results

Note. Displaying search strategy and results in the PRISMA flow diagram [12].
**APPENDIX B**

Table 1.

**Inclusion and exclusion criteria**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Article</strong></td>
<td>Full text: peer reviewed articles, case studies, dissertations. Written in English.</td>
<td>Editorial or commentary articles. Non-English article.</td>
</tr>
<tr>
<td><strong>Study Design</strong></td>
<td>Qualitative, Quantitative, Mixed Methods</td>
<td>None</td>
</tr>
<tr>
<td><strong>Target Population</strong></td>
<td>Children 18 years of age or younger with a limb difference, without developmental delays, cognitive impairments, or syndromes.</td>
<td>Young people older than 18 years of age with a limb difference. Children with developmental delays, cognitive impairments. or syndromes</td>
</tr>
<tr>
<td><strong>Characteristics (Age)</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* The inclusion and exclusion criteria for each characteristic of the review.
Table 2.

**Excluded articles and reasons for exclusion.**

<table>
<thead>
<tr>
<th>First Author, Year of Publication, Country of Origin</th>
<th>Reason for Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angliss, 1974, Australia</td>
<td>Articles focused on prosthetic use and did not evaluate any domain of self-concept</td>
</tr>
<tr>
<td>Lussier, 1980, United Kingdom</td>
<td>Articles considered to be editorial or commentary literature</td>
</tr>
<tr>
<td>Frank, 1986, United States</td>
<td>Participants were older than 18 years of age</td>
</tr>
<tr>
<td>Scatena, 1990, United States</td>
<td>Articles considered to be editorial or commentary literature</td>
</tr>
<tr>
<td>Smith, 1992, United Kingdom</td>
<td>Articles considered to be editorial or commentary literature</td>
</tr>
<tr>
<td>Fernando, 2001, United States</td>
<td>Case studies of orthopedic conditions and physical disabilities other than limb differences</td>
</tr>
<tr>
<td>Didierjean-Pillet, 2002, France</td>
<td>Non-English article</td>
</tr>
<tr>
<td>Sheriff, 2004, United States</td>
<td>Included a majority of participants older than 18 years of age</td>
</tr>
<tr>
<td>Sheffler, 2009, United States</td>
<td>Assessed quality of life, mobility and function, did not discuss/evaluate self-concept.</td>
</tr>
<tr>
<td>Hussain, 2011, Cambodia</td>
<td>Focused on children’s perspectives of prosthetics and did not discuss/evaluate self-concept.</td>
</tr>
<tr>
<td>McLaughlin, 2014, United Kingdom</td>
<td>Focused population included children with orthopedic conditions other than limb differences.</td>
</tr>
<tr>
<td>Adkinson, 2015, United States</td>
<td>Systematic review of research instruments used in children with congenital limb differences</td>
</tr>
<tr>
<td>Vannuscorps, 2015, Italy</td>
<td>Articles considered to be editorial or commentary</td>
</tr>
<tr>
<td>Mano, 2019, Japan</td>
<td>Focused on lexical–semantic body knowledge, did not discuss/evaluate self-concept.</td>
</tr>
</tbody>
</table>

Note. First author, year of publication, country of origin and reason for exclusion from the scoping review were included for each article that was excluded during the second phase of review.
### Table 3.

**Characteristics of included studies**

<table>
<thead>
<tr>
<th>First Author, Publication Date</th>
<th>Study Location</th>
<th>Study Design</th>
<th>Number of Participants</th>
<th>Characteristics of Participants</th>
<th>Characteristics of Control Group</th>
<th>Data Collection</th>
<th>Timing of Measures</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Varni, 1989</td>
<td>United States</td>
<td>Quantitative, cross-sectional, exploratory</td>
<td>41 children</td>
<td>26 boys, 15 girls. Mean age = 10.5 years, range of 8-13 years (SD= 1.6). 34 children had congenital limb differences, 7 children had acquired limb differences. The mean family socioeconomic (SES) status based on the Hollinghead’s four factor index was 42 (SD= 13.6), indicating average, middle class family SES.</td>
<td>N/A</td>
<td>Self-Perception Profile for Children (SPPC), Social Support Scale for Children (SSSC), Family Environment Scale (FES), Children’s Hassles Scale (CHS), Children’s Depression Inventory (CDI), Degree of Limb Loss Scale (DLLS)</td>
<td>Completed prior to outpatient clinic visit</td>
<td>Micro stressors predictive of general self-esteem ($r = -0.27$, $p &lt; 0.05$). Classmate social support highly predictive of general self-esteem ($r = 0.55$, $p &lt; 0.001$). Physical appearance self-perception predictive of general self-esteem ($r = 0.64$, $p &lt; 0.001$). Family Conflict ($r = -0.39$, $p &lt; 0.02$) and organization ($r = 0.44$, $p &lt;0.005$) predictive of general self-esteem. General self-esteem was found to be significantly predictive of depressive symptomology ($r = -0.58$, $p &lt; 0.001$).</td>
</tr>
<tr>
<td>Varni, 1991</td>
<td>United States</td>
<td>Quantitative, cross-sectional, exploratory</td>
<td>51 children</td>
<td>32 boys, 19 girls. Mean age = 10.3 years, range of 8–13 years (SD = 1.65). 43 children had congenital limb differences and 8 children with acquired limb differences. Mean family SES based on the Hollinghead’s four factor index was 41.9 (SD= 11.7), indicating average, middle class family SES.</td>
<td>N/A</td>
<td>SPPC, SSSC, Dyadic Adjustment Scale (DAS), CHS, CDI, DLLS, State-Trait Anxiety Inventory for Children (STAIC)</td>
<td>Completed prior to outpatient clinic visit</td>
<td>Higher SES correlated with lower perceived physical appearance ($r = -0.35$, $p &lt; 0.02$). Higher classmate, parent, and teacher social support associated with higher perceived physical appearance ($r = 0.49$, 0.42, and 0.48, $p &lt; 0.001$). Higher daily hassles associated with lower perceived physical appearance ($r = -0.45$, $p &lt; 0.001$). Higher maternal and paternal perceived marital discord were associated with lower perceived physical appearance ($r = -0.41$ and -0.60, $p &lt; 0.01$). Peer acceptance, scholastic competence, and athletic competence accounted for 37% of the variance in perceived physical appearance ($R^2 = 0.367$, $F = 8.89$, $p &lt; 0.001$).</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Design</td>
<td>Sample Size</td>
<td>Gender</td>
<td>Mean Age</td>
<td>Range</td>
<td>SES</td>
<td>Measures</td>
</tr>
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<tr>
<td>Varni, 1992</td>
<td>United States</td>
<td>Quantitative, cross-sectional, exploratory</td>
<td>49 children</td>
<td>30 boys and 19 girls. Mean age = 10.3 years, range of 8-13 years (SD = 1.67 years). 42 children had congenital limb differences, 7 children had acquired limb differences. Mean SES based on Hollinghead’s four factor index was 42.3 (SD = 12.6), indicating average middle-class family.</td>
<td>N/A</td>
<td>CDI, STAIC, SPPC, DLLS, SSSC</td>
<td>Completed prior to outpatient clinic visit</td>
<td>Self-esteem correlated with all 4 perceived social support domains (p &lt; 0.05). Perceived social support domains also significantly accounted for explained variance in general self-esteem (38%). Perceived classmate social support was a significant predictor variable for general self-esteem in the expected direction (beta = .556, p &lt; .005).</td>
</tr>
<tr>
<td>Varni, 1993</td>
<td>United States</td>
<td>Quantitative, cross-sectional, exploratory</td>
<td>54 children</td>
<td>32 boys and 22 girls. Mean age = 10.1 years, range of 8-13 years (SD = 1.69 years). 46 children had congenital limb differences, 8 children had acquired limb differences. Mean family SES based on Hollinghead’s four factor index was 41.7 (SD = 11.5), indicating average middle-class family SES.</td>
<td>N/A</td>
<td>Beck’s Depression Inventory (BDI), STAIC, Family Relationship Index (FRI), DAS, SSSC, DLLS, CDI, SPPC</td>
<td>Completed prior to outpatient clinic visit</td>
<td>Paternal and maternal perceived marital discord accounted for 27% of the variance in child self-esteem (R² = .274, F = 4.52, p &lt; .02). Classmate, parent, teacher and friends social support accounted for 37% of the variance in child self-esteem (R² = .371, F = 6.48, p &lt; .001). The risk and protective factors predicted 52% of the variance in child general self-esteem (R² = .524, F = 3.67, p &lt; .01). Parent, classmate, teacher and friend social support accounted for 25% of the variance in child general self-esteem (R² = .251, F = 2.63, p &lt; .05).</td>
</tr>
<tr>
<td>Pasek, 1996</td>
<td>United States</td>
<td>Qualitative: Phenomenological participant observation.</td>
<td>14 children</td>
<td>7 males and 7 females with a limb difference, between the ages of 13 to 19 years old, who attended a 6-day ski trip.</td>
<td>N/A</td>
<td>Participant observation data collection methods included videotape, interviews, self-report questionnaires.</td>
<td>Daily progress notes by ski instructors and participants, and 1-month post camp questionnaire.</td>
<td>All subjects indicated satisfaction to self, and 12 subjects indicated satisfaction to others (family members and friends). Analysis of interviews concluded that the interaction with peers and supportive adults were effective in enhancing self-esteem as skill mastery and would likely to carry over into other situations.</td>
</tr>
<tr>
<td>Wijma, 2002</td>
<td>United States</td>
<td>Quantitative, cross-sectional, descriptive</td>
<td>42 children</td>
<td>20 boys and 22 girls. Mean age = 12.07 years, ranged from 8-18 years old. 32 Erb’s palsy, 1</td>
<td>42 subjects to age- and gender- norms from the Harter and Achenbach norms.</td>
<td>Measures: SPPC, Functional Ability Measure (FAM),</td>
<td>Completed immediately following study enrollment.</td>
<td>Children with BPP do have lower self-concept in athletic competence, t (41) = -2.03, p &lt; .05, t (41) = 2.40, p &lt; .05. Girls</td>
</tr>
</tbody>
</table>
Klumpke’s palsy, and 9 total palsy. Severity of disability ranged from 0-14, mean = 9.98.

