PSN

Pediatric Department

CE 1.5 ANCC Contact Hours

Advocating for the Child: The Role of Pediatric Psychology for Children With Cleft Lip and/or Palate

Courtney Zulauf, MA
Tawny Spinelli, BA
Janine Rosenberg, PhD

Children with cleft lip and/or palate (CL ± P) undergo several surgical procedures from birth to adulthood to achieve functional, aesthetic, and psychosocial normalcy. Although children with CL ± P have normal physical development apart from their CL ± P, they face increased risk for emotional, social, behavioral, and academic concerns. In this article, we discuss how the psychology team helps support children with CL ± P and their families. We also explore how the child's overall functioning is evaluated through interview and assessment tools. Throughout, we validate the need for specialized considerations related to having a CL ± P such as increased risk for peer victimization as well as readiness for medical and surgical procedures. By examining the psychology team's role across a child's lifespan, we hope to show that our goal is to advocate for the child and to encompass the child's voice throughout the treatment process.

As part of an urban hospital system in the Midwest, we have the privilege of working at one of the oldest and largest facilities in the world dedicated to the evaluation and treatment of individuals with cleft lip and/or palate (CL ± P) and other craniofacial conditions. To provide the best ongoing care, each patient is supported by an interdisciplinary team, which includes surgeons, nurses, a speech and language pathologist, an audiologist, orthodontists, dentists, a geneticist, a pediatrician, and a psychology team.

As the psychology team, our role includes assessing development across the lifespan, evaluating readiness for recommended surgical procedures, and providing interventions like psychological testing and family or individual therapy, when necessary. Typically, during infancy, new patients and their caregivers meet with the entire interdisciplinary team for an initial consultation. After this, the patient and caregivers meet with providers at least once per year until adulthood, when they transition out of clinic services. Frequently, we encourage caregivers to follow up more often with the psychology team, especially when the child is young and developing rapidly, if there are additional concerns, or when there are scheduled surgical procedures.

Through this article, we demonstrate the role of the psychology team for individuals with CL ± P. We discuss how we assess and monitor a child's emotional, social, behavioral, and academic functioning and development. To highlight unique challenges that exist for children with CL ± P, we discuss our protocol during infancy, childhood, and the adolescent years and provide case examples (referred to as PJ) of children with CL ± P.

INFANT PROTOCOL (BIRTH THROUGH 4 YEARS)

When a child is born, caregivers may experience a mix of emotions. When a child with CL ± P is born, caregivers face additional challenges and stressors and may show a range of reactions to their child's diagnosis such as shock, grief, worry, guilt, and other types of psychological distress (Endriga, Speltz, & Mouradian, 1994). In addition, caregivers of children with CL ± P must try to adjust to the diagnosis while immediately needing to make medical decisions about their child's care. They may also experience uncertainty about treatment and

Courtney Zulauf, MA, is a doctoral candidate in clinical psychology, Psychology Department, University of Illinois at Chicago.

Tawny Spinelli, BA, is a graduate student in the clinical psychology JD/PhD program, Department of Psychiatry and Behavioral Sciences, Northwestern University, Chicago, Illinois.

Janine Rosenberg, PhD, is pediatric psychiatrist at UI Health, Departments of Surgery and Psychiatry, University of Illinois Hospital and Health Science System, Chicago.

The authors report no conflicts of interest.

Address correspondence to Courtney Zulauf, MA, Psychology Department, University of Illinois at Chicago, 1007 W Harrison St, M/C 285, Chicago, IL 60607 (e-mail: czulau2@uic.edu).

DOI: 10.1097/PSN.0000000000000232

intervention as well as stigmatizing attitudes (Nelson, Kirk, Caress, & Glenny, 2012).

> PJ was seen for an initial psychological consult when he was three months old. Early in the pregnancy, PJ's mother was informed that the baby would be born with physical anomalies. Upon hearing the news, PJ's mother stated that she began to question why her son has cleft. She described how she immediately felt guilty because she continued smoking after she found out she was pregnant, and she felt like that might be related to his diagnosis. PJ's mother continued to feel guilty after PJ was born and had a difficult time adjusting to his cleft diagnosis. It was not until after the family met with the craniofacial team, that PJ's mother expressed feeling able to accept the idea that her child would require medical treatment to repair the cleft lip and palate.

