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Psychosocial Experiences That Support Positive Self-Concept in Children with Cleft Lip and/or Palate Adopted from China

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PSYCHOSOCIAL EXPERIENCES THAT SUPPORT POSITIVE SELF-CONCEPT IN

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by

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ABSTRACT

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Cleft lip and/or palate (CL/P) is the most common birth defect occurring in the United States (Parker et al., 2010). Children diagnosed with CL/P and their families face significant burden associated with frequent and costly medical appointments (Tolarova, Al-Kharafi, & Tolar, 2018). Children with CL/P are at higher risk for associated genetic conditions, neuropsychological correlates (Conrad, Richman, Nopoulos, & Dailey, 2009), and psychosocial stressors such as social difficulties and internalizing symptoms (Richman, McCoy, Conrad, & Nopoulos, 2012). Self-concept and other self-perceptions have been found to mediate the relationship between negative events and internalizing symptoms (Feragen, Borge, & Rumsey, 2009; Rumsey & Harcourt, 2005). Therefore, further research into experiences that support self-concept in children with CL/P will contribute to an understanding of protective factors for psychosocial difficulties. Children adopted from China who have CL/P often experience different clinical pathways for medical treatment such as receiving corrective surgeries later than non-international adoptees (Swanson et al., 2014). In addition, children adopted from China with cleft lip and palate may face additional challenges related to acculturation, discrimination, or bullying. The existing research offers very little information on the unique challenges and strengths of children adopted from China with CL/P. Thus, it is unknown if children adopted from China with CL/P have different strategies for development and maintenance of positive self-concept.

Previous research has not focused on the perspectives of young children, particularly from a qualitative viewpoint (Sharif, Callery, & Tierney, 2013). The present study adds to the psychosocial literature base of children with CL/P who have been adopted from China by qualitatively exploring child experiences with a strengths-based approach, consistent with the evolving trend in the literature (Stock & Feragen, 2016). The present study utilizes Interpretive Phenomenological Analysis (IPA) to understand social, family, personal, and healthcare factors that support positive self-concept in children and adolescents with cleft lip and palate adopted from China.

To my parents,

Momma and Dada Brown.

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CH 1

Introduction

Cleft lip and/or cleft palate (CL/P) are the most common birth defects, with approximately one in 600 births in the U.S. occurring with cleft lip, cleft palate, or both (Parker et al., 2010). It is estimated that one in 500 births in China occurs with CL/P. Because China is one of the most populous countries in the world, this results in a high prevalence of individuals with CL/P of Chinese descent (Kling, Taub, Ye, & Jabs, 2014). Cleft lip (CL), cleft palate (CP), or both (CLP) occur as the result of malformation of lip or palate during pregnancy. Individuals may be diagnosed prenatally with a routine ultrasound but are often diagnosed after birth. In addition, some types of submucous cleft palate may not be diagnosed until later in life (Centers for Disease Control, 2017). Etiology of CL/P is still being investigated, particularly of syndromic forms of CL/P (Dixon, Marazita, Beaty, & Murray, 2011). Risk factors of CL/P have been identified, including those of heritability and maternal risk factors during pregnancy such as tobacco use (Xuan et al., 2016), diabetes (Correa et al., 2008), and use of certain medications (Hernandez, 2014). Cleft lip manifests as either a unilateral or bilateral cleft, resulting from lack of fusion in the lip and nose areas. Similarly, cleft palate consists of lack of fusion in the upper oral region of the mouth. Level of visible difference in appearance can vary widely among individuals with CL or CLP, which may have implications for perceptions of self and social functioning (Feragen & Borge, 2010).

CL/P can occur as an independent condition but may also be associated with other syndromes (Goodacre & Swan, 2012). Over 400 associated genetic syndromes have been identified (National Institute of Dental and Craniofacial Research, 2018) and can complicate both research and clinical practice (Wyszynski, Sárközi, & Czeizel, 2006). In addition to genetic

syndromes that may present with CL/P, there are also other associated conditions. These are likely to include ADHD (Richman, Ryan, Wilgenbusch & Millard, 2004; Nopolous et al., 2010), specific learning disorders (Broder, Richman, & Matheson, 1998), language impairment (Conrad, Richman, Nopoulos, & Dailey, 2009), and cognitive deficits, particularly related to memory (Conrad, Richman, Nopoulos, & Dailey, 2009).

A diagnosis of CL/P can present a number of challenges for affected individuals and their families. There are several associated difficulties that directly result from physical malformations, including feeding (Miller, 2011), speech and language, and hearing (Jocelyn, Penko, & Rode, 1996). Parents must adjust to caring with an infant with CL/P with these additional concerns. Medical visits in infancy and early childhood are frequent and costly (Waitzman, Romano & Scheffler, 1994; Tolarova, Al-Kharafi, & Tolar, 2018). Surgical repairs typically occur once during in infancy and at least one additional time during childhood (Tolarova, Al-Kharafi, & Tolar, 2018). Medical concerns are typically addressed by a multidisciplinary cleft lip and palate and craniofacial team that includes pediatric, speech pathology, audiology, nursing, genetic, otolaryngology, psychology, and other specialty services (Robin et al., 2006). For internationally adopted children, medical care prior to adoption may not have been adequate or complete. Further, access to ongoing specialty care of therapies (e.g. feeding, speech) may not have been accessible to children residing in orphanages (Swanson et al., 2014).

Statement of the Problem

In addition to ongoing medical needs, there are a range of psychosocial concerns that impact affected individuals and caregivers, which vary across the lifespan (Hunt et al., 2005).

As children age, there are psychosocial concerns such as peer difficulties that occur addition to those in the family context. The preschool time period may see an onset of awareness of difference and dialogues with peers about their visible difference (Rumsey & Harcourt, 2005). The school age years may see an onset in bullying or teasing, speech and learning concerns, and internalizing symptoms (Richman, McCoy, Conrad, & Nopoulos, 2012). Adolescence brings about increased autonomy in medical decisions and can be a time of continued internalizing symptoms for some subgroups although the literature generally supports positive psychological adjustment (Richman, McCoy, Conrad, & Nopoulos, 2012; Hunt, Burden, Hepper, & Johnston, 2005; Stock & Feragen, 2016).

For children who have been internally adopted, there can also be challenges throughout childhood and adolescence. Research suggests that pre-adoption adversity, even mild, predicts internalizing and externalizing problems that tend to worsen with age (Tan & Marfo, 2016). In a review of adoption research trends, Palacios and Brodzinsky (2010) acknowledged a corpus of research suggestive of greater likelihood of adoptees to be referred for mental health treatment, exhibit psychological problems, and perform poorer in school compared to non-adoptees. This body of literature allows us to consider that there may be a cumulative effect of having been internationally adopted and also living with CL/P.

Within the literature on psychosocial outcomes, there is little understanding of *how* individuals and their families cope with stressors associated with the CL/P condition (Norman et al., 2015). Some research suggests overall positive psychological adjustment, but few studies explore the factors contributing to these positive outcomes (Hunt, Burden, Hepper, & Johnston, 2005; King, Shultz, Steel, Gilpin, & Cathers, 1993; Stock & Feragen, 2016). Further, there have

not been studies that describe the psychological adjustment outcomes of internationally adopted children with CL/P.

Research has implicated the role of self-appraisal, self-concept, and other self-perceptions in positive psychosocial outcomes for those with CL/P (Feragen, Borge, & Rumsey, 2009; Rumsey & Harcourt, 2005). For example, results from one study suggested that when individuals with CL/P experienced teasing, their perceptions about the teasing or bullying were more predictive of greater satisfaction with appearance and psychosocial resilience (Feragen, Borge, & Rumsey, 2009). A review article authored by Richman, McCoy, Conrad, and Nopoulos (2012) implicated the importance of self-appraisal (satisfaction with appearance) over objective variables such as type of cleft, age, and gender in predicting positive psychosocial outcomes. Self-appraisal and other variants of self-perceptions are important tools in understanding adaptive coping and overall positive psychological and social adjustment for those with CL/P. These factors are important because the literature suggests that poor self-perceptions result in higher incidence of depression, anxiety, and interpersonal problems (Ferro & Boyle, 2013). Such internalizing concerns can result in reduced medical adherence as well (Grenard et al., 2011). Thus, understanding of factors that support self-concept and therefore, reduce internalizing symptoms, is of value to all members of the medical team including specialty providers and mental health clinicians.

Significance of the Study

There is a significant gap in the psychosocial literature on this population. While there are some studies related to medical, speech, and language outcomes for internationally adopted children, there is little that describes the psychological and social outcomes for internationally adopted children with CL/P. To date, the primary researcher was not able to locate any published

research comparing internationally adopted to non-adopted children with CL/P, studies that examined self-concept, nor any studies that examined psychological adjustment in this population. This speaks to the need for more research to be conducted with children with CL/P adopted from China, and their families. Thus, the present study utilized qualitative methods particularly due to the lack of previous research in order to provide future researchers with guidance. Further, while it is difficult to generalize from qualitative research, the present study also aimed to be useful to providers working with this population.

The present study explored experiences of children with CL/P adopted from China within biopsychosocial and phenomenological frames. Self-concept was chosen as a guiding construct for the present research study because of its prominence in the literature for non-adopted children with CL/P (see Stock & Feragen, 2016) as well as the compatibility of the construct within the biopsychosocial framework and a strengths approach. In other words, the present study aimed to characterize biological, social, and psychological factors that support positive self-concept. Of note, the present study implemented definitions for constructs related to self-perceptions and self-concept as these have been noted to have significant overlap in the literature (Bong & Skaalvik, 2003). Thus, the following will emphasize use the term "self-concept" to encompass views of the self that include perceptions of appearance, self-esteem, competence, and general self-worth (Skaalvik & Bong, 2003).

Research that focuses on identifying factors that bolster and experiences associated with positive self-concept for individuals should include the voices of children since much of the previous literature has relied on parent-report (Sharif, Callery, & Tierney, 2013). Moreover, research that has included the viewpoints of children or adolescents has emphasized adolescents and young adults (Sharif, Callery, & Tierney, 2013). The present study therefore focused on

school age children. This gave voice to those that have not been able to describe their experiences of living with CL/P and what has helped them thrive. These perspectives will be valuable to medical and other providers working with this population.

Purpose Statement

The present study sought to understand social, family, personal, and healthcare experiences that support positive self-concept in children with CL/P who have been adopted from China.

Research Questions

What interactions and experiences with family, school, friends, and the medical system contribute to a positive self-concept?

How do children with CL/P adopted from China and their families incorporate culture and CL/P into self-concept?

Assumptions

There are several assumptions that should be noted for the present study:

1) Living with CL/P alters individual experiences of daily living and family functioning (Nusbaum et al., 2013).

2) Positive or negative psychosocial outcomes as a result of adverse social and medical experiences are mediated by cognitive appraisals and perceptions, which represent the most reasonable place of intervention (Feragen, Borge, & Rumsey, 2009; Richman, McCoy, Conrad, & Nopoulos, 2012).

3) Healthy self-perceptions lead to positive psychological and social outcomes and reduce the likelihood for negative psychological and social outcomes (Mann, Hosman, Schaalma, & deVries, 2004).

4) Researchers have shifted from a deficit to growth orientation, thus a psychosocial strength perspective is warranted (Stock & Feragen, 2016).

Definitions

Cleft lip (CL): A birth defect characterized by one or more gaps in the upper lip resulting from failure of the embryonic parts of the lip to unite (Merriam-Webster, 2018).

Cleft Palate (CP): Congenital fissure of the roof of the mouth (Merriam-Webster, 2018).

Cleft lip and palate (CLP): A combination of both cleft lip and cleft palate. For purposes of this study, "CL/P" will refer to individuals affected by cleft lip, cleft palate, or both. "CL/P" will also include individuals pre- or post-surgical repair.

Craniofacial: Affecting the structure of the head or face regions (American Craniofacial and Cleft Palate Association, 2017).

Self-concept: The way an individual views oneself (Kapp-Simon, Simon, & Kristovich, 1992); A composite view of oneself (Avison & Rosenberg, 1981). Some researchers view *self-concept* as having both cognitive and affective components (Hughes, Galbraith, & White, 2011).

Psychological Adjustment: Areas of coping, adaption, or adjustment to CL/P as they pertain to the individual. These can include satisfaction with appearance, depression, or anxiety. Multi-faceted construct of general psychological well-being (Feragen & Stock, 2016).

Psychosocial Functioning: Encompassing individual psychological components and social factors that interact with each other to impact overall functioning of the individual.

Chapter 2

Literature Review

The following will describe important background information regarding CL/P medical information and related concerns. Differences between medical care for children from China and for children from the United States will be discussed. This literature review will then describe the relevant psychosocial literature related to individuals living with CL/P. Given the relative scarcity of literature that focuses exclusively on children, select studies with adolescent and adult participants are included. Notably, a review or meta-synthesis of CL/P literature with children and/or adolescents was not found. Thus, two psychosocial reviews that comprised studies across the lifespan are included in this literature review. Finally, the little psychosocial research that has been conducted with children with CL/P adopted from China will be discussed. Please note that "CL/P" means cleft lip and/or palate, "CLP" means cleft lip and palate, and "CP" and "CL" designate cleft palate or lip only, respectively.

CL/P Background Information

CL/P are congenital birth defects that form in utero at approximately four weeks (CL) or nine weeks (CP) gestational age. During development, tissues that typically conjoin from each side of the cranium fail to form a fissure. The opening is termed a "cleft" and can vary in size from a small slit to a large opening (Centers for Disease Control, 2017). A cleft lip can be visibly unilateral or bilateral and complete or uncomplete. Thus, level of visible difference will vary for those with cleft lip. An individual with cleft palate may have a fissure in the soft palate (incomplete) or both hard and soft palates (complete). It is also possible to have a submucous cleft, which occurs when the cleft impacts the hard or soft palate and remains covered by the lining of the mouth (Mossey, Little, Munger, Dixon, & Shaw, 2009).

Incidence and prevalence. Estimates of incidence and prevalence of CL/P vary but generally state that CL/P occurs with approximately 1 in 600 live births. According to the Centers for Disease Control and Prevention (CDC), "about 2,650 babies are born with a cleft palate and 4,440 babies are born with a cleft lip with or without a cleft palate" (Parker at al., 2010). International estimates of cleft lip with or without cleft palate range from 7.94 to 9.92 per 10,000 live births (International Perinatal Database of Typical Oral Clefts Working Group, 2011; Tanaka, Mahabir, Jupiter, & Menezes, 2012). Clefts are the most common birth defect occurring in the United States (Parker et al., 2010), although some families protest considering CL/P as a birth defect or disability (Nusbaum et al., 2008). Estimates suggest that 46% of clefts include both cleft lip and palate, 33% are isolated cleft palate, and 22% include isolated cleft lip (Goodacre & Swan, 2011).

CL/P occurs differentially among ethnic lines with the highest incidence in children of Asian and Native American descent and the lowest incidence in children with African ancestry (Tanaka, Mahabir, Jupiter, & Menezes, 2012). There is also a noted gender difference with type of cleft with males more often having a CL and females more often having a CP (Dixon, Marazita, Beaty, & Murray, 2011). Within the United States, it is common for children with CL/P to have been adopted from China or other East Asian countries (Hansson, Svensson, & Becker, 2012). The estimated incidence of CL/P in Chinese infants varies due to small sample sizes and the absence of a universal classification system; however, approximately 1 in 500 births has been one estimated figure (Kljohnsoning, Taub, Ye, & Wang Jabs, 2014). A recently conducted retrospective study reviewed 205,679 patients in China from 2000 to 2011. Results showed that CL/P was more common in males (64%), that CLP was the most common diagnosis (43%) followed by isolated cleft palate (32%) and isolated cleft lip (25%), and that the initial age

of surgery in year 2011 was 1.8 years for lip repair and 5.9 years for palate repair (Kling, Taub, Ye, & Wang Jabs, 2014). This time frame supports previous reports about the surgeries occurring much later in Chinese children than those in the United States (Swanson et al., 2014). In addition to the increased prevalence of CL/P among individuals of Asian descent, there has also been a huge impact of China's One Child Policy which was in effect for 35 years. During that time, 120,00 children were internationally adopted from China. Of those, 85,000 were adopted by families in the United States (Johnson, 2016).

Etiology. CL/P is a combination of genetic and environmental factors (CDC, 2017). Environmental factors that are associated with increased risk for having a child with CL/P include maternal tobacco use (Little, Cardy, & Munger, 2004), pregestational diabetes mellitus (Correa et al., 2008), and use of certain medications (Hernandez, 2014). Other potential environmental factors that have garnered some research support include maternal obesity, infection, and radiation exposure (Mossey, Little, Munger, Dixon, & Shaw, 2009). Genetic etiology is best understood as it pertains to syndromic forms of CL/P, which encompass 30% of all manifestations of cleft, and is less understood for "isolated", non-syndromic forms of CL/P (Dixon, Marazita, Beaty, & Murray, 2011). Candidate genes for non-syndromic forms of CL/P have been identified but the work remains challenging because CL/P is a largely heterogeneous condition. Although both environmental and genetic factors contribute to the occurrence of CL/P, it is important for medical providers working with parents to assure them that having a child with a cleft is not their fault (Young, O'Riordan, Goldstein, & Robin, 2001).

Associated conditions. CL/P is considered to present as either non-syndromic (isolated) or syndromic. Occurrences of cleft with additional congenital anomalies are considered to be syndromal. The most common syndrome associated with CL/P is van der Woude syndrome and

additional genetic syndromes include Treacher-Collins, Stickler, Loey's-Dietz (Shkoukani, Chen, & Vong, 2013), Apert, Turner, and Pierre-Robin Syndromes (Hadadi et al., 2017). Each of these syndromes presents its own unique challenges such as breathing concerns during infancy for those diagnosed with Pierre-Robin Syndrome (Venkatesh, 2009). Other associated conditions may include heart anomalies and malformations of vertebral columns (Milerad, Larson, Hagberg, & Ideberg, 1997).

Neuropsychological correlates. In addition to associated syndromal and non-syndromal medical anomalies that may impact diagnosis and treatment trajectory of a child with CL/P, there are neuropsychological correlates. Children with non-syndromal CL/P are more likely to experience mild expressive and receptive language deficits while children with syndromal CL/P are more likely to experience cognitive impairment (Richman, Eliason, & Lindgren, 1988; Conrad, Richman, Nopoulos, & Dailey, 2009). A recent study found that children with nonsyndromic CL/P were at higher risk for a variety of neurodevelopmental disorders, Specifically, children with CL had increased risk for intellectual disability, psychiatric disorders, and language disorders. Children with CLP additionally had increased risk for Autism Spectrum Disorder (Tillman et al., 2018).

There is inconsistent evidence on whether type of cleft impacts language development though neuroimaging studies suggest that there are structural differences in male children with CP that are associated with specific cognitive deficits (Richman, McCoy, Conrad, & Nopoulos, 2012). Children and adults with CP have been found to have lower IQ compared to a reference group (Laasonen et al., 2004; Persson, Becker, & Svensson, 2008). In addition, children with CL/P with accompanying syndromes or associated conditions are more likely to have impaired cognitive function (Feragen, Borge, & Rumsey, 2009).

Studies of learning and academic development in children with CL/P suggest a significantly higher rate of specific learning disorders in this population with a prevalence rate of 30-40% (Broder, Richman, & Matheson, 1998). In particular, reading disabilities are common in those with CL/P and may be correlated with subtle deficits in verbal labeling of visual information, memory, and processing speed (Richman, 1980; Richman & Eliason, 1984; Richman, Eliason, & Lindgren, 1988; Richman, Wilgenbusch, & Hall, 2005). Notably, patterns of reading deficits do not always align with standard impairment models of reading (i.e. deficits in phonological awareness), but rather are characterized by a dysnomia model of reading disability, where memory plays a key role (Richman & Ryan, 2003). For example, one group of researchers found that the reading disabilities occurred at twice the rate in those with visual memory deficits compared to those without visual memory deficits (Richman, Wilgenbush, & Hall, 2005).

Auditory memory deficits have also been implicated in the literature and may be more likely or more severe in those with CP (Conrad, Richman, Nopoulos, & Dailey, 2009) though conflicting findings have been reported (Conrad et al., 2014). Reading disabilities generally appear to decline with age although reading impairments in males with CP do not show the same decline rate (Richman, McCoy, Conrad, & Nopoulos, 2012). There is some evidence to suggest overall academic achievement difficulties such as enrollment in special education services (Collet et al., 2014) and an increased likelihood of repeating a grade (Lorot-Marchand et al., 2015). Difficulties appear to be worse for those with CP or CLP (Collett et al, 2014; Damiano et al., 2006) and for those with hearing impairment (Tierney et al, 2015).