Loneliness Measure, Sentence completion task.

Boys with BPP have higher self-concept than girls in the Harter sample in the areas of scholastic competence, t (20) = 2.15, p < .05, physical appearance, t (20) = 3.05, p < .01, and global self-worth, t (20) = 2.61, p < .05. Boys with BPP (M = 2.69) show a difference only for athletic competence where they have lower self-concept than boys in the Harter sample (M = 3.08), t (19) = -2.10, p < .05. Study revealed that attitude toward disability is, first of all, related to global self-worth - a domain which is highly correlated (r = .76) with Rosenberg’s measure of self-esteem.

<p>| Ylimäinen, 2010 | Sweden | Quantitative: cross-sectional, exploratory | 140 children | 72 boys (51%), ages 8–16 years old. Mean age: boys = 11.7 years, girls = 11.8 years. | N/A | Measures: DISABKIDS Chronic Generic Measure (DCGM-37) | Completed prior to outpatient clinic visit or over the phone. | Girls with longitudinal limb difference (LLD) had significantly (p = 0.03) lower scores in the emotion subscale than girls with transverse limb difference (TLD). Girls with bilateral LLD had significantly lower overall HRQoL (p = 0.01), physical limitations (p &lt; 0.01) and social inclusion (p &lt; 0.01) than girls with unilateral or multiple LLD. Girls with LLD in lower limbs had significantly lower overall HRQoL (p = 0.01) and social inclusion (p &lt; 0.01) than girls with LLD in upper limbs and girls with multiple LLDs. Children who were ‘always’ or ‘very often’ bothered by unexpected attention related to their limb difference had significantly lower overall HRQoL (p &lt; 0.01, p &lt; 0.01) and social exclusion (p &lt; 0.01, p &lt; 0.01). Boys also scored |</p>
<table>
<thead>
<tr>
<th>Source</th>
<th>Country</th>
<th>Methodology</th>
<th>Sample Size</th>
<th>Age Details</th>
<th>Measures</th>
<th>Time Details</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andersson, 2011</td>
<td>Sweden</td>
<td>Quantitative: cross-sectional, exploratory</td>
<td>92 children</td>
<td>53 boys and 39 girls. Mean age 10.6 (SD= 0.8), range = 9–11 years.</td>
<td>49 children without hand deformities (21 boys, 28 girls), aged 9–13 (mean 11). The comparison group was of similar Swedish children aged 9–13 years old taken from Gothenburg mainstream classrooms.</td>
<td>At the time of outpatient, post-op, follow-up around the age of 10 years (9–11 years).</td>
<td>Between the mild and the severe hand in the intellectual and school status subscale mean score, considerably lower children with mild deformities versus children with severe hand deformities (p = 0.002). Children with mild deformities gave significantly lower scores than children with severe hand deformities (p = 0.034) on popularity. Children with severe hand deformities had significantly higher Intellectual and School Status (p=0.028) subscale compared to the comparison group. Children with mild deformities had significantly lower popularity mean scores (p = 0.026). Children with severe hand deformities, girls had significantly lower scores than the boys on ‘Happiness and Satisfaction’ (p = 0.047). Boys with mild hand deformities had significantly lower total PHCSCS scores (p = 0.018) than boys with severe hand deformities. Differences across the mild and severe hand deformity groups on ‘Intellectual and School Status’ (p = 0.001) and ‘Physical Appearance and Attributes’ (p = 0.040).</td>
</tr>
<tr>
<td>Indelicato, 2019</td>
<td>United States</td>
<td>Qualitative: Participatory action research (PAR)</td>
<td>17 children</td>
<td>11 boys and 6 girls. participants were and 7 were male. Mean age = 16 years old, range= 14–18 years. 11 children identified as White, 4 Multiracial and 2 Hispanic.</td>
<td>N/A</td>
<td>Continuously over 3 days</td>
<td>Three overarching themes related to self-image: self-perception, camp participation, and coping. Three distinct subthemes within each theme and one overarching subtheme across the main themes. Subthemes for self-perception were resilient/ perseverant,</td>
</tr>
</tbody>
</table>
goal-oriented, and unique. Subthemes for camp participation were growth, confidence, and safe space. Subthemes for coping were activities, hope/faith, and difficulty trusting/feeling closed off from others. Overarching subtheme across all main themes was a desire for connection with others.
APPENDIX C: MANUSCRIPT #3 –

SELF-CONCEPT DEVELOPMENT IN SCHOOL-AGED CHILDREN WITH CONGENITAL UPPER LIMB DIFFERENCES: A MIXED METHODS STUDY

(SUBMITTING TO Nursing Research)
Self-Concept Development in School-Aged Children with Congenital Upper Limb Differences: A Mixed Methods Study

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Terry Badger declares she has no conflicts of interest.
Abstract

Background: School aged children enter an essential phase of psychosocial development in which they begin to form their self-concept. Having a negative self-concept has a direct relationship on the gradual evolution of a child’s personality and can influence academic and career success, peer interactions and relationships, generativity and life satisfaction and meaning. There is limited research examining self-concept in children with congenital upper limb differences.

Objectives: This mixed methods study created a rich description of self-concept in school-aged children with congenital upper limb differences (CULD).

Methods: This convergent mixed methods study used the Piers-Harris Children’s Self-Concept Scale (PHCSCS) questionnaire and a modified photovoice methodology to explore self-concept in school aged children with CULD. The results from the PHCSCS were merged with the qualitative findings from the 63 photographs and 63 written descriptions provided by the children.