Supporting Acceptance

Although caregivers are given the news of their child's cleft diagnosis prenatally or soon after birth, many caregivers require additional time and support to fully process the information and reach acceptance. If caregivers continue to experience hesitance or denial, it not only hinders their own ability to accept the diagnosis but also hinders their child's ability to accept the diagnosis in the future. In contrast, caregivers who work to accept the diagnosis and embrace challenges are more likely to promote and instill confidence, self-acceptance, and increased self-esteem in their child. Therefore, as soon as a child is born, the psychology team's primary goal is to focus on how caregivers are adjusting to their child's diagnosis while also helping caregivers feel supported, process, and eventually accept their child's diagnosis.

The process of caregiver acceptance starts from the day caregivers hear that their child has CL ± P. Feelings of shame may appear immediately upon a child's birth with a mother's inability to breastfeed, especially when a cleft palate is present (Lockhart, 2003). Acceptance may be further challenged when caregivers struggle with how to share the news with family and friends. Especially during infancy, many families who have a child with CL ± P experience frequent negative reactions from friends, family, and the public, adding to their emotional strain (Nelson et al., 2012). For example, family members or friends may not always be supportive and might put the blame on caregivers or may try to explain or impose their beliefs of why the child has CL ± P onto the caregivers.

The psychology team encourages caregivers to discuss the experience of finding out about their child's diagnosis, their feelings and reactions, and how they are currently coping. During this discussion, we try to assess both positive (e.g., acceptance and active coping) and negative (e.g., self-blame and avoidant coping) predictors of adjustment. As was described by PJ's mother, the birth of a child with CL ± P may be accompanied by questions and even self-blame. We try to normalize reactions and help caregivers understand that they are not alone in this process. We check in about social support and, if we believe caregivers would benefit from extra support, find resources in their community such as online or in-person support groups. Regularly assessing and building elements of emotional and social support into care helps reduce potential stigma and promote overall caregiver coping (Beecham, Sloper, Greco, & Webb, 2007; Wong & Heriot, 2008).

Capturing a Child's Story

Just like chubby cheeks, a CL ± P is part of a baby's individuality, and it should not prevent a caregiver from capturing a child's early years. However, for some caregivers who are struggling with acceptance, they may try to hide or deny their child's diagnosis. Caregivers who have not adjusted well may not want to take many or any pictures of their child, especially before their first cleft lip surgery, and may struggle to talk openly about their child's story. In addition, caregivers may get inundated with questions about their child's condition that they may not be ready to answer. Some caregivers may be afraid that sharing their child's story will portray to the child that they are different.

As part of the psychology team, we are receptive to caregivers' reservations about capturing their child's CL ± P story, and we help caregivers work through those hesitations. This means encouraging caregivers to take photographs of their child, go out into public before surgery, and share their child's story with others. Their comfort with answering questions and discussing their child's CL ± P can set the tone for how others respond and also help spread awareness. Caregivers are also encouraged to begin sharing the story with their child as early as toddlerhood, because this helps model how the child may want to tell the story and answer questions about his or her diagnosis. For instance, a caregiver might tell a younger child that he/she was born with a hole in the lip, and doctors helped to fix it. Honest, direct, and open communication with age-appropriate language helps children understand their story from a young age, which in turn helps promote positive outcomes, such as confidence and self-awareness.

> PJ's mother reported that recently he has been asking questions about why his lip "looks different" than other children. PJ's mother reported that she typically responds by showing him pictures from when he was born and explaining that doctors needed to fix his lip.

Educating Caregivers

For caregivers to further accept the diagnosis, offering resources and educating the caregiver about the long-term implications is also essential. For example, we provide caregivers with CL ± P-related pamphlets and websites

(e.g., Cleft line and Children's Craniofacial Association), videos of reconstruction surgical procedures, before and after surgery photographs, and developmental milestone guidelines. These resources allow caregivers to hear other caregivers' stories, gain support, normalize feelings, and better understand the diagnosis. It also helps caregivers better manage and cope with treatment (Franck & Spencer, 2005; Kain et al., 2007). Sometimes at our clinic, we even match caregivers so they can connect with others in a similar situation. Our Craniofacial Center also hosts two annual get-togethers for caregivers and their children who have craniofacial conditions. Not only does this increase social support and well-being for caregivers, but as children get older, they also benefit from meeting and interacting with other children of various ages with identical or similar diagnoses.