Attention-deficit/hyperactivity disorder (ADHD) is another neuropsychological correlate associated with CL/P, though the research has been mixed. A study from Richman, Ryan,

Wilgenbucsh, and Millard (2004) suggested the over diagnosis of ADHD in children with CL/P. The authors examined 177 cases of non-syndromic cleft (ages 7 to 12), wherein 18% of the sample had been diagnosed with ADHD. Following neuropsychological assessment, the researchers found only 31% of those initially diagnosed met DSM criteria. Moreover, the researchers concluded that while ADHD may be likely to be over diagnosed, learning impairments were under diagnosed (Richman, Ryan, Wilgenbucsh, & Millard, 2004). A second study conducted by Nopoulos and colleagues (2010) found higher parent- and teacher-reports of hyperactive, impulsive, and inattentive symptoms on behavioral rating scales for boys with CL/P only.

In summary, there is a degree of conflicting evidence regarding cognitive, learning, academic, and executive function differences between children with CL/P and those without. Difficulty in drawing conclusions is likely related to the need for additional research as well as to the methodological challenges associated with past research including the heterogeneity of the population and wide variety of utilized measures (Richman, McCoy, Conrad, & Nopoulos, 2012). However, psychologists working with children and adolescents with CL/P should be aware of neuropsychological findings and how these vary across development and demographic variables. Psychologists play an important role in evaluating for and monitoring these concerns, a critical task especially if specific learning disorders tend to go undiagnosed.

Treatment. The treatment of cleft lip and palate is extensive and costly. During the newborn period, infants and families receive diagnosis, parental counseling, support with feeding, and referrals to specialists or a multidisciplinary team. Initial surgical cleft lip repair in the United States typically takes place at approximately three months with onset of orthodontic care occurring as needed around six months of age (Tolarova, Al-Kharafi & Tolar, 2018). A

second surgery often occurs to repair the cleft palate at approximately nine months of age (Kasten et al., 2008). Speech evaluations and therapy begins around nine months of age with the possibility of additional medical procedures such as placement of ventilation ear tubes. Orthodontic cares are often ongoing throughout childhood and adolescence (Tolarova, Al-Kharafi, & Tolar, 2018). Other possible surgical procedures include revision of cleft palate, revision of cleft lip, bone grafting, repair of palatal fistulae, pharyngeal flap repair, and maxillary osteotomy (Goodacre & Swan, 2008).

One study, based in the Netherlands, found that due to the age of adoption, some children were receiving initial repair surgeries later than recommended (Werker, de Wilde, Mink van der Molen, & Breugem, 2017). Adopted children have also been found to be more likely to receive surgical revisions and have a higher fistula rate (Swanson et al., 2014).

Adoption

There is a lack of published qualitative and quantitative research studies about psychosocial experiences of children with CL/P who have been internationally adopted from China. One study, conducted in Sweden, explored parent experiences of adopting Chinese children who have CL/P. The researchers sent 33 families a written survey, constructed by the research team, with questions regarding the adoption experience with a primary focus on what knowledge the families felt they had about the medical needs of their child. Results indicated that most families knew about the possibility that their child could be a carrier of resistant bacteria, though not all families endorsed full understanding of the implications (Hansson, Östman, & Becker, 2013). Additional findings reported by the authors include parent perceptions that attachment was not negatively impacted by hospitalization for cleft repair and that they were satisfied with surgical results. This study provides some preliminary information about parent

experiences related to adoption for this population but does not offer in-depth child or parent experiences.

Specialty Care in Multidisciplinary Clinics

Multidisciplinary care is the recommended comprehensive treatment strategy for the treatment of CL/P. (McGrattan & Ellis, 2013). According to the American Cleft Palate Craniofacial Association (ACPA), team care should include an identified patient coordinator, speech-language pathologist(s), and "access to professionals in the disciplines of psychology, social work, audiology, genetics, general and pediatric dentistry, otolaryngology, and pediatrics/primary care" (ACPA Standards for Interdisciplinary Team Care, 2016). Other standards include the responsibility of the team to coordinate collaborative care, conduct initial evaluations and re-evaluations, and have mechanisms in place for needed referrals. Additional standards relate to patient and family communication and cultural competence (ACPA Standards for Interdisciplinary Team Care, 2016). Notably, the standards require access to a psychologist or other mental health clinician; the provider does not necessarily have to on site within the clinic as long as a referral mechanism is in place. Thus, the make-up and coordination mechanisms of interdisciplinary teams are flexible. ACPA provides approval to cleft palate and craniofacial medical teams across the United States. This process seeks to assure that multidisciplinary teams are providing the highest quality care for families.

Specialty care is critical for the care of children with cleft lip and palate as the condition is associated with a range of physical and functional concerns. Moreover, research suggests that families are more likely to receive recommended care and report higher satisfaction with healthcare services when they are in the care of a multidisciplinary team (Austin et al., 2010). Team care is well situated to handle the variable concerns present for children with CL/P. For

example, feeding is an initial primary concern for families and their infants (Young, O'Riordan, Goldstein, & Robin, 2001). Due to the nature of the cleft, infants often have difficulty creating a seal around mothers' nipples or on regular baby bottles (Robin et al., 2006). Thus, infants with cleft lip often require a special bottle nipple for initial feeding (Nahai, Williams, & Thomas, 2005). Swallowing can also be a concern, due to oral musculature abnormalities, though sucking is typically a greater issue than swallowing (Clarren, Anderson, & Wolf, 1987).

In addition, appointments with the multidisciplinary team during the first year of life typically include a consultation with a geneticist to determine whether the cleft is associated with a genetic syndrome. This is important to determine associated risk factors for the child, recurrence risk for additional children, and prognosis (Robin et al., 2006). Surgical consults are also important for families during the first months of the child's life. A surgeon will discuss surgical options with the family inclusive of both aesthetic and functional needs. Often, surgery is important for successful speech function later in life (Robin et al., 2006).

Speech concerns fall under the purview of both surgeons and speech and language pathologists. Velopharyngeal insufficiency management is an ongoing concern for both of these specialties, which can occur as a result of "structural abnormalities, neurogenic etiologies, or mislearning" (Robin et al., 2006, p.1117). Velopharyngeal insufficiency is an impairment in the successful closure of airflow between nasal and oral passages, causing hypernasality and possible articulation errors of speech (Robin et al., 2006). Speech remains an ongoing focus for treatment into childhood and sometimes adolescence. Speech therapy is often utilized once one or more surgeries corrects any anatomical issues that affect velopharyngeal insufficiency.

As noted, the above concerns with feeding and speech are both addressed within a multidisciplinary team by surgery and speech and language pathology specialty services.

Another specialty service, audiology, works with families to address hearing deficits. Children with CL/P often present with otitis media with effusion (fluid in ears) and potential hearing loss. Thus, placement of ear tubes is often a needed procedure for children with Eustachian tube dysfunction (Flynn, Möller, Jönsson, & Lohmander, 2009).

Other specialties that see children with CL/P include nursing, otolaryngology, dental, and orthodontics. Surgical procedures, such as bone grafting, may be needed to correct maxillofacial issues and subsequent ongoing cares with dental and orthodontics are necessary to ensure proper teeth alignment and hygiene (Robin et al., 2006). It is important for the range of specialists involved in the healthcare of a child with CL/P to work together as the work of one specialty may impact the work of another; for example, surgical alteration of the pharyngeal flap will impact ongoing speech therapy provided by a speech and language pathologist.

Moreover, integrated care is consistent with recommendations for the American Academy of Pediatrics (AAP) to provide families with an accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective "medical home" (AAP, 2002). In summary, clinical and research spheres appear to concur that multidisciplinary team care for craniofacial and CL/P conditions are desirable in terms of practicality and effectiveness. Despite this seeming consensus, reviews of studies that examine differential treatment outcomes in individual versus multidisciplinary treatment suggest limited evidence to fully support the superiority of multidisciplinary care. Of greater certainty is the lack of full understanding of the interplay of factors involved in team care (McGrattan & Ellis, 2013). For instance, McGrattan and Ellis (2013) noted that families of low socioeconomic status may have reduced access to team care, which could impact satisfaction with care and health-related outcomes. Research that continues to explore longitudinal outcomes related to individual versus

multidisciplinary care will be valuable, especially given the diversity in make-up and coordination of craniofacial teams (Austin et al., 2009).

Psychological Services in Multidisciplinary Care. Psychology is an invaluable specialty housed in multidisciplinary clinics (Goodacre & Swan, 2008). A survey conducted by Hood, Cradock, and Vander Wal (2011) found that psychologists serve a multitude of functions on craniofacial care teams. The authors concluded that psychologists commonly provide education to patients and families about the diagnosis, associated conditions, and psychosocial correlates; screening and brief interventions for bullying, stigma, and teasing; assessment and intervention around medical procedure-related anxiety and fears; parent support; and ensuring that the patient has a voice in treatment (Hood, Cradock, & Vander Wal, 2011). Psychologists serve in a consultative role both to families and to other specialties of the craniofacial team (Goodacre & Swan, 2008). Given that psychosocial needs vary by family, a psychologist's role shifts depending on the need of the patient and their caregivers. For example, a school-aged child who comes to yearly appointments with no signs of psychosocial distress and no upcoming surgical procedures may simply need a brief psychological screening, education, and assurance that psychology services are available in the future if needed. Alternatively, an adolescent with ADHD symptoms who presents with academic underachievement and behavioral concerns may benefit from regular therapy sessions in addition to a referral for a neuropsychological evaluation.

Chronic Condition Experience

Definitions or chronic illness or chronic conditions vary. Often, a chronic condition is defined as a condition of extended duration, lack of spontaneous resolution, and lack of a cure (Goodman, Posner, Huang, Parekh, & Howard, 2013). CL/P is often referred to as a chronic

condition in the literature, especially since the diagnosis is associate with frequent medical appointments, associated risk factors, and ongoing medical care from multiple specialties. However, CL/P differs from other chronic conditions in that it is technically a birth defect that can be corrected with surgery. Some individuals or family members may not identify as having a birth defect or chronic condition. Moreover, certain medical procedures are likely to be completed by late adolescence or early adulthood (Goodacre & Swan, 2008). Although this is generally true, researchers have pointed out that medical care into adulthood is important (Chuo et al., 2005). Since there are likely experiential similarities between those with CL/P and other chronic conditions, it is worthwhile to consider such parallels. However, individual definitions in one's personal beliefs and identity with that of someone with a chronic condition will vary. Thus, the present study will refrain from assuming a chronic condition model but rather allow participants to define whether or not they have a birth defect or chronic condition and simply focus on participant experiences.

Psychological Adjustment and Social Functioning

Psychological adjustment is an umbrella term, often synonymous with "psychological well-being", and includes multiple facets of psychological health in the context of a specific stressor(s). In this case, the stressor is the ongoing burden associated with having the condition of CL/P, which can change physical, social, and emotional trajectories compared to children without CL/P. According to Stock, Hammond, Owen, Kiff, Shanly, and Rumsey (2016), psychological adjustment is a multifaceted construct that includes predisposing factors; early indicators; and key domains during childhood, adolescence, and adulthood. These indicators vary through the lifespan and attempt to delineate normative experiences that any child may encounter from those specific to someone with CL/P. To that end, this section of the literature review is

intended to provide a broad overview of previous research that addresses psychological health as it pertains to the individual, inclusive of the domains identified by Stock and colleagues (2016).

In addition to an overview of psychological adjustment, the nature of the present study necessitates the concurrent examination of social functioning among children with CL/P across childhood development. Thus, the following will integrate studies of psychological adjustment, inclusive of internalizing and externalizing problems and coping, as well as studies related to social functioning.

Early Childhood. Young children are at the age where they may begin to notice their own facial differences and self-confidence may decrease (Broder & Strauss, 1989). Associated with feeling different than peers, children with CL/P may socially withdraw (Broder & Strauss, 1989). Parents may become overly protective of their children with facial differences which may impact parent behavioral management strategies. Parents may have limited social support, which is more likely with young children with deficient social skills (Benson, Gross, Messer, Kellum, & Passmore, 1991).

One study that examined the emotional regulation of children with CL/P found less expressed disappointment compared with non-affected children. The authors posit that children with CL/P may have developed resiliency and/or strong skill sets in emotional regulation in the face of early adversity (Endriga, Jordan, & Speltz, 2003). In addition, the authors found a significant impact of maternal stress on expressed disappointment, implicating the importance of reducing parental stress in order to benefit emotional regulation of their children (Endriga, Jordan, & Speltz, 2003).

Young children with CL/P may be vulnerable to dental anxiety as there are often dental concerns that require intervention early in life (Krikken et al., 2015). Young children between

the ages of 4 and 9 years old have been found to be at greater risk for separation anxiety with a prevalence rate of 24% compared to the U.S. prevalence rate of 3 to 5%. Risk of separation anxiety disorder was associated with speech and feeding concerns as well as low socioeconomic status (Tyler, Wehby, Robbins, & Damiano, 2013).

School Age. Onset of internalizing and externalizing concerns may occur during school age years (Hunt, Burden, Hepper, & Johnston, 2005). Social concerns, manifested as either deficits in social competence (including skills in pragmatic communication) or withdrawal, may be associated with teasing around facial appearance or speech difficulties (Murray et al., 2010). Children may report feeling alienated from peers, general emotional upset, and depression (Murray et al., 2010). Given that childhood anxiety disorders commonly appear between the ages of 8 and 10 years (Kendall et al., 2010), children with CL/P who are genetically predisposed to anxiety and have additional psychosocial stressors (e.g. poor self-concept or experiences of social difficulty) may be at higher risk for internalizing symptoms.

The burden of medical care can be felt for individuals in early and middle childhood. Results from a retrospective qualitative study with adults suggested mixed feelings toward medical care, simultaneously feeling that it was beneficial but noting the difficulties and frustrations associated with long commutes, frequent visits, and procedures (Alansari, Bedos, & Allison, 2014). Participants described an appreciation of their medical care but also remembered feeling "defective", especially during childhood (Alansari, Bedos, & Allison, 2014).

Gender differences in middle childhood vary across studies and thus, no general rules about gender differences can be stated with regard to psychological and social outcomes. One retrospective chart-review study examined a variety of measures across cognitive, social, and psychological domains. The authors found interactions between gender, cleft visibility, and

presence of an additional condition such that the additional condition increased attention and hyperactivity difficulties in girls to a greater extent than boys whereas emotional distress was relatively worse for boys (Feragen & Stock, 2014). Findings also suggested greater emotional problems in boys with CLP and girls with CP, relative to girls with CLP and boys with CP (Feragen & Stock, 2014). These results again emphasize the heterogeneity of CL/P as a condition and the complex interplay of genetic, cultural, social, and psychological factors impacting well-being outcomes.

      Psychosocial Reviews. Two teams of researchers have comprehensively synthesized psychosocial outcomes for those with CL/P in the last two decades. Hunt, Burden, Hepper, and Johnston (2005) published a systematic review that examined these outcomes for both children and adults with CL/P. Of the 64 articles that were included in the study, the authors investigated the extent to which those with CL/P are at risk for poor psychosocial functioning, the type of potential poor functioning, whether there is a relationship between type of cleft and outcomes, and whether developmental stages impact children's outcomes. The authors concluded that the literature suggested overall adaptive psychosocial functioning. Upon closer inspection of those areas that may be problematic, the authors reported some impairment for adults related to concerns with facial appearance and speech. For example, dissatisfaction with facial appearance was found to be a predictor for depressive symptoms in adults with CL/P. For children, they reported that a small number of studies found evidence of increased external locus of control and social environment sensitivity. One study included in the review found higher rates of hostility and negative self-worth (Tyl et al., 1990 as cited in Hunt, Burden, Hepper, & Johnston, 2005). Further synthesis of individual study data suggested indications of higher self-concept in children with CL/P as well indications of reduced self-concept, both personally and socially. Similarly,

self-esteem was found to be generally average with some domain-specific impairments around appearance. One study indicated that children who accepted their cleft had higher self-esteem (Starr, 1978 as cited in Hunt, Burden, Hepper, & Johnston, 2005). Mixed results were found regarding satisfaction with speech, with potential externalizing symptoms associated with worse speech ability and internalizing symptoms associated with good speech ability. Mixed results were also found for externalizing behaviors.

With regard to social functioning, the review summarized previous findings that indicated higher rates of school drop-out for children with CL/P, fewer friends, and reduced likelihood of marriage. Attachment was also examined as a specific area of potential psychosocial impairment in those with CL/P. No consistent attachment differences in mother-child dyads for those with CL/P versus without were found and one study indicated higher attachment scores, supporting an "infant vulnerability" hypothesis (Coy et al., 2002), where mothers may be extra protective over children with visible differences.

Hunt and colleagues then examined prevalence and severity of impairment as a function of cleft type. Children with CLP reportedly have the lowest self-concept scores. Those with cleft lip, with or without cleft palate, reportedly had greater dissatisfaction with appearance. On the contrary, those with unilateral CLP had lower rates of depressive symptoms than those with CP only or with bilateral CLP. Finally, in examination of developmental differences, there were few studies from which to draw data. Evidence may suggest the greatest amount of appearance dissatisfaction during adolescence.

A more recent comprehensive review of the literature was conducted by Stock and Feragen (2016). The authors included 148 quantitative and qualitative studies between 2004 and 2015, effectively providing an update to the review from Hunt and colleagues (2005). Stock and

Feragen looked at the following domains of adjustment: development, behavior, emotional well-being, social functioning, satisfaction with appearance, and treatment. With regard to cleft type, the authors found some suggestion of higher prevalence of difficulties for those with CP. Neurological differences were found in those with CL/P including decreased volume and surface area of cerebrum and cerebellum, and "soft signs" of neurological dysfunction in children (Stock & Feragen, p. 781). In addition, neurological abnormalities were associated with reduced scores on cognitive, language, and reading measures.

With regard to behavior problems, mixed findings were apparent with some studies suggesting higher rates of conduct problems (see Ha et al., 2013) and others reporting equivalent or lower rates of conduct concerns (see Millar et al., 2013). Similarly, there were mixed findings regarding externalizing behaviors. Internalizing behaviors appeared to be more common in females with CL/P (see Ha et al., 2013).

Within the domain of emotional well-being, Stock and Feragen (2016) reviewed studies that indicated poorer emotional functioning relative to control groups for individuals with CL/P. Results were mixed regarding gender differences with some studies supporting greater difficulties in emotional functioning for females (see Eslami, Majidi, Aliakbarian, & Hasanzadeh, 2013; Feragen & Stock, 2016) and some supporting greater emotional difficulty for males (see Mani et al., 2010). Results regarding age differences were also mixed with one reported study suggesting that teenage years involved greater emotional difficulty (Broder, Wilson-Genderson, & Sischo, 2012) while another suggested that younger children experienced greater challenges (Bos & Prahl, 2011).

In review of the area of self-concept, the authors found mixed evidence. Some studies reported average levels of self-concept, some reported above-average, and at least one reported below average self-concept in young children. Self-esteem data had similarly variant findings.

Results from studies that investigated parent-child relationships suggest that mother-infant attachment can be disrupted in early months following birth and return to levels consistent with those of control groups by 18 months (Murray et al., 2008). The same study from Murray and colleagues (2008) found that mothers may look at or engage with their infants less. A second study from Despars and colleagues (2011) did not find any difference in parental-infant attachment.

Studies that explored peer relationships in those with CL/P broadly suggest concerns with social functioning. Individuals with CL/P have been found to have poorer social functioning, yet other studies do not support reduced social competence or functioning. Four studies reportedly found a fear of social evaluation or self-consciousness (see Berger & Dalton, 2009; Chimruang et al., 2011; Demir et al., 2011; & Murray et al., 2010). Studies have suggested gender differences in social functioning related to living with CL/P. For example, females at age 16 with a visible cleft had more peer difficulties compared to same-aged females without a visible cleft; for males at age 16, this pattern was reversed (Feragen, Stock, & Kvalem, 2015). Teasing was identified as a significant concern, relating to speech or appearance. Teasing reportedly occurs throughout childhood and appears to diminish with age (Stock & Feragen, 2016). Teasing was found to predict internalizing and externalizing concerns over and above simply having CL/P, which speaks to the importance of social factors in influencing psychological well-being. Similarly, social acceptance was implicated as a significant influence in both self-perceptions (see Havstam, Laaso, & Ringsberg, 2011) and social competence (see Slifer et al., 2004, 2006).

