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Facilitating positive psychosocial outcomes in craniofacial team care: Strategies for medical providers

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Key words: craniofacial conditions; multidisciplinary treatment; psychosocial adjustment; quality of life

Introduction

The treatment of congenital craniofacial conditions is complex and multifaceted, requiring long-term intervention from a wide range of medical providers. In addition to the ongoing burden of care, affected individuals and their families may experience a number of psychological and social challenges. For parents, the diagnostic experience can induce feelings of shock, guilt, and grief, and concerns for their child's future (see Nelson et al., 2012 for a review). Families must adjust to their child's diagnosis, process a wealth of medical information, and prepare for their child to undergo surgical intervention. As the child grows older and enters school, potential concerns center on teasing and bullying, behavioral conduct, medical absences, and educational difficulties, in addition to associated speech and hearing issues (see Stock & Feragen, 2016 for a review). Periods of transition may be particularly challenging, such as moves between schools, and the transfer from child to adult services.

In coping with these challenges, it has been assumed that those patients with the most severe diagnoses would fare the worst. However, research has consistently demonstrated that objective factors, including the severity of the condition, gender, age, and surgical