Results: Mean self-concept was 51.22 (±10.43). Mean domain scores: behavioral adjustment 52 (±8.19), freedom from anxiety 48.56 (±10.42), happiness and satisfaction 49.44 (±10.73), intellectual and school status 54.78 (±10.31), and social acceptance 49.89(±8.64). Nine participants described five themes of self-concept: emotions, sense of accomplishments, positive view of oneself and one’s physical body, hobbies, and a sense of connection. Children defined their self-concept through expressions of self-efficacy, self-image, and social identity.

Implications: Results created a more comprehensive description of self-concept, and expanded understanding of the social identity of school-aged children with congenital upper limb difference. Future research is needed to examine the relationships between self-efficacy, self-image, and social identity to develop interventions promoting healthy self-concept development.

Key Words: Self-Concept, Children, Mixed Methods
Self-Concept Development in School-Aged Children with Congenital Upper Limb Differences: A Mixed Methods Study

Congenital upper limb differences (CULD) are physical differences of the hand or upper extremity that are present in birth, and have the potential to influence both the appearance and the function of the child’s hand (American Academy of Orthopaedic Surgeons [AAOS], 2020). CULDs occur in 20 out of every 10,000 babies born, and are more prevalent in boys than girls (2020). Children with CULD more frequently encounter negative social interactions such as social stigmatism and exclusion as a direct result of having a physical difference (Franzblau, 2015; Hatzenbuehler et al., 2013; Varni et al., 1992; Varni, 1989). These negative interactions increase a child’s risk of developing psychological conditions (examples: depression, anxiety, mood disorders), and for negatively affecting their psychosocial development (Achenbach, 2015; Parker et al., 2015).

Psychosocial development is a progressive process of human development that is affected by environmental factors and ultimately determines an individual’s psychosocial health (Erikson & Erikson, 1997). Psychosocial health is a state of mental, emotional, social, and spiritual well-being (Hatzenbuehler et al., 2013). School-aged children, those between the ages of 6 to 12 years old, enter an essential phase of psychosocial development in which they form their self-concept (Parker et al., 2015). Self-concept formation is an evolutionary process that culminates in a person’s internal sense of who they are (Martens, 2021; Parker et al., 2015). Additionally, the creation of person’s self-concept is the cornerstone for all further psychosocial development (Jhangiani et al., 2014; Mascall, 1986). Having a negative self-concept has a direct relationship on a child’s personality (Mascall, 1986) and can influence academic and career success, peer
interactions and relationships, generativity and life satisfaction and meaning over the child’s lifetime (Jhangiani et al., 2014; Newman & Newman, 1979).

There is currently only one study examining self-concept and psychosocial development in children with CULD. Andersson et al.’s (2011) study explored self-concept and psychological well-being in children with hand and upper extremity differences using a quantitative exploratory approach (2011). Children with hand differences have overall positive self-concept scores which were equal to a comparison group of children without hand differences (Andersson et al., 2011). Within the hand difference group, children with mild limb differences had significantly lower self-concept scores than those children with more severe and visible limb differences. Children with a more mild or minimally visible limb difference may be at greater risk for poor self-concept development.

To assist children with CULD in developing positive self-concepts, it is crucial to better understand the unique factors affecting self-concept development. This mixed methods study explored self-concept to create a rich description of self-concept development in school-aged children with congenital upper limb differences.

**Theoretical Framework**

The theory of self-concept development in childhood served as the theoretical framework for this study (Figure 1). Self-concept is described as an internal sense of who one is. Self-concept is derived by the triadic reciprocal determinism of social identity, self-efficacy and self-image (Parker et al., 2015). Social identity is defined as the perception of one’s roles, involvement, and memberships in social groups (Abrams & Hogg, 1990) and self-image is defined as the summation of a person’s perceptions of themselves and their physical body.
(Bacchini & Magliulo, 2003). Lastly, self-efficacy is the summation of the emotions, feelings and opinions a person holds about their own abilities and talents (Bacchini & Magliulo, 2003).

Figure 1.

*Theory of theory of self-concept development in childhood.*

**METHODS**

**Design**

The purpose of this convergent mixed methods study was development in school-aged children with CULD. Self-concept was measured by the Piers-Harris Children’s Self-Concept Score (PHCSCS) questionnaire, and described with a modified photovoice methodology, which is a photo-elicitation research method. Participant’s sociodemographic information were collected via chart reviews, and PHCSCS scores which were obtained via interviewer administration of the self-report instrument. The qualitative data was comprised of 63 photographs with 63 written descriptions, and was electronically collected from the study.
supplied iPod Touches using QualtricsXM (2020). The convergent mixed methods design enabled the comparison and subsequent merging of the quantitative data with the qualitative findings from the modified photovoice methodology A diagram of the mixed methods research study design is displayed in Figure 2.

Figure 2.

*Diagram of the mixed methods research study design (QUAL+quant).*

Sample and Sampling

Nine school-age children with a CULD participated in the study. Inclusion criteria were children with a CULD difference between the ages of 6 to 12 years old. Children who met the following criteria were excluded from participation in the study: upper extremity differences
acquired through trauma, children with cognitive or developmental disabilities and delays and/or syndrome. Similar mixed methods and photovoice studies in children had samples sizes ranging from 3 to 15 participants (Abma & Schrijver, 2020; Adams et al., 2017; Malka et al., 2018; Shannon, 2013); thus a , a sample size of 10 participants was established. Enrollment and recruitment ceased when thematic saturation or a lack of new emerging themes (Green & Thorogood, 2004) was achieved with 9 participants.

**Recruitment**

Participants were recruited from the outpatient hand and upper extremity clinic at Shriners Hospital for Children Northern California (SHCNC). SHCNC is a non-profit, pediatric medical center in Sacramento, California that provides highly specialized medical care and rehabilitation to children with congenital and complex medical needs. In 2020, SHCNC cared for over 24,000 pediatrics patients (Carpenter, 2021). Of those patients, 153 children were identified through chart reviews as having met inclusion criteria and 9 participants were successfully enrolled.

**Data Collection**

Participant sociodemographic information was collected through chart reviews, and PHCSCS surveys were investigator-administered in a quiet outpatient clinic exam room. Participants were educated on the use of the study provided iPod Touch and the research team ensured the device’s adaptability and usability for children with CULD. QualtricsXM (2020), was pre-installed on each handheld device and was used to collect the qualitative data. After the quantitative data had been collected, participating children began the photovoice methodology by participating in a 15-minute training session. During the training session the following prompts:
“What makes you, you” and “Who are you” were discussed at length and examples were provided. Participants were instructed on basic photography techniques and the iPod Touch’s camera functions were reviewed. Participants began collecting and submitting photographs with written descriptions via QualtricsXM (2020). Participants were asked to submit a minimum of one photograph per day for the seven days following enrollment. As an incentive for study participation, the participants were able to keep the iPod Touches for personal use after the completion of the study.

Sociodemographic Information

Age, gender, ethnicity, race, zip code, type of CULD, academic grade level, parental marital status, and presence and number of siblings was collected through chart review.

Piers-Harris Children’s Self-Concept Scale 3rd Edition

The PHCSCS is a brief self-report measure of self-concept in children between the ages of 6 to 22 years old. The measure consists of 58- descriptive statements, written at a first grade reading level, utilizing a yes or no answer format. The PHCSCS can be administered in English or Spanish by an interviewer, by paper or by electronic formats, and takes an average of 10 minutes to complete. In addition to providing overall self-concept scores, the PHCSCS also provides scores for the following associated six domains: behavioral adjustment, freedom from anxiety, happiness and satisfaction, intellectual and school status, physical appearance and attributes, and social acceptance. Raw self-concept scores are converted to T-scores (mean= 50, standard deviation 10) and percentage ranks. T-scores for overall self-concept scores are less than or equal to 29T is very low, 30T to 39T is low, 40T to 44T is low average,
45T to 55T average, 56T to 59T is high average, 60T to 69T is high, and equal to or greater than 70T is very high (Piers & Harris, 2018)

**Modified Photovoice Methodology**

Photovoice is a visual research methodology which combines ethical photography and community participation to foster positive social and cultural change (Wang, 1997). This research study utilized a modified photovoice methodology to be appropriate for children, which began with the identification of an issue, which for this study is the need for a more comprehensive understanding of self-concept development in school age children with CULD. The process then proceeded with the recruitment of the target population, 9 school-aged children with CULD. Next, participating children were educated on the purpose, aims and technology to be used during the study. Photo-documentation occurred as the participants collect photographs addressing the study prompts over the 7 days following enrollment. Photo-elicitation is traditionally a method where researchers present photographs for discussion with participants in a one-on-one interview or in small focus groups; neither was possible due the age of children and the COVID pandemic. For this modified approach for children, participants provided written descriptions with each photograph they submitted. This provided contextual meanings of each photograph and ensured that the participant’s “voice” was maintained throughout the remainder of the process. This approach was chosen to maintain children’s privacy and allow children to share personal information in a confidential manner.

