

## Body Appreciation, Self-Esteem, and Resilience in Adolescents with a Congenital Hand or Upper Extremity Anomaly

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In partial fulfillment of the requirements for the degree Doctor of Health Science By: Terri Beckwith, MPH, CCRP

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# Body Appreciation, Self-Esteem, and Resilience in Adolescents with a Congenital Hand or Upper Extremity Anomaly

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#### Abstract

Adolescents with a congenital hand or upper extremity (CHUE) anomaly who underwent surgical correction at an early age may be sensitive to psychosocial well-being during a vulnerable period of development. As a dominant amount of literature focuses on improving and maintaining functional capacity after surgery, it is also necessary to understand psychosocial factors (PSFs) that may contribute to long-term treatment outcomes. The purpose of this study was to explore PSFs of body appreciation, self-esteem, and resilience within a population of adolescents with a surgically corrected CHUE anomaly; ascertain if these factors are influenced by gender, age, or extremity involvement; and determine what variables may predict resilience in the population. Using a non-experimental, analytic cross-sectional study design at a tertiary pediatric orthopedic institution, a total of 31 participants responded to a survey incorporating the Body Appreciation Scale-2 (BAS-2), the Rosenberg Self-Esteem Scale (RSES), and the Child and Youth Resilience Measure (CYRM-R). Statistical significance (p = .011) was found for RSES scores between young (10-13 year-old) and old (14-19 year-old) adolescents. Correlation coefficients were greater than .30 for both BAS-2 and RSES scores when compared to CYRM-R scores. Multiple regression analysis resulted in a model that explained 44.3% of the variance, with a linear predictive model of F(2, 25) = 9.96, p < .001;  $R^2 = .44$ . Patients who appreciate and find value regarding their anomaly are speculated to have greater resilience and therefore more favorable long-term outcomes.

*Keywords*: adolescent, body appreciation, self-esteem, resilience, congenital hand anomaly

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# Body Appreciation, Self-Esteem, and Resilience in Adolescents with a Congenital Hand or Upper Extremity Anomaly

The period of adolescence, 10 to 19 years of age as defined by the World Health Organization (2019), is a critical time when psychosocial well-being is exceptionally vulnerable due to developmental growth and new social experiences (Albert et al., 2013). During the adolescent years, individuals are more sensitive to external influences by fellow peers, social media, and cultural standards of acceptance (McElhaney et al., 2008). In addition, adolescents with chronic health conditions or physical differences have an increased risk of enduring greater psychological and social conflicts (Andersson et al., 2011; Sawyer et al., 2007). As such, those with a visible congenital hand or upper extremity anomaly may internalize their experiences more frequently and repercussions more intensely than their fellow peers.

The prevalence of a congenital hand or upper extremity anomaly is estimated at 21 to 27 cases for every 10,000 live births (Ekblom et al., 2010; Goldfarb et al., 2017). Most of these cases require surgical intervention at a young age to promote growth restructure and physical development (Little & Cornwall, 2016), indicating a substantial amount of professional medical care and the potential for permanent scarring or unique aesthetics (Krakowski et al., 2016). Consequently, this may heavily shape adolescents' perception of themselves, their decisions, and social interactions as they grow older (Krakowski et al., 2016), posing a considerable amount of variability in how they adapt to their physical anomaly (Wallander et al., 1998). Therefore, it is important to evaluate the psychosocial factors (PSFs) that may contribute to healthy well-being in adolescents with a congenital hand or upper extremity (CHUE) malformation.

Multiple PSFs considerably contribute to the healthy psychological functioning of those with a chronic condition or physical limitation, such as stress or social support. In young patients

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with a CHUE anomaly, body appreciation, self-esteem, and resilience are specific PSFs that may offer insight into this population's well-being as they significantly overlap in their psychological constructs (Olsoon et al., 2013; Smolak, 2004; Trzesniewski et al., 2006). Comparing their extremity appearance with normative peers may negatively influence opinions about their body, and by association self-esteem, as physical appearance connects to perceptions of self-worth and self-respect (Baudson et al., 2016). Both constructs arguably relate to traits of acceptance, selfefficacy, and adaptability, common elements associated with overcoming adversity, also recognized as resilience (Ungar, 2004). Patients with a CHUE anomaly must endure treatment and acclimate to new hand or upper extremity function during years of significant development, in which case a strong sense of resilience may empower one to thrive despite a corrected yet visible physical malformation.

#### **Problem Statement**

Within the PSFs of body appreciation, self-esteem, and resilience, variables of gender, age, and extremity involvement may play a role in achieving healthy well-being. Females commonly have higher body dissatisfaction and lower self-esteem than their male peers in this age group (Frost & McKelvie, 2004), making it appear that males may be less affected by differences related to appearance. Also, as adolescents age, they are likely to become more comfortable with themselves and capable of more responsibilities upon entering young adulthood (Steinberg & Cauffman, 1996). As a result, maturity may influence how those with a CHUE anomaly become more accepting of their condition and less bothered by their physical difference. Extremity involvement may additionally play a role in the well-being of the population. In social circumstances, it is arguably easier to conceal an abnormality on a single extremity than on both. This is especially true if it is not the dominant hand, or specifically the

right hand, which frequently is more common and culturally preferred (Papadatou-Pastou et al., 2019). For those in which both extremities required treatment, concealment is less likely and may have a greater impact on PSFs of body appreciation, self-esteem, and resilience.

## **Purpose Statement**

The purpose of this study was to explore the PSFs of body appreciation, self-esteem, and resilience in adolescents with a surgically corrected CHUE anomaly and ascertain if the selected PSFs were influenced by gender, age, and extremity involvement. Additionally, to determine which variables predicted high resilience within the population.

## **Research Questions**

This study answered the following research questions:

- In adolescents with a surgically corrected CHUE anomaly, was there a significant difference in body appreciation, self-esteem, and resilience scores by demographics of gender and age?
- 2. In adolescents with a surgically corrected CHUE anomaly, was there a significant difference in body appreciation, self-esteem, and resilience scores between those who have single extremity involvement compared to those with both extremity involvement?
- 3. In adolescents with a surgically corrected CHUE anomaly, what variables, including PSFs of body appreciation and self-esteem, predicted higher resilience?

## **Research** Objectives

The following objectives addressed the study's research questions.

 To determine if there was a significant difference in body appreciation as measured with The Body Appreciation Scale-2 (BAS-2), between:

- a. Genders (male and female)
- b. Age (younger (10-13 years) and older adolescents (14-19 years))
- c. Extremity involvement (single extremity and bilateral extremity)
- 2. To determine if there was a significant difference in self-esteem, as measured with the Rosenberg Self-Esteem Scale (RSES), between:
  - a. Genders (male and female)
  - b. Age (younger (10-13 years) and older adolescents (14-19 years))
  - c. Extremity involvement (single extremity and bilateral extremity)
- 3. To determine if there was a significant difference in resilience as measured with the Child and Youth Resilience Measure (CYRM-R) between:
  - a. Genders (male and female)
  - b. Age (younger (10-13 years) and older adolescents (14-19 years))
  - c. Extremity involvement (single extremity and bilateral extremity)
- 4. To determine what variables, including body appreciation and self-esteem, predicted high resilience.

## Significance of the Study

The results of this study provided critical insight into the PSFs of body appreciation, selfesteem, and resilience in the adolescent population with a surgically corrected CHUE malformation. These results can help healthcare providers and parents understand the potential shortcomings in mental health and well-being among youth and find ways to strengthen supportive networks. Additionally, youth educational communities may utilize the findings to develop elemental topics for public health programs that promote compassion and inclusion in the adolescent population.

## **Definition of Terms**

The following terms were used within the project:

- Adolescent: An individual between the ages of 10 and 19 (World Health Organization, 2019).
- Congenital anomaly: Anatomic or structural anomaly that occurs in the womb and can be identified prenatally, at birth, or sometimes later in life (World Health Organization, 2020).
- Self-esteem: The resulting score after completing the patient-reported outcome instrument related to an individual's positive or negative attitude towards themself, and beliefs regarding their worth, value, and abilities (Rosenberg, 1965).
- Body appreciation: The resulting score after completing the patient-reported outcome instrument related to the favorable acceptance, opinion, and respect of one's body while dismissing media-promoted concepts of beauty ideals (Avalos et al., 2005)
- Resilience: The resulting score after completing the patient-reported outcome instrument related to the capacity to utilize and negotiate psychological, social, cultural, and physical resources to sustain well-being when exposed to adversity (Resilience Research Centre, 2016, para. 4).