A Child's First Surgery

Children with CL ± P typically have their first surgery within the first 6 months of life, and part of the education process for caregivers is to discuss their feelings, concerns, and expectations around their child's first surgical procedures. Many caregivers have conflicting emotions regarding surgery and sometimes become frustrated that providers cannot give them a clear idea of the type and amount of treatment that their child might undergo (Nelson et al., 2012). We encourage caregivers to ask questions and raise concerns to their child's surgeon and nurse team. Furthermore, we have caregivers discuss how they plan to prepare for the surgery and recovery. This includes gathering information about who will take the child to the hospital, who is available to care for the child after surgery, and whether the caregivers have friends or family nearby for support.

Assessing a Child's Development

With any child, the first few years of life are critical for setting a child on a path to developmental success. Children with CL ± P are expected to achieve developmental milestones within expected age limits, with the exception of speech and language skills. Some of these problematic early milestones for speech and language development may include delayed first words, difficulty developing consonants sounds, and delayed vocabulary acquisition (Chapman, Hardin-Jones, & Halter, 2003; Jones, Chapman, & Hardin-Jones, 2003). As the psychology team, we educate caregivers about early warning signs and help emphasize the importance of encouraging receptive and expressive language skills through the use of books, labeling common objects, and encouraging imitations of words. We work closely with our clinic's speech and language pathologist and audiologist, especially during the infancy years, because of the challenges with hearing loss in addition to speech delays (American Cleft Palate-Craniofacial Association, 2018).

Although children with CL ± P are not at increased risk for other developmental delays, we evaluate all areas including cognitive, receptive and expressive language, and fine and gross motor skills by routinely conducting formal standardized developmental testing. First, we test to get a baseline measurement of a child's development and later, to see whether the child is developing at a rate similar to same-age peers. Using testing results, we objectively discuss with the caregivers how their child is developing and recommend activities to foster growth in the home such as increasing tummy time, reading books, or providing infants with hands-on stimulation to practice manipulation and early problem-solving skills. When more significant delays exist, we typically refer the infant to early intervention services, which include speech, occupational, physical, and developmental therapy from birth to 3 years. Once the child ages out of early intervention at age 3 years, the family is referred to their local school where services will continue, if needed.

Some caregivers may need time to process and accept that their child requires additional support. We try to normalize the use of services by expressing to caregivers that between 66% and 84% of children with CL ± P receive speech therapy at some point in their lives (Hardin-Jones & Jones, 2005) and that children benefit from such services (Blakeley & Brockman, 1995). This helps ensure that caregivers receive support and resources for their child as early as possible.

CHILDHOOD PROTOCOL (AGE 5 THROUGH 12 YEARS)

As children develop and enter school, their daily activities widen to include not only the family but also the school and larger neighborhood. As activities become more complex, more nuanced challenges may arise.

Assessing for Learning and School Problems

Because of multiple doctors' appointments, children with CL ± P are more likely to have lower grades and miss more school days (Knight, Cassell, Meyer, & Strauss, 2015). In addition, factors associated with CL ± P may increase the likelihood of learning problems. In particular, specific learning disorders as well as attention-deficit/hyperactivity disorder (ADHD) occur more frequently (up to 35%–40%) in children with CL ± P (Chapman, 2011). Proper evaluation and psychological testing helps determine whether a learning disorder exists and what, if any, school support is needed. However, children in public schools often face long waitlists or experience resistance to receive the formal academic evaluations necessary to provide them with accommodations and services. In addition, schools often do not offer formal testing unless symptoms are severe and/or are upon request from a caregiver. Oftentimes,

caregivers may not know what their rights are within the school regarding a child with special learning needs and, therefore, we provide caregivers with resources, such as handouts that explain the process or sample letters asking for their school to evaluate their child. Caregivers of patients may also be asked to sign release forms, allowing the psychologists to advocate for the child. Once a release is signed, the psychology team reaches out to the school to express our concerns and need for an evaluation, collaborate with school staff to clarify information and make effective recommendations.

If a child has a more complex presentation or a school cannot/is not willing to provide evaluations (i.e., private schools), psychologists are trained in the administration and interpretation of a wide array of assessments, many of which serve as acceptable means to request support and accommodations from schools. During a psychological evaluation, academic functioning, general intellectual ability, attention concerns, and psychological functioning are assessed. Following any psychological evaluation conducted by our team, we meet with caregivers to provide feedback regarding their child's performance and our recommendations. In addition, we write a full report to share with a child's caregiver and school, and to advocate for services if needed.