**Data Analysis**

**Quantitative Analysis**
Descriptive statistical analysis was performed using STATA statistical software (StatCorp., 2021). Statistical analysis described the distribution (frequencies and percentages), central tendencies (mean) and dispersion (range and standard deviation) of the sociodemographic information, self-concept scores, and the six domain scores (behavioral adjustment, freedom from anxiety, happiness and satisfaction, intellectual and school status, physical appearance and attributes, and social acceptance).

**Qualitative Analysis**

Qualitative data, including both photographs and captions were uploaded into NVivo (QSR International Pty Ltd., 2020) for data analysis. 63 Photographs and the accompanying 63 written descriptions were analyzed using a directed approach to content analysis which was guided by the theory of self-concept (Hsieh & Shannon, 2005). Analysis began by identifying key concepts as coding categories and then creating operational definitions for each category as derived from the guiding theory. Next, the photographs and written descriptions were inductively coded by multiple members of the research team. Codes were then organized into subcategories and themes which were subsequently organized into the predetermined coding categories. No new data emerged during the analysis of the ninth participant’s data.

**Mixed Methods Integration and Analysis**

Mixed methods integration and analysis occurred once both the quantitative and qualitative data sets had been independently analyzed. The 3 key steps of mixed methods integration and analysis used for this study were integration data analysis procedures, representation of integration results, and interpretation of the integration (Creswell & Plano Clark, 2018). During this mixed methods data analysis, a joint display was created to show a
side-by-side comparison of the quantitative, qualitative, and integrated findings. Points of concordance, discordance, and expansion provided additional rich insights into self-concept development of school-aged children with CULD.

**Rigor and Trustworthiness**

Rigor and trustworthiness are two key concepts that ensure the quality and credibility of a mixed methods research study. To ensure quantitative rigor in this research study, a review of psychometric properties of possible instruments was conducted while designing the research study. The PHCSCS was selected and used during this study due its acceptable psychometric properties (high inter scale correlations = .77 to .83, Cronbach’s $\alpha = .92$ (Flahive et al., 2015; Franklin Jr. et al., 1981)). The PHCSCS included measures for response bias (RES) and inconsistent response (INC) for each completed survey. Each completed survey was well under the acceptable thresholds (RES < 0.7, INC < 0.7).

All 4 criteria of trustworthiness were included into the study design to ensure qualitative rigor in the proposed study. Credibility was maintained by having participants written descriptions for each photograph to ensure that their voices and meanings were maintained throughout data analysis. To ensure transferability, precise descriptions of the study’s participants, setting, and research procedures, contexts and assumptions were provided and discussed for future use (Trochim et al., 2016). Dependability was ensured by maintaining a detailed audit trail to promote accurate coding and reporting of results. Lastly, an audit trail as well as bracketing and reflexive journaling was employed to ensure confirmability.

**Results**

**Participant Demographics**
Table 1 displays a summary of the participant’s sociodemographic data. Of the nine participants, 56% were female. Participant’s ages ranged from 8 years to 12 years old, with a mean age of 9.8 (standard deviation (SD)=1.45) years old. 11% of participants were in the 2\textsuperscript{nd} grade, 33% in the 3\textsuperscript{rd} grade, 11% in the 4\textsuperscript{th} grade, 33% in the 5\textsuperscript{th} grade and 11% in the 6\textsuperscript{th} grade. Additionally, 33% of the participants reported their race as White, 22% Asian, 22% Other, 11% American Indian or Alaska Native, and 11% Black or African American. 56% of participants reported their ethnicity as Not Hispanic or Latino. 89% of the participants reported their parents as married and living together, while 11% were not married/ living separately. All participants reported having siblings, with 11% having 1 sibling, 44% had 2 siblings, 33% had 3 siblings and 11% had 4 siblings. Participants included in the study had the following types of CULD: acrosyndactylyl, asymmetric arthrogryposis, hypoplastic thumb, multiple hereditary exostoses, symbrachydactyly, Sprengel’s deformity, thumb deficiencies, and ulnar deficiencies.

Utilizing the home address 5-digit zip code, socioeconomical status (SES) was determined using the Area of Deprivation Index (ADI). The ADI allows for rankings of neighborhoods by socioeconomic disadvantage in a region of interest, both locally and nationally, and it includes the following domains: income, education, employment, and housing quality (University of Wisconsin, 2019). ADI scores are ranked on a scale of 1 to 100 nationally and 1 to 10 locally or statewide. Scores of 1 reflected communities which experience the least deprivation comparatively. The state ADI scores ranged from 5 to 10, with a mean of 7.89 (SD = 1.62). The national ADI scores ranged from 14 to 74, with a wean of 33.1 (SD = 18.27).

Table 1

*Descriptive statistics of the 9 participants (N = 9)*
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number (%)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>9.8 (±1.5) years</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>2 (22%)</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>2 (22%)</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5 (56%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4 (44%)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2 (22%)</td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2 (22%)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Hispanic or Latino</td>
<td>4 (44%)</td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>5 (56%)</td>
<td></td>
</tr>
<tr>
<td>Grade Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>3rd</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td>4th</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>5th</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td>6th</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>Parents Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married Living Together</td>
<td>8 (89%)</td>
<td></td>
</tr>
<tr>
<td>Not Married Living Separately</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>Number of Siblings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>4 (44%)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>3 (33%)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>1 (11%)</td>
<td></td>
</tr>
<tr>
<td>State ADI Score</td>
<td>7.89 (±1.6)</td>
<td></td>
</tr>
<tr>
<td>National ADI Score</td>
<td>33.11 (±18.3)</td>
<td></td>
</tr>
</tbody>
</table>

**Quantitative Results**

The mean self-concept score of school-aged children with CULD was 51.22 (±10.43).

The mean scores for the 6 domains are as follows: behavioral adjustment 52 (±8.19), freedom from anxiety 48.56 (±10.42), happiness and satisfaction 49.44 (±10.73), intellectual and school
status 54.78 (±10.31), and social acceptance 49.89 (±8.64). The mean scores, standard deviations, percentile ranges and the minimum and maximum range for self-concept and the 6 domains are displayed in Table 2.

Table 2

Summary of the PHCSCS scores

<table>
<thead>
<tr>
<th>Scales</th>
<th>Mean (Standard Deviation)</th>
<th>Percentile Range</th>
<th>Min to Max Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Concept</td>
<td>51.22 (±10.43)</td>
<td>29-71%</td>
<td>32-66</td>
</tr>
<tr>
<td>Behavioral Adjustment</td>
<td>52 (±8.19)</td>
<td>29-71%</td>
<td>35-58</td>
</tr>
<tr>
<td>Freedom from Anxiety</td>
<td>48.56 (±10.42)</td>
<td>29-71%</td>
<td>32-58</td>
</tr>
<tr>
<td>Happiness and Satisfaction</td>
<td>49.44 (±10.73)</td>
<td>29-71%</td>
<td>26-57</td>
</tr>
<tr>
<td>Intellectual and School Status</td>
<td>54.78 (±7.77)</td>
<td>29-71%</td>
<td>41-61</td>
</tr>
<tr>
<td>Physical Appearance and Attributes</td>
<td>52.78 (±10.31)</td>
<td>29-71%</td>
<td>26-57</td>
</tr>
<tr>
<td>Social Acceptance</td>
<td>49.89 (±8.64)</td>
<td>29-71%</td>
<td>34-60</td>
</tr>
</tbody>
</table>

Qualitative Results

Children with CULD defined their self-concept through expressions of self-efficacy (20 photographs and written descriptions, self-image (4 photographs and written descriptions), and social identity (39 photographs and written descriptions). As displayed in Figure 3, the following five prominent themes of self-concept development arose from the photographs and written descriptions: emotions, sense of accomplishment, positive view of oneself and one’s physical body, hobbies, and sense of connection.