#### **Literature Review**

While there has been extensive literature published on pediatric congenital upper extremity anomalies, including hand malformations, much of the focus centers on the anatomical progression of physical development, approaches to surgical intervention, and potential genetics that may be associated with the anomaly (Bae et al., 2018; Bae & Goldfarb, 2014; Kozin & Zlotolow, 2015; Ozols et al., 2019; Stutz et al., 2014; Widerberg et al., 2016; Winfeld & Otero, 2016). As a result, there is an under-representation in the literature regarding psychosocial factors, such as body appreciation, self-esteem, and resilience, that may contribute to long-term outcomes of intervention for such pediatric orthopedic conditions. Consequently, researchers are finding that such concepts are concerns for these individuals and require empirical evidence prior to interventions or therapies.

#### **Body Appreciation**

Body appreciation is defined as an individual's favorable acceptance, opinion, and respect of one's physical body while dismissing the media-promoted ideals of what it means to have beauty (Avalos et al., 2005). In comparison to the term 'body image', appreciation may act as an inclusive construct of the concept, as body image refers to the multi-dimensional domains that encompass body-related behaviors, perception of physical characteristics, such as weight or height, and feelings towards one's body (Cash, 2004; Quittkat et al., 2019). Body appreciation is a significant factor associated with general health as it directly influences daily decisions regarding diet, nutrition, reputable exercise habits, and how one presents themselves to others (Avalos et al., 2005). In addition, a positive sense of body appreciation promotes an ability to engage in social circumstances without reservations of impending physical attributes and internally value one's self outside of rigid media aesthetic standards (Avalos & Tylka, 2006).

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Conversely, having an unhealthy or negative view is related to body dissatisfaction, social physique anxiety, and detrimental idealizations of what it may mean to be accepted in society (Avalos et al., 2005). Such idealizations may lead to depression, anxiety, body dysmorphic disorders, or extreme physical interventions, such as unnecessary cosmetic or surgical procedures (Sarwer, 1997; Tylka & Kroon Van Diest, 2013).

#### **Body Appreciation and Adolescents**

With respect to the adolescent population, body appreciation may be a significant factor influencing psychosocial and cognitive development (Zarrett & Eccles, 2006). This transition period from childhood into young adulthood is when new habits begin to take shape in addition to physical, social, and emotional progression (Zarrett & Eccles, 2006). For example, an adolescent may become more consciously aware of eating habits and how one's household and culture represent a relationship with food or physical activity (Das et al., 2017). Additionally, with developmental maturity, adolescents begin to acknowledge their appearance in parallel to their peers and what may pass as acceptable beauty standards seen in media and social platforms (Kenny et al., 2016).

Within the field of pediatrics, a dominant amount of research pertains to body image rather than body appreciation (Smolak, 2004), yet the terminology is on the rise. In a study by Bacevicience and Jankauskiene (2020), the relationship between body appreciation and irregular eating behaviors was studied within a population of older adolescents using the BAS-2 scale, and patient-reported measures related to body dissatisfaction, body functionality, self-esteem, and participation in sports. Body appreciation was negatively correlated with a higher body mass index, body dissatisfaction, and irregular eating habits, while positive correlations were found among self-esteem, body functionality, and sports participation (Bacevicience & Jankauskiene,

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2020). The authors concluded that higher body appreciation in adolescents is associated with less irregular eating habits, preventing an unhealthy relationship with food consumption (Bacevicience & Jankauskiene, 2020).

In a similar study (Marta- Simões et al., 2020) of 362 Portuguese adolescents recruited through participating schools, researchers examined well-being using self-reported outcome measures related to affiliative memories, social safeness, and body appreciation. The authors found significant correlations among all concepts and noted that body appreciation appears to directly contribute to physical, psychological, and social environments, such as school or related activities (Marta- Simões et al., 2020).

## **Body Appreciation and Pediatric Orthopedics**

Research specific to body appreciation is limited within pediatric orthopedics. Yet, body image has recently become a focal interest of researchers in the field, potentially creating a path for body appreciation. Schwieger et al. (2016) analyzed and compared body image and quality of life in female patients with idiopathic scoliosis between two groups, those treated with observation and those treated with a brace. Patient-reported outcome measures were assessed at baseline, six months, and two-year follow-up provider visits (Schwieger et al., 2016). No significant difference was found between body image or quality of life between groups at all time points (Schwieger et al., 2016). Yet, poor quality of life was significantly correlated to poor body image in each group through two years of follow-up (Schwieger et al., 2016). The authors concluded that body image be assessed at initiation and through treatment to ensure the best outcomes (Schwieger et al., 2016). Concerns about adolescent idiopathic scoliosis have also prompted researchers to develop and validate a version of the Body Image Disturbance Questionnaire (Cash et al., 2004) specific to the condition. Auerbach et al. (2014) analyzed data

in two phases using a modified version of the questionnaire in conjunction with three similar assessments related to body esteem, body function, and depression. Data was collected from 49 scoliosis patients and 98 age-matched controls. Study results were consistent, showing a high level of discriminant validity among similar assessments (Auerbach et al., 2014). The authors concluded that the Body Image Disturbance Questionnaire is a valid instrument specific to pediatric orthopedic scoliosis and can be used to examine body image disturbance within the population (Auerbach et al., 2014).

### Body Appreciation and Congenital Hand or Upper Extremity Malformations

In adolescents with a congenital hand or upper extremity anomaly, topics tangent to body appreciation and body image are beginning to take shape, such as discussion of anomaly appearance and intervention satisfaction. Kelley et al. (2016) conducted a qualitative study with 33 children and their parents using semi-structured interviews to learn how hand malformation and treatment influenced daily life, including school and extra-curricular activities. Forty-eight percent of children were bothered by their hand's appearance, and 73% of children and parents expressed functional difficulties (Kelley et al., 2016). The authors suggested that early hand therapy focused on improving functional adaptation would be beneficial; however, a thorough discussion on body image and self-esteem factors should also occur. Similarly, Franzblau et al. (2015) qualitatively explored stress and coping in adolescents with congenital hand anomalies who received surgical intervention. Forty patients and parents were interviewed about stress associated with hand function, appearance, and emotional coping methods (Franzblau et al., 2015). Among the identified and analyzed themes, 27% of children and parents reported stress related to hand appearance, with 30% expressing concealment as a coping strategy (Franzblau et al., 2015). The authors concluded there is an amount of anticipated stress when addressing

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treatment for congenital hand differences. Still, it would be beneficial to improve the identification of such potential stressors to direct resources towards supportive systems and coping strategies (Franzblau et al., 2015).

Gaps of study, specific to body appreciation in relation to congenital hand and upper extremity malformations, are evident within the field of pediatrics and exceedingly so in the specialty of pediatric orthopedics. Individuals with congenital hand and upper extremity malformations have observable differences in their physique; therefore, it is imperative to ensure positive body appreciation within this population to initiate healthy decisions into adulthood.

#### Self-Esteem

Self-esteem refers to an individual's positive or negative attitude towards themselves and their beliefs regarding their worth, value, and abilities (Rosenberg, 1965, as cited by DuBois, 2003). Dynamic experiences determine the development of self-esteem from birth to adulthood, which formulate a sense of belonging and acceptance, and the desire for personal fulfillment (Ellis, 1995). Positive and balanced self-esteem helps prevent the likelihood of poor mental health and poor relationships, and it decreases the fear of making mistakes and failing (Meisenhelder, 1985). As adolescents begin to take ownership of their decisions and evaluate their sense of belonging in society (Mann et al., 1989), their psyche is more impressionable and vulnerable to the impact of events, such as creating new peer relationships, taking risks, acknowledging physical appearance, and setting healthy boundaries (Prior et al., 2014; Reniers et al., 2016; Schreuders et al., 2019; Seddig, 2020). Consequently, if adolescents attain healthy self-esteem, they are more equipped to navigate such events (Bialecha-Pikjul et al., 2019).