> PJ's teachers have been concerned about his academics since preschool, and the school has regularly suggested that PJ be held back to give him time to catch up to his peers. PJ is currently receiving mostly Bs and Cs. PJ is reported to spend hours each evening completing his assignments, on top of additional time he devotes toward enhancing his basic skills in reading and math. PJ's mother is very concerned about how he is going to manage as he progresses in school. According to PJ's mother, reading and math have always been most challenging for him. His mother noted that at school and at home, PJ requires new information to be repeated often, only to forget it sometime later. Due to academic concerns, PJ received psychological testing and was diagnosed with Specific Learning Disorder in Reading and in Math.

Qualification for School Accommodations

Through formal testing and diagnosis, it may be determined that a child requires additional school support and qualify for services through an Individualized Education Plan (IEP) or a 504 plan. The psychology team can help provide families with information about what supports are available for their child within the school. Services may include a child being pulled out for one-on-one help, having an in-class learning specialist or aid, accommodations to sit in the front of the class to hear better, or time with a social worker if a child is feeling anxious or is being teased by peers (e.g., because of their cleft). A very common service in the school for children with CL ± P is speech therapy services, which is often offered through an IEP. An IEP is given when a child has a specific learning disorder, other health-impaired diagnosis (such as ADHD), autism, impairments related to speech and language, hearing, vision, or orthopedic, emotional disturbance, intellectual disabilities, or traumatic brain injury. On the other hand, a 504 plan is a formal plan, typically consisting of accommodations, for children who demonstrate physical or emotional disabilities but do not require special education. For instance, children who demonstrate behavioral or issues with attention or psychosocial concerns without any academic concerns may be served with a 504 plan instead of an IEP.

> As a result of the psychological evaluation PJ was provided with an IEP. The IEP included small group pull out services three times a week for reading and math. It also provided accommodations such as extended time on tests, timed tasks, and homework; PJ is also allowed to retest material, wear headphones if he becomes distracted by peers, and has been given an extra set of books to keep at home. Next year PJ will be attending middle school. PJ's mother reported that she is requesting to have PJ's IEP carry over to his new school.

Once the child has accommodations in place, we monitor progress and follow-up as necessary. Sometimes, this requires persistence of the caregivers, along with the psychology team, to work with the school to ensure that a child receives all of the proper services and/or accommodations. Once supports are in place at school, we work with caregivers to discuss ways that they can help reinforce these same goals for their child's development at home (e.g., online reading websites and breaking up instructions into smaller steps).

Preparing a Child for Surgery

After a child receives cleft lip and palate surgical procedures in infancy, their next surgery is usually a bone graft surgery between 8 and 12 years of age. The purpose of this surgery is to help hold a child's adult teeth in place. Oftentimes, a surgery in childhood may be accompanied by a wide array of emotions, because children are old enough now to be aware of what surgery entails. Prior to surgical scheduling, the psychology team meets with the child and his or her caregivers to assess for readiness and discuss the medical necessity for surgery (e.g., functional and speech). This discussion also explores how surgery might impact social, physical, and/or emotional functioning. We encourage the child to ask questions and discuss concerns with the surgeon and nurses, such as missing school or not being able to play sports while recovering. By providing a safe environment to process the child's

emotions as well as expectations toward surgery and recovery, the psychology team helps equip the child to have a more successful outcome. We provide strategies to help the child feel more comfortable in the hospital such as bringing their favorite toy, pillow, or stuffed animal or using relaxation techniques (e.g., deep breathing and visualization) to help ease this process.

Having Children Share Their Story

Children with CL ± P may become increasingly aware of their physical difference, as they enter school and interact more with peers. They may feel self-conscious about how they look or talk compared with others. In turn, the child's peers may also be more aware of the CL ± P, and as peers notice differences, they may begin to ask questions. For many children, school will be the first time they need to answer questions about their appearance and/or speech without their caregiver present. As mentioned earlier, if caregivers accept the diagnosis and openly share the child's story, a child too will feel more accepting and share the story with his or her peers. During each follow-up psychological consultation, we assess the child's understanding of his or her CL ± P. We often have children practice how they might respond to a peer who asks questions. We work with caregivers to teach their child about the CL ± P, even at a young age, as well as to educate teachers and peers. Furthermore, the psychology team explores any barriers that may be keeping a caregiver from talking openly to their child about the CL ± P (i.e., young age of child, fear of response, and cultural differences).