Another finding that supports the significant role of self-perceptions (beliefs and cognitions about the self) is the fact satisfaction with appearance has been found to mediate the relationship between social events and internalizing symptoms (Feragen et al., 2010).

Of final important element from the review by Stock and Feragen (2016) is their review of studies that have examined quality of life (QoL) and health-related quality of life (HRQoL). Findings again support the overall positive adjustment of those diagnosed with CL/P though self-perceptions were identified as important factors associated with QoL (see Broder, Wilson-Genderson, & Sischo, 2014; Pisula, Lukowska, & Fudalej, 2014).

These comprehensive reviews from Hunt, Burden, Hepper, and Johnston (2005) and Stock and Feragen (2016) provide broad, yet descriptive, accounts of the psychosocial literature for this population. Both of these reviews included child and adult studies, which limits a unique understanding of children with CL/P. Both sets of authors identified methodological problems with past literature including lack of longitudinal data, lack of control groups, small sample sizes, and lack of uniformity among measures. In fact, Stock and colleagues (2016) initiated a workgroup to narrow down the measures that are used in CL/P psychology research. However, this initiative was based out of the United Kingdom and it is unclear to what extent CL/P researchers around the world will consistently use the identified measures. An additional methodological challenge that is important to note is that of associated syndromes and conditions. An associated syndrome is typically a genetic condition with its own anomalies. An associated condition might include a learning disorder or ADHD, for examples. Studies that include participants with and without associated conditions or syndromes may not carefully allocate equal groups and thus, results may be partially or completely attributable to these additional conditions. On the other hand, exclusion of those with these conditions, as is

commonly the case in studies that only include "isolated" or "non-syndromic" cases, may do a disservice to accurately characterizing the population.

Despite the limitations of past research and the inability to draw hard and fast conclusions about the psychological, emotional, and social functioning of children with CL/P, these reviews highlight a number of key points that guide the foundations of this study.

In summary of the psychosocial research, it is clear that the field has been met with significant methodological challenges especially with regards to quantitative research. Research has focused on a deficit model in the past and this area necessitates a strengths-based perspective (Feragen, Borge, & Rumsey, 2009). Previous studies have largely been quantitative; this is evidenced by the number of quantitative studies (n=128) compared to qualitative studies (n=16) and mixed methods studies (n=4) from the Stock and Feragen (2016) review. This suggests that further qualitative research would be valuable to the area of health psychology research with individuals with CL/P. A final key point relates to the significance of self-perceptions. These reviews indicate that CL/P alone does not predict poor functioning across psychological, behavioral, or social domains. Rather, the way that an individual cognitively responds to social challenges, evaluates his/her own appearance and social competence, may be more helpful in predicting domain-specific functioning.

Perceptions of Self

Self-perceptions are critical in understanding adjustment to CL/P and may protect against stigmatization (Alansari, Bedos, & Alliso, 2014). The relationship between meaning-making and self-image has also been explored in qualitative studies. Communication and an active coping approach have been identified as useful in "making sense" of CL/P (Havstam, Laakso,

Ringsberh, 2011). Self-perceptions can include constructs such as self-esteem, self-concept, and resilience.

Self-esteem. Self-esteem is typically conceptualized as the way one values himself or herself or the degree of negative or positive views toward the self. Self-esteem can be examined globally, which connects to general psychological well-being, or examined specifically, which can connect to behavior (Rosenberg, Schooler, Schoenback, & Rosenberg, 1995).

In a recently published study that examined body image and quality of life in adolescents with craniofacial conditions, Crerand, Sarwer, Kazak, Clarke, and Rumsey (2017) found that scores in these domains generally fell within the average range, consistent with much of literature on psychosocial functioning. Upon closer examination, the authors found that adolescents with craniofacial conditions were more likely to report concerns with facial features while the reference group was more likely to report concerns related to other bodily features (Crerand, Sarwer, Kazak, Clarke, & Rumsey, 2017). Adolescents with craniofacial conditions were also more likely to report less investment in their appearance compared to the reference group. Across all adolescents, females reported significantly higher levels of investment in appearance relative to males (Crerand, Sarwer, Kazak, Clarke, & Rumsey, 2017). Finally, the authors found that body image disturbance was associated with lower quality of life across participants (Crerand, Sarwer, Kazak, Clarke, & Rumsey, 2017). The findings from this study highlight the importance of body image as a construct, which can add nuance to measures of satisfaction with appearance. Results from this study implicate the importance of body image for quality of life and also emphasize that females may be more vulnerable to body image disturbance relative to males.

A qualitative study conducted with Japanese adults with CL/P investigated self-esteem and found four processes that individuals experienced over time: noticing, understanding, no denial, and affirmation of life (Omiya, Ito, & Yamakaze, 2012). Within these four processes, the authors identified seven factors that supported advancement through these processes: received sufficient explanation about CL/P, didn't receive a negative message about CL/P, felt the presence of someone who accepted their feelings and was supportive, encountered people with the same condition, made efforts to demonstrate one's own ability, accumulated experiences of facing one's CL/P condition, and deepened their understanding of the CL/P condition (Omiya, Ito, & Yamakaze, 2012). Individuals with higher self-esteem were more likely to have progressed through more of the identified stages through support from the process factors. This study illustrates the importance of accepting and affirming one's CL/P condition in achieving self-esteem.

A final important theoretical conceptualization of self-esteem is valuable to describe here given the oft reported finding of globally average self-esteem, self-concept, or psychological adjustment for children and adolescents with CL/P. Although detailed analysis of findings in these studies suggest specific areas of vulnerability for children and adolescents with CL/P, global measures indicate overall adaptive functioning (Stock & Feragen, 2016). Crocker and Major (1989) suggested a protective process related to membership of a stigmatized group. The authors proposed that individuals who may be stigmatized can attribute negative feedback to the prejudice of others, compare themselves to others within the same group, and emphasize within-group strengths while de-emphasizing within-group challenges (Crocker & Major, 1989). This theory may provide some explanation for why global self-esteem outcomes for children with CL/P either fall within or above the expected average range.

Self-concept. Self-concept is a multi-faceted construct that often includes self-perceptions and perceptions of social judgments (Hunt, Burden, Hepper, & Johnston, 2005). There are several scales that measure self-concept in children and adolescents. A longstanding scale used in CL/P literature is the Primary Self-Concept Inventory (Muller & Leonetti, 1974), which measures the following factors: physical size, emotional state, peer acceptance, helpfulness, success, and student behavior. Another example is the Pictorial Scale of Perceived Competence and Social Acceptance Scale for Young Children (Harter & Pike, 1984), which has two factors: general (cognitive and physical) competence and social acceptance (peer and maternal). The Tennessee Self Concept Scale (TSCS; Fitts & Warren, 1996) is an additional example, measuring physical, moral, personal, family, social, and academic/work areas. Others include the Self-Perception Profile for Adolescents (Harter, 1988), Self Description Questionnaire (Marsh, 1990), Inferred Self Concept Scale (McDaniel, 1976), and the Multidimensional Self Concept Scale (Bracken, 1992). The variety of tools used to measure self-concept shows the complexity of the construct and lack of agreement in the field on how best to define and operationalize it. Moreover, the aforementioned scales do not always have clear theoretical basis (Butler & Gasson, 2005).

An early study from Kapp-Simon (1986) found that young children with CL/P, between ages 5 and 9, were significantly more likely to have self-concept scores that fell in the at-risk range than children without CL/P. Children with lower relative self-concept scores viewed themselves as less acceptable to others and more likely to need assistance. The author presented several explanations for these results: children may be exposed to less social situations, reducing social competence (Tobiason & Hiebert, 1984); children may feel less competent due to concerns with speech or appearance (Richman, 1983). A second study conducted shortly after Kapp-

Simon's (1986) with the same scale (Primary Self-Concept Inventory; Muller & Leonetti, 1974) found negative self-concept in children with CL/P and, in contrast to Kapp-Simon (1986), found that cleft type did have an impact, with children with CLP having lower self-concept scores.

Leonard, Brust, Abrahams, and Sielaff (1991) conducted a survey study using the Piers-Harris Self-Concept Scale (Piers, 1984), which provided scores in perceptions of behavior, intellectual and school status, physical appearance and personal attributes, anxiety, popularity, and happiness/satisfaction. For participants ages 8 to 18 years (*M*=12), the authors found global self-concept scores that generally fell within the average range based on norming samples used for the Piers measure (Leonard, Brust, Abrahams, & Sielaff, 1991). Adolescent girls were identified as having scores below the average for popularity, anxiety, and happiness/satisfaction domains.

Self-concept appears to be the most prevalent operationalized measure related to self-perceptions in the CL/P literature. Self-concept is a broad construct with varying operational definitions, depending on the study. Given the qualitative and specifically, phenomenological, nature of the present study, utilization of the term "self-concept" is well-suited to provide guidance for research aims and interview questions, while not imposing an overly narrow topic area.

Resilience. As understanding of psychosocial risk factors and outcomes has expanded for children with CL/P, a limited number of studies have included a strengths-based or resilience perspective. Models of resilience for CL/P may or may not fit depending on the implemented theoretical framework. Resilience research has mostly been born from an ACEs (Felitti et al., 1998), abuse, neglect, or other traumatic experiences context (Searle, Neville, & Waylen, 2017). Researchers have attempted to use resiliency models to capture the health functioning of those

with CL/P, especially when they demonstrate psychological functioning greater than unaffected individuals. For example, one qualitative study with 15 adults utilized a self-determination theory to investigate psychological growth and resilience. The authors found that many participants attributed their strengths to having been born with CL/P (Searle, Neville, & Waylen, 2017). This study is a good example of a theoretically-based qualitative study, though it focused on adults. It also suggests the importance of "need-supporting environments" and the reciprocal relationship between social support and personal autonomy (Searle, Neville, & Waylen, 2017).

Strauss proposed three steps to re-conceptualize the factors that support overall health in individuals with CL/P: creating optimism, asking children and parents new and different questions, and launching a new model for research that focuses on health and resilience (Strauss, 1999). Strauss highlighted the benefits that could result if medical providers framed CL/P as a unique variant of human experience, rather than something to be corrected (Strauss, 1999).

Feragen, Kvalem, Rumsey, and Borge (2010) utilized the concept of emotional resilience in their study of 289 Norwegian adolescents with CL/P. The adolescents with facial differences reported fewer depressive symptoms than those in the reference group, which the authors interpreted as emotional resilience. They also advised careful consideration of how to interpret positive outcomes on measures of psychological adjustment. Important, too, from this study was the mediating role of personal appearance perceptions in the association between social acceptance and depressive symptoms (Feragen, Kvalem, Rumsey, & Borge, 2010). This again highlights the importance of self-perceptions in their contributions to psychological well-being and coping with cleft.

Adoption and Cultural Considerations

CL/P occurs differentially among ethnic lines with the highest incidence in children of Asian and Native American descent and the lowest incidence in children with African ancestry (Tanaka, Mahabir, Jupiter, & Menezes, 2012). There is also a noted gender difference with type of cleft with males more often having a CL and females more often having a CP (Dixon, Marazita, Beaty, & Murray, 2011). Within the United States, it is common for children with CL/P to have been adopted from China or other East Asian countries (Hansson, Svensson, & Becker, 2012). One study, based in the Netherlands, found that due to the age of adoption, some children were receiving initial repair surgeries later than recommended (Werker, de Wilde, Mink van der Molen, & Breugem, 2017). Adopted children have also been found to be more likely to receive surgical revisions and have a higher fistula rate (Swanson et al., 2014). Despite the need, there is little research that specifically examines cross-cultural considerations among children and adolescents with CL/P in the United States (Zeytinoglu & Davey, 2012). In fact, much of the current research that informs our understanding of cultural differences in the treatment and associated psychosocial concerns come from studies conducted in countries outside of the United States (see Werker, de Wilde, Mink van der Molen & Breugem, 2017).

Reactions to CL/P may differ based on culture (Black, Girotto, Chapman, & Oppenheimer, 2009; Zeytinoglu & Davey, 2012). For example, Japanese mothers have reportedly reacted more intensely to receipt of the diagnosis (Nastume, Suzuki, & Kawai, 1987 as cited in Zeytinoglu & Davey, 2012). Nigerian families may attribute CL/P to evil spirits (Adeyamo, James, & Butali, 2016). Thus, it is recommended that providers working with families from diverse cultures explore personal and family meaning as well as attributions related to the diagnosis of CL/P.

Summary of Gaps and Aims

Previous research has focused on adolescents and adults with CL/P and has not focused on children in early and middle childhood (Sharif, Callery, & Tierney, 2013). Those studies that have investigated psychosocial functioning in this age range often rely on parent or teacher report (Sharif, Callery, & Tierney, 2013). This is problematic because previous research has demonstrated discrepancies between caregiver and child perspectives (Feragen, Borge, & Rumsey, 2009). Perspectives of children are often not included in CL/P research (Hall, Gibson, James, & Rodd, 2013; Sharif, Callery, & Tierney, 2013) and thus a focus on children is warranted for the present study. There has also been little work to date on psychosocial interventions for children and adolescents (Norman et al., 2015). Thus, the present study will likely be important in identifying factors that support positive self-concept and therefore, are amenable to intervention.

The literature about children who have been adopted from China with CL/P is few and far between. While there is literature about medical outcomes, there are no studies led by health psychologists which explore psychosocial outcomes or factors for this population. Despite the need, there is little research that specifically examines cross-cultural considerations among children and adolescents with CL/P in the United States (Zeytinoglu & Davey, 2012). In fact, much of the current research that informs our understanding of cultural differences in the treatment and associated psychosocial concerns come from studies conducted in countries outside of the United States (see Werker, de Wilde, Mink van der Molen & Breugem, 2017).

The present literature review has highlighted the importance of self-perceptions and self-concept in mediating the relationship between experiences associated with living with CL/P and psychological outcomes such as depression, anxiety, and self-esteem. For instance, perceptions of teasing were more predictive than the actual diagnosis of CL/P or teasing event (Richman,

McCoy, Conrad, & Nopoulos, 2012). An exploration of self-concept might, therefore, be relevant for children with CL/P adopted from China.

Qualitative research is a worthy pursuit in this literature base because there have been few previously published qualitative research studies (see review from Stock & Feragen, 2016). Those that have been conducted are often presented in brevity, due to the nature of the journal in which they are published. Thus, rich presentation of the findings is rare. Qualitative methodologies have been identified as useful in research with children with facial differences (Beaune, Forrest, & Keith, 2004). Moreover, theoretical frameworks for qualitative analysis are not typically comprehensive. For example, grounded theory is often cited as the theoretical framework, yet a theory will not be described in the results or discussion sections (see Alansari, Bedos, & Allison, 2014; Chapados, 2000; Havstam, Laakso, & Ringsburg, 2011). It is important that further research in the psychosocial research with children and adolescents with CL/P adopted from China is conducted thoughtfully, with research questions and a data analytic framework that are informed by theory.

In summary, the purpose of the present study was to conduct a phenomenological, qualitative study with school age children adopted from China to elicit their experiences about living with CL/P. Utilizing a strengths-based approach to develop interview questions, the study aimed to elicit resilience, strengths, and other positive qualities that the participants possess. Qualitative data were analyzed through use of Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009), which emphasizes the importance of participants' lived experiences through semi-structured interviews with child and parent participants.

Chapter 3

Method

This chapter will serve to identify and describe the theoretical frameworks that inform the research questions, aims, and data analysis including the biopsychosocial model and Interpretive Phenomenological Analysis (IPA). The present chapter will couch these frames within the broad area of pediatric psychology as it relates to the population of interest and associated research questions. This chapter will also review participants and recruitment, data collection, and data analysis. Please note that "CL/P" means cleft lip and/or palate, "CLP" means cleft lip and palate, and "CP" and "CL" designate cleft palate or lip only, respectively.

Interpretive Phenomenological Analysis (IPA)

Interpretive Phenomenological Analysis (IPA) is a methodological framework that guides researchers in the design, data collection, and data analysis of qualitative research studies. IPA rests on three theoretical foundations: phenomenology, hermeneutics, and idiography (Smith, Flowers, & Larkin, 2009). Phenomenology is essentially the study of experience. Smith and colleagues (2009) described the philosophical underpinnings of phenomenology. These include the emphasis on examination of experience as it is with a mindful attention to details and the essence of experience that may otherwise have been taken for granted. An additional emphasis within phenomenology initially proffered by the philosopher, Heidegger, is the notion of intersubjectivity or the 'self in context' (Heidegger, 1962, as cited in Smith, Flowers, & Larkin, 2009). This highlights the importance of others and the environment in the lived experiences of the individual. Merleau-Ponty (1962, as cited in Smith, Flowers, & Larkin, 2009) described embodiment and the role of the human experience housed within a physical form that interacts with the world. Suggesting that biology and physiology play an important mediating role in lived

experiences is an important early philosophical element of phenomenology that aligns well with a biopsychosocial model of understanding. Finally, Sartre's perspectives inform a moral and existentialist facet of phenomenology whereby lived experiences are wedded to the process of meaning-making and self-discovery (Smith, Flowers, & Larkin, 2009). These philosophical underpinnings of phenomenology provide a theoretical basis for the structure of IPA.

Hermeneutics is another theoretical foundation of IPA that has philosophical roots. Described as a theory of interpretation, hermeneutics is related to phenomenology in that it describes the interpretation of experience. Smith, Flowers, and Larkin (2009) review relevant philosophers with regards to hermeneutics. Schleiermacher explained two kinds of interpretation: psychological and grammatical. The psychological interpretation was viewed as the perceptions and internal experiences of the individual while the grammatical referred to linguistic and associated cultural and contextual factors (Schleiermacher, 1998, as cited in Smith, Flowers, & Larkin, 2009). Heidegger also contributes to the historical philosophical context with respect to hermeneutics. According to Heidegger, the "fore-ception" is always present in the interpreter. Thus, while the interpreter will always analyze the data and the experiences of others through their own lens, one must prioritize the new object and attempt to disregard preconceptions. A final important inclusion in a background understanding of hermeneutics is the hermeneutic circle. The hermeneutic circle describes the dynamic, multi-directional, and layered relationships between the part and whole (Smith, Flowers, & Larkin, 2009).

A third significant theoretical foundation for IPA is idiography, the sense of detail and particulars that is manifested in systematic and in-depth analysis (Smith, Flowers, & Larkin, 2009). In contrast to the nomothetic model oft used in psychology, an idiographic approach lends itself to carefully selected, small, homogenous samples (Smith, Flowers, & Larkin, 2009). Broad,

generalizable results are deferred in favor of rich, in-depth analysis. Idiography deals in the specifics of human experience and combines well with interpretive phenomenology.

In summary, IPA has its roots in phenomenology, hermeneutics, and idiography. The present study utilized these as foundations by allowing the data to speak for itself while recognizing the influence of the researchers. The lived experiences of children with CL/P adopted from China were the objects of discovery and the data will be characterized according to the data itself, informed by theoretical frameworks, yet allowed to stand on its own.

IPA Rationale

Interpretive Phenomenological Analysis is often used in health psychology literature to describe illness experience. Jonathon Smith (1996) wrote on the merits of IPA in the field of health psychology and the field has since seen an increase in the number of studies utilizing IPA. Brocki and Wearden (2006) evaluated the use of IPA in health psychology in their review of 52 articles. The authors noted the diversity of implementation of IPA as demonstrated by varying sample size, methodological criteria, researcher role, and level of claimed generalizability. Despite this variability, particularly related to the interpretive elements of IPA, Brocki and Wearden (2006) concluded that IPA is an ever-increasing qualitative method that has particular benefits for enriching health psychology research.

More recently, Jonathan Smith (2011) contributed another review of the use of IPA in the field of health psychology. In his review of 293 studies published between 1996 and 2008, Smith characterized the state of the literature with regard to implementation of IPA. Most studies were originated in the United Kingdom with only five emerging from the United States. Illness experience encapsulated approximately 25% of the corpus of studies with other predominant foci including psychological distress, carers' experiences, client therapy experiences, and health

professionals' experiences, among others (Smith, 2011). The author of the review goes on to evaluate the quality of the included studies and designated studies as "unacceptable", "acceptable", or "good". Criteria for "good" included adherence to the theoretical foundations, transparent reporting, coherent, and sufficient sampling (Smith, 2011). Smith determined that 9 (18%) studies were "unacceptable", 28 (55%) were "acceptable", and 14 (27%) were "good". The author also characterized the studies by condition type; notably, there were no studies that examined cleft or craniofacial conditions. In fact, a search in relevant medical and psychological databases with the terms, "interpretive phenomenological analysis" and "cleft" returned one study that used IPA to study the experiences of older adults living with CL/P (see Hamlet & Harcourt, 2015).