#### Self-Esteem and Adolescents

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The study of self-esteem in the pediatric adolescent age group is a vastly explored topic. Many studies focus on self-esteem related to physical attributes, such as obesity, exercise, eating habits (Liu et al., 2015), and mental health ailments, such as depression, anxiety, and social adjustment (Trzesniewski et al., 2006). More recently, social media use has arisen as a worrisome commodity impacting adolescent self-esteem. Adolescents who emotionally invest in social media and use it more often than three hours a day and during night hours are more likely to exhibit lower self-esteem (Woods & Scott, 2016).

#### Self-Esteem and Pediatric Orthopedics

Similar to the topic of body appreciation, research specific to self-esteem in pediatric orthopedics is emerging in the field of scoliosis. In a study by Zhang et al. (2011), 46 patients with adolescent idiopathic scoliosis were divided between two surgical and non-surgical intervention groups with self-esteem and life satisfaction assessed at the initial visit and one year after treatment. No differences were found between groups at the initial visit for life satisfaction, but self-esteem scores were higher in the non-surgical group (Zhang et al., 2011). At one year of follow-up, life satisfaction and self-esteem scores were significantly higher in the surgically treated group, and self-esteem in the non-surgical group significantly decreased over time (Zhang et al., 2011). The authors concluded that within the adolescent idiopathic scoliosis population, both concepts of self-esteem and life satisfaction are significantly impacted by surgical intervention (Zhang et al., 2011).

## Self-Esteem and Congenital Hand or Upper Extremity Malformations

Self-esteem in the adolescent population of those with congenital hand or upper extremity deformities has not thoroughly been examined. This is largely due to the use of validated self-reported assessments that focus simultaneously on functional extremity improvement and general

quality of life, such as the Pediatric Outcomes Data Collection Instrument (PODCI) or the Patient-Reported Outcomes Measurement Information System (PROMIS) (Bae et al., 2018; Miller et al., 2020; Waljee et al., 2015; Wall et al., 2020). As these assessments are reliable, valid, and offer ease of administration, at times, they may be limited depending on the researcher's interests or concerns. Using a tool built for a specific PSF may provide more detail about a population. In a recent systematic review, Miller et al. (2020) examined 23 studies of upper limb anomaly management, including hand-specific differences, to determine what types of psychological assessment tools are frequently used. Only one study utilized a specific selfesteem inventory and self-imaging profile, a 10-year follow-up study by Bellew et al. in 2011. Bellew et al. (2011) reviewed psychological factors of 25 patients who underwent a toe-to-hand transfer that included validated self-esteem and self-image measures, among others. Ninety-one percent of parents and 88% of patients reported they were "satisfied" or "very satisfied" with surgical intervention results, based on variables of function, appearance, donor-site, psychosocial well-being, and public reaction (Bellew et al., 2011). Study results suggested that patients and families generally had positive clinical outcomes, yet the RSES used in the study appears both atypically scored and interpreted. Only patients aged 18 years and older in the sample completed the assessment (11 out of 25), despite it being a reliable and valid tool for those younger in age (Bagley & Mallick, 2001). Additionally, the reported cohort average of 15.46 in the author's sample was compared to a normative of 34.73 (Bellew et al., 2011). This suggests an unclear reversal and comparison of the scale's outcome value, in which the reader may find self-esteem not to be representative of the sample. The methods used to study this PSF could stand for improvement and clarification to better understand the study's results.

The study of self-esteem is prevalent in many adolescent populations; however, it has yet to be explored in depth with congenital hand or upper extremity differences. Considering that surgical intervention is a predominant choice of treatment in this population, self-esteem is a factor that should be preserved and supported alongside treatment. Promoting healthy selfesteem in this population allows patients to understand their extremity differences should not hinder their attitude towards their self-worth.

### Resilience

The concept of resilience refers to the capacity to utilize and negotiate psychological, social, cultural, and physical resources to sustain well-being when exposed to adversity (Resilience Research Centre, 2016, para. 4). It serves as a vital construct in overcoming stressful obstacles and difficult circumstances by rebuilding a sense of psychological balance (Hart et al., 2012). Having strong resilience prevents an unhealthy extension of negative emotions that may arise during such occurrences and lowers the risk of developing unhealthy mental health conditions (Ristevska-Dimitrovska et al., 2015). Considering the nature of resilience, multiple perceptions exist as to how the concept is best represented. Some authors have concluded it to be in sync with one's personality and linked to specific traits (Oshio et al., 2018). Others have concluded it to be a process of overcoming and becoming inoculated to adverse events (Bonanno, 2004). As resilience research is emerging in the adolescent population, reviewing the limited literature from both perceptions is important. This may provide an easier way to understand coping strategies within the patient population of those with a congenital hand or upper extremity malformation that required surgical intervention (Leys et al., 2020). Yet, for this study, the researchers anticipated a methodical approach from the view of unique traits.

Treatment for a congenital anomaly requires continuous adaptation among social interactions in which such traits will continue to develop from adolescence into adulthood.

#### **Resilience and Adolescents**

Establishing resilience in adolescence is a crucial factor for cognitive development. It directs an adolescent to harness personality traits used to overcome challenges or setbacks that naturally occur during this period, such as peer pressure, bullying, relationships, or academic shortcomings (Olsson et al., 2003). Moreover, such psychological strength arguably equips adolescents for the natural next stages of social development as young adults, including consequential decisions and outcomes, such as attending college, starting a career, or living abroad.

Resilience has been studied in pediatric conditions that commonly involve sensitive treatment options or complex decision-making for families with exceptional consequences, such as violence, trauma, or cancer (Isokääntä et al., 2019; Ortiz & Sibinga, 2017; Ridings et al., 2019; Rosenberg et al., 2018; Van Schoors et al., 2015; Wu et al., 2015). Additionally, the concept was explored in parents and caregivers of such patients. A study by Quezada et al. (2016) examined 51 sets of pediatric burn patients and their guardians to understand how the concept of resilience connects post-traumatic stress and burn survivor adjustment. Both parents and patients reported high levels of resilience, and specifically within burn patients, age and stability by caregiver were associated with more resilience (Quezada et al., 2016). The authors concluded that early intervention and caregiver well-being are strong indicators for positive survivor adjustment (Quezada et al., 2016). Similarly, Pagorek-Eshel and Finklestein (2019) examined anxiety, self-differentiation, and resilience in a population of 89 pairs of parents and adolescents exposed to missile fire for 13 years. No significant difference was found between

adolescent and parent-reported resilience; however, higher family resilience was predicted by higher individual adolescent resilience, highlighting the value of a familial network contributing to protective factors against violence (Pagorek-Eshel & Finklestein, 2019).

## **Resilience and Pediatric Orthopedics**

Resilience in the realm of pediatric orthopedics has not been examined as thoroughly but is beginning to become a topic of interest in idiopathic arthritis and concussion work. In a qualitative phenomenological study exploring daily living with juvenile idiopathic arthritis, the concept of taking ownership and being proactive about one's life emerged as an arching theme (Cartwright et al., 2015). Through in-depth interviews, adolescents described how they managed the disease and found ways to live as typical teenagers, despite the condition. The researchers concluded that resilience allowed patients to establish resourcefulness, adjust to medical challenges, and develop a strong sense of personal worth. (Cartwright et al., 2015). Laliberté Durish et al. (2018) studied psychosocial resilience in relation to children with a history of concussions and orthopedic injuries. Seventy-five children completed the Connor-Davidson Resilience Scale combined with a Post-Concussion Symptom inventory to determine if psychological resilience is a significant predictor of persistent post-concussive s symptoms (PCS) (Laliberté Durish et al., 2018). The authors found that high psychological resilience may be a protective factor for mediating PCS since low psychological resilience was significantly correlated to persistent PCS (Laliberté Durish et al., 2018).