> PJ reported that he is uncomfortable sharing his story about his cleft with others. He tells peers when they ask that he fell off his bike. When asked in session about his scar, PJ still believed that he has it because he fell from his crib when he was young. PJ's mother expressed how as PJ became older she began to feel uncomfortable telling him the truth about his cleft because she was afraid it would make him 'different.'

Peer Teasing

Likely because of appearing and/or speaking differently, children with CL ± P are at increased risk for peer teasing. In one study, 69% of children with CL ± P reported taunting and peer victimization at school, and 84% reported it was directly linked to their CL ± P (Lorot-Marchand et al., 2015). As children develop and move through school, curiosity from peers about the CL ± P may turn into teasing if the child does not know how to respond confidently to questions. As a result, negative interactions with peers may become chronic.

During each visit, the psychology team assesses for peer teasing, and if present, a plan is created to help the child and family cope. First, we encourage children to tell their caregivers and teacher or other trusted adult at the school when an incident occurs. We also teach the child strategies for how to respond to peer teasing using handouts and/or role-playing. Some strategies include ignoring peers, responding with a joke, or having them educate the teaser. This helps turn the focus back to the teaser and educate others about the CL ± P so that the teasing does not continue.

> PJ reported that he has been teased in the past regarding his cleft. He described how classmates have called him "ugly" and have asked him why he talks funny. PJ reported that he told his teacher when he was being teased and the teasing has since stopped. PJ reported that although he no longer is being teased, he worries frequently about the possibility of it reoccurring.

The psychology team also encourages increasing social interactions through extracurricular activities and programs outside of school. If there is a particular hobby or sport that the child expresses interest in, we encourage the family to pursue those activities. This allows the child to meet other children outside of school who have similar interests and gives the child a chance to excel, which boosts self-esteem. Peer social support becomes increasingly important, as the child continues to grow and enters adolescence.

ADOLESCENT PROTOCOL (AGE 13 THROUGH 18 YEARS)

Adolescents are navigating potentially perilous developmental years of transitioning from childhood into adulthood. This is a time when more adult-like challenges are faced without having mastered much-needed tools and cognitive abilities. A number of critical developmental steps occur for all adolescents during this transition period such as social challenges, decisions about life after school, and gaining independence and autonomy. Adolescents with CL ± P are faced with the same developmental milestones as other adolescents without CL ± P, while also facing decisions about medical care. Once patients enter the adolescent phase, we emphasize spending some time with adolescents alone, which allows adolescents to be the focus of their medical care and demonstrates to them that their opinions and autonomy are important.

Empowering an Adolescent's Voice

Up until now, adolescents may feel that their caregivers and medical team made many of the decisions about treatment. In early childhood, many of the procedures and surgeries were medically necessary. However, as children develop, secondary procedures may be elective or predominantly cosmetic. Therefore, adolescents have a choice in whether those procedures take place. Unfortunately, if the doctor and/or caregiver encourages and/or

recommends a surgery, the adolescent may reluctantly accept it despite feeling conflicted or adamant against it. Alternatively, an adolescent may decide to go through with a surgery, but have unrealistic expectations and/or become confused or distressed with the outcome. To avoid this, we encourage adolescents to become more proactive during their care visits by encouraging them to ask questions, raise concerns, and take notes. In doing so, we help adolescents "find their voice" and empower them to share their thoughts and opinions at all medical appointments and potential surgical procedures. The psychology team also assesses the adolescent's perception and understanding of their treatment plan as well as his or her expectation toward surgery and recovery. Providing the adolescent with a voice is increasingly important, because 23% of adolescents with CL ± P feel excluded from making treatment decisions (Lockhart, 2003).

> PJ underwent jaw surgery last spring. PJ stated that he was unsure about how he felt about the surgery. He stated that he was unhappy with the appearance of his jaw after the surgery and he has been discussing with the surgeon another surgery. PJ described how he would like his jaw more aligned and his face to be more symmetrical. PJ's next jaw surgery is scheduled for this fall. In addition to working on the jaw, the surgeon will also shave down his nose during the same surgery. PJ stated that he is ready for surgery even though he knows it will hurt. PJ stated that he knows he cannot predict how his face will look different after surgery but he is still all right with undergoing another surgery. However, he mentioned that during the most recent surgery, he had to take off 3 weeks from school and that it became overwhelming for him when he returned back to school and had to try to catch up.