Figure 3

Thematic map of self-concept development
Emotions were discussed in five of the participating children’s written descriptions of their photographs. The children’s likes, hobbies and dislikes were reported in relationship to the pursuit of a positive emotion. For example, an 11-year-old submitted the photograph in Figure 4, and wrote:

“I love playing with my fidgets. They make me calm when I am mad or bored and they are so satisfying to play with.”

Figure 4.

*Photograph of fidgets.*

A 12-year-old submitted the photograph is Figure 5, and wrote:
“I wear this sweater all the time because my dad gave it to me, and it brings me comfort.”

Figure 5

Photograph of sweater.

Participating children did not write about negative emotions, nor did they provide images of people, places, objects etc., that provoked the feeling of a negative emotions. Emotions were exclusively discussed from a positive perspective.

A sense of accomplishment was described by eight of the participating children. Children photographed their artistic creations, scholastic achievements, and provided positive written descriptions of their accomplishments. For example, an 11-year-old submitted a photograph of himself with his schoolwork and included the following written description:

“I know a lot of stuff. I learn a lot of stuff every day at school and that has helped me through a lot.”

A 9-year-old submitted a photograph of himself smiling, while holding a golden dollar, and wrote:
“I got the golden dollar at Amazing Facts, but it wasn’t a real golden dollar it was a paper dollar, but I got to go to the bookstore.”

A sense of accomplishment was also expressed by a 10-year-old when she submitted a photograph of her painting, shown in Figure 6 below, accompanied by the following written description.

“I made this decoration for my room just to show my talent.”

Figure 6

Photograph of decoration

Of the nine participants, two children expressed characteristics of a positive self-image. A positive perception of oneself and one’s physical body when demonstrated by a 9-year-old who submitted smiling portraits of himself, accompanied by the following written descriptions:

“I pick me best I am the best!” and “This is me”

Additionally, a positive self-image particularly a positive view of oneself was echoed by a smiling self-portrait submitted by an 8-year-old accompanied the following description:

“This is me, I like me.”
The next prominent theme of self-concept described by participating children was hobbies. Eight participating children described their social identity by sharing their hobbies. A 12-year-old shared her artwork, displayed in Figure 7, and wrote:

“I like to draw in my free time.”

Figure 7

Photograph of drawing

Another hobby, reading and literature was highlighted by a 10-year-old who submitted the photograph in Figure 8 with the following description:

“This is my chosen bookcase, and these are my favorite books. I love to read.”

Figure 8

Photograph of bookcase
An 8-year-old shared her hobby, music by sharing a photograph of her pink guitar (displayed in Figure 9) accompanied by:

“I like playing my guitar.”

Figure 9

Photograph of guitar

The fifth theme, sense of connection was described by all nine of the participating children. Sense of connection was described by participating children through their relationships with their family member, friends, and pets. For example, an 11-year-old submitted a photograph of his eye (Figure 10) with the accompanying description:

“These are my eyes, and I can see a lot of things like toys, my cat, my dog, and my friends, and my teacher, and my mom and dad and my grandma.”
A sense of connection through friendships was reported by three participating children. For example, an 8-year-old described the importance of her friendship by sharing photographs of herself and her friends, smiling at a sleep over and at the country fair. Additionally, an 11-year-old submitted a photograph (Figure 13) of his video gaming system and wrote:

“I like playing VR because I can play with my friends and that makes me happy.”
Six children reported a sense of human connection through photographs and descriptions of family members, particularly their parents and siblings. An 11-year-old submitted a photograph of herself and her mother smiling with the following description:

“I love spending time with my family because they make me feel safe and comforted when I am sad, and they all make me laugh all the time.”

A sense of connection was also described by six children as they shared photographs of their pets. Most children shared photographs of their dogs however, a 12-year-old shared a photograph of her bearded dragon (Figure 14) with the following description:

“This is my bearded dragon, Michael. I got him for my ninth birthday, and I like to hang out with him.”

Figure 12

Photograph of bearded dragon
Children described their relationships with their pets, their pet’s habits and how playing and interacting with their pets made them feel. Relationships with their pets provided participating children with a positive sense of connection.

Children did not identify having a limb difference as a key component of their self-concept. Limb differences were not photographed nor addressed in the written descriptions by any of the participating children.

Integration of Mixed Methods Results

The mixed methods integration and analysis was based upon the guiding theoretical framework; therefore, the guiding concepts (also known as categories) included self-efficacy, self-image, and social identity. Five themes were identified during qualitative data analysis and included: emotions, sense of accomplishment, positive view of oneself and one’s physical body, sense of connection and hobbies. Concordance and expansion provided additional clarification regarding the theoretical relationships between guiding concepts and themes. Table 4 presents the joint display of the quantitative, qualitative, and mixed methods integration results.
Table 3

Joint display for mixed methods meta inferences

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Qualitative Results</th>
<th>Quantitative Results</th>
<th>Mixed Methods Meta inferences</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-Efficacy</strong></td>
<td>Emotions: The pursuits of positive emotions influenced children’s likes, dislikes, hobbies, and connections. Emotions were exclusively discussed from a positive perspective.</td>
<td>Evaluated themselves as well behaved but acknowledged a few difficulties with their conduct.</td>
<td>Concordance. Both the qualitative and quantitative results endorse children with CULD maintain a primarily positive emotional state and engage in activities to promote positive emotions. Additionally, both sets of results suggest that children with CULD have positive perceptions of their academic performances and overall life appraisals.</td>
</tr>
<tr>
<td></td>
<td>Sense of accomplishment: Children demonstrated a sense of accomplishment by sharing and providing positive descriptions of their artistic creations and scholastic achievements.</td>
<td>Reported mostly positive emotional states, but acknowledged a few difficulties related to their moods.</td>
<td></td>
</tr>
<tr>
<td><strong>Self-Image</strong></td>
<td>Positive perception of oneself and one’s physical body: Self-reflections of the children’s overall selves, appearances and physical characteristics were discussed in an exclusively positive perspective.</td>
<td>Reported both positive and negative perceptions of their appearance and physical characteristics, however the positive outnumbered the negative reports.</td>
<td>Concordance. Although self-image was least references concept, both the qualitative and quantitative results suggest that children with CULD possess overall positive self-reflections of their overall selves and their physical bodies. Limb differences were not found to be a key component of a children’s self-image.</td>
</tr>
<tr>
<td></td>
<td>Limb differences were not included in the children’s self-reflections and evaluations of their physical bodies.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social Identity</strong></td>
<td>Sense of connection: Children expressed a sense of connection through the positive descriptions of their relationships with their community, friends, family members, and pets.</td>
<td>Reported an overall satisfaction with their social functioning, while acknowledging occasionally difficulties with peer interactions.</td>
<td>Expansion. A more comprehensive understanding of the social context of school-aged children with CULD was revealed. Community, family members, friends and pets serve as important sources of connection.</td>
</tr>
<tr>
<td></td>
<td>Hobbies: By describing their interests and preferred activities, children enthusiastically shared their hobbies, which included: art, music, physical activities/sports, reading/literature, technology and videogaming.</td>
<td></td>
<td>Hobbies serve as a key source of social identity for children with CULD. Findings suggest that hobbies may serve as pathway for a sense of connection and may also influence a child’s emotions and sense of achievement.</td>
</tr>
</tbody>
</table>
Results from both the qualitative and quantitative data endorsed concordance within the concept of self-efficacy. Children with CULD acknowledged occasional decreases in their moods or emotional state, but primarily report maintaining an overall positive emotional state. Children with CULD also more often engaged in activities that promoted positive emotions and provoked a sense of accomplished. Integrated results also found that school-aged children with CULD have positive perceptions of their academic performances and overall life appraisals.