## **Resilience and Congenital Hand or Upper Extremity Malformations**

For the adolescent population with congenital hand or upper extremity malformations, no studies exist that directly and specifically assess the concept of resilience to the best knowledge of the researcher and time of study, exploiting a gap for needed research endeavors. Therefore, it is important to study resilience in this adolescent population to determine if protective or predictive factors exist and how they may influence immediate and long-term health outcomes after treatment.

Having a congenital hand or upper extremity ailment is a unique condition that may make challenges experienced as natural growth more severe or difficult to overcome. Yet, adolescents with these conditions may have a higher capacity or threshold of resilience than their fellow peers due to the experiences endured with treatment and through more supportive networks. As resilience is a concept to be explored in this specific adolescent population, establishing an initial assessment of resilience is instrumental in understanding how these adolescents utilize their psychological, social, and physical resources to maintain well-being.

#### **Connections between Body Appreciation, Self-Esteem, and Resilience**

The relationship between body appreciation and self-esteem is described by an individual's internal perception and attitude toward themselves (Avalos et al., 2005). As self-esteem includes belief about self-worth, the favorable acceptance and value of one's body is viewed as a layered component of the construct. Having a positive sense of body appreciation may be associated with having a positive sense of self. Inversely, having lower self-esteem may include a poor sense of body appreciation. This relationship has frequently been explored by the tangent term of body image and self-esteem with similar conclusions (Danielsen et al., 2012; Mendelson et al., 2002; Webser & Tiggemann, 2003). In adolescent patients with congenital hand or upper extremity malformation, having positive body appreciation and high self-esteem may indicate an adolescent favorably accepts their body and believes themself worthy despite their congenital differences.

#### Social Comparison Theory and Protective Factor Model of Resilience

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The connection of resilience to body appreciation and self-esteem may be viewed through a lens of Social Comparison Theory, which focuses on how an individual will naturally evaluate themself by comparison to others to determine social or personal worth (Festinger, 1954, as cited by Gerber et al., 2018). An individual will either engage in upward comparison, which includes comparing one's self to another believed to be superior or more skilled, or downward comparison, which includes comparing one's self to another believed to be less skilled or inferior (Festinger, 1954, as cited by Gerber et al., 2018). Consequently, either comparison runs a risk of potential pitfalls, yet under healthy circumstances, may inspire behavior to improve upon one's self or take stock of accomplishments and resources (Festinger, 1954, as cited by Gerber et al., 2018).

In an adolescent patient with a congenital hand or upper extremity anomaly who underwent successful treatment, comparing themself to others without such a condition may allude to upward emotions of unfairness, inferiority, or discouragement (Sullivan et al., 2016). Yet, promotion and preservation of high regard to self-esteem and its constructs, including body appreciation, allow an adolescent to draw on strengths from past experiences and reflect on one's supportive network, resulting in a sense of hardiness. This capability ultimately modifies the upward comparison to constructive action, as the adolescent either dismisses the comparison or overcomes it by acknowledging the value of their accomplishments or finding resourceful ways to grow.

Additionally, the lineage between variables of body appreciation, self-esteem, and resilience is demonstrated through the Protective Factor Model of Resilience within Resilience Theory, which focuses on the interplay between risk factors and protection mechanisms that reduce a negative outcome or moderate exposure effect (Ledesma, 2014; Ungar, 2004). Such

factors offset or mediate a conceivable impact that would otherwise have an opposing effect on a desired outcome. Self-factors or personality factors, also described as internal resilience variables, yield protection in favor of the individual's well-being (O'Leary, 2010). Body appreciation and self-esteem are considered internal variables that theoretically may act as a protective mechanism towards adversity, such as a congenital hand or upper extremity malformation. Therefore, the resilience created by these two factors would mediate the influx of rigid beauty and physical acceptance standards in the adolescent treated for the condition and beliefs of value or worth in this developmental period.

## **Summary**

Among reviewed studies that focus on pediatric congenital upper extremity anomalies, especially hand malformations, the specific concepts of body appreciation, self-esteem, and resilience are limited. Most publications focus on functional capacity and broad, allencompassing health questionnaires related to quality of life. As such, it is necessary to examine the relationships of body appreciation, self-esteem, and resilience to better understand this vulnerable population and work towards tailoring treatment and improving long-term outcomes resulting from surgical interventions.

#### Method

#### **Study Type and Design**

This was a non-experimental study using an analytic cross-sectional design. The primary researcher (T. B.) investigated body appreciation, self-esteem, and resilience in adolescents with a CHUE anomaly who underwent surgical intervention. Upon approval from the University of Indianapolis and the University of Texas Southwestern Institutional Review Boards (IRB),

recruitment of eligible participants occurred through Scottish Rite Hospital for Children (SRH) from February 05, 2021, to May 31, 2021.

## Setting

This study was managed through the SRH's Center of Excellence in Hand Disorder department (Hand Center). Clinics within this department provide specialized care for the pediatric population with orthopedic hand and upper limb anomalies, including complex reconstruction following trauma. Families or health care providers may request appointments to within the clinic, and both private and public insurance plans are accepted. Additionally, the institution provides financial program assistance to those who may need this resource for treatment. As a result, patients seen in the clinics are composed of robust demographics and a wide variety of CHUE conditions.

### **Participants**

Using convenience sampling, the primary researcher recruited adolescents who underwent surgical intervention for a CHUE malformation and had an established relationship with the institution through the SRH Center of Excellence in Hand Disorder's treatment clinics. Inclusion criteria were defined as a patient who was currently between  $\geq 10$  and  $\leq 19$  years old, diagnosed with a CHUE malformation and underwent surgical intervention for treatment purposes, and could understand and speak English. Specific diagnosis of a CHUE anomaly included one or more of the following on either hand or upper extremity: polydactyly, syndactyly, symbrachydactyly, vascular malformation or overgrowth syndrome of the upper extremity due to somatic mutation, radial or ulnar dysplasia, ectrodactyly, brachydactyly, camptodactyly, clinodactyly, or thumb hypoplasia (Goldfarb et al., 2015; Oda et al., 2010). Exclusion criterion included adolescents diagnosed with a CHUE anomaly in conjunction with an additional congenital orthopedic-related ailment. For example, a patient with polydactyly and hip dysplasia did not meet inclusion criteria, nor did a patient with thumb hypoplasia and clubfoot.

## Data

The primary researcher collected demographics, participant characteristics, and outcome data through an anonymous survey. Demographic data included: current age (years), gender (male or female), race (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, White or Caucasian), and ethnicity (Hispanic or Latino or not Hispanic or Latino). Participant characteristic data consisted of current school grade (middle school, high school, college), height (feet and inches) and weight (pounds) for body mass index calculation, diagnosis of CHUE (list of previously described diagnoses), family history of CHUE (yes, no, or unknown), hand or upper extremity involvement (left, right, bilateral), number of surgeries, and age at the time of surgery (under one year, one to two years, three to four years, four years or older). Outcome data included the BAS-2 to assess body appreciation, the RSES to assess self-esteem, and the CYRM-R to assess resilience.

#### Instruments

#### **Body Appreciation Scale-2**

The BAS-2 is a self-reported 10 item measurement tool with statements related to acceptance of, favorable opinion of, and respect of one's body (Tylka & Wood-Barcalow, 2015). Participants responded to each item using a five-point Likert-like scale ranging from 1 = Never to 5 = Always. Results were scored by averaging participant responses for all items. Scores ranged from 1 to 5, with a higher score indicating higher body appreciation. The BAS-2 is freely available to use in research with notification to primary authors. Tylka and Wood-Barcalow

(2015) reported good internal reliability with Cronbach  $\alpha = .91 - .94$  and a three-week test-retest stability (r = .90). Psychometric properties of the BAS-2 have also been established in the adolescent population and determined to have consistent reliability with Cronbach  $\alpha = .94 - .95$  (Halliwell et al., 2015), .93 - .94 (<u>Góngora</u> et al., 2020), and .91- .94 (Lemoine et al., 2018). Construct validity for the BAS-2 has been established in the young adult population with strong positive correlations to appearance evaluation in the Appearance Evaluation subscale of the Multidimensional Body Self-Relations Questionnaire (r = .80, p < .001), self-esteem with the RSES (r = .62, p < .001), proactive coping with the Proactive Coping subscale of the Proactive Coping Inventory (r = .42, p < .001), and inversely related to body surveillance with the Body Surveillance subscale of the Objectified Body Consciousness Scale (r = .42, p < .001) (Tylka & Wood-Barcalow, 2015). In a systematic review by Kling et al. (2019), the BAS-2 was found to have supportive convergent and discriminant validity properties and strong structural validity with a one-dimensional factor structure through exploratory factor analysis (Tylka & Wood-Barcalow) and confirmatory factor analysis (Lemoine et al., 2018).