Social Functioning

The adolescent years are an important time to build relationships outside of one's immediate family. Unfortunately, many adolescents with CL ± P continue to struggle with social interactions and express dissatisfaction with their appearance (Pope & Ward, 1997), and many deal with feelings of being unpopular, anxiety, or unhappiness (Thomas, Turner, Rumsey, Dowell, & Sandy, 1997). The psychology team continues to monitor and foster an adolescent's social functioning and development and similar social recommendations that were provided during the childhood years are also provided now.

Psychological Functioning/Mood

Because of increases in psychopathology during the adolescent years, it is increasingly important to assess for symptoms of psychopathology and variations in mood at each visit (Costello, Copeland, & Angold, 2011). Furthermore, children with CL ± P are at increased risk for psychopathology and are actually two times as likely as noncleft peers to show clinical levels of anxiety and depression (Hunt, Burden, Hepper, & Johnston, 2005; Hunt, Burden, Hepper, Stevenson, & Johnston, 2006). When we work with adolescents, we spend part of the session with adolescents alone in case they are not comfortable sharing all information in front of their caregivers (i.e., drug use and depressive thoughts). Given that suicidal thoughts are common for adolescents with CL ± P, we assess for this as well during each visit (Herskind, Christensen, Juel, & Fogh-Anderson, 1993). Routinely, we have adolescents and their caregivers fill out questionnaires about their mood to gather more information about their current functioning. If we become concerned about an adolescent's mood, we discuss options to address this. Depending on the severity, psychotherapy may be recommended and is offered through our clinic. However, if psychotherapy cannot be provided at our clinic for varying reasons, such as scheduling conflicts or travel time, patients are referred to a location that is more accessible.

> PJ reported that he does not leave the house much and does not find many things enjoyable. He stated that his mood changes from bored to not feeling much. PJ also stated that certain things, like people teasing him, makes him angry. PJ stated that he has trouble sharing his feelings, even with friends. When asked about thoughts of suicide, PJ stated that he has never thought of death until his friend passed away this summer. PJ described feeling unsafe in new neighborhoods as well as on his block. PJ was offered individual therapy as a way of discussing his emotions and coping skills. PJ agreed and stated that he felt relieved to be able to talk to the clinician today. Interestingly, while PJ's mother was in the room, she reported no concerns with mood.

Preparing an Adolescent for Transition of Care

As adolescents turn into young adults, the psychology team plays a critical role in the facilitation of health care transitions. Successful transitions require adolescents to have knowledge and skills that result in improved self-management in adulthood. Common barriers to successful transitions include poor awareness or knowledge of transition, lack of preparation among providers and families, patient/family anxiety, transition based on age rather than readiness, dramatic decrease in resources, insurance coverage changes, and lack of acceptance of their facial appearance. The psychology team helps ensure that a transitioning adolescent has all the information needed and feels comfortable and empowered to have a voice in his or her medical treatment. We verify that not only have they had all necessary medical care but also, they have had all elective surgical procedures they desire. We ensure that the adolescent wants to and feels like her or she is ready to "graduate" from our clinic. Supporting adolescents during this transition is crucial to increasing long-term positive outcomes.

CONCLUSION

Although infants, children, and adolescents with CL ± P face difficulties unique to their congenital anomaly, they all have the potential to live a happy and healthy life. The role of the psychology team is to assess and monitor a child's social, emotional, behavioral, and academic functioning throughout the child's life because wants and needs will change as the child gets older, needs more surgical procedures, and enters different stages of life. This continuous monitoring allows for trust to build between the family and the treatment team and increases the chance for the most positive outcome. Our overarching goal as members of the psychology team is to advocate for the child and to encompass the child's voice throughout development. Working on an interdisciplinary team allows us to collaborate with providers and provide ongoing quality care for children with CL ± P throughout their lifespan. Together, we can give children with CL ± P and caregivers the tools to achieve psychosocial normalcy.

REFERENCES

American Cleft Palate-Craniofacial Association. (2018). *Parameters for evaluation and treatment of patients with cleft lip/palate or other craniofacial differences.* Chapel Hill, NC: Author.