In summary, IPA is a burgeoning qualitative method in the health psychology literature. IPA is an inductive process that seeks to ensure validity, reliability, and integrity of the research. The literature shows that many of these studies are coming from the United Kingdom and have not yet been significantly used with CL/P or craniofacial populations. This suggests a need for rich qualitative analysis through use of such a framework.

Biopsychosocial Framework

A biopsychosocial framework was utilized to contextualize the present study's research questions and findings. Engel (1977) was one of the first proponents of the biopsychosocial model in the study of disease and illness. Engel identified the importance of social, psychological, and behavioral dimensions of disease and illness (Engel, 1977). A growing body of research has recognized the shortcomings of a biomedical model for understanding etiology and coping with medical acute or chronic conditions (Suls & Rothman, 2004). For example, stress and social support have been implicated as major players in symptom presentation and

management (Suls & Rothman, 2004). The biopsychosocial model is a critical framework to utilize in conducting research with those with CL/P as it necessitates an emphasis on and exploration of the whole person and their contexts (Zeytinoglu & Davey, 2012). Use of this model in the present study allowed for incorporating all relevant psychosocial factors such as level of acculturation/assimilation, adoption, and social functioning in addition to the overlay of a chronic medical condition.

Participants

Participants were eligible for participation in the study if they had a diagnosis of CL, CP, or CLP, were between the ages of 8 and 12, were internationally adopted from China, and spoke English. Exclusionary factors included unwillingness of children or parents to participate; lack of English proficiency for either child or parent; active suicide ideation, altered mental status, or other acute mental health concern; and cognitive or developmental delay that would reduce ability to freely give consent/assent or understand interview questions. The present study sought to recruit approximately 12 participant dyads (i.e. child and caregiver(s)). Smith, Flowers, and Larkin (2009) recommended three to ten participants for in-depth interviews, but also encouraged flexibility depending on the scope of the project and experience of the research team. Fourteen child-parent dyads were approached for participation in the present study. Of those, one participant was disqualified due to suicide ideation. Two declined in person. Two agreed to participate later by phone but were not able to be reached.

Nine child-participant dyads agreed and completed participation in the study. The child subsample included six girls and three boys. The mean age for child participants was 9.8 years (*SD*=1.19). All of the child participants had cleft lip and palate (CLP). Five families endorsed speech and/or hearing concerns. Presence of speech and/or hearing concerns was coded as

present for that child participant if either the child or parent raised the subject during the course

of the interview (*n*=5), or if the primary researcher had difficulty understanding the participant

when speaking, most typically due to articulation error (*n*=2). This was measured during the data

analysis when transcripts included multiple quotes from child participants that were indistinct or

unclear to the primary researcher. Parents were consistently the participants who discussed

speech/hearing concerns, while children did not explicitly mention speech/hearing unless

prompted to by a parent. It is possible that this is an underestimation of the true rate of

speech/hearing concerns in the sample due to the high frequency of such problems for the

pediatric CLP population; although specific prevalence rates for speech and/or hearing deficits

are difficult to find for school age children, studies have documented high rates of speech

concerns particularly for those with unilateral cleft lip and palate (see Lohmander & Persson,

2008). Underestimation of speech/hearing deficits in this sample is likely due to lack of

interview questions specifically eliciting speech-hearing information; it may also reflect reduced

salience for those families that did not discuss speech/hearing deficits, particularly if such

concerns have improved since earlier childhood years. Finally, about half of the sample endorsed

social and/or emotional concerns (*n*=4), again measured by child and parent report during the

course of interviews. See Table 1 for complete demographics.

Recruitment and Setting

Participants were recruited from a multidisciplinary craniofacial and CL/P clinic, a

treatment setting where patients and their families receive medical care from multiple specialty

providers. Patients and caregivers were approached by the researcher and given an informational

flyer at the beginning of their medical appointment. The flyer included an abbreviated version of

the informed consent form and emphasized that participation or lack of participation in the

research study would not influence their healthcare at the clinic in any way. Families were allowed five minutes to read the flyer and discuss potential participation privately. Following adequate time to read over the flyer, participants were again approached by the researcher in the waiting room and asked if they were willing to participate in the study. Willing participants were given the opportunity to complete interviews immediately if time allowed (i.e. they had arrived early for their appointment). If this was not possible, interviews were arranged to occur in between visits with specialty providers or following completion of the healthcare appointment. The Cleft Lip and Palate Clinic Psychologist was available to provided clinical care to any child or parent who may have experienced emotional distress during the interview. However, this did not occur for any of the patients or caregivers.

Data Collection

Qualitative data was collected from children and their parents through semi-structured interviews. Children and parents were allowed to choose whether they preferred interviews to be completed privately or together, i.e. with both child and parent(s) present in the room. Regardless of who was present in the room, for each participant dyad, both a child and parent interview were conducted. The interview protocol (see appendix B) was written with an emphasis on informal language so that school age children could easily understand the questions. Interviews were audio-recorded and then transcribed verbatim. Following transcription, interviews were de-identified prior to data analysis by the primary researcher and addition coders.

Data Analysis

Interview transcripts were analyzed with interpretive phenomenological analysis (IPA; Smith & Flowers, 1997). The primary researcher and two additional doctoral level researchers assisted in qualitative coding and theming. Participation of multiple coders allows for bias-

checking, collaboration, and consensus processes. The first step of the data analysis was reading and re-reading the transcripts to gain familiarity. Coders then initially coded the transcripts, which consisted of simple line by line descriptor labels of the data. These could include simple, process, or content remarks such as "describing emotional upset" or "challenge of surgery". Initial codes were descriptive, linguistic, or conceptual (Smith, Flowers, & Larkin, 2009). Descriptive codes were content-focused, linguistic often manifested as in-vivo codes that utilize the language used by the participant, and conceptual codes utilized a beginning level of interpretation was likely influenced by the psychological lens of the coder (Smith, Flowers, & Larkin, 2009).

The next level of analysis was the process of developing emergent themes. Charts with transcript excerpts and initial coders were created by the primary researcher to faciliate development of emergent themes consistent with the raw data. In the process of developing emergent themes, the volume of themes was reduced relative to the volume of initial codes. Emergent theme development sought to include the interpretation of the researchers while also maintaining accurate representation of participant quotes. In contrast to the looseness and openness of open codes, emergent themes were developed to succinctly reflect an understanding (Smith, Flowers, & Larkin, 2009). For both initial coding and emergent theme development, de-identified transcripts were distributed evenly amongst the three coders. Child and parent dyads were separated so that one coder did not code both the child and parent of any one dyad at a particular level of analysis. Following independent development of emergent themes, the primary researcher edited and consolidated the list of themes for both children and parent subsamples separately. Emergent themes were retained if they arose in at least one third of

interviews. This list of emergent themes was then reviewed by other coders to ensure accurate characterization of researcher interpretations.

Following the development of emergent themes, researchers collaboratively developed superordinate themes. Several strategies were used to identify patterns amongst emergent themes. Abstraction involved the clustering of emergent themes and labeling the group with a new superordinate theme. For example, emergent themes of depression, anxiety, and loss could be captured with a superordinate theme of "emotional outcomes". A second strategy of developing superordinate themes was subsumption, when an emergent theme became a superordinate theme and brought together other related emergent themes. Polarization, another strategy, focused on different, opposing themes. For example, the superordinate theme of "appearance perceptions" could include negative and positive perceptions of appearance. Additional tools in the development of superordinate themes included contextualization (the frame of the themes), numeration (frequencies of themes within and across transcripts), and function (examining functional role of themes for the participant) (Smith, Flowers, & Larkin, 2009). Collaboratively developing superordinate themes encouraged discussion of researcher bias and interpretation and how best to maintain accurate representation of original, raw data.

Human Subjects Protection

A completed application, study protocol, and consent and assent forms was approved by Institutional Review Board (IRB) of a large, Midwestern university. Non-coercion of child participation was emphasized throughout the study. Measures to ensure non-coercion included allowing families private time to review study information before committing to participation, a private child assent process, explicit statement of the voluntary nature of participation, and explicit statement that research participation or non-participation would not impact medical care

in the clinic. Risks and benefits of the study were reviewed verbally and in writing. A clinical

psychologist was available for adverse events. The primary researcher did not access electronic

medical records during the course of the study.

Participants were additionally advised of how their data was protected. Audio recordings

were transferred to and stored on an encrypted flash drive. Audio recordings were destroyed

following interview transcription. Transcripts were immediately de-identified and stored on a

password-protected computer. A coded participant tracking document was aggregated into

participant demographic data following completion of data collection.

Chapter 4

Results

The following results reflect the emergent and superordinate themes developed to understand factors that support positive self-concept in children with CL/P adopted from China. Initial coding and development of emergent themes was conducted separately for child and parent interviews given the different interview questions and potentially different content. However, because the reason for collecting parent data was to gain additional perspective on the lived experiences of children with CL/P adopted from China, superordinate themes were developed to act as an overarching thematic structure that included both child and parent emergent themes. Thus, the following results will be organized by superordinate themes, the broadest level of analysis in IPA, with emergent themes for children and parents presented within the context of the relevant superordinate theme. For select superordinate themes, the language was modified to best represent the data from child and parent subsamples. Illustrative participant quotes are presented in support of each theme. The superordinate themes reflecting data from the child subsample include the following: (1) Sense of self, (2) Family is primary source of support, (3) Adoption as part of identity, (4) Cultural identity development, (5) Coping with cleft, and (6) Social factors. The superordinate themes reflecting data from the parent subsample include the following: (1) Child's strengths, (2) Family strengths, (3) Adoption process and meaning making, (4) Cultural identity development, (5) Coping with cleft, and (6) Social factors.

Superordinate Theme 1

Sense of Self (Child). Emergent themes included within this superordinate theme include: *Pride in extra-curriculars/interests, Self-efficacy in extra-curriculars, Positive attributes*

and preferences, and *Appearance perceptions.* When asked to describe themselves, participants often replied with their activity involvement, typically endorsing *pride and self-efficacy in extra-curricular activities and interests.* For example, one participant reported they are really good at "singing and doing gymnastics". One participant reported they "like to play basketball and soccer. [They] like dance and [they] like art and hanging with [their] friends". Another participant reported their age and activity involvement: "I am 8 years old. I like dancing and do sports." A different child participant also endorsed enjoyment and self-efficacy in dancing. Another participant reported that they "felt proud of [acting activity]". For a final illustrative quote, one participant reported that they "made [their] first basket during a [basketball] game".

When asked about individual strengths, child participants overwhelmingly described *positive attributes*. For example, one participant noted that they "are nice and fun to be with". Another participant reported they are "very good with acting, cats, dogs and horses - with someone supervising, obviously". Other reported attributes included "creative", "nice", "caring", "weird", "good sense of humor", and "funny. Similarly, participants described who they were in terms of preferences. One participant stated, "I like to play Fortnite and I like to swim and play basketball and I was adopted from China." Notably, this was the only participant that described their sense of self as it related to being adopted from China. Another participant reported that they "like Star Wars and LEGOs…technology and engineering, and robotics." Another participant reported liking art and "drawing random things".

When asked to share facets they liked and disliked about their appearance, child participants typically reported neutral or positive overall *appearance perceptions*. One participant shared a quote illustrative of positive appearance perceptions: "I like it. I like my new glasses. I like my thick hair. I like my dimples." The same participant responded, "not really",

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when asked if there was anything they did not like about their appearance. Another participant reported that they "like that [their] hair is long". However, some participants had difficulty answering the question about what they liked or disliked about their appearance. For example, one participant stated "I don't have anything for that" when asked what they liked about the way they looked. Another reported they "don't know… don't think about it". Others simply responded, "no", when asked if there was anything they didn't like about the way they looked.

Three participants described negative appearance perceptions regarding orofacial features. The first noted that his smile is weird. When asked how he felt about his smile being "weird", the participant replied, "disgusting". A second participant who endorsed negative appearance perceptions stated, "I don't like how I have a flat nose. You know what I'm saying? It's different but also unique". A third participant reported, "I have like a little scratch by my lip". That same participant responded, "it's okay", when asked if there was anything they did like about their appearance.

Child's strengths (Parent). Emergent themes included within this superordinate theme include: *Child has many positive qualities, Involved in hobbies and activities,* and *Child is resilient and adaptive.* Just as children described themselves in terms of positive attributes, parents, too, emphasized the *positive qualities* of their children. Children were described as "lovable", "caring", "an angel", "outgoing", sweet", "helpful", "awesome big sister", "creative", "compassionate", and "polite". One mother described her child as "very kind and like rainbows and butterflies every day. She rarely gets upset or down. She just kind of muddles through." Another parent participant described her child as "very caring and kind, very sensitive and well she's got a heart of gold." With these positive qualities was also parent awareness of child sensitivity. For example, one parent described her child in the following way: "She is, she's very

loyal. She is very sensitive, kind-hearted. And on the other opposite end of the spectrum, she is very stubborn and very fiery…. And is hurt very easily."

Children were often described to be *involved in hobbies and activities.* It was rare for parents to not indicate involvement in at least one extra-curricular and/or hobby. It was also typical for parents to recognize their child's performance or skills in those activities. One mother mentioned that her child is good at video games. Another mother pointed out that her child was very good at dance, swim, and baseball. Another parent participant reported that the whole family partakes in "camping, climbing, hiking, biking, and paddle sports". Another participant described their child's strengths with origami and LEGO's: "He's a quick learner, like very quick like the origami… And the one thing I was very impressed is when he was - before he even started school- he asked me to come down and watch and do LEGO's". Another participant recognized their child's efforts in a school-based group that works to stand up to bullying.

A final area of strength noted by the parent subsample was the *resilience and adaptiveness* of their children. For example, one parent participant described adaptation her child had to make for speech challenges: "Well because communication is difficult at first, so we adopted her at age 2 and she couldn't ask what she want, what she can do, and so, she have to [*sic*] figure things out on her own." Another participant described resilience in the form of implementing feeding strategies:

> What was amazing was how she figured out how to eat over there because we were worried about, you know, what kind of bottles to bring or 'how are we going to get her to eat?'. And that was not an issue - she had figured everything out.

As a final example illustrative of resilience, one participant described how her child had transitioned following the adoption:

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The trip went good [*sic*]- it was uneventful, no nothing. And he was good. I mean, I can

see now when I look back at pictures, he was, I just thought he was super quiet and kind

of serious… but now I can look at the pictures and think, "well he was like shell

shocked". He had no idea what was going on. Just taking it in. But no, he, he was just

good [*sic*]. He transitioned really well.

Superordinate Theme 2

    Family is primary source of support (Child). Emergent themes included within this

superordinate theme include: *Safety and validation, Individual and Family values, Spending time*

together, and *Parents instill and reinforce pride.* By and large, child participants described their

parents and/or family to be their primary source of support. This superordinate theme emerged

when children participants were asked about family, adoption, coping, and cleft domains. *Safety*

and validation was an emergent theme that captured the sense of consistent presence, comfort,

and support provided by parents. For instance, one participant simply stated that parents help by

"making me less scared". That same participant described how their mother helped them

navigate peer teasing: "she just tells me to ignore it, because she is just trying to be mean to me

and trying to make me feel bad." Similarly, another participant described family support in the

context of having a trouble with a friend. When asked how family helped them through the

situation, the participant replied, "by making me feel better and that I wouldn't have to feel bad

about what I didn't do." This emergent theme was evident, too, when children discussed advice

they would give to other children who were adopted. For example, one participant stated, "that

no matter what, their families [*sic*] is going to take care of you. That's why they adopted you,

because they wanted another kid, or they wanted a kid". When asked about who or what helped

with coping during and after surgery, all participants simply reported that their family had helped them. It was much less frequent for children to endorse peer support for coping around surgeries.

Children demonstrated the ways in which they acquired and internalized *family values*. One participant stated that they "like that on the inside I am sympathetic to animals and people", suggesting that kindness, sympathy, and/or empathy are valued in their family. That same participant described the importance of God and faith to them as an individual and to their family:

> And I feel really happy when I'm listening to ceremonies - is that what those are
>
> called? Testimonies, like Christian testimonies. Like, I know that I can do
>
> anything, but when I can see what he can actually do, it's like wow!

One participant noted that they would tell another child who is adopted to "just be yourself and …be who you are". Another participant reported liking their brother because "he is smart" suggesting a value of intelligence in the family. That same participant described their family to be "honest" and helpful".

Spending time together was emphasized across the child participant subsample. When asked to describe family strengths or things they liked about their family, child participants described appreciation for spending time together, inclusive of doing specific activities and just generally supporting each other. One participant reported enjoying picnics and going out on boats with family. Another participant reported enjoying traveling with family. Another participant reported that their family is "really good at taking care of [them]". A final illustrative example was when one participant described their family to be "really good at supporting and loving each other, and being there for someone…also, to just be like a family".

The final emergent theme demonstrative of family as a primary source of support was the ways in which *parents instilled and reinforced pride* in their children. This was evident in vivo for child-parent dyads where the parent was in the room during the child interview. For example, one child participant was having a difficult time identifying something of which they were personally proud. The mother in the room then offered, "What about when you earned your black dress?" At that, the child participant replied, "I was happy and excited". Another child reported feeling proud when their mother gives them compliments. That same participant was encouraged by mother to share how they completed a recent science packet. Another participant was also prompted by their mother to share their accomplishments in basketball. These interactions were demonstrative of the ways in which parents were able to verbally reinforce pride in their children.

Family strengths (Parent). Emergent themes included within this superordinate theme include: *Family emphasizing togetherness and support, Family values, often including faith, Talking though situations helps child cope,* and *Use of humor.* Parent participants were asked about family strengths and what they've observed about how their child copes with tough situations. It was evident across the entire subsample, that *families emphasized togetherness and support.* One example of family being supportive to support coping was when one mother talked about being there for the surgery: "Well, I guess just reassuring him that we're going to be there when he gets out. That's all you can do." All of the families emphasized spending time together and being supportive as a family strength. One mother said, "I think we're very close. Very supportive… spending time together. Um, being there for each other. Yeah, that's pretty much, I mean, we're, we're blessed [*sic*]." Another parent stated, " I would say that we… we like to have

fun, you know, we like to laugh, just enjoying hanging out together, doing things together." The same parent elaborated further on their take on family togetherness:

We enjoy being together. We kind of have, we definitely have a blended family with my wife being originally from Japan and my daughter being from China and my oldest daughter being a combination of American and Japanese, so we have a unique mix of cultures going on in our household. But it's been… we enjoy spending time together.

When asked about family strengths, another parent participant became tearful, and stated, "I think we spend a lot of time together. We kind of focus on the family".

In addition to the togetherness described by parent participants, *family values, often including faith* were discussed. One participant described values of respect and helpfulness:

Being respectful of each other. Being helpful when you're trying to get everybody to kind of…everybody's got their responsibilities in the family, even if you are eight or six or five - you still have responsibilities to get our family to work right.

A different participant endorsed values of "church, definitely church, education." Similarly, another participant stated, "I think the number one thing that's important to our future. The number one thing that's most important to our family is that we put God first in our family." That same participant went on to state that "we value…each other and we value caring for other people. And we value adventure - doing things together."

In addition to family values, parent participants highlighted the importance of *talking through situations to help their children cope.* One mother described helping a child talk through an interpersonal situation:

And she and she got [*sic*] kind of emotionally attached to the situation where we had to talk her through and say, "actually this is a very unhealthy situation"…So we had to just

talk her through that and just explain it. I think over in general [*sic*], that's how we

handle some hard situations that maybe she can't see coming.

Another parent also reported helping their child talk through interpersonal situations, stating, "So

we had to have a lot of conversations about, um, the fact that other kids mature at different

rates." A final example came from a participant also describing assisting in interpersonal

situations:

I guess he's sensitive so if someone were to say something to him… sometimes he will

kind of almost shut down a little bit. and then we have to talk about - that you tell me

everything and you need to -when you're ready-I'm here to help you. We have to work

together to work to find a solution to the problem.

A final family strength identified by the majority of the parent subsample was the *use of humor.*

One participant reported they "like to have fun. [They] tease each other a lot. [They] laugh a lot."