#### Rosenberg Self-Esteem Scale

The RSES is a self-reported 10 item measurement tool related to overall feelings of selfworth and acceptance (Rosenberg, 1965). Each of the 10 items is a statement in which the participant responded on a four-point Likert-like scale from 1 = strongly agree to 4 = strongly disagree. Results were scored by totaling response values, ranging from 10 to 40, with a higher score indicating higher self-esteem. The RSES is freely available for professional research and is the most used tool to measure self-esteem (Schmitt & Allik, 2005). Psychometric properties have been established in the adolescent population with a Cronbach  $\alpha = .86$  indicating good internal consistency (Bagley et al., 1997), with one-week test-retest stability (r = .82) (Fleming & Courtney, 1984), and with a two-week test-retest stability (r = .87) (Dittmann et al., 2009). In a review of self-esteem measures in weight management for children and adolescents, the RSES has acceptable face, convergent, discriminant, and content validity properties (Rosenberg, 1965 as cited by Tirlea et al., 2019). Construct validity for the RSES has been established among young adults in relation to self-esteem and self-concept dimensions. Positive correlations were found in self-concepts of academic (r = .38, p < .01), social (r = .28, p < .01), emotional (r = .50, p < .01), family (r = .28, p < .01), and physical (r = .46, p < .01) (Martín-Albo et al., 2007). Construct validity of the RSES is also supported by outcomes in an adolescent population in which high self-esteem was found to be negatively correlated with the four sub-scales of emotional and behavioral disorders (Bagley & Mallick, 2001).

#### Child and Youth Resilience Measure

The CYRM-R is a self-reported 17-item measurement tool related to personal skills, peers, social skills, caregiving, and support (Jefferies et al., 2018; Resilience Research Centre, 2016). Each of the 17 items is a statement answered by the participant using a five-point Likert-like scale ranging from 1 = not at all to 5 = a lot. Results are summed to gain the total score, ranging from 17 to 85, with a higher score representing higher resilience. The CYRM-R is available free of charge and can be used with permission. In a review of resilience measurement scales by Windle et al. (2011), the CYRM was found to have high content validity, extensive research efforts piloted in 11 countries, and appears to target the adolescent age group well. Psychometric properties are still in development as the CYRM has been modified from an original 58 (CYRM-58) item scale down to 28 (CYRM-28), and currently a revised 17 (CYRM-R) (Resilience Research Centre, 2018; Ungar et al., 2008). The CYRM-R has demonstrated good internal consistency with an overall Cronbach  $\alpha = .87$ , .82 for the personal resilience subscale,

and .82 for the relational resilience subscale (Jefferies et al., 2018; Resilience Research Centre, 2018). Test-retest stability has not been reviewed in the CYRM-R, yet within the CYRM-28, test-retest for the total scale at a two-week interval was found to be r = .82, and at a three-month interval r = .75, indicating stability (Daigneault et al., 2013). Additionally, construct validity has been demonstrated in the CYRM-28 with significant associations between the Satisfaction with Life Scale and the CYRM-28 overall (r = .40, p < .001) and notably the CYRM-28 context of Social/Cultural (r = .37, p < .001), and also the Strengths and Difficulties Questionnaire (SDQ) Prosocial Scale and the CYRM-28 overall (r = .41, p < .001) and notably the CYRM-28 context of Spiritual/Community (r = .34, p < .001) (Sanders et al., 2015).

#### Procedures

#### Recruitment

The primary researcher requested a waiver of consent and Health Insurance Portability and Accountability Act (HIPAA) with the primary IRB (University of Texas Southwestern) to pre-screen records to identify eligible subjects for participation through the SRH Hand Center. To meet the age requirements for the current year of the study, the researcher requested a list of surgical cases from the years 2001 to 2011 from the institution's Health Information Management department, as treatment for CHUE anomalies is frequently initiated from birth up to pre-school age (Blauth & Schneider-Sickert, 2012; Oda et al., 2010). A total of 186 records met inclusion criteria. This list was generated using current procedural terminology (CPT) and internal classification of diseases (ICD-10 and ICD-9) coding for inclusion diagnoses, existing surgical case(s), age parameters, and contact information. The list was then formatted into Excel by the analyst and emailed to the primary researcher using the encrypted hospital network. An IRB-approved recruitment letter was mailed through the SRH Hand Center addressed to the potential participant (and a parent or legal guardian if under 18 years of age) using the last known mailing address. The letter included a summary of the study, the contact information of the researcher, a quick response (QR) code, and a uniform resource locator (URL) link via Redcap (Vanderbilt, n.d.) that allowed anonymous one-time access to the study survey questions. Letters returned to the institution were re-addressed with an updated address using a third-party program licensed by the institution.

The option to receive a \$5.00 incentive was offered to the participant after completing all survey questions. This was funded by the primary institution's internal research advisory panel upon approval of the study. After a participant completed the anonymous set of questionnaires, they were given the option to volunteer an email address to receive an electronic gift card. This link disconnected from the questionnaire platform and connected to another to ensure the anonymity of recorded responses for the questionnaire.

### Informed Consent

A waiver of written consent was requested from the primary IRB for those interested in participating in the study. Individuals who used the QR or URL in the recruitment letter were directed on their personal electronic device to an online introductory page in which an IRBapproved information sheet, created by the primary researcher, regarding a summary of the study was displayed for review. Participants confirmed if they were under the age of 18 years, and if so, the mandatory parent or guardian permission was obtained before continuing. This was achieved via a yes or no response to a question directed towards the parent or legal guardian. Once achieved, the participant continued onto the study-specific material to anonymously respond to survey questions. Contact information of the primary researcher was available on this page in case participants or guardians had any questions, commentary, or concerns in which they wished to address before starting. Participants were also informed that the survey did not have a save-and-return option, yet participants could stop participating for any reason if they wished to do so.

#### **Data Collection**

Study data were collected and recorded through an anonymous survey using Redcap (Vanderbilt, n.d.). Each participant answered questions that did not contain any protected health information or allowed study personnel to determine a link between preliminary screening procedures and survey responses. Questions were divided into sections that consisted of basic demographic information and participant characteristics, assessments of body appreciation, self-esteem, and resilience, and an additional option for commentary.

#### Data Management

Survey data were housed in a secure Redcap (Vanderbilt, n. d.) database to which only approved research personnel had access. Recorded data were exported into an Excel file compatible for uploading into a program for statistical analysis and saved on the primary institution's secure network with password protection. All files and study documents were saved per the institution's IRB and clinical research standard operating procedures.

#### **Statistical Analysis**

All data were analyzed using descriptive and inferential statistics with IBM SPSS Statistics for Windows, Version 24.0 (IBM Corp., Armonk, NY). All tests were two-tailed with a set statistical significance level of less than .05. Normality of the data was determined using Shapiro-Wilk tests and visual inspection of normal Q-Q plots, histograms, and boxplots. Equality of variance was assessed using Levene's tests. Descriptive data were reported to summarize

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study participants. Normally distributed continuous data (current age, body mass index, number of surgeries, RSES score, and CYRM-R score) were reported as means and standard deviations. Frequencies and percentages were used to report gender, race, ethnicity, diagnoses, family history, and specificity of respective extremity involvement. Ordinal data (school grade, age at time of surgery, and BAS-2 score) and continuous data not normally distributed were reported as mode or median and interquartile range.