Results from both the qualitative and quantitative data endorsed concordance within the concept of self-image. Although self-image was the least referenced concept, results suggested that children with CULD possessed overall positive self-reflections of their overall selves and their physical bodies. Limb differences were not found to be a key component of the children’s self-image.

Qualitative results offered expansion within the concept of social identity by revealing children’s extended social context. Combined with community and pets, family members and friends served as important sources of connection for children with CULD, and a rich description of their social context from the children’s perspectives. Nearly all (n=8) of the participating children shared photos of their pets and described the relationships with their pets as making them happy. Children also talked about their families making them feel safe and happy, with siblings being the most referenced family members. Activities and hobbies with siblings evoked positive emotions from participants. For example, an 8-year-old wrote the following:

“Today I went to the fair. I got to hang out with my older brother and his friends. I got to go on some rides with my friends from school.”

This child engaged in her community with her brother and their friends, highlighting the importance of her social context.
Discussion

Findings created a rich description of self-concept development in children with CULD by combining two unique methodologies. Children with CULD had positive self-concepts that fell within the average category and are reflective of having a healthy and balanced self-evaluation (Piers & Harris, 2018). These findings those by Andersson (2011) which found that children with hand differences had overall self-concept scores equal to a comparison group of children without hand differences.

Concordance of the integrated results revealed that children with CULD described their self-concept in terms of their self-efficacy, self-image, and social identity. When referring to their self-efficacy, children described a primarily positive emotional state. To promote positive emotions, children with CULD engaged in activities and maintained supportive relationships with peers and their family members. Children described relationships with their parents and siblings as making them feel happy and safe. Supportive relationships within the family unit of a child with a CULD has been shown to encourage positive emotions, increase a child’s sense of self-efficacy, and decrease the likelihood of developing depressive symptomology (Varni et al., 1989; Varni & Setoguchi, 1991).

Children also described creating art as making them feel happy and being a means for expressing emotions. The pursuit of activities or hobbies that provoked positive emotions were frequently related to the children’s sense of accomplishment. School-aged children with CULD described their artistic creations and scholastic accomplishments from a positive perspective. These findings align with those of Pasek and Schkade (1996) which reported perceived skill mastery as promoting a sense of accomplishment and increasing the child’s self-esteem levels.
Additionally, children with CULD who report high levels of perceived academic accomplishment have been shown to have high levels of self-efficacy and positive overall self-concepts (Wijma, 2002). In concordance with existing literature, the results of this study further highlight self-efficacy as an important component of self-concept during the school-aged years for children with CULD. However, the results of this study provided innovative insights into how children describe self-efficacy. Emotions and a sense of accomplishment not only contribute to a child’s self-efficacy, but they are also important themes utilized by children when describing their self-concepts.

Although self-image was the least referenced concept by participating children, concordance of the qualitative and quantitative results found that children with CULD possess overall positive self-reflections of themselves and their physical bodies. An important finding from the qualitative literature was that children did not photograph or describe their limb differences, which suggests that they are not a key component of the children’s self-image for this sample of children. This finding correlates with findings from a recent photovoice project by Indelicato et al. (2019) in which limb differences were not described as a key point of children’s self-image. Perhaps, children with a CULD have unconsciously accepted their physical differences since it was present at birth and as they have grown, they have continued to embrace their physical bodies.

Expansion about social identity provided by the qualitative results offered a more comprehensive understanding of children’s social identity. School-aged children with CULD reported hobbies and a sense of connection as important aspects of their social identities. Findings suggested hobbies may serve as pathway for a sense of connection and may also
influence a child’s emotions and sense of achievement. Hobbies described by the participants included: art, exploring nature music, reading and literature, technology and videogaming; however, the context of the pandemic influenced the ability to engage with peers. When referring to technology and videogaming, children often used these hobbies to engage with family, friends, and peers. Technology and videogaming has become an important platform for providing children with a sense of connection through digital connectivity. For children with CULD, digital connectivity provides a means for inclusivity into their social context. Children who have been previously excluded, such as children with limb differences are finding social inclusion through digital connectivity (Unicef, 2018).

Digital connectivity has been increasingly important the past three years as children’s social context has significantly changed as a result of living through the COVID pandemic. In person access to peers has been significantly limited and children’s typical day has been changed as a result of the pandemic. School-aged children have been immersed in online learning, and social engagement with peers has occurred primarily through means of digital connectivity. Other forms of peer engagement such as sports and organized activities were limited or cancelled due to national health mandates. The pandemic-imposed social restrictions interrupted new friendships opportunities (Hallett, 2021) for school-aged children with CULD.

Quarantine and shelter-in-place mandates significantly shifted children’s daily schedules, and instead of being in a classroom setting with their peers a majority of the week, children were at home with their families. This shift in social context was reflected in the study’s findings as children with CULD more often described relationships with their parents, siblings and pets as opposed to relationships with their peers. Relationships with family members have provided
school-aged children with a critical boost in their sense of connection during the pandemic (Hallett, 2021) and children who report increased feelings of connection with their family members are less likely to develop depressive symptomology (Schacter & Margolin, 2019).

Results of this study regarding the effect of the COVID pandemic have imposed on children’s social context must be interpreted with caution; however, as the long-term effects of the pandemic have yet to be determined. The lack of children with CULD reporting friends is an interesting finding, as developmentally during the school-aged years children are typically exhibiting an increased need for peer acceptance including a need for a close, intimate bond with a same-sex peer (Parker et al., 2015). The discordance of the results from this study and prior research merits further exploration of the social context in which this study was conducted.

Despite the changes in children’s social context, school-aged children with CULD continued to describe their self-concept through the triadic determinism of self-efficacy, self-image, and social identity; thereby supporting the guiding theoretical framework, the theory of self-concept. Themes identified by the participating children crossed over between the concepts within self-concept. For example, hobbies which are part of social identity can provide a means for a child to feel a sense of accomplishment. As stated previously, a sense of accomplishment has been shown to increase a child’s self-efficacy which subsequently has been shown to positively affect the child’s self-image (Indelicato et al., 2019). Therefore, to reflect the fluidity of the self-efficacy, self-image, and social identity the model has been updated to reflect areas of overlap and convergence. This is displayed in Figure 13 below.

Figure 13

*Revised theory of self-concept*
Study Strengths

This study successfully used a mixed method design to gain a more comprehensive understanding of self-concept development in a diverse group of school aged children with CULD. School-aged children with CULD successfully and enthusiastically engaged in the age-appropriate research methodology during which they shared intimate aspects of their self-concept with the research team. Such rich data would not have been obtained using other research methodological approaches.

Additionally, the use and revision of the theory of self-concept in childhood provided a developmentally appropriate theoretical framework for the study. The framework approached self-concept from a unique perspective which allowed for children’s descriptions of their self-concept to be embraced, and subsequently led to the expansion of our knowledge regarding their social identities.

Study Limitations
The participant’s age ranges were the first limitation noted. The proposed age range was 6 to 12 years of age; however, the minimum age of the included participants was 8. Of the remaining potential participants, children 6 or 7 years of age with a CULD were not available for participation in the study.

The second noted limitation of the study was the lack of geographic diversity. Although Shriners Hospital serves children from all over the west coast, all participants were from California and were from within 4 hours driving distance of the hospital.