One participant talked about using humor to cope with questions about adoption:

But no, we've always talked about her looking different, but everybody's different.

Everybody looks different. And we kind of joke about when people say, "are you

adopted?" And then we go, "no, she's from…", you know, so we make it…

Another participant simply stated, "we enjoy each other's company. We have fun".

Superordinate Theme 3

Adoption as part of identity (Child). Emergent themes included within this

superordinate theme include: *Adoption story details are meaningful, Pride in adoption, Open and

honest conversations about adoption,* and *Book, photos, binder commemorate adoption.* Child

participants were asked to share what they knew of the story of their adoption. For all of the

participants, this occurred prior to the age of two years old, meaning that the children themselves

could not remember the adoption. However, child participants often knew quite a bit about the *meaningful details* of their adoption story, such as who was there to pick them up in China, specific elements of the trip, and who was waiting to meet them when they returned home. For instance, one participant reported that the rest of their family was "waiting in the pool" when they arrived home and that they had eaten Oreo's. Another participant reported losing their stuffed platypus on the trip. Another participant stated, "I wouldn't let mom pick me up." That same participant described being at the zoo, saying, "I love that story. And we were by the gorillas". Another participant endorsed positive feelings toward their adoption story: "I think it's really cool, especially when I actually kind of have an excuse to go back there".

Similarly, child participants articulated pride in their adoption stories. By and large, children had positive perceptions of their adoption and were eager to share what they knew about their story. One participant stated that, "…and I also feel happy about the adoption that we had. That is God moment [*sic*] right there." Another participant appeared to have both positive perceptions of their adoption story while also curious about their biological parents: "I like it because then I wouldn't be here, but I also wish I could meet my parents. Like my real parents".

Child participants were able to describe how they and their families had *open and honest conversations about adoption*. This was evident in the comfort that participants demonstrated in discussing adoption with the interviewer as well as the content of their replies. Contrasted with questions about cleft and appearance perceptions, children typically had more to say regarding their adoption story. When asked when they first learned the story of their adoption, one participant said, "I don't know. Maybe like five or something?" The participant's mother elaborated:

We've always talked about it. We have a binder of some pictures of when he was in the orphanage…the binder with the white cat. [to child] Remember you have the pictures of you in the crib and then you with your other friends from the orphanage that were in the walkers - we have pictures of that. So, we've always been very open. We've never not talked about it.

The quote above illustrates an additional theme of *Book, photos, binder commemorate adoption.* Children, or parents during the child interview, often discussed the photo binder or book that was used to tell the story of their adoption. One mother reported, "I have at least four books full of pictures from China, from before and after…because she was so little to remember. We wrote it all down, so she could kind of relive it." One child participant stated, "and we have pictures - we have a big binder about my adoption."

Adoption process and meaning making (Parent). Emergent themes included within this superordinate theme include: *Inspired to adopt, Social support while adopting is helpful, Impact of developmental trauma, Regular conversations normalize adoption, Burden of decision-making, waiting, and preparation,* and *Adoption is an adjustment for all family members.* These emergent themes were profound and often evoked emotion of parent participants. Each parent or parent dyad described how they were *inspired to adopt.* For all families, this meant a thoughtful decision-making process and typically years of waiting. One mother reported, "I decided when I was 16 and saw a documentary on China and adoption." Another mother described their decision-making process:

I always wanted a big family. And before my husband got married, we always, you know, kept that open. That was never a shut door. And we just felt it was the time to…

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that we could open up the door, you know? And so…. Yeah. So, we prayed. We were

open to whatever God had in our plan.

Another participant also described the importance of faith in their family's decision to adopt,

stating, "I think we just felt like that was what God wanted us to do."

Social support while adopting was described as helpful for families. It was common for

families to learn about the adoption process or take classes with others, and then to make the trip

to China with other families also adopting. One participant described how the process

encouraged the development of relationships after the adoption:

Everything went smoothly, and we were there with a travel group of 10 people. We still

keep in touch with two of the other families, um, who the girls are the same age as

[child]. So, we've gotten together every year since that we've been back just about, not

completely. But we build relationships, you know?

Social support was also helpful for some participants who spoke with others about CL/P prior to

the adoption. One participant reported:

…talking about it and then we talked to [a doctor's] parents. And he had a really good

friend who is actually a doctor at [clinic]. A pediatrician. And his daughter is adopted

with cleft palate. So, he's like, "why don't you talk to [doctor] once and get his

perspective?"

The impact of developmental trauma was highlighted by parents to whom it was relevant.

Three parent participants endorsed experiences of developmental trauma sequalae including

attachment concerns, regression, disruptive behavior, or social/emotional concerns. One parent

participant described CL/P as secondary to the issues related to developmental trauma, stating,

"yeah we had a lot of developmental issues…Lots of neglect that we weren't prepared for prior to

the adoption." When asked if there was anything they wanted their medical to know about their family that they didn't already know, that same participant emphasized the impact of developmental trauma and further elaborated on the toll it can take on the family:

Just the impact of developmental trauma and how it affects a family. You know, I have a [*sic*]…it probably hasn't been formally diagnosed, but I probably have some secondary PTSD from, you know, dealing with the, um, the trauma, developmental trauma stuff.

Another participant described behaviors observed in her child following the adoption:

I would just say mostly in the beginning when [child] was home, probably the first maybe four or five years. And not that it was any trouble or anything, but we would see her resort back to her coping mechanisms from China or from early on. We just figured we knew how she dealt with things in her orphanage just by how she responded to some things at home.

Just as child participants highlighted the pattern of open and honest conversations about adoptions, parent participants also verbalized ways in which *regular conversations normalize adoption.* One participant stated, "…very open. It's not, we've always been open with her adoption and her cleft lip/palate right from the beginning." Another parent concisely reported that they as the parents "don't hold anything back" in terms of open and honest conversations. One parent described the dialogue around racial differences: "We do. We talk about the difference of the way that he looks and the way that I look. And that's because he's Chinese. Yeah and so sometimes we'll talk about his eyes, his almond shaped eyes, right?" Another parent participant dyad reported they have ongoing conversations about adoption, often in response to their child's questions. One parent reported always trying to talk about adoption as it comes up as their child ages: "So, now obviously as she grows older, you know there's questions of why she

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doesn't look like us and why doesn't…you know, just the whole adoption story. We've always tried to keep that in front of her."

Families consistently described the *burden of decision-making, waiting and preparation.* Seven of the nine families were on the healthy child adoption list before being switching to the special needs lists, which invariably resulted in expediting the waiting period. Across those who were initially on the healthy child list, the wait was years. For instance, one father reported:

Because so many people were wanting to adopt from China, that process was really extended. So, it could take anywhere from two to three to four years before you get matched with a child. We initially went that route. Then I started reading about children who had minor medical conditions like cleft lip and palate that were also on a waiting list. That waiting list was much shorter.

In terms of decision-making, the same father reported that his wife needed more time to make the decision: "The more we heard about it, the more we thought it sounded like something we wanted to do. I was eager to do it and [mother] had to put a little more thought into it." In describing the stress of the adoption process, another participant stated, "it's a difficult journey. There's highs and lows constantly, waiting and you know…it's the paperwork and the red tape and trying to navigate through that and still stay on course and you know, hope that this happens."

In addition to the burden of the time prior to and during the adoption, participants identified the time after as *adjustment* period for the child and rest of the family. One participant reported tension between their adopted child and biological children, stating that "they weren't, you know, the boys at first were kind of not for adoption". Another parent provided a similar example, noting that "It's a long process because the children, the sibling needs time to adjust

and that's not our time. We, as adults, we have to make adjustment. But the sibling …they need to take time."

Superordinate Theme 4

  Cultural identity development (Child). Emergent themes included within this superordinate theme include: *Understanding of the word 'culture', Incorporating Chinese culture in small ways,* and *Limited contact with others from China, adopted or with cleft.* Child participants were asked about their understanding of the word 'culture', what they knew about China, and what it means to them to be adopted or to look differently than their family in terms of race and facial differences. Participants were also asked if they knew others from China or who had been adopted. When asked about their *understanding of the word 'culture',* the majority of the subsample indicated a basic or lack of understanding of the construct. Two participants gave an answer that suggested advanced understanding for their age. One participant described their understanding of culture with the following:

  Um, I know that they have a different language, culture, silk - but we do have silk, but

  from China. And what else…(inaudible) and I also learned that my aunt has been there

  and that when you hear the language - it's so beautiful. It's so beautiful…. I think that that

  means like the way they do [*sic*]… you that the way they live, like culture, our culture. I'd

  say, come here. They have black peoples that (inaudible) and, and language too -that'd be

  part of culture. I know that they have letters, Chinese culture, and characters and sounds.

  And so, like letters. So, for CH that would be SH and it would just be one character.

Another participant described culture as "kind of the lifestyle, what your food is, what you do there for fun, or how the houses are". For those that had more of a challenging time articulating understanding of culture, they often had concrete knowledge of China. For instance, one

participant mentioned that "most things are made there". Several of the participants identified

awareness of the Great Wall of China.

When queried about how they and their families incorporated Chinese culture, child

participants described awareness of specific tangible items in their home to commemorate

adoption or Chinese heritage. They also described attending cultural events such as Chinese New

Year. The presence of these cultural artifacts and activities represented families *incorporating*

Chinese culture in small ways. Several of the participants reported having their name in Chinese

characters somewhere in their home. One mother reported that her adopted children "know how

to play and how to count 1 2 3 4 5 in Chinese". One participant stated they "have like a map,

kind of like a picture that is a map of a place", describing a Chinese map. Another participant

stated they had a friend who had also been adopted from China and described shared cultural

celebrations:

> Oh! So yeah, I went to my friend's house and I think we're doing this every year now. We
>
> celebrate Chinese New Year's with them and then she usually, well last year she asked
>
> me to sleep over there and have some fun.

Although some participants endorsed having friends who were also adopted or knowing children

or adults from China, participants generally did not know many others who shared similar

identity statuses such as being adopted, being Chinese, or having CL/P. Overall, child

participants had l*imited contact with others from China, adopted or with cleft.* For those

participants that did identify others from China or who had been adopted, they were able to name

such people and how they had to come to know them. For several families, other known Chinese

children were met through community-building or networking as a result of the adoption process.

Cultural identity development (Parent). Emergent themes included within this superordinate theme include: *Lack of perceived discrimination toward child, Contextualizing diversity of community, Incorporating Chinese culture in small ways,* and *Cultural exposure is child-led.* Parent participants all *denied discrimination toward their child.* This was often *contextualized in the diversity of the community*, with both ethnically homogenous and heterogenous communities identified as contributing factors. When asked about any bullying or discrimination, one parent participant simply stated, "not that I have seen. Not that she's ever told me about. It's a pretty open community." Another participant reported not having seen discrimination and then reporting, "we're not completely diverse in [small city], but there's enough diversity even in her school…" Another participant framed standing out in a small community as a positive, stating, "So, it was a wonderful way [*sic*] in this small little town where there's, everybody kind of looks the same and comes from similar families to have something, you know, somebody different." On the other hand, one participant identified the value of a diverse community: "As far as Chinese, we have enough kids…. I mean [town] isn't known for like total population diversity, but we have enough in the community of Asian and African American and Spanish that it's not…no one is really like, 'oh you're different'. And there's other adoptees from China in her school."

Just as child participants discussed *incorporation of Chinese culture in small ways*, so did parent participants. One participant said, "and we, you know, we try in different ways to do what we can to incorporate small touches. So she knows that we understand where she's from." Another stated, "so, one thing that we have tried to...I mean, it's not huge, but we try. So, we'll try to go to Chinese New Year." For another example, a participant reported, "well we have a couple books that we have read. And we made several meals. In fact, mom just made those

Chinese pork buns just this past Sunday?" An illustrative remark was offered by another parent: "So, you know, so some simple things. But it's not like we're totally immersed in it either." One parent highlighted the challenges in White parents providing cultural exposures outside of their own background, reporting, "yeah. I think it's hard because I feel badly that she doesn't have a lot of memory of her beginning in China. You know, for her, she's very Americanized."

Parent participants often described *cultural exposures to be child-led.* One participant stated that "we might wait until she is a little bit older and maybe has more of a need to learn the culture or want to learn the culture instead of just say 'here you go.'" Another parent described their attitude toward exposure to Chinese culture for their multiple adopted children:

> We don't necessarily feel the need to, you know, push it down their throats. Like if you don't have an interest in it, in your culture, that's okay. I mean, if you want to want to do a Homeland tour some year we can maybe do that, but at this point, that doesn't seem to be a desire.

Similarly, another parent offered the following:

> So, she hasn't been real interested in learning about China. But we have done things. We have a lot of books, we have CDs, but very little interest. And we've never pushed that 'cause [*sic*] I figured that would come when she's older.

Superordinate Theme 5

Coping with cleft (Child). Emergent themes included within this superordinate theme include: *Cleft associated with surgeries, Cleft is just part of life, Concrete understanding of cleft,* and *Optimistic about cleft outcomes.* To elicit child participants' attitudes toward CL/P and their strategies for coping with surgeries and managing a chronic condition, children were asked about their understanding of CL/P, good and bad parts about CL/P, surgery, and coping skills. When

asked about CL/P, it was typically *associated with surgeries*, implicating multiple surgeries throughout childhood as a salient part of managing the condition. Additionally, it was typical for the child subsample to have clear memories of bone graft surgery given the age of the children and the typical age for that particular surgery. When asked what one participant knew about CL/P, they simply replied, "That I've had a lot of surgeries on it." In another child interview, a mother described how many surgeries a child with CL/P might undergo:

> Yeah, you've had two on the palate and then he came home with… the lip was already repaired, but when he said Dr. [redacted] had taken out scar tissue, he had taken it out of the lip… so that was another surgery. Oh, that's right, the nose too. So, he's had, oh and that recent one with the bone graft. And you've had two with your nose. Turbinate reduction.

Another mother reported that her child has had "12 to 15 surgeries" including those related to CL/P and hearing (i.e. ear tubes).

Child participants noted the salience of surgeries in their life and they also showed a resilience in coping with CL/P. *Cleft is just part of life* is an emergent theme that captures this resilience, represented in the ways participants talked about positive coping with CL/P. It was also reflected in the absence of negative verbalizations about cleft. For one example, a participant was asked how having a cleft affected life now. The participant responded with a lengthy pause. The interviewer then suggested, "and maybe it doesn't [affect your life now]". To this, the participant responded, "yeah, it doesn't". Another participant replied, "no", when asked if there were any hard parts about CL/P. A different participant stated that they "don't really pay attention" to CL/P. During one interview, a mother augmented her child's absence of content regarding challenges related to CL/P: "Yeah. We [*sic*] it's just kind of what we do. It's not like it's

something that not a hyper focus on or anything like that. It's just part of life…part of what we do."

Also appropriate to the age of the subsample, children demonstrated a *concrete understanding of cleft.* One participant noted that CL/P is "just like the part of your mouth, I guess you could say, is not right". Another child simply said, "I had a hole." Similarly, another child stated, "I have a cut lip".

Child participants articulated an *Optimism about cleft outcomes.* This was evident when participants gave advice to other hypothetical children with CL/P, often stating that surgeries will make things better, be worth it, or fix any problem. For example, one participant reported they would tell another child, "It's okay; they're not going to hurt you. And that your mom or your dad is going to be there with you and that you might have no school." Another child explained that one of the good parts about CL/P was having surgeries because they result in the cleft being corrected. Another child participant found the positives of bone graft surgery, reporting: "I like it because I'm a lounge lizard and then I don't have to do anything. And then my brothers ask me 'can I watch the TV?' I'm like, ah, ha ha ha ha [*sic*]".

Coping with cleft (Parent). Emergent themes included within this superordinate theme include: *Transparent conversations normalize appearance differences, Matter of fact conversations,* and *Cleft is not a big deal, but is still chronic.* Similar to themes that emerged around open conversations surrounding adoption for both children and parents, parent participants also endorsed open dialogue with regard to CL/P. These conversations appeared to be a useful strategy for *normalizing appearance differences* related to CL/P. Similarly, these conversations were often described as *matter of fact*, giving simple education to children to

explain facial differences. One participant described their family's approach to discussing appearance:

> So, every once in a while, she'll come back and she'll be a little sad if someone said anything. But, we just try to keep it real general, or just, "you know what? We're all born differently". It's like I have a different nose than you and I have this tooth that is weird, you know? We just try to make it like…all of us are different and you were just born that way and God made you special in your way. And every one of us has something special about us. So, we just try to keep it even keel like that. So, it's just yeah [*sic*], we try to keep it so it's not a big issue.

Another participant reported responding to child's questions about why her lip was different with **"**ya [*sic*] know, your lips looks fine, sweetie. It's because of surgery and your face changes and grows and develops as you get older. So, don't worry about it." An example was provided by another participant: "But no, we've always talked about her looking different, but everybody's different. Everybody looks different." Another parent reported that their family is "very open. It's not, we've always been open with her adoption and her cleft lip/palate right from the beginning. So, it was never uncomfortable or odd or different. It's who she is. It's a normal thing for us."

Parent participants described the nuance and dichotomy of CL/P being both a burdensome, chronic condition yet also manageable. This was summarized in the emergent theme of *Cleft is not a big deal but is still chronic.* One parent participant simply stated, "we try to keep it simple," when describing their approach to managing cleft. Another participant captured the dichotomy:

> So, it's not like a… it's not like heart damage and… it's not like an ongoing chronic condition, but it is…. And so, I have gone back to the agency and said, "I think that by

stating it this way, you're doing families a disservice". 'Cause [*sic*] this is, this has been

very much ongoing.

That same participant emphasized how worth it both adoption and CL/P are for the joy of raising

their child:

…but really the adoption piece along with the medical piece, it's like I said before, it's

been hard, but not undoable. And the joy that she's brought to the family has… it's been

like double, you know, to, you know, totally worth [*sic*]. And she's not defined by the

medical condition, but she's defined by who really God created her to be.

Another parent articulated coping with CL/P by comparing CL/P to other potentially more

burdensome circumstances: "No, no. This is nothing compared to what some other people need

to do. This is nothing." Another parent participant reported that "cleft is such a…It feels like

such a minor thing when you look at all… I mean she could be sitting an orphanage because of

one operation that would, you know, that would heal her…"

Superordinate Theme 6

Social factors (Child). Emergent themes included within this superordinate theme

include: *Only discusses adoption with trusted persons, Perceptions of bullying/teasing, Peer*

questions interpreted benignly, and *Speech and/or hearing is hard part about cleft.* When asked

about sharing adoption story with peers or answering questions about race or background, child

participants typically reported they *only discussed adoption with trusted persons*. One participant

reported she would only share information with best friends: "Well my best friends, I would tell

them I was adopted and then if… yeah." An exchange between the interviewer, a child, and their

mother illustrated the importance of trust when disclosing adoption status or details:

Interviewer: Do you feel comfortable talking to friends about [adoption]?

Participant: It depends on who they are.

Mother: Because why?

Participant: Because I'm very guarded about that.

Participant: If my teacher (inaudible) - I'd be really mad at this lady for telling (pointing to mother).

Interviewer: For telling teacher?

Participant: If I don't trust her, but I do, so don't worry.

Another participant reported that they "don't really" talk with friends about being adopted. When asked if they would feel comfortable answering questions about adoptions from friends, the participant replied, "kind of".

Two emergent themes pertained to social experiences of teasing/bullying. When asked about their *perceptions of bullying/teasing*, child participants most often reported some experiences of teasing or bullying (n=6). A minority of the subsample denied experiences of teasing or bullying (n=3). Notably, for those that did endorse teasing/bullying, the interactions were described to be relatively minor by both children and parents. In other words, there were no reports from children regarding pervasive, harmful bullying. One participant reported being bullied due to her size:

Well, I've been bullied because on the bus, there's this girl named [redacted], she has this really good friend named [redacted], and she always brings [indistinct] on the bus and she never lets me touch it [*sic*] and I go to the front of the line because my brother is there. Then she's like, "she thinks she is so small, she can just fit in".

Another participant noted that "there were these two boys that for lunch when they passed the table they pretended to spray the table." Another participant described their "brother picking on

[them]" as a stressor in their life when asked if there had been anything hard in their life to deal with. "They would chase me around" was offered by a participant in description of peer interactions at school. These quotes show suggest the possibility that children with CL/P experience teasing/bullying and/or may also be sensitive to those experiences.