Beecham, J., Sloper, P., Greco, V., & Webb, R. (2007). The costs of key worker support for disabled children and their families. *Child: Care, Health and Development, 33*(5), 611–618.

Blakeley, R. W., & Brockman, J. H. (1995). Normal speech and hearing by age 5 as a goal for children with cleft palate: A demonstration project. *American Journal of Speech Language Pathology, 4*(1), 25–32.

Chapman, K. (2011). The relationship between early reading skills and speech and language performance in young children with cleft lip and palate. *Cleft Palate-Craniofacial Journal, 48*(3), 301–311.

Chapman, K. L., Hardin-Jones, M., & Halter, K. A. (2003). The relationship between early speech and later speech and language performance for children with cleft lip and palate. *Clinical Linguistics and Phonetics, 17*, 173–197.

Costello, E. J., Copeland, W., & Angold, A. (2011). Trends in psychopathology across the adolescent years: What changes when children become adolescents, and when adolescents become adults? *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 52*(10), 1015–1025.

Endriga, M. C., Speltz, M. L., & Mouradian, W. (1994, April). *Change in maternal stress during infancy.* Presented at the annual meeting of the American Cleft Palate-Craniofacial Association, Toronto, Canada.

Franck, L. S., & Spencer, C. (2005). Informing parents about anesthesia for children's surgery: A critical literature review. *Patient Education and Counselling, 59*, 117–125.

Hardin-Jones, M., & Jones, D. (2005). Speech production of preschoolers with cleft palate. *Cleft Palate-Craniofacial Journal, 42*(1), 7–13.

Herskind, A. M., Christensen, K., Juel, K., & Fogh-Anderson, P. (1993). *Cleft lip: A risk factor for suicide.* Presented at the 7th International Congress of Cleft Palate and Related Craniofacial Anomalies; Queensland, Australia, 156.

Hunt, O., Burden, D., Hepper, P., & Johnston, C. (2005). The psychosocial effects of cleft lip and palate: A systematic review. *European Journal of Orthodontics, 27*(3), 274–285.

Hunt, O., Burden, D., Hepper, P., Stevenson, M., & Johnston, C. (2006). Self-reports of psychosocial functioning among children and young adults with cleft lip and palate. *The Cleft Palate Craniofacial Journal, 43*(5), 598–605.

Jones, C. E., Chapman, K. L., & Hardin-Jones, M. A. (2003). Speech development of children with cleft palate before and after palatal surgery. *Cleft Palate Craniofacial Journal, 40*, 19–31.

Kain, Z. N., Caldwell-Andrews, A., Hayes, L.C., Weinberg, M.E., Wang, S.-M., & MacLaren, J., et al. (2007). Family-centered preparation for surgery improves perioperative outcomes in children. *Anesthesiology, 106*(1), 65–74.

Knight, J., Cassell, C., Meyer, R., & Strauss, R. (2015). Academic outcomes of children with isolated orofacial clefts compared with children without a major birth defect. *The Cleft Palate-Craniofacial Journal, 52*(3), 259–268.

Lockhart, E. (2003). The mental health needs of children and adolescents with cleft lip and/or palate. *Clinical Child Psychology and Psychiatry, 8*(1), 7–16.

Lorot-Marchand, A., Guerreschi, P., Pellerin, P., Martinot, V., Gbaguidi, C., & Neiva, C., et al. (2015). Frequency and socio-psychological impact of taunting in school-age patients with cleft lip-palate surgical repair. *International Journal of Pediatric Otorhinolaryngology, 79*, 1041–1048.

Nelson, P., Kirk, S., Caress, A., & Glenny, A. (2012). Parents' emotional and social experiences of caring for a child through cleft treatment. *Qualitative Health Research, 22*(3), 346–359.

Pope, A., & Ward, J. (1997). Self-perceived facial appearance and psychosocial adjustment in pre-adolescents with craniofacial anomalies. *Cleft Palate and Craniofacial Journal, 34*, 396–401.

Thomas, P., Turner, S., Rumsey, N., Dowell, T., & Sandy, J. (1997). Satisfaction with facial appearance among subjects affected by a cleft. *Cleft Palate-Craniofacial Journal, 34*(3), 226–231.

Wong, M. G., & Heriot, S. A. (2008). Parents of children with cystic fibrosis: How they hope, cope and despair. *Child: Care, Health and Development, 34*(3), 344–354.

DOI: 10.1097/PSN.0000000000000240