Inferential statistics were conducted to investigate the specific research objectives of the study. To determine if there were significant differences between BAS-2, RSES, and CYRM-R scores between males and females, older (14-19 years) and younger (10-13 years) adolescents, and between single or bilateral extremity involvement, independent *t* tests, Mann- Whitney *U* tests, or Fisher's exact tests were conducted dependent upon the distribution of data. Scores for the BAS-2 were rounded up to the nearest whole number with tenth place values less than five rounded down and tenth place values greater than or equal to five rounded up.

Multiple linear regression analysis was conducted to determine if BAS-2, RSES scores, and other collected variables predicted a CYRM-R score. Variables selected as possible predictors were determined by bivariate analyses and the clinical expertise of the primary researcher. To be entered into the regression model a significance of .05 was required for comparison of differences and a correlation coefficient of at least .30 for measures of association. The enter method was used to identify significant predictor variables.

Six assumptions for multiple regression, based on recommendations of Field (2017), were explored including: 1) presence of a linear relationship between the dependent variable and independent variables determined by visual inspection of a scatterplot of studentized residuals against unstandardized predicted values and partial regression plots; 2) independence of observations as determined with the Durbin-Watson statistic being close to 2.0; 3) lack of multicollinearity based on r < .85 and tolerance values above .20 among independent variables; 4) presence of homoscedasticity determined by visual inspection of studentized residuals against unstandardized predicted values; 5) no significant outliers determined by lack of cases with greater than  $\pm$  3 standard deviations for standardized predicted values and standardized residuals; and 6) presence of normally distributed residuals determined by visualization of the standardized residuals histogram and the probability plot.

#### Results

Out of 186 patients who met the inclusion criteria at the institution, a total of 31 responded to the survey (response rate = 16.67%). Participant demographics and characteristics are described in Table 1. The mean age (standard deviation, minimum- maximum) of respondents was 13.03 years (1.92, 10-17). Respective diagnoses per extremities are described in Table 2. No respondents reported a diagnosis of ectodacytly, brachydactyly, camptodactyly or clinodactyly. Fifteen participants (48.4%) reported a single surgical intervention as a component of their treatment, while 16 (51.6%) reported more than one. The initial surgical intervention occurred under 2 years of age for 55% of left extremities and 47.5% of right extremities, and over 2 years of age for 45% of left extremities and 52.6% of right extremities.

# Body Appreciation, Self-Esteem, and Resilience Among Gender, Age, and Extremity Involvement

A total of 31 participants completed the BAS-2 with averaged scores ranging from a minimum of 2.9 to a maximum of 5.0. The median (interquartile range) for the cohort was 4.5 (2.1). After rounding the scores to the nearest whole number, there was one score of "sometimes", 14 scores of "often" and 16 scores of "always". The sometimes score was

combined with the often scores resulting in 15 (48.8%) of the participants reporting often and 16 (51.6%) reporting always. To determine if there was a significant difference in body appreciation between gender, age, and extremity involvement, as stated in the first study objective, Fisher's exact tests were used. No statistically significant differences were found for each comparison, as detailed in Table 3.

Twenty-nine participants completed the RSES with a mean (standard deviation) score of 33.03 (5.22). To determine if there was a statistical difference in self-esteem between gender, age, and extremity involvement, as stated in the second study objective, parametric statistical *t* tests were used for each comparison. Both gender and extremity involvement were not found to be statistically significant. However, scores between young and old adolescents were found to be statistically significant, as detailed in Table 4. One participant completed the RSES but did not provide an age; this score was removed from the respective analysis as it was unable to be stratified.

Twenty-nine participants completed the CYRM-R with a median (interquartile range) score of 78.00 (12.00). To determine if there was a statistical difference in resilience between gender, age, and extremity involvement, as stated in the third study objective, both parametric *t* tests and non-parametric Mann-Whitney *U* tests were used for each comparison of CYRM-R scores. No statistically significant differences were found for each analysis, as detailed in Table 5. One participant did not provide an age and was removed from the respective analysis due to the inability to stratify into an age category.

Additionally, one respondent's CYRM-R score was removed from all statistical analyses of resilience as it was classified as an outlier. This score, when included, significantly skewed data and produced inconsistent results. Taking into consideration the small sample size of the adolescent cohort, it is limited in analysis and therefore believed by the researcher justified for artificial removal.

## **Variables Predicting Resilience**

To determine what variables might predict the dependent variable of resilience, as stated in the fourth study objective, bivariate analysis was performed in preparation for multiple regression modeling. No significant differences in adolescent demographic and characteristics were found when compared to CYRM-R scores; therefore, none were added as possible predictors. There were only two independent variables that had correlation coefficients greater than .30, BAS-2 scores and RSES scores, so they were included in the analysis.

Multiple regression analysis was conducted using the enter method to determine if CYRM-R scores could be predicted by BAS-2 and RSES scores. All assumptions were met as detailed in the Method section. The two-predictor linear regression model was statistically significant, F(2, 25) = 9.96, p < .001;  $R^2 = .44$ , and explained 44.3% of the variance. Only one predictor, BAS-2 score, significantly added to the model. The predicted CYRM-R for adolescents who answered "always" on the BAS-2 was 7.27 points greater than the predicted score for adolescents who answered "often" on the BAS-2. Regression coefficients and standard errors can be found in Table 6.

### Commentary

Once participants completed all demographic and patient-reported outcome surveys, they were provided the option to include additional commentary regarding their diagnosis and treatment. Five respondents expressed feeling confident despite their anomaly, including the desire to share their stories with their peers, and were not teased about their differences. One respondent expressed they may occasionally experience pain and at that time wish they still had their extra fingers.

#### Discussion

PSFs greatly contribute to the well-being of adolescents as they develop through stages of physical and mental growth. Adolescents with congenital differences of the hand or upper extremity may be more vulnerable to these periods of growth due to their anatomical differences and the frequency of medical attention as young children. The primary focal points within the literature evaluating health outcomes for this cohort are placed on functional capabilities. As a result, factors explicitly associated with mental health may be overlooked. Therefore, the purpose of this study was to explore the PSF's of body appreciation, self-esteem, and resilience in adolescents with a surgically corrected CHUE malformation and ascertain if these PSFs are influenced by gender, age, and extremity involvement. Additionally, this study aimed to determine variables that significantly predicted resilience within the population.

#### **Body Appreciation**

No statistically significant differences were found between BAS-2 scores and age, gender, or extremity involvement within this cohort of adolescents, suggesting that these variables do not influence the PSF of body appreciation. As all respondents initiated surgical treatment before the age of four years, 42% of participants before the age of two, a sense of aesthetic acceptance regarding the CHUE may initiate early and continue to grow over time, allowing subjects to become increasingly comfortable amid social circumstances or physical changes (Cartwright et al., 2015).

The primary clinical goal of intervention is to improve and maintain the functional capacity of the affected extremity (Bae et al., 2018). This goal, established at initial treatment

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and continued through follow-up, may act as a continuing reminder that the assessment of the physical appearance of one's hand or upper extremity ailment is inferior. As such, an adolescent participant may not equate the same merit of the extremity to aesthetic elements of personal appearance frequently sensitized during this period of growth, such as facial features, bodily proportions, hair, and clothes (Quittkat et al., 2019).

Kelly et al. (2016) concluded that continued discussions regarding body image would be an integral component of treatment that may promote more favorable outcomes for patients undergoing care for hand or upper extremity differences. Similarly, Franzblau et al. (2015) described the importance of having resources to manage stress or coping associated with such an ailment. The non-significant results regarding body appreciation within this cohort may reflect the treating institutions' approach to clinical care. All subjects were treated at the same institution, within the same department, by two leading pediatric orthopedic surgeons specifically specializing in hand and upper extremity ailments during the specified time frame.

The department culture and administration of clinical care may have provided support in which a thorough discussion of anticipated changes from surgical intervention occurred, thus promoting the assessment concepts of acceptance, favorable opinion, and respect of one's body (Tylka & Wood-Baralow, 2015). Many of the institution's core values align with prioritizing families and ensuring providers incorporate concepts of integrity, education, and accountability within their care (Scottish Rite for Children, 2021). Additionally, at sequential follow-up visits, each visit may have reinforced the concepts of acceptance and comfort regarding the anomaly as pediatric providers assess physical improvement and engage in conversation directly with the patient. When initially screening, eligible patients with more than one surgical case (38% of

respondents) recorded may have valued the clinical care enough to continue with the additional surgical case and approach to treatment.