Although the majority of the subsample reported experiences of teasing/bullying, child participants and their parents also were able to *benignly interpret questions from peers*. Similarly, participants demonstrated resilience and adaptive coping with questions about adoption and race. For example, one participant reported responding with a sense of humor when peers ask how to say "hi" in Chinese: "Mostly, when I tell them, they ask me, 'how do you say "hi" in Chinese?' And I'm like, 'konnichi wa' [laughs]." The same participant reported that peer questions are not rude or mean. The mother of that same participant reported that her brothers had desensitized her to teasing: "I always say she isn't going to be upset if someone says something rude because her brothers have always been like that to her so she's gonna [*sic*] be like, whatever". Another child participant reported that they had been asked by peers why they had a scratch on their lip or asked about their adoption story. The participant stated, "I just kind of left. I didn't really feel comfortable talking about it then". The participant then stated they felt more comfortable talking about adoption now with peers.

Speech and hearing were highlighted as CL/P sequalae that were more socially challenging and distressing to children and their families. One mother pointed out that her child felt singled out for being removed from class to receive speech therapy services. Another parent reported that the hearing impairment was an unexpected outcome following adoption: "But I will say that the hearing piece we did not know about in her, you know, you get, you get mashed and

you get all the information… the hearing piece we found out later." When asked about the hard parts of CL/P, one participant responded, "like speaking with R's".

      Social factors (Parent). Emergent themes included within this superordinate theme include: *Social skills challenges, Sensitivity can contribute to interpersonal challenges,* and *Speech and hearing deficits increase risk.* Although parent participants generally denied significant social stressors for their children, about half of the sample had some social and emotional problems that were identified. Typically, this included emotional dysregulation, social skills deficits, or social immaturity. Of the four with social and emotional concerns, two also had speech or hearing impairment. One parent described social skills challenges, noting that her child "is struggling with her friends, just trying to find her place." That same parent reported "at the end of the day, she's just a very honest and sweet girl. And is hurt very easily…" Another parent reported that her child doesn't understand sarcasm.

      Participants often noted sensitivity in their children, which was often described to be both a strength and something that could *contribute to interpersonal challenges*. One participant described her child in the following way:

      [Child] cares deeply about people. So, I think sometimes she can get sucked into a situation and not… though she's very perceptive - sometimes she has a hard time disassociating with happening from getting from getting emotionally involved [*sic*].

Another participant described her child's sensitivity:

      I guess he's sensitive so if someone were to say something to him… sometimes he will kind of almost shut down a little bit. And then we have to talk about - that "you tell me everything and you need to -when you're ready-I'm here to help you."

Finally*, speech and hearing were noted to increase risk of social challenges*. This was evident in the overlap in the sample of families who endorsed both speech/hearing impairment as well as social/emotional challenges. It was also evident as parent participants characterized teasing, bullying, or self-consciousness related to speech and hearing impairments as more difficult for children to cope with relative to any bullying/teasing related to CL/P or race. One parent described both speech and social skills challenges as a source of bullying:

> … some of that might be brought upon by behaviors too. You know, when you react silly, then kids are more likely to kind of use you as a target. So, um, [*sic*] but speech as well. I don't, I haven't heard anything, but I still wonder if you know, if there's some of that.

Another participant indicated that she is "probably am more concerned about how people think about how she talks then about how she looks or her color."

Chapter 5

Discussion

The present study aimed to understand factors that support positive self-concept in school age children with CL/P adopted from China. Qualitative, semi-structured interviews with both children and their parents allowed for the collection of rich data on topics of child and family strengths, coping and resilience, adoption, cultural identity, appearance perceptions related to cleft and race, and medical experiences. This chapter interprets the results through a biopsychosocial lens and integrates those with conclusions about self-concept, with mindful attention to cultural considerations. This chapter additionally situates the results and their interpretations in the context of current psychosocial literature on this unique population, discusses implications for providers and researchers, and addresses strengths and limitations of the present study.

Positive Self-concept

Self-concept as a construct has historically been associated with methodological limitations in research due to the lack of consistency on its operational definition (Skaalvik & Bong, 2003). In that sense, self-concept can be a subjective and vague construct. Although such limitations have restricted ability to draw consistent conclusions about self-concept for children with CL/P, exploration of self-concept in the present qualitative study allowed for inclusion and openness to a variety of factors that were salient for children and their parents.

The present sample overwhelmingly described positive self-concept for child participants. Children typically described themselves in terms of positive attributes, such as naming good qualities when asked how a friend would describe them. All of the children were actively involved in activities through school or community that harnessed athletic or creative

skill sets. These activities, too, allowed children opportunities to build peer relationships and social skills. Children endorsed self-efficacy in these activities, evident even in examples where children reported anticipatory anxiety with performances or being in a state of learning something new. Emergent themes developed around **sense of self** for the child subsample also reflected identity developmental theories for self-concept. School age children are known to describe themselves in terms of preferences, interests, and attributes, often positioning themselves in comparison to peers (Harter, 2003, 2006). Advancing cognitive development and integration of peer feedback via perspective-taking can account for the shift in content of self-concept from early childhood to middle childhood (Berk, 2010).

Parents also described their children in terms of strengths. When asked to specifically identify challenges that their children had faced and how they had coped individually and as a family, parents consistently framed challenges in a positive perspective. For example, problems were either described as minor, resolved, or manageable. Children were described as resilient and adaptive in response to adoption transition, developmental challenges (e.g. feeding), and surgeries. This theme, **child's strengths**, not only illustrated how parents see their children but also suggests a mechanism through which parents support positive self-concept in their children.

Although the present sample described positive self-concept that spanned several domains including belongingness and role in their family, appearance perceptions, activity involvement, and peer involvement, it was also common for children and parents to endorse challenges. These challenges were typically described as subclinical social and emotional difficulties, such as having social immaturity, social skills problems, or emotional reactivity. However, two of the nine child participants were currently receiving behavioral health services for clinically significant social and emotional challenges. Despite these challenges, the

superordinate theme of positive **sense of self** was evident across the sample. This underscores the value in using a strengths-based approach to research and present findings on self-concept in this population. For example, a narrow definition of self-concept in the present study could have limited respondents' ability to recognize specific and global individual and family strengths. Further, the finding that the child participants in this study demonstrated positive self-concept despite challenges highlights the children's strengths and resiliencies. These individual strengths, considered with family strengths and support, may support coping with social and emotional difficulties.

Factors Contributing to Positive Self-concept

The biopsychosocial framework is important for contextualizing results. Initially offered by Engel (1977) in opposition to the biomedical model of disease, the framework guides researchers and providers in conceptualizing illness with consideration of psychological and social factors in addition to the previous emphasis on medical factors. Brofenbrenner's ecological theory (1979, 1986) is a relevant theory to integrate into a conceptualization using the biopsychosocial framework. In particular, the interpersonal dynamics between children and other individuals, groups, communities, and systems offer a valuable means for discussing the cultural considerations of self-concept of the present sample. An integration and application of these theories for health populations has been suggested in previous research (Lehman, David, & Gruber, 2017). Thus, the following discussion of factors contributing to positive self-concept will be organized in alignment within a dynamic biopsychosocial model (Lehman, David, & Gruber, 2017).

Biological. All of the child participants were diagnosed with cleft lip and palate (CLP), with none having only cleft lip (CL) or cleft palate (CP). The superordinate theme of **coping**

with cleft for child and parent subsamples characterizes the helpful strategies employed by children and their parents to cope with CLP. Child participants communicated that they were accustomed to CLP as just part of their lived experience, having never known anything else. When asked to describe CLP, child participants typically had difficulty finding the words to accurately explain it. For those that articulated a reply, they used simple language such as describing CLP as a "hole", "scratch", "scar" or "not right". This was indicative of a concrete understanding of CLP, likely reflective of both cognitive development and potential self-consciousness or other negative emotions restricting willingness to discuss the topic. It was noted by the researcher that child participants were often much more talkative when discussing their adoption story compared to discussing CLP. Surgeries were emphasized as something associated with CLP with child participants often not personally remembering early childhood surgeries but remembering bone graft surgery which typically had occurred within the last one to two years. In coping with surgeries, the resounding theme was that family supported them prior to and following surgery. It seemed that child participants had internalized messages of safety, lack of pain, and positive outcomes associated with surgery. When asked about advice for others, child participants communicated an understanding that anesthesia prevented pain, that parents were with them, and that surgery would repair CLP in some way. This speaks to the importance of appropriate education and reassurance provided by parents and medical providers about surgical procedures.

Overall, child participants did not emphasize CLP as part of their self-concept. In response to broad questions about who they were, none of the participants volunteered CLP as a salient part of their identity. When asked specific questions about CLP, participants communicated a sense that **cleft is just part of life**. This theme was also evident in data gathered

from parent participants who described ongoing conversations about CLP and associated medical care while also deemphasizing the importance of CLP.

Though CLP itself was not a salient factor contributing to self-concept, for those with speech and/or hearing difficulties, CLP seemed to play a more active role. Speech and hearing impairments were associated with a greater sense of feeling different than peers. This was reinforced by services often provided at school; for example, being removed from class for speech therapy was a reminder to participants that they were different. Similarly, it was more common for child participants to experience interpersonal difficulties as a result of such impairments. For several of the participants, speech impairments were significant enough to reduce the researcher's ability to understand the participant. Thus, it was inferred that speech problems directly impaired communication with others. Moreover, speech was noted to be a likelier target for teasing and bullying than race or facial differences.

Psychological. Psychological factors contributing to positive self-concept that were identified by the sample included pride and self-efficacy in activities, identification with positive attributes, identification with individual and family values, and appearance perceptions. It was clear that child participants defined who they were by their activities and interests. Children were enthusiastic about their enjoyment of dance, gymnastics, games, and a variety of other activities. Children also endorsed self-efficacy in these activities. It was evident that self-efficacy and interest had a positive relationship such that positive self-efficacy in an activity was associated with interest while negative self-efficacy was associated with limited interest. This is consistent with Bandura's theory of self-efficacy (1977). For most participants, the positive areas were highlighted. However, there were some examples of dislikes that were provided by child

participants. For example, challenges in reading or math were associated with also disliking those subjects.

Children identified with positive attributes, often suggestive of the values they had internalized thus far in their lives. For example, children identified being kind, helpful, or creative. Behavioral and developmental explanations are helpful in framing these results. Behaviorally, it is likely that behaviors consistent with these values (e.g. helping a sibling) were modeled by parents and older siblings (Bandura, 1977). Values were likely also modeled via open and honest conversations, which was a theme for both subsamples. Further, value-consistent behaviors were also likely reinforced through labeled praise while value-inconsistent behaviors were likely not reinforced to the same degree. In terms of moral development, Kohlberg's theory (1971) would support the notion that during early school age years, values are driven by rewards and punishments as opposed to associated with a comprehensive set of internalized moral principles.

Social. Family was the most salient social factor contributing to positive self-concept. This is consistent with developmental literature implicating the priority of family over peer influence during school age years (see Berk, 2010). Children communicated a sense of satisfaction with their place in the family, such as being adopted or their birth order respective to siblings. Child participants described feeling supported by parents in the context of peer, school, or medical difficulties. This included an understanding that parents would not abandon them. Status as an adopted child also appeared to support children's sense of belonging in the family; children reported they felt truly wanted because of the lengths parents had to go through to adopt.

Parent participants provided important reflections on how they support their child's self-concept. Parent participants unfailingly described a cohesive, supportive family system that emphasized belonging and togetherness. All of the families were intact, which could be one structural element supporting togetherness. Further, although data regarding socioeconomic status was not collected, it is reasonable to assume that families in the present sample were in the middle to upper class as they had enough money to afford the cost of international adoption with current estimates to be between $15,000 and $25,000 (International Adoption Help, 2017).

Faith and/or religion was identified by many of the parent participants as an important family value and source of support. Because international adoption agencies are often faith-based, it is possible that, for this population, religious affiliation is more common than in the general population. Religious affiliation has been identified as a coping tool for stress in previous research (Ano & Vasconcelles, 2004), though there is a paucity of research that examines religious coping for child or CL/P populations. Social support, belonging, and community associated with religious practices has been implicated as a factor in the protective nature of religious affiliation, particularly in cultures which value faith (Gebauer, Sedikides, & Neberich, 2012).

In addition to family, peer relationships were identified as social factors contributing to self-concept. Both positive and negative peer interactions were described by the present sample. On the one hand, it can be inferred that child participants benefitted from peer interactions in the course of activity involvement and school. On the other hand, over half of the present sample endorsed a degree of interpersonal difficulty. Since one of the guiding research questions of the present study is to understand the factors that support positive self-concept (in opposition to negative self-concept), coping successfully with peer difficulties appears to be a prudent avenue

in understanding development of positive self-concept. Interpreting peer questions as curiosity, without malicious intent, was identified as an effective coping strategy. Parents appeared to provide significant support in talking through interpersonal situations and reframing negative peer experiences. This has been implicated in previous literature (see Chapados, 2000) as helpful for coping with bullying and teasing. Interestingly, it is unknown whether children who experience racial microaggressions during school age years accumulate such occurrences and suffer a reduction in self-concept or cultural identity later in life. Such an outcome would be consistent with research that describes the deleterious impact of racism-related stress for Asian-Americans (see Hwang & Goto, 2008. Liang & Fassinger, 2008). Thus, while interpreting questions about CLP, adoption, or race benignly may be a beneficial coping skill that protects self-concept, it is possible that such a coping skill does not capture the nuance that may exist for racial minority children.

Cultural Identity as Part of Self-concept

Child participants did not emphasize their race or Chinese heritage as part of their self-concept. It was more common for children to emphasize adoption and role in their family as part of their identity. Because child participants did not have firsthand memory of China, with the exception of two participants who traveled to China to pick up younger siblings, this may implicate the inherent difficulty of connecting to a culture to which the children and parents both have limited firsthand knowledge. It may also generally reflect child participants' stage of racial identity development.

Helms (1995) described the people of color racial identity model to have five statuses of development: (1) conformity, (2) dissonance, (3) immersion-experience, (4) internalization, and (5) integrative awareness. In brief, the model characterizes a movement from conformity with

the dominant culture with accompanying internalized biases and negative beliefs about one's own racial identity to a sense of biculturalism where one does not harbor negative biases or beliefs about persons from either dominant or minority cultures. Rather, an individual who has reached the integrative awareness stage is likely to understand that overarching systems oppress and marginalize specific groups of people, as opposed to the individuals of those groups. An encounter experience may or may not occur for people of color, which encourages a move from dissonance to immersion. For the present subsample of child participants, it appeared they were likely in the conformity stage of racial identity development, having not had an encounter that encourages a rejection of the dominant culture in favor of Chinese or Asian culture. One parent participant acknowledged the relative conformity with American culture, describing their child to be largely "assimilated".

Child and parent participants incorporated Chinese culture into their lives in small ways. This included having material possessions from China such as photos, dishes, maps, jewelry, or books. Families also reported engaging in some cultural events such as attending Chinese New Year celebrations or making Chinese food. None of the families endorsed a more immersive cultural experience, such as taking language classes or regularly attending culturally relevant activities or settings. Additionally, parents described cultural exposures to be child-led, refraining from imposing Chinese values, traditions, or education upon them.

Literature regarding transracial adoption can help contextualize the cultural themes of the present results. Transracial adoption has a history of controversy in the United States since the trend began in the 1950s-1960s (Barn, 2013). Backlash against domestic adoptions of African Americans and Native Americans emerged during the civil rights era and controversy continued into the 1990's despite United States legislation in support of transracial adoption (Barn, 2013).

There is a body of literature that suggests negative outcomes for both domestic and international transracial adoptees. Adverse effects on cultural identity and belonging have been noted (see Feigelman 2000, Samuels 2009). Indeed, racial/cultural identity and cultural competence of parents have been primary themes in transracial adoption literature (Barn, 2013). Despite the documented concerns, there is also literature in support of transracial adoption that suggests the benefits outweigh the disadvantages (see Bartholet 2007; Simon and Roorda 2009).

Parents are responsible for the "transmission of cultural values, beliefs and behaviors that promote racial/ethnic identity development." They are also responsible for "helping the child develop appropriate strategies to adequately confront prejudice, racism and discrimination" (Barn, 2013). Findings from the present study suggest that parents of children adopted from China transmit cultural understanding via photos, books which commemorate the adoption story, Chinese artifacts in the home, and attendance of cultural events. Parents indicated that engagement in these activities tended to diminish over time with parents often citing ambivalence on the part of their child or children. Parent participants in the present study consistently denied that their children had experienced racial discrimination. The bullying and teasing that was endorsed by both subsamples centered around other topics including speech, body size, facial appearance, and behavior. It is possible that these accounts may accurately reflect a lack of discrimination. It is also possible that children and their parents could be unaware of the most common form of discrimination, microaggressions, subtle remarks that tend to invalidate, insult, or otherwise denigrate an individual based on their group membership (Sue, 2010). Child participants, too, may not be able to yet articulate experiences of discrimination.

There has been an exponential increase in published research studies over the last 15 years which specifically explore racial socialization among children adopted from China. In one

study, Thomas and Tessler (2007) examined factors that contributed to bicultural competence of adoptive parents of children from China. Using data from a longitudinal survey of adoptive adults, the authors found that parental belief in the importance of bicultural socialization, residence in communities with higher proportions of Asian people, and parental networks with Chinese adults supported the development of children's bicultural competence. The authors note that:

> Compared to many children of immigrants, these adopted children only achieved modest levels of cultural competence. It is possible, however, that a relatively low threshold of cultural learning may be sufficient for the development of a positive ethnic identity among children whose parents are of the dominant ethnic group (p. 1214).

This is an important point to keep in mind when considering the perspectives of parents in the present study. Although racial and ethnic identity development has been implicated as an important element for positive well-being among racial minority individuals (Smith & Silva, 2011), the needs may shift for this population such that the mild to moderate levels of cultural exposure described by children and parents in the present sample may be sufficient, especially when considered in conjunction with the variety of other individual and family strengths.

Chen, Lamborn, and Hu (2017) conducted a more recent qualitative study examining strategies of Euro-American parents in encouraging racial and ethnic socialization of their children adopted from China. The authors found that connections with Asian Americans, openness regarding adoption, and support in addressing stereotypes and discrimination were strategies employed by parents to promote socialization. Thematic findings from the present study echo results discussed in previous literature. In particular, parent participants demonstrated awareness of the importance of their child's culture of origin through their efforts to maintain

exposures to Chinese culture. Parents also discussed the value of connecting with other Asian American individuals, whether through the adoption process, school, or other community source. Although parent participants in the present subsample did not discuss strategies for supporting their children with racial discrimination, it is possible that as their children grow older, need for such assistance will become more salient.

In addition to values associated with faith or religion, Euro-American values were evident across the sample. Parent participants often discussed the importance of education and work ethic. Although not explicitly discussed, the American emphasis on individualism was apparent in parents' approach to child-led cultural exposures. The influence of individualism on self-concept was also seen in the **sense of self** theme as child participants often described themselves in terms of individual attributes or abilities, rather than in relation to others. These values and subsequent behaviors illuminate the ways in which parents successfully transmit some elements of Chinese culture (e.g. exposure to events and traditions) but cannot as effectively transmit belief systems (e.g. value of collectivism).

Implications for Providers

Medical providers. Families participating in the present sample generally described neutral or positive attitudes toward their medical team. This theme may have been supported by the nature of the setting, as all participating families were recruited in a multidisciplinary cleft clinic approved by the American Cleft Palate-Craniofacial Association (ACPA). Thus, it is possible that participants who receive specialty care from medical providers in isolated clinics may have different perspectives toward their child's healthcare.

It was common for parents to indicate that their CL/P providers knew their family better than the child's pediatrician due to the frequency of medical appointments. Families were

specifically asked if there was anything they wanted their medical team to know about their family that they didn't already know. For those parents that indicated a desire for their medical team to know further information about their family, that request was framed in a positive light. Parent participants wanted their medical providers to know that they appreciated good care for their child and further wanted providers to know about the strengths and resilience of their child. One parent wanted their providers to know about the importance of trauma-informed care. With these parent perspectives in mind, it is recommended that medical providers integrate a strengths-based approach as much as is possible despite the inherent focus on deficits often found in medical fields. Similarly, with the increased risk for developmental trauma in internationally adopted children, it is recommended that medical teams train their providers in trauma-informed care.