The third noted limitation was that this study was conducted during the COVID pandemic, which may have altered the participants social context. The change in day-to-day activities has the potential to impact the findings of this study. Had this study been completed prior to the COVID pandemic or if it is repeated after the pandemic restrictions have fully lifted, results may differ.

A third limitation of this study was that no data was collected on the ways in which participants typically interacted with their peers. This study did not examine children’s preferred platform (in person, chat, facetime, social media etc.) for peer interaction, or how often they engaged with peers daily. Future inquiry about peer interactions should also include the methods (in person, phone, tablet or computer) used and how often the children interacted with their peers both pre and post COVID.

**Implications for Nursing Practice**

Nursing is uniquely situated to identify children that may be at risk for poor psychosocial health and refer these children and their families to essential social supports. Based on the results of this study, nursing can encourage children to participate in hobbies, and other activities that
create a sense of accomplishment or connection such as engaging in the community or pet ownership. Incorporating the results from this study into nursing practice may help promote healthy psychosocial development including developing a positive self-concept for children with CULD.

**Implications for Future Research**

A secondary finding of this study were the changes that occurred in children’s social contexts as a result of growing up during the COVID pandemic. Additional longitudinal research is needed to identify areas of psychosocial development that have been most significantly impacted by the pandemic to better understand the needs that children may have as they progress into adulthood.

By further researching and exploring self-concept development in all children, not only children with congenital limb differences, the theory of self-concept will also continue to evolve and will offer a foundation from which to visual self-concept throughout childhood. The creation of middle range theories will inspire future researchers to create interventions aimed at promoting healthy self-concept and improving children’s overall psychosocial well-being.

**Conclusion**

The completion of this mixed methods study led to the creation of a rich description of self-concept in school-aged children with CULD. Expansion of the results facilitated the revision of the guiding theoretical framework and illuminated important aspects of the children’s social context from a first-person perspective. Additional studies are needed to understand self-concept and its associated concepts more fully to develop interventions aimed at improving children’s psychosocial development and well-being.
References


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Qualtrics. (2020). *Qualtrics XM Services.* In


StatCorp. (2021). *Stata Statistical Software: Release 17*


APPENDIX D:

SHRINERS HOSPITAL FOR CHILDREN IRB APPROVAL LETTER
Certificate of Action

Investigator Name: Sally Martens, MSN, FNP-C  
Board Action Date: 02/25/2022

Investigator Address: 2426 Stockton Blvd  
Sacramento, CA 95817, United States  
Approval Expires: 02/25/2023

Continuing Review Frequency: Annually

Sponsor: Shriners Children's  
Institution Tracking Number: NCA2202  
Sponsor Protocol Number: NCA2202

Amended Sponsor Protocol Number:

Study Number: 1327579  
IRB Tracking Number: 20220630

Work Order Number: 6-1516664-1

Protocol Title: SELF-CONCEPT DEVELOPMENT IN SCHOOL-AGED CHILDREN WITH CONGENITAL UPPER LIMB DIFFERENCES: A MIXED METHODS STUDY

THE FOLLOWING ITEMS ARE APPROVED:

Investigator  
Advertisement - Flyer - We are recruiting children with #33363070.0 - As Submitted  
Qualtrics Survey Daily Photo Upload Screenshots #33363070.0 - As Submitted  
Updated Protocol (11-30-2021)  
Consent Form [NO]

Please note the following information:

THE IRB HAS APPROVED THE FOLLOWING LOCATIONS TO BE USED IN THE RESEARCH:
Shriners Children's (aka Shriners Hospitals for Children)- Northern California, 2426 Stockton Blvd., Sacramento, California 95817

ALL IRB APPROVED INVESTIGATORS MUST COMPLY WITH THE FOLLOWING:

As a requirement of IRB approval, the investigators conducting this research will:

• Comply with all requirements and determinations of the IRB.
• Protect the rights, safety, and welfare of subjects involved in the research.
• Personally conduct or supervise the research.
• Conduct the research in accordance with the relevant current protocol approved by the IRB.
• Ensure that there are adequate resources to carry out the research safely.
• Ensure that research staff are qualified to perform procedures and duties assigned to them during the research.
• Submit proposed modifications to the IRB prior to their implementation.
  o Not make modifications to the research without prior IRB review and approval unless necessary to eliminate apparent immediate hazards to subjects.
• For research subject to continuing review, submit continuing review reports when requested by the IRB.
• Submit a closure form to close research (and the IRB’s oversight) when:
  o The protocol is permanently closed to enrollment
  o All subjects have completed all protocol related interventions and interactions
  o For research subject to federal oversight other than FDA:
    ▪ No additional identifiable private information about the subjects is being obtained
    ▪ Analysis of private identifiable information is completed
• For research subject to continuing review, if research approval expires, stop all research activities and immediately contact the IRB.
• Promptly (within 5 days) report to the IRB the information items listed in the IRB’s “Prompt Reporting Requirements” available on the IRB’s Web site.

This is to certify that the information contained herein is true and correct as reflected in the records of WCG IRB. WE CERTIFY THAT WCG IRB IS IN FULL COMPLIANCE WITH GOOD CLINICAL PRACTICES AS DEFINED UNDER THE U.S. FOOD AND DRUG ADMINISTRATION (FDA) REGULATIONS, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) REGULATIONS, AND THE INTERNATIONAL CONFERENCE ON HARMONISATION (ICH) GUIDELINES.
• Not accept or provide payments to professionals in exchange for referrals of potential subjects ("finder's fees.")
• Not accept payments designed to accelerate recruitment that are tied to the rate or timing of enrollment ("bonus payments") without prior IRB approval.
• When required by the IRB ensure that consent, permission, and assent are obtained and documented in accordance with the relevant current protocol as approved by the IRB.
• Promptly notify the IRB of any change to information provided on your initial submission form.

Consistent with AAHRPP’s requirements in connection with its accreditation of IRBs, the individual and/or organization shall promptly communicate or provide, the following information relevant to the protection of human subjects to the IRB in a timely manner:
• Upon request of the IRB, a copy of the written plan between sponsor or CRO and site that addresses whether expenses for medical care incurred by human subject research subjects who experience research related injury will be reimbursed, and if so, who is responsible in order to determine consistency with the language in the consent document.
• Any site monitoring report that directly and materially affects subject safety or their willingness to continue participation. Such reports will be provided to the IRB within 5 days.
• Any findings from a closed research when those findings materially affect the safety and medical care of past subjects. Findings will be reported for 2 years after the closure of the research.

For Investigator’s Brochures, an approval action indicates that the IRB has the document on file for the research.

If the IRB approved an e-consent process that involves uploading the approved consent form to an e-consent platform, please ensure that the consent form(s) approved for your site is the version of the consent form that gets uploaded to the platform.

If the board approves a change of Principal Investigator - Once approved, the new Principal Investigator is authorized by WCG IRB to carry out the study as previously approved for the prior Principal Investigator (unless the Board provides alternate instructions to the new Principal Investigator). This includes continued use of the previously approved study materials. The IRB considers the approval of the new PI a continuation of the original approval, so the identifying information about the study remains the same.

If your research site is a HIPAA covered entity, the HIPAA Privacy Rule requires you to obtain written authorization from each research subject for any use or disclosure of protected health information for research. If your IRB-approved consent form does not include such HIPAA authorization language, the HIPAA Privacy Rule requires you to have each research subject sign a separate authorization agreement.

If this study includes data monitoring committee/data safety monitoring board, please note that the reports of all meetings of this committee should be submitted to the IRB even if the outcome of the meeting results in no changes to the study.

For research subject to continuing review, you will receive Continuing Review Report forms from WCG IRB when the expiration date is approaching.

Thank you for using this WCG IRB to provide oversight for your research project.