#### Self-Esteem

No significant differences were found between genders on self-esteem scores, indicating that gender does not influence the self-esteem of those with a surgically corrected hand difference in this cohort. Previous literature has found that females frequently report lower selfesteem during adolescence compared to their male counterparts (Frost & McKelvie, 2004). Yet, results of this study suggest both genders may value and find worth in their hand differences in the same manner. Similarly, score comparisons between single and bilateral extremity involvement were not statistically significant, suggesting that extremity involvement does not differ in self-esteem within the cohort. Participants may not believe their extremity involvement limits their abilities, or they may find self-esteem through a lens of capability. If they are capable of completing a task sufficiently, this equates to value and worth.

Statistically significant differences were found on self-esteem scores between the young (greater) and old adolescent (lower) age groups, with the older group averaging a lower RSES score (less self-esteem), indicating age may play a factor in self-esteem among those with a surgically corrected hand difference. Adolescents in the older age stratification may be exposed to more independent social circumstances, such as dating, a first job, or transitioning into a larger school, events in which they may more frequently reflect on their abilities or worth and compare themselves to peers (Ghandour et al., 2019). Having a surgically corrected anomaly may be a component in this reflection or comparison and consequently, directly impact self-esteem resulting in a lower score. Respondents stratified in the early adolescent age group may still be limited in their social structures or independence, as no younger adolescents reported being in

high school. With higher parental or teacher monitoring commonly associated with younger education and associated extracurricular activities, factors associated with self-esteem, such as worth or abilities, may more frequently be re-assured by their caregiver than in older years.

## Resilience

In this sample population, no statistically significant differences were found on CYRM-R scores between age, gender, or extremity involvement, suggesting that these variables do not influence the capacity to utilize and negotiate psychological, social, cultural, and physical resources to sustain a sense of well-being during circumstances of adversity (Resilience Research Centre, 2016, para. 4). As respondents with a corrected CHUE anomaly gradually progress in social independence though their adolescent years, their perception of any limitations, restrictive beliefs, or adversity associated with their anatomical difference may frequently evolve. Opportunities may present themselves in which an adolescent is allowed to build skills or adapt, such as from academic pursuits, social activities, or extracurriculars, and thereby promote elements of resilience. They may have fewer expectations about their decisions or take more risk and still manage to cope with the outcome easily (Tymula et al., 2012). Adolescents with a CHUE difference may have developed traits of resourcefulness and self-awareness by knowing when faced with a difficult situation, it's within their best interest to take stock and utilize available tools or resources. With medical care initiated at an early age, it likely involved an adult or community support system that established a level of trust in which an adolescent would feel comfortable enough to seek guidance on how to proceed and move forward. Additionally, regardless of age, gender, or extremity, a respondent may generally have more optimism towards their unique experience with a corrected CHUE difference. The median CYRM-R score of the cohort was high, and of participants that provided commentary, all responses were overall

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positive in nature. Additionally, early treatment may also have established a strong sense of empathy for a health condition, allowing the adolescent to learn how to relate with others more quickly than peers without a congenital or physical difference. In doing so, this may equate to stronger peer-to-peer relationships and feelings of inclusion despite their extremity difference (Stinson et al., 2016), potentially helping to build hardiness that follows into adulthood.

### **Prediction of Resilience**

Resilience was predicted by variables of BAS-2 score and RSES score. Respondents with a surgically corrected CHUE anomaly who had strong body appreciation and high self-esteem were predicted to additionally have strong resilience. These results are reflective of factors discussed in the literature and associated with the Protective Factor Model of Resilience in Resilience Theory (Ledesma, 2014; Ungar, 2004). Both strong body appreciation and self-esteem may act as internal variables that allow the participant to mediate any limitations associated with a CHUE. When a respondent holds favorable acceptance of their surgically corrected CHUE anomaly as an inclusive body part, and additionally finds value and worth in their difference, they are consequently protecting themselves from feeling insecure or inadequate in their abilities. Exposure to rigid media portrayals of beauty, or circumstances that require strong selfconfidence, may not be portrayed by the respondent as being unachievable, and their CHUE is not seen as an element that holds them back. Results from this study indicate that such skills found in the PSFs of body appreciation and self-esteem contribute to the necessary abilities needed to attain strong resilience.

#### Limitations

Primary limitations for this study include institutional recruitment and limited sample size. This study used a convenience sample from a facility that specializes in the treatment of

pediatric orthopedic conditions, which may not be representative of the population of adolescents who undergo surgical correction for a CHUE anomaly. Clinical care and treatment may include elements specific to the institution that influence responses to body appreciation, self-esteem, and resilience. Additionally, the sample size of the study is limited despite the awareness of an anticipated response rate for a previous study at the same institution (Butler et al., 2017). Having a smaller sample size to achieve respective study objectives may have provided low statistical power or reproducibility. Additionally, the smaller size of the sample limits diversity among clinical diagnoses and the collected variable related to ethnicity.

### **Implications and Future Research**

This research utilized reliable and validated patient-reported outcome assessments in a sample of a population not previously reported or compared in the literature. The results contribute to the knowledge and value of evaluating PSFs in relation to early surgical intervention and long-term outcomes within a pediatrics population exhibiting congenital differences. Findings provide insight into factors that protect against a specific physical adversity that may be perceived as limiting during a stage of growth frequently described as more vulnerable than others (McElhaney et al., 2018). With age being a variable that can significantly influence self-esteem, and PSFs of body appreciation and self-esteem predicting resilience, health care institutions should ensure clinical care takes steps to acknowledge an adolescent's perceptions of self-worth, value, and abilities to navigate resources independently. Conclusions from this research may be used to tailor patient care to individuals or families who may require a stronger supportive framework during treatment or need more resources to ensure the best outcomes are achieved for the patient and their mental health.

Future research should focus on ways to attain a larger and robust sample size. This would allow for more stratification among collected variables, such as by specific diagnosis, ethnicity, or location of congenital extremity concern, providing stronger evidence for conclusions resulting from comparative analysis. Additionally, a larger sample size would offer deepened exploration of age in relation to self-esteem and predictors of resilience, findings significant within this study. One approach would be to collaborate with other institutions that specialize in surgical treatment of CHUE in the pediatric population. Not only would this provide an increased sample size but provide more robust diversity among the population in terms of demographics and diagnoses.

Future research may also focus on the PSF changes observed from pre-adolescence into adolescence and potentially early adulthood. A longitudinal cohort approach would allow researchers to understand changes in PSF's experienced by participants as they grow into adulthood and attain more responsibilities. Factors associated with body appreciation, selfesteem, and resilience are likely to fluctuate depending upon the internal or external expectations of the participant, in which the view of their CHUE may also change.

Finally, future research should incorporate a comparison of patient-reported outcome measures used in this study with others frequently used in pediatric orthopedic clinical care and published in the literature for this population, such as PROMIS or PODCI. The comparison would offer insight regarding whether encompassing measurement tools equate to the same sensitivity as the BAS-2, RSES, or the CYRM-R, and result in similar study objective findings. **Conclusion** 

Understanding the relationship between PSF's and congenital health conditions in the pediatric population is critical when attempting to achieve optimal outcomes of treatment.

Adolescents with a CHUE that receive early surgical intervention are exposed to greater medical care than their peers and may be more sensitive to the acceptance of their anomaly, however, results of this study suggest they do not find their condition limiting with respect to gender or extremity involvement. Exploring the PSFs of body appreciation, self-esteem, and resilience within this sample indicated that gender and extremity involvement do not appear to impact these PSFs. Age, however, is a variable that may play an integral role in self-esteem, and both PSFs of body appreciation and self-esteem are strong indicators for high resilience. Patients who appreciate their anomaly, find confidence in their abilities, and attain traits that promote hardiness, are speculated to have the best long-term outcomes from surgical intervention.

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Participant Demographics and Characteristics (N = 31)

Item		N (%)
Gender	Male	16 (51.6)
	Female	15 (48.4)
Race	White	21 (67.7)
	Not White	8 (25.8)
	Not Reported	2 (6.5)
Ethnicity	Hispanic or Latino	7 (22.6)
	Not Hispanic or Latino	23 (74.2)
	Not Reported	1 (3.2)
Adolescent Age Group	Young	19 (61.3)
	Old	10 (32.3)
	Not Reported	2 (6.4)
Body Mass Index	Healthy	15 (48.4)
	Not Healthy	11 (35.5)
	Not Reported	5 (16.1)
Education	Middle School	22 (71.0)
	High School	9 (29.0)
Family History	No	22 (71.0)
	Yes	6 (19.4)
	Not Reported	3 (9.6)
Extremity Involvement	Left	11 (35.5)

## UPPER EXTREMITY DIFFERENCES

Right	9 (29.0)
Both	11 (35.5)

Diagnosis	N (%)			
	Right	Left		
Polydactyly	6 (30.0)	7 (31.8)		
Syndactyly	3 (15.0)	4 (18.2)		
Symbrachydactyly	0	1 (4.6)		
Overgrowth or Vascular Malformation	2 (10.0)	2 (9.1)		
Radial or Ulnar Dysplasia	3 (15.0)	3 (13.6)		
Thumb Hypoplasia or Amyoplasia	1 (5.0)	3 (13.6)		
I do not know	5 (25.0)	2 (9.1)		
Total Extremities	20 (100)	22 (100)		

Participant Clinical Diagnosis by Extremity

Characteristic		Often	Always		
		N (%)	N (%)	р	
Gender	Male	6 (37.5)	10 (62.5)	.289	
	Female	9 (60.0)	6 (40.0)		
Age	Young <sup>a</sup>	8 (42.1)	11 (57.9)	.245	
	Old <sup>b</sup>	7 (70.0)	3 (30.0)		
Extremity	Single	10 (50.0)	10 (50.0)	1.00	
	Bilateral	5 (45.5)	6 (54.5)		

Comparison of Body Appreciation Scale-2 by Gender, Age, and Extremity

*Note*. <sup>a</sup> Young = aged 10-13 years. <sup>b</sup> Old = aged 14-19 years.

Comparison of Rosenberg Self-Esteem Scale by Gender, Age, and Extremity

Characteristic	2	N	M (SD)	р
Gender	Male	15	34.0 (4.2)	.311
	Female	14	32.0 (6.1)	
Age	Young <sup>a</sup>	18	35.1 (3.7)	.011 *
	Old <sup>b</sup>	10	30.8 (4.4)	
Extremity	Single	19	33.1 (5.3)	.922
	Bilateral	10	32.9 (5.3)	

*Note*. <sup>a</sup> Young = aged 10-13 years. <sup>b</sup> Old = aged 14-19 years.

\* p < .05

Comparison of Child and Youth Resilience Measure-R by Gender, Age, and Extremity

Characteristic	;	Ν	M(SD)	р
Gender <sup>a</sup>	Male	14	80.0 (10.0)	.112
	Female	14	74.5 (11.0)	
Age	Young <sup>b</sup>	18	77.7 (6.7)	.116
	Old <sup>c</sup>	9	73.1 (7.3)	
Extremity	Single	18	77.2 (6.1)	.371
	Bilateral	10	74.7 (8.5)	

*Note*. <sup>a</sup> Median and interquartile range reported. <sup>b</sup> Young = aged 10-13 years. <sup>c</sup> Old = aged 14-19 years.

Results of Multiple Linear Regression for Predictors of Resilience

Predictors	В	SE	95% CI Lower	95% CI Upper	t	р
Constant	60.52	6.82	46.47	75.57		
BAS-2 Score	7.27	2.18	2.78	11.77	3.33	.003*
RSES Score	0.36	0.21	-0.08	0.80	1.69	.103

*Note*. BAS-2 = Body Appreciation Scale-2; RSES = Rosenberg Self-Esteem Scale

\* p < .05

### Appendix A

Permission of Use for the Body Appreciation Scale-2 (BAS-2)

The following is a screenshot stating the BAS-2 is available for use in research studies (Tylka &

Wood-Barcalow, 2015).

#### Appendix. Body Appreciation Scale-2 (Final Version)

Permission to use this measure is not required. However, we do request that you notify the corresponding author via email if you use the Body Appreciation Scale-2 in your research. Please seek permission if any item is modified.

For each item, the following response scale should be used: 1 = Never, 2 = Seldom, 3 = Sometimes, 4 = Often, 5 = Always.

**Directions for participants**: Please indicate whether the question is true about you never, seldom, sometimes, often, or always.

- 1. I respect my body.
- 2. I feel good about my body.
- 3. I feel that my body has at least some good qualities.
- 4. I take a positive attitude towards my body.
- 5. I am attentive to my body's needs.
- 6. I feel love for my body.
- 7. I appreciate the different and unique characteristics of my body.
- My behavior reveals my positive attitude toward my body; for example, I hold my head high and smile.
- 9. I am comfortable in my body.
- I feel like I am beautiful even if I am different from media images of attractive people (e.g., models, actresses/actors).

Scoring Procedure: Average participants' responses to Items 1–10.

### **Appendix B**

Permission of Use for the Rosenberg Self-Esteem Scale (RSES).

The following is a screenshot stating the RSES is available for use in research studies

(University of Maryland, 2021).



The Rosenberg Self-Esteem Scale is perhaps the most widely-used self-esteem measure in social science research. Dr. Rosenberg was a Professor of Sociology at the University of Maryland from 1975 until his death in 1992. He received his Ph.D. from Columbia University in 1953, and held a variety of positions, including at Cornell University and the National Institute of Mental Health, prior to coming to Maryland. Dr. Rosenberg is the author or editor of numerous books and articles, and his work on the self-concept, particularly the dimension of self-esteem, is world-renowned.

There is no charge associated with the use of this scale. However, please be sure to give credit to Dr. Rosenberg when you use the scale by citing his work in any publications, papers, and reports. The Rosenberg Self-Esteem Scale may be used without explicit permission. However, the Rosenberg family would like to be kept informed of its use, which can be done by emailing <u>sociology@umd.edu</u>.

Self Esteem: What Is it?

Rosenberg Scale FAQ

Using the Self Esteem Scale

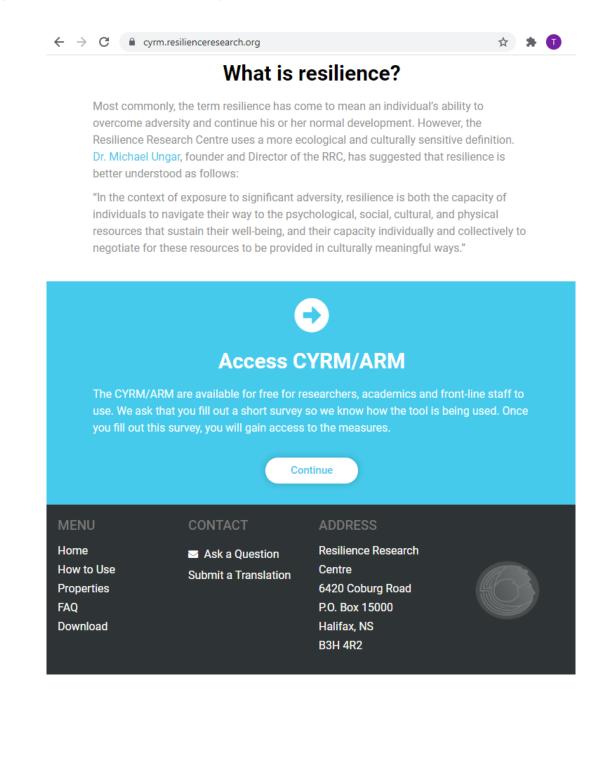
Last modified: 06/22/2021 - 2:52 pm

## Appendix C

Permission of Use for the Child and Youth Resilience Measure (CYRM-R)

The following is a screenshot stating the CYRM-R is available for use in research studies

(Resilience Research Centre, 2016).



## **Appendix D**

### **Recruitment Letter**



### Appendix E

### Information Sheet and Entry to Survey Platform