Children and parents in the present sample endorsed overall adaptive coping with frequent medical appointments, surgeries, and ongoing therapies (e.g. speech). One parent did discuss the trauma for her and her child associated with bone graft surgery, describing shock at the amount of blood and hair loss on the scalp. Though this was not a theme that emerged for the entire parent subsample, it was evident that bone graft surgery was a salient recent challenge for families. It is recommended that providers working with families prior to bone graft surgery provide education on surgery aftercare including expectations around appearance changes and wound dressing. Psychoeducation on pediatric medical traumatic stress and secondary medical traumatic stress can also be beneficial and could be given by medical or psychology providers. The National Child Traumatic Stress Network (NCTSN) is a useful online resource for healthcare providers and parents who wish to learn more about strategies for coping with difficult medical procedures, signs and symptoms of pediatric medical traumatic stress, and when

to seek psychological care. Further, children who present with developmental and/or medical trauma benefit the most from early intervention (NCTSN, 2016). Medical providers can act as a first line of defense for screening families that may not already be participating in ongoing mental health services.

Some of the families in the present sample reported having consulted with medical teams prior to the adoption, once they had learned of their child's CL/P diagnosis. Families also reported that although adoption agencies were typically very thorough with preparing families for the adoption process, complete information about CL/P was not always available. In particular, complete information about the severity of their child's CL/P, nature of previous medical care, and likely medical needs upon entering the United States was not always clearly delineated. For medical providers interfacing with these families prior to adoption, it is recommended that they prepare parents for the range of possible CL/P sequalae. These include velopharyngeal insufficiency and/or hypernasal speech (Kaye, Che, Chew, Stueve, & Jiang, 2018), language delay (Morgan et al, 2017), feeding problems (see Duarte, Bossardi Ramos, & de Almeida Freitas Cardoso), hearing deficits, ear infections (Sheahan, Miller, Sheahan, Earley, & Blayney, 2003), increased risk of carrying resistant bacteria (Hansson, Svensson, & Baker, 2012) and increased risk for need of secondary surgeries after initial repair(s) (Swanson et al., 2014; Werker, de wilde, van der Molen, & Breugem, 2017).

In addition to the aforementioned recommendations, it is advised that multidisciplinary care clinics adhere to ACPA Standards of Team Care for Cleft and Craniofacial Teams. As of 2018, there were 175 ACPA approved teams in the United States and Canada (ACPA, 2018). Standards necessitate inclusion of a care coordinator, speech and language, surgery, and orthodontic specialties. They also require access to psychology, social work, audiology, genetics,

dentistry, otolaryngology, and pediatrics/primary care. The standards further specify that "the Team must maintain a list of reliable community resources for any services that are not provided by the Team itself. Some record of assessment and/or treatment follow-up should exist in the centralized Team record" (ACPA, 2016). Thus, it is important for teams without embedded specialties to ensure access and follow up with those services outside the team. With regard to access to psychology, the standards specify that patients should have access to "a psychologist who does neurodevelopmental and cognitive assessment". It is recommended that medical teams take great care to faithfully ensure that families have followed up with psychology referrals, whether for assessment, consultation, or intervention.

Finally, in light of present findings implicating the benefit of social support for these families, it is recommended that medical teams facilitate communication between families who have adopted children from China. It is not uncommon for care coordinators or social workers to connect families with CL/P, but it could provide specific benefit to connect those with internationally adopted children. This would allow parents opportunity to give and receive support around issues that may be unique to their children (e.g. discussing adoption, handling regressive or attachment concerns). It would also allow children the opportunity to spend time with others like them, which could normalize their race and adoption experiences, and provide cultural connection. Such connections would likely be beneficial for families who travel long distances to their multidisciplinary care or live in rural areas.

Psychologists. Findings from the present study support the presence of or access to a psychologist, per ACPA Standards for Team Care. While an embedded psychologist is likely most beneficial to provide immediate consultation and intervention for patients and their families, it is recognized that this is not always possible. Psychologists play important roles in

providing multidisciplinary healthcare to children with CL/P. The present sample had a higher rate of social and/or emotional problems compared to peers without CL/P, with about half of the sample reporting a degree of concern in these domains. However, children were not assessed for a current DSM-5 diagnosis, so it is unknown what proportion of the present sample met criteria for a clinically significant mental health disorder. Nevertheless, the present findings support recommendations from previous literature (Feragen & Stock, 2016) to screen children with CL/P for social/emotional concerns. It should be also noted that the present sample described greater social challenges when there was greater impairment in speech and when there was an associated hearing concern. Thus, psychologists should be aware of the higher risk for this subset of the population. Social/emotional screening can be conducted by medical providers when necessary; however, screening by the team psychologist would allow for further assessment and tailored referrals when pertinent.

In addition, the rates of neurodevelopmental conditions including ADHD, learning disabilities, and Autism Spectrum Disorder are higher for children with CL/P (Tillman et al., 2018). Overlaying the increased risk for behavioral and mental health problems for children adopted from China who experienced early abuse or neglect (Xing Tan & Marfo, 2016), there is significant need to screen for a range of potential comorbidities. Children who fall into these categories may particularly benefit from referral to a comprehensive psychological or neuropsychological evaluation (ACPA; see Richman, McCoy, Conrad, & Nopoulos, 2012).

Similarly, psychologists can provide education to parents on how to request Individualized Education Plans or Section 504 evaluations through their public school to facilitate provision of appropriate accommodations for learning. Accommodations might include allowance for absences and make-up work for medical appointments, tutoring or one to one

instruction, speech therapy, social skills group participation, or other behavioral supports for social and emotional development. Recommendations to seek evaluation through the child's school can also be beneficial for situations in which there are barriers to accessing a psychological evaluation (e.g. waitlist, insurance authorization, geographic location).

With regards to interventions with children with CL/P adopted from China, psychologists can assist with peer difficulties. Psychologists can assess child and family attitudes to peer questions, teasing, bullying, or discrimination. It may be a helpful coping strategy to reframe peer questions as normative curiosity rather than maliciousness. Rehearsal of social situations can also be helpful. Psychologists working with families can either role play with children to support practice of responses to peer questions or comments, or they can provide instruction to parents for such an intervention. Child participants in the present study seemed to have greater ease talking with the primary researcher and adults about adoption and CL/P but indicated they did not often talk to peers about these topics. It may be beneficial for parents to support their children in disclosing CL/P to peers in order to reduce perceived stigma.

Finally, psychologists can give parents education and resources regarding racial and ethnic socialization, identity development, and discrimination. Results from this study support the benefits of at least a mild degree of cultural exposure. This was most evident in families' joy around adoption books, binders, or photo albums. Such tangible items can allow children to understand their adoption story in a meaningful way. The benefits of cultural exposure were also evident for the child and parent participants who endorsed pride in their Chinese culture. For instance, one parent participant described how she had begun an annual classroom tradition of giving out red envelopes commemorating Chinese New Year. Such examples highlight the ways in which parents can support racial and ethnic pride. Parents may also benefit from learning

about how racial identity may change over time with the influence of the child's overall development and interactions with the environment. Open and honest conversations about CL/P, adoption, and race should be encouraged to normalize identity statuses which can be stigmatized.

Similarly, psychologists may have unique multicultural competence as a result of their academic and clinical training, which can support an understanding of and preparation for racial discrimination. Psychologists can provide education to parents on microaggressions and types of discrimination (e.g. individual, institutional, structural) that their children may face currently or in the future. Strategies for assisting children through general social problems would also be applicable in this respect. Parents can support their child's coping with instances of racial discrimination by fostering open dialogue around race and other individual differences, and social rehearsal.

Directions for Future Research

Just as a strengths-based approach is recommended for clinical care, such an approach is also recommended in research. Much of the literature has examined pediatric craniofacial populations through a deficit lens and thus, future research would benefit from incorporating a focus on strengths and resiliencies (Feragen, Borge, & Rumsey, 2009; Stock & Feragen, 2016). More psychosocial research is needed with children with CL/P adopted from China, as there is very little current understanding of how psychosocial outcomes may differ between such individuals and the general pediatric CL/P population. This has meant a complete lack of research which examines cultural considerations for this specific population.

Future qualitative and quantitative research could further examine the relationship between self-concept and racial/ethnic socialization and identity for children with CL/P adopted from China. Such research could also include application of theoretical models related to cultural

and racial socialization practices among international transracial adoptive parents (see Jaegoo Lee, Vonc, & Crolley-Simic, 2015). Given the recent increase in research on international transracial adoption of children from China, it will be beneficial to also identify samples with medical conditions to explore the potential interaction of cultural and medical factors that contribute to self-concept. Longitudinal studies would be particularly helpful in evaluating in self-concept and racial/ethnic identity development over time. Given the preponderance of studies which center parent perspectives, it is recommended that both future qualitative and quantitative studies aim to emphasize children's experiences. For studies which include parent perspectives, it is recommended that fathers be included as most previous studies related to parents' experiences of raising a child with CL/P mainly include mothers (Nelson, Kirk, & Caress).

Children with CL/P adopted from China are at greater risk for adverse medical outcomes relative to the general pediatric CL/P population (Swanson et al., 2014; Werker, de Wilde, Mink van der Molen, & Breugem, 2017). Thus, examination of posttraumatic medical stress and medical coping would be useful. Similarly, measures and theories of posttraumatic growth (see Calhoun & Tedeschi, 2014) may be applicable to the present population when considering the possible trauma associated with early childhood adverse experiences prior to adoption and re-occurring surgeries.

Finally, it is recommended that future research investigate and/or include methods for measuring the severity of speech and hearing concerns. Measures used by physicians or speech and language pathologists may be useful to include in studies that explore the impact of speech/hearing deficits on social and emotional functioning in children with CL/P.

Strengths

Given the stark lack of previous psychosocial literature with children with CL/P adopted from China, the present study offers valuable considerations that can guide future research and afford psychologists and other providers further understanding of this population. Such knowledge can inform best practices within multidisciplinary care clinics.

In-depth presentation and interpretation of the present study's findings is an important strength as published qualitative studies with pediatric craniofacial populations are often presented in brevity (see Hall, Gibson, James, James & Rodd, 2011; Havstam, Laakso, & Ringsberg, 2011). From a methodological standpoint, this makes it challenging for consumers of the work to evaluate the appropriateness and integrity of research design, methodological framework, and data analysis. In particular, qualitative studies often lack sufficient detail about researcher qualifications, structure of coding team, means of promoting researcher reflexivity and reducing bias, and actual steps of data analysis (Nelson, Glenny, & Caress, 2011). From an impact perspective, qualitative studies presented in brevity diminish the value of the results and discussion when important information must be condensed. The present study included sufficient details in all of these areas to ensure ability of readers to evaluate methods and so that the findings could have the most impact. Furthermore, the present study's coding team took great care to promote trustworthiness of the data according to IPA protocol.

An additional strength of the present study is the inclusion of both child and parent data. This allowed for additional perspectives that could not be gained from either subsample alone. Similarly, the focus on school age children adopted from China allowed for exploration of lived experiences for two intersecting populations that are understudied in pediatric craniofacial populations: school age children and children adopted from China. Although there are studies that include parent perspective only on school age children, this was the first study, to the best of

the primary researcher's knowledge, which examined lived experiences of school age children with CL/P from their perspective.

Limitations

As with all qualitative studies, ability to generalize the present results to the greater population of children with CL/P adopted from China is not possible. Furthermore, it is recommended that the current findings be interpreted within the cultural contexts associated with international adoption from China to the United States by predominantly affluent White families. An understanding of the factors that support self-concept in other cultural contexts, such as in different countries or in cases of domestic adoption, would likely differ given the influence of unique cultural variables.

A potential limitation of the present sample was the lack of diversity for some facets of identity. This included the participation of predominantly mothers (fathers: n=1) and affluent and White parents (non-White parent: n=1). Although these parent characteristics were homogenous in the parent subsample, the latter characteristics are likely representative of the United States population of internationally adopting parents (Hellerstedt et al., 2008). The sample was also geographically restricted to the Midwest; however, the sample represented a mix of rural, suburban, and urban areas.

IPA as a methodological framework brings limitations which can vary based on the sample size. The present study included nine child-parent participant dyads, resulting in 19 total participants. This represents a large sample size according to IPA standards. Such a large sample has the benefit of assuring interconnectedness at the group level as well as the "saturation" in some methodologies (Merriam & Tidselll, 2016). However, richness of idiographic analysis may

have been compromised in favor of emphasizing group level thematic analysis (Flowers, Smith, & Larkin, 2009; Pietkiewicz & Smith, 2014).

Summary

The present research study is an in-depth qualitative study that offers important findings regarding an understudied population. This study highlights individual and family strengths and factors contributing to positive self-concept through a biopsychosocial lens with additional commentary on cultural considerations. It is the hope of the researcher that this study will inform clinical care provided by psychologists and medical teams, and encourage further research with this population.

Table 1.

Sample Demographics

Age	M=9.88	SD=1.19
Gender		
Female	6	67%
Male	3	33%
Diagnosis		
CLP	9	100%
Comorbidities		
Speech	5*	56%
Hearing	4*	44%
Social/emotional	4*	44%
Parents		
Mother	9	89%
Mother and Father	1	11%

*Parent-reported during interviews

Table 2.

Superordinate and Emergent Themes

Child		Parent	
Superordinate	Emergent	Superordinate	Emergent
Sense of self		Child's strengths	
	Pride in extra-curriculars/interests		Child has many positive qualities
	Self-efficacy in extra-curriculars		Involved in hobbies and activities
	Positive attributes and preferences		Child is resilient and adaptive
	Appearance perceptions		
Family is primary source of support		Family strengths	
	Safety and validation		Family emphasizing togetherness and support
	Individual and family values		Family values, often including faith
	Spending time together		Talking though situations helps child cope
	Parents instill and reinforce pride		Use of humor
Adoption as part of identity		Adoption process and meaning making	
	Adoption story details are meaningful		Inspired to adopt
	Pride in adoption		Social support while adopting is helpful
	Open and honest conversations about adoption		Impact of developmental trauma
	Book, photos, binder commemorate adoption		Regular conversations normalize adoption
			Burden of decision-making, waiting, and preparation
			Adoption is an adjustment for all family members
Cultural identity development		Cultural identity development	
	Understanding of the word 'culture'		Lack of perceived discrimination toward child
	Incorporating Chinese culture in small ways		Contextualizing diversity of community
	Limited contact with others from China, adopted or with cleft		Incorporating Chinese culture in small ways
			Cultural exposure is child-led
Coping with cleft		Coping with cleft	
	Cleft associated with surgeries		Transparent conversations normalize appearance differences
	Cleft is just part of life		Matter of fact conversations
	Concrete understanding of cleft		Cleft is not a big deal but is still chronic
	Optimistic about cleft outcomes		
Social factors		Social factors	
	Only discusses adoption with trusted persons		Social skills challenges
	Perceptions of bullying/teasing		Sensitivity can contribute to interpersonal challenges
	Peer questions interpreted benignly		Speech and hearing deficits increase risk
	Speech and/or hearing is hard part about cleft		

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    for a child born with cleft lip and/or palate: Impact of the timing of diagnosis. *Journal of Marital*

    and Family Therapy, 43(1), 82-99. doi:10.1111/jmft.12182

We are conducting a research study with children with cleft lip and/or palate between the ages of 8 and 12 years old adopted from China. This is because there is limited available research about school age children with cleft lip and/or palate who have been adopted from China and how best to help them adjust and cope. We want to learn about your child and family's strengths, challenges, and ways of coping. We would like to talk with both you and your child.

Study Title: Psychosocial Experiences that Support Positive Self-Concept in Children with Cleft Lip and/or Palate Adopted from China

Researchers: Samantha Everhart, MS, doctoral researcher; Collaborator: Patricia Marik, PsyD, Pediatric Psychologist; Dr. W Hobart Davies, Psychology, PhD

What: A researcher will interview your child for 20-45 minutes and ask questions about their experiences with cleft lip and/or palate, adoption, family, and friends. A researcher will interview you, the parent(s), for 20-45 minutes to ask about experiences adopting a child from China who also has medical needs related to cleft lip and/or palate.

When: If you are interested in participating, we can do the study after you are done seeing all of your medical providers. If there is time to conduct one or both interviews in between providers, we can arrange that with the clinic coordinator.

Informed Consent: If you are interested in participating, the researcher will talk to you and your child more in-depth about the interview, how information will be stored and protected, possible risks, and anticipated benefits of being in the study. Participation is completely voluntary and will not affect healthcare services in the clinic. Only children who know that they have been adopted should participate in this study.

What happens if we are interested? A researcher will talk to your family in the waiting room after you have been given time to review this flyer. We can then go to a private room to go over paperwork and informed consent. Priority will be given to meeting with medical care providers. Researchers will work with the clinic to ensure that the study will not disrupt your day in the clinic. If you are interested in participating, but not today, you may either let the researcher know today or contact one of the researchers at a later time to arrange the interview(s): Samantha Everhart: brown435@uwm.edu; W. Hobart Davies: hobart@uwm.edu

Appendix B: Semi-structured Interview Questions

Semi-structured Interview Questions-Child

The following continues to use the abbreviation of CL/P to represent "cleft lip and/or palate".

During the interview, the researcher will utilize the same language as the participant, such as "cleft".

"Thank you for taking the time to talk with me today. I am going to ask questions about you, your friends, your family, and your health. Take as much time as you need to answer the questions. If you don't want to answer a question or don't have an answer, we can skip that one. Remember, we can stop anytime."

Personal

- Tell me about yourself. (*As needed prompts*: What are some things that make you who you are? What would a friend say about you?)

- What are some things you are really good at? (*As needed prompts*: Some kids are good at sports, some kids are really good friends, what kinds of things are you good at?)

  o Tell me about the last time you felt proud or happy because of something you did well.

- What do you like about the way you look? Is there anything you don't like about the way you look or your body? (*As needed prompt if "yes":* Have you found anything that helps you feel better about that?)

- What kinds of things come up in your life that are hard to deal with? (*As needed prompts:* Some kids might have problems with homework or get into an argument with friend.)

  o When is the last time you had a problem like that? What did you do to make it better?)

Cultural/Adoption

- Tell me what you know about the story about your adoption. What have your mom or dad told you about your adoption?

- What do you know about China?

- Do you know other kids or adults from China?

- Is anyone else in your family adopted? If so, from where? Does he/she have a cleft too?

- Do you know what the word "culture" means? What does it mean to you?

  o In your family, do you have things in your house from China? Do you have things you do that other people from China do (like eat certain food or celebrate certain holidays)?

- What does it mean for you to come from a different background than your family?

- Has anyone ever asked you questions about the way you look?

  o When was the last time that happened? What part of how you look did they ask about? How did you respond?

- Have you talked with friends about being adopted?

  o What things have you told them?

  o How do you feel about talking about being adopted with friends?

Medical

"Now I'm going to ask you some questions about your cleft lip and/or palate. What do you call your cleft lip and/or palate?"

- What do you know about your CL/P? (What is it?)

- What are some hard things about having CL/P?

- What are some good things about having CL/P?

- How does having a cleft affect your life now? (*As needed prompts:* Has it affected who you are? How?)

  o When was the hardest time about having a cleft? What was going on?

- Have you had surgeries or other difficult procedures that you remember? Tell me about the last one. How did you cope?

- How do doctors (and other medical providers) make you feel good about who you are?

Family

- What is something that your family is really good at? (*As needed prompt:* Can you give me an example?)

- Tell me the about how you learned about your CL/P. (*As needed prompt*: When did your family first talk to you about CL/P?)

  o What have your parents told you about your CL/P?

- What do you and your family talk about related to your cleft now? Tell me about the last conversation you had about CL/P.

- Tell me about the last time you had a problem that your family helped you with.

Friends

- What do your friends know about your CL/P?

- How do you feel about talking about your cleft with friends? What things would you tell them?

- Has anyone ever teased or bullied you?

  o What happened? How did you handle it? Who helped you?

- Do you have any friends with CL/P?

Concluding Questions

- What advice would you give another child who is learning how to cope with having CL/P?

- What advice would you give to a child who is adopted? What about their parents?

- What advice would you give to parents who have a child with CL/P?

- What do you want your doctors to know about you that they don't already know?

- Is there anything you would like to ask me?

<div align="center">Semi-structured Interview Questions-Parent</div>

- What are some strengths or good qualities of your child?

- What are some strengths of your family?

- What things are important to your family?

- Tell me about a recent time that your child had a problem in his/her life? How did they cope with that?

- Were there things you were not prepared for?

- Tell me how you decided to adopt your child?

  - Tell me about the experience of adopting a child with CL/P.

  - Tell me about the experience of adopting a child from a different country.

  - What was the process like?

- How do you talk about CL/P in your family? How do you talk about CL/P with your child?

- Do you talk about appearance with your child? How do you talk about looking different (because of cleft, because of race)?

- Did your family decide to incorporate Chinese culture into your home or community after adoption? (*As needed prompts*: What are some examples?)

- Has your child faced any discrimination or bullying because of either CL/P or race? How does your family address those concerns?

  o Do you have a specific example? How did you respond?

- What advice would you give to parents initiating the process of international adoption of a child with CL/P?

- What do you want your doctors to know about your family?

- Is there anything you would like to ask me?

Samantha A. Everhart (née Brown)

Education

2020 (Anticipated)	Ph.D. Counseling Psychology Department of Educational Psychology University of Wisconsin - Milwaukee Milwaukee, WI Advisors: Stephen Wester, Ph.D.; W. Hobart Davies, Ph.D. Dissertation: Psychosocial Experiences that Support Positive Self-Concept in Children with Cleft Lip and/or Palate Adopted from China
2015	M.S. Community Counseling Department of Educational Psychology University of Wisconsin - Milwaukee Milwaukee, WI Advisor: Shannon Chávez-Korell, Ph.D.
2011	B.S. Psychology College of Letters and Science University of Wisconsin - Madison Madison, WI

Predoctoral Internship

Children's Hospital of Orange County: *Orange, CA; August 2019 - Present*

Consultation and Liaison (Core Rotation)
- Assess safety and risk, provide psychoeducation, support adjustment to and coping with illness, provide patient and family support around hospitalization, assist medical teams and families in implementation of behavioral plans to support inpatient medical outcomes. Supervisors: Mery Taylor, Ph.D., Harpreet Kaur, Ph.D.

Endocrine (Specialty Rotation)
Diabetes
- Serve consultative role in multidisciplinary diabetes clinic, interpret and respond to PHQ-A depression screenings, assess safety/risk and mood, provide brief intervention and referral. Conduct consultation intakes and provide brief adherence-focused therapy for individuals with type 1 and 2 diabetes. Supervisor: Sabrina Stutz, Ph.D.

Gender
- Assess gender dysphoria and psychosocial functioning of gender-nonconforming patients, consult with medical team, administer and interpret screening measures, provide recommendations to patients and families. Supervisor: Mery Taylor, Ph.D.

Outpatient Therapy (Core Rotation)

- Conduct semi-structured intake assessments, provide evidence-based treatment to children and adolescents with co-occurring medical and mental health conditions. Utilize cognitive-behavioral and dialectical behavioral therapy approaches. Utilize measures to track progress.
  Supervisor: Alyssa Jones, Psy.D.

Oncology (Specialty Rotation)
- Serve as consultant to oncology medical team and make recommendations to support psychological and physical functioning of patients in the hospital, provide therapeutic support to patients with and survivors of cancer.
  Supervisor: Eve Nguyen, Ph.D.

Emergency Department (Core Rotation)
- Utilize Columbia-Suicide Severity Rating Scale (C-SSRS) to assess safety and risk of patients presenting to emergency department with acute mental health concerns, provide family-based crisis intervention (FBCI) to patients and families. Conduct safety planning with patient and family, facilitate transfer to inpatient psychiatric care, provide outpatient referrals. Attend weekly Mental Health Emergency Services meeting.
  Supervisor: Sharonne Herbert, Ph.D.

Assessment (Core Rotation)
- Conduct intake assessments, administer neurodevelopmental assessments, score and interpret assessment results, write reports, provide feedback on assessment results to patients and families.
  Supervisor: Marni Nagel, Ph.D.

Doctoral Clinical Practicum Experience

Children's Hospital of Wisconsin: *Milwaukee, WI; August 2018 – May 2019*

- **Gastroenterology Clinic**
Conducted multidisciplinary intake assessments for children with possible feeding disorders and comorbid neurodevelopmental and medical conditions. Provided behavioral feeding interventions and fed therapeutic meals in a one-to-one outpatient setting using behavioral strategies.
Conducted intake assessments, provided education and behavioral interventions for children with encopresis, constipation, and enuresis. Developed collaborative treatment goals with members of the multidisciplinary team.
Supervisors: Alan Silverman, Ph.D., Andrea Begotka, Ph.D.

- **Gender Health**
Facilitated bi-weekly therapeutic support group for parents and caregivers of gender non-conforming adolescents.
Supervisors: Amy Ridley Meyers, Ph.D.; Jacquelyn Smith, Ph.D.

Children's Hospital of Wisconsin: *Milwaukee, WI, August 2017 – August 2018*

- **Psychological Assessment in Psychiatry Clinic**
Conducted structured intake assessments, identified and administered psychodiagnostic assessments for children and adolescents (inclusive of cognitive, achievement, personality, and social/emotional measures), scored and interpreted assessments, provided feedback to patients and families, wrote integrated reports. Observed Parent-Child Interaction Therapy (PCIT)

sessions, received training in Child Directed Intervention, Parent Directed Intervention, time-out sequences, coding, and assessment in PCIT.
Supervisors: John Parkhurst, Ph.D.; Jacqueline Kawa, Ph.D.

- **Consultation/Liaison Service (6/2018)**
Screened for posttraumatic symptoms in pediatric inpatients, provided psychoeducation, provided parent and patient support around hospitalization, assisted medical teams and families in implementation of behavioral plans to support inpatient medical outcomes.
Supervisor: Patricia Marik, Psy.D.

Children's Hospital of Wisconsin: *Milwaukee, WI, August 2016 – May 2017*

- **General Child Clinical in Psychiatry Clinic**
Conducted structured intake assessments, provided evidence-based treatment for patients and families with diverse backgrounds and presenting concerns. Utilized cognitive-behavioral, family systems, and play therapies. Implemented a manualized treatment for anxiety (Coping Cat).
Supervisor: Matthew Jandrisevits, Ph.D.

- **Outpatient Pediatric Psychology in Psychiatry Clinic**
Provided evidence-based treatment for adherence and co-occurring behavioral concerns to patients with chronic medical conditions including cystic fibrosis, diabetes, kidney disease, and liver disease. Participated in providing assessment, family support, behavioral interventions, and medical team collaboration on the consultation and liaison service. Observed a psychological evaluation for kidney transplant readiness. Attended monthly renal case conferences.
Supervisor: KristiLynn Cedars, Ph.D.

- **Consultation/Liaison Service (5/2017)**
Screened for posttraumatic symptoms in pediatric inpatients, provided psychoeducation, provided parent and patient support around hospitalization, assisted medical teams and families in implementation of behavioral plans to support inpatient medical outcomes.
Supervisor: Patricia Marik, Psy.D.

Family Options Counseling, LLC: *Brookfield, WI; August 2015- January 2017*

- Conducted individual intake assessments. Provided individual, family, and group therapy to children and adolescents. Facilitated Aggression Replacement Training group, facilitated emotional regulation group, facilitated a skills-based group for adolescents with developmental delays. Provided court-mandated treatment for adolescents in the juvenile justice system and assessed sexual re-offense risk. Submitted progress reports to care coordinators. Attended Individualized Education Plan (IEP) and other team care meetings. Assisted in client case management to support therapy attendance and caregiver involvement in treatment.
Supervisor: Kimberly Young, Ph.D.

Master's Clinical Practicum Experience
Walker's Point Youth and Family Center: *Milwaukee, WI; January 2015 – May 2015*
- Conducted individual and family intake assessments, provided solution-focused therapy to adolescents residing in short-term shelter. Provided therapy aftercare services to clients and

caregivers. Facilitated psychoeducation groups with adolescent shelter residents. Reported suspected abuse and neglect to Child Protective Services. Answered 24-hour crisis-line, made community referrals, and coordinated client care.
Supervisor: Lori Runge, M.S.W.

Milwaukee LGBT Community Center: *Milwaukee, WI; August 2014 – December 2014*
- Conducted individual intake assessments, provided individual and couples therapy to LGBTQ+ adult clients, facilitated therapeutic group for LGBTQ+ elder adults, developed and implemented adolescent and young adult psychoeducation group.
Supervisor: Devin Thomas, M.S.W

Other Clinical Experience

Racine Juvenile Detention Center: Qualified Mental Health Professional: *Racine, WI; April 2019 – July 2019*
- Conducted intake assessments with juvenile detainees, maintained caseload of ongoing counseling clients. Collaborated with Alternatives to Corrections Education program to provide mental health services to those enrolled in the program. Facilitated AODA and aggression replacement training psychoeducation groups. Assessed and monitored safety of detainees placed on suicide precautions including making recommendations for step-down procedures. Provided crisis intervention and collaborated with security and medical staff.
Supervisor: Melissa Caldwell, Ph.D.

Sheboygan County Detention Center: Qualified Mental Health Professional*: Sheboygan, WI; October 2016 – January 2018; December 2018 – April 2019*
- Identified at-risk detainees from medical screenings. Provided mental health services to detainees including brief support and ongoing therapy, responded to medical and security referrals, assessed and monitored safety of detainees placed on suicide watch and in segregation, facilitated therapeutic groups for juvenile detainees. Provided crisis intervention and housing recommendations to security staff. Presented suicide-prevention training to correctional officers.
Supervisor: Melissa Caldwell, Ph.D.

Walker's Point Youth and Family Center: Youth and Family Specialist: *Milwaukee, WI; May 2014 – January 2015*
- Conducted structured intake assessments for housing. Managed and directed household duties of youth shelter, supervised adolescent residents and volunteers, answered crisis-line and provided crisis counseling and referrals. Facilitated psychoeducation groups with adolescent shelter residents.
Supervisor: Benjamin Hastil, M.S.W

Walker's Point Youth and Family Center: Volunteer Counselor: *Milwaukee, WI; October 2013 – May 2014*
- Conducted intake assessments for housing. Facilitated psychoeducation groups with adolescent shelter residents. Reported suspected abuse and neglect to Child Protective Services. Answered 24-hour crisis-line and made community referrals.
Supervisor: Amy O'Neil, M.S.

Briarpatch Services Inc: Youth Counselor: *Madison, WI; August 2011 – August 2013*
- Conducted intake assessments with adolescent and families. Managed independent caseload of clients inclusive of counseling provision, case management, and phone follow-up. Provided brief solution-focused counseling to adolescents and families in crisis. Provided ongoing aftercare counseling. Partnered with local high schools to provide school-based counseling services to underserved populations. Provided monthly on-call service for 24-hour crisis-line. Attended weekly group supervision with master's level practicum students and licensed supervisors. Submitted and received a grant through Runaway and Homeless Youth Training and Technical Assistance Center (RHYTTAC) and organized a local homeless awareness event. Represented Briarpatch Services Inc. at national RHYTTAC conference. Participated in AmeriCorps training and volunteer events.
Supervisors: Jeanne Schneider, M.S.; Ann Bohlman, M.S.W.

Briarpatch Services Inc: Volunteer Counselor: *Madison WI; June 2010 – August 2011*
- Conducted intake assessments with adolescent and families. Led crisis counseling and therapy sessions, facilitated youth groups, answered crisis-line, reported suspected abuse and neglect to Child Protective Services.
Supervisor: Jennifer Burkel, M.S.W.

Research Experience

University of Wisconsin – Milwaukee: Child Stress and Coping Lab, *Milwaukee, WI; May 2017 - Present*
- Facilitated undergraduate qualitative coding teams. Collaborated on research studies investigating attitudes toward school-based BMI measurement, relationships between pain acceptance and self-efficacy and quality of life outcomes, and treatment stagnation in adolescents with co-occurring obesity and chronic pain. Contributed to manuscript writing and editing.
Supervisor: W. Hobart Davies, Ph.D.

University of Wisconsin – Milwaukee: Efficacy of Psychotherapy: *Milwaukee, WI; October 2013 – May 2018*
- Contributed to study design, developed interview protocols for trauma counselor qualitative project, and submitted IRB. Conducted qualitative interviews with adolescents and adults, coded and themed qualitative data using interpretive phenomenological analysis (IPA) and consensual qualitative research (CQR). Conducted meta-analyses of therapy efficacy from data collection to write-up phases. Contributed to manuscript writing and editing. Facilitated weekly lab meeting.
Supervisor: Thomas Baskin, Ph.D.

University of Wisconsin - Madison: Center for Investigating Healthy Minds: *Madison, WI; June 2011 – August 2012*
- Administered computerized tasks to participants in NCCIH (formerly NCCAM) funded study about neuropsychological outcomes of long-term meditation. Observed fMRI participant tasks, assisted participants in task initiation and transitions, labeled and stored saliva samples, entered data, coded ECG and EEG data in MATLAB.
Supervisor: David Bacchuber, B.S.
Primary Investigators: Richard Davidson, Ph.D.; Giulio Tononi, M.D., Ph.D.

University of Wisconsin - Madison: Language and Cognition Lab: *Madison, WI; September 2010 – May 2011*
- Contributed to experimental design, administered computerized tasks to participants, gained proficiency in eye-tracking software and equipment.
  Supervisor: Gary Lupyan, Ph.D.

University of Wisconsin - Madison: Affective Disorders Lab: *Madison, WI; 2009*
- Coded diagnostic interviews and entered data for Life Experiences Project, a study investigating the interaction of life events and mood disorder symptoms.
  Supervisor: Lyn Abramson, Ph.D.

Presentations

Everhart, S. A., Lambrou, N. H., Cochran, K. C., Davies, H. W., & Marik, P. K. (2020, April). *"It was meant to be": Challenges and strengths of school-aged children with cleft adopted from China: A qualitative study.* To be presented at the American Cleft Palate Craniofacial Association Annual Convention, Portland, OR. (Conference Canceled).

Davies, W. H., Lang, A. C., Lim, P. S., **Everhart, S.A.,** Linneman, N. G., & Alderfer, M. A. (2019, August). *Ethical challenges surrounding use of qualitative research in clinical settings to improve care.* Presented in the Symposium "Ethical issues in the clinical practice of pediatric psychology" (M. Agoston & K. Fehr, Chairs) at the American Psychological Association Convention, Chicago, IL.

Everhart, S. A. (2019, August). *Current state of literature on consensual nonmonogamy across disciplines.* Poster presented at the American Psychological Association Annual Convention, Chicago, IL.

Linneman, N. G., Lang, A. C., Lim, P., **Everhart, S. A.,** Davies, W. H., & Alderfer, M. A. (2019, August). *Ethical challenges in using qualitative methods to improve pediatric clinical care.* Poster presented at the American Psychological Association Annual Convention, Chicago, IL.

Cass, T. J., **Everhart, S. A.,** Edwards, J. A., Hunter, B. L., Johnson, C. K., Wellinghoff, A., & Baskin, T. W. (2019, April). *Implementation of trauma treatment by real world providers.* Poster presented at Midwestern Psychological Association Annual Meeting, Chicago, IL.

Everhart, S. A. & Davies, W. H. (2019, April). *Pain acceptance and self-efficacy predict mental health outcomes.* Poster presented at Midwestern Psychological Association Annual Meeting, Chicago, IL.

Everhart, S. A., Gremillion, M. L., Lang, A. C., Davies, W. H., Weisman, S. J., & Hainsworth, K. R. (2019, April). *Perceived barriers to physical activity engagement in adolescents with co-occurring chronic pain and obesity.* Poster presented at Society of Pediatric Psychology Annual Conference, New Orleans, LA.

Everhart, S. A., Hunt, J. C., Linneman, N. G., Carbonelli, M., Woronzoff Verriden, A., & Baskin, T. (2018, August). *Meta-analysis of psychological interventions for pain vis-à-vie mental health outcomes.* Poster presented at American Psychological Association Annual Convention, San Francisco, CA.

Everhart, S. A., Igler, E. C., Lang, A. C., Austin, J.E., & Davies, W. H. (2018, April). *Attitudes toward weight measurement in a secondary school setting.* Poster presented at Society of Pediatric Psychology Annual Conference, Orlando, FL.

Igler, E., **Brown, S**. **A.**, Lang, A. C., Austin, J. E., & Davies, W. H. (2018, April). *Perspectives on weight measurement within a physical education classroom.* Poster presented at International Conference on Eating Disorders, Chicago, IL.

Brown, S. A. & Kozlowski, M. (2017, July). Counseling and de-escalation with challenging clients. In R. Ramos (Director). *Eviction Defense Project Training.* Lecture conducted from Legal Action of Wisconsin Eviction Defense Project, Milwaukee, WI.

Manuscripts

Lambrou, N. H., Cochran, K. C., **Everhart, S. A.,** Flatt, J. D., Zuelsdorf, M. O'Hara, J. B., Weinhardt, L., Flowers Benton, S., & Gleason C. E. (2020, February). Learning from transmasculine experiences with healthcare: Tangible inlets for reducing health disparities through patient-provider relationships. *Transgender Health.*

Igler, E. C., **Everhart, S. A.,** Austin, J., Lang C., & Davies, H. W. (under review).
Student concerns regarding school-based weight measurement: Implications for policy.

Lang, A. C., Lim, P. S., **Everhart, S. A**., Linneman, N. G., Davies, H. W., & Alderfer, M. A. (in preparation). Challenges in qualitative methods to improve pediatric clinical care: Researcher perspectives.

Gremillion, M. L., Lang, A. C., **Everhart, S. A.,** Davies, W. H., Weisman, S. J., & Hainsworth, K. R. (in preparation). The lived experiences of youth with co-occurring pain and obesity: Important insights and applications.

Teaching Experience

Marquette University, Adjunct Instructor: *Milwaukee, WI; September 2018 – May 2019*
Spring 2019   Education 1220: Psychology of Child and Adolescent Development in a Diverse Society
Fall 2018   Education 1220: Psychology of Child and Adolescent Development in a Diverse Society

University of Wisconsin -Milwaukee, Adjunct Instructor: *Milwaukee, WI; June 2018 – December 2018*
Fall 2018   Counseling 715: Multicultural Counseling
Summer 2018   Counseling 600: Introduction to Clinical Mental Health Counseling

University of Wisconsin - Milwaukee, Teaching Assistant; *Milwaukee, WI; September 2017 – May 2018*
Spring 2018   Counseling 755: Pre-Practicum
Fall 2017   Counseling 755: Pre-Practicum, Counseling 765/970: Practicum

North Park University, Adjunct Instructor: *Grayslake, IL; September 2016 – December 2016*
Fall 2016   CPSY 4120: Biopsychosocial Disorders of Human Development

Advising Experience

University of Wisconsin - Milwaukee, Student Practicum Coordinator: *Milwaukee, WI; August 2015 – August 2017*

- Presented informational sessions to master's students, collected and maintained student-site contracts and contact forms, responded to student inquiries. Coordinated application process for school counseling placements through Milwaukee Public Schools. Coordinated affiliation agreements and online permissions for student practicum placements, maintained online resources and databases, coordinated enrollment with graduate office staff. Disseminated practicum announcements, conducted outreach to community partners and site supervisors.

Service to the Profession

Journal of Pediatric Psychology Student Journal Club, 2019-2020

Student Ambassador for Society of Pediatric Psychology Annual Conference, Division 54, 2019

Student Reviewer for Society of Counseling Psychology, Division 17 proposals to American Psychological Association Annual Convention, 2019

Additional Training

2019	Trauma-Focused Cognitive Behavioral Therapy Medical University of South Carolina, Online Course
2019	Treating Somatic Symptoms: Targeting Risk and Resilience Factors to Optimize Short- and Long-term Health in Complex Patients Society of Pediatric Psychology Annual Conference New Orleans, LA
2017	Counseling with Transgender Clients University of Wisconsin - Milwaukee LGBT Resource Center Milwaukee, WI
2017	Using Acceptance and Commitment Therapy (ACT) with Adolescents with Medical Conditions: An Advanced Skill-Building Workshop Society of Pediatric Psychology Annual Conference Portland, OR
2012	Advanced Motivational Interviewing Three Day Workshop Provided by certified MINT trainer Madison, WI

Student Leadership

2018-2019	Vice President, Student Researchers in Educational Psychology
2017-2018	Treasurer, Counseling Psychology Student Association
2016-2017	President, Counseling Psychology Student Association
2014-2015	Treasurer, Counseling Student Organization

Professional Memberships

2018-present	Society of Pediatric Psychology - Student Affiliate
2015-present	Society of Counseling Psychology - Student Affiliate

2013-2015   American Counseling Association - Student Affiliate

Scholarships Received

2019   Sydney G. Hambling '37 Scholarship
2018   Greater Milwaukee Foundation Donald P. Timm Fund Scholarship
2017   Arthur & Magdalene Singer Scholarship
2014   Sydney G. Hambling '37 Scholarship