DISTRIBUTION OF COPIES:
Contact, Company
Shriners IRB Office, Shriners Hospitals for Children
Shannon Terkoski, RN, BSN, CCRP, MS, Shriners Children’s (aka Shriners Hospitals for Children)
Sally Martens, MSN, FNP-C, Shriners Children’s (aka Shriners Hospitals for Children)- Northern California
APPENDIX E:

THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD APPROVAL LETTER
ACKNOWLEDGEMENT OF AN EXTERNAL IRB UPDATE

March 18, 2022

Sally Martens

Dear Sally Martens:

On 3/18/2022, the IRB Office reviewed the updated information for the following study that is relying on an external IRB as the IRB of record:

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Study Information
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<tr>
<td>IND, IDE or HDE:</td>
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</table>

This notification serves to acknowledge the updates you provided for the above listed study. If not already submitted, you may be required to also submit these updates to WCG IRB, Inc.

- The University of Arizona maintains a Federalwide Assurance (FWA) with the Office for Human Research Protections (OHRP) (FWA #00004218).
- All research procedures should be conducted according to the approved protocol and policies and guidance of the IRB of record.

As a reminder, please promptly notify the local IRB Office upon:
1. Modification in cases of:
   a. PI/Co-PI changes
   b. Key personnel changes
   c. Alteration of Banner required consent language

2. Proposed changes that affect the local protocol and report any local unanticipated problems involving risks to participants or others

3. Notification that WCG IRB, Inc. has renewed its approval at continuing review

4. Closure of the study

We value your feedback and would appreciate you taking the time to complete our survey about your experience with the IRB staff: https://u.arizona.qualtrics.com/jfe/form/SV_dqQ5VxogpmPXiUd.

If questions arise at any time during your study, please email the general IRB inbox at VPR-IRB@arizona.edu
APPENDIX F:

STUDY RECRUITMENT FLYER
SELF-CONCEPT RESEARCH STUDY!

We are recruiting children with upper limb differences to participate in a study that will explore self-concept development through the use of photography.

You may qualify to participate if you:
- Are between the ages of 6 – 12 years old
- Have a congenital upper limb difference

If you qualify, the visit will last between 30-45 minutes. During the visit your child will complete a survey and they will be instructed on the use of the camera they will be using to collect and submit photographs.

To learn more or to see if you qualify:
Shriners Hospitals for Children Northern California
2425 Stockton Blvd
916-453-5030
APPENDIX G:

PIERS-HARRIS CHILDREN’S SELF-CONCEPT SCALE AUTOFORM
The Way I Feel About Myself (Piers-Harris™ 3)

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<th>Gender</th>
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<tr>
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<th>Examiner</th>
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<tr>
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<td></td>
<td></td>
<td>□ American Indian/Alaska Native □ Asian □ Black/African American □ Hispanic/Latino □ Native Hawaiian/Pacific Islander □ White □ Other</td>
<td></td>
</tr>
</tbody>
</table>

1. I am popular. [ ] Yes [ ] No
2. My friends like my ideas. [ ] Yes [ ] No
3. I worry that people will make fun of me. [ ] Yes [ ] No
4. I am easy to get along with. [ ] Yes [ ] No
5. I have a nice face. [ ] Yes [ ] No
6. I sit alone at lunch. [ ] Yes [ ] No
7. I get nervous when the teacher calls on me. [ ] Yes [ ] No
8. My family is disappointed in me. [ ] Yes [ ] No
9. I am excited about the future. [ ] Yes [ ] No
10. My classmates make fun of me. [ ] Yes [ ] No
11. I hate school. [ ] Yes [ ] No
12. I don’t like the way I look. [ ] Yes [ ] No
13. I get worried when we have tests in school. [ ] Yes [ ] No
14. I am unhappy. [ ] Yes [ ] No
15. My classmates in school think I have good ideas. [ ] Yes [ ] No
16. I participate in school activities. [ ] Yes [ ] No
17. I am smart. [ ] Yes [ ] No
18. I worry a lot. [ ] Yes [ ] No
19. I think bad thoughts. [ ] Yes [ ] No
20. I can give a good report in front of the class. [ ] Yes [ ] No
21. I am a good person. [ ] Yes [ ] No
22. I am not popular. [ ] Yes [ ] No
23. I forget what I learn. [ ] Yes [ ] No
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>24.</td>
<td>It is usually my fault when something goes wrong.</td>
<td>Yes</td>
</tr>
<tr>
<td>25.</td>
<td>I wish I were different.</td>
<td>Yes</td>
</tr>
<tr>
<td>26.</td>
<td>I am cheerful.</td>
<td>Yes</td>
</tr>
<tr>
<td>27.</td>
<td>I get into a lot of fights.</td>
<td>Yes</td>
</tr>
<tr>
<td>28.</td>
<td>I am a happy person.</td>
<td>Yes</td>
</tr>
<tr>
<td>29.</td>
<td>I am often afraid.</td>
<td>Yes</td>
</tr>
<tr>
<td>30.</td>
<td>I like my hair.</td>
<td>Yes</td>
</tr>
<tr>
<td>31.</td>
<td>I am nervous.</td>
<td>Yes</td>
</tr>
<tr>
<td>32.</td>
<td>I have a hard time finishing my homework.</td>
<td>Yes</td>
</tr>
<tr>
<td>33.</td>
<td>I do many bad things.</td>
<td>Yes</td>
</tr>
<tr>
<td>34.</td>
<td>I cry easily.</td>
<td>Yes</td>
</tr>
<tr>
<td>35.</td>
<td>It is hard for me to listen in class.</td>
<td>Yes</td>
</tr>
<tr>
<td>36.</td>
<td>I daydream at school.</td>
<td>Yes</td>
</tr>
<tr>
<td>37.</td>
<td>I behave badly at home.</td>
<td>Yes</td>
</tr>
<tr>
<td>38.</td>
<td>I am lucky.</td>
<td>Yes</td>
</tr>
<tr>
<td>39.</td>
<td>I am a good reader.</td>
<td>Yes</td>
</tr>
<tr>
<td>40.</td>
<td>I feel alone.</td>
<td>Yes</td>
</tr>
<tr>
<td>41.</td>
<td>I cause trouble to my family.</td>
<td>Yes</td>
</tr>
<tr>
<td>42.</td>
<td>I have a hard time finishing my work at school.</td>
<td>Yes</td>
</tr>
<tr>
<td>43.</td>
<td>I am often sad.</td>
<td>Yes</td>
</tr>
<tr>
<td>44.</td>
<td>My parents (or caregivers) expect too much of me.</td>
<td>Yes</td>
</tr>
<tr>
<td>45.</td>
<td>I like my body.</td>
<td>Yes</td>
</tr>
<tr>
<td>46.</td>
<td>It is hard for me to follow in class.</td>
<td>Yes</td>
</tr>
<tr>
<td>47.</td>
<td>I am an important member of my class.</td>
<td>Yes</td>
</tr>
<tr>
<td>48.</td>
<td>I am among the last to be chosen for games and sports.</td>
<td>Yes</td>
</tr>
<tr>
<td>49.</td>
<td>I cause trouble at home.</td>
<td>Yes</td>
</tr>
<tr>
<td>50.</td>
<td>I have many friends.</td>
<td>Yes</td>
</tr>
<tr>
<td>51.</td>
<td>I like the way I am.</td>
<td>Yes</td>
</tr>
<tr>
<td>52.</td>
<td>It is hard for me to make friends.</td>
<td>Yes</td>
</tr>
<tr>
<td>53.</td>
<td>I am strong.</td>
<td>Yes</td>
</tr>
<tr>
<td>54.</td>
<td>I am ashamed of myself.</td>
<td>Yes</td>
</tr>
<tr>
<td>55.</td>
<td>People bully me.</td>
<td>Yes</td>
</tr>
<tr>
<td>56.</td>
<td>I like my size.</td>
<td>Yes</td>
</tr>
<tr>
<td>57.</td>
<td>I am shy.</td>
<td>Yes</td>
</tr>
<tr>
<td>58.</td>
<td>I am dumb about most things.</td>
<td>Yes</td>
</tr>
</tbody>
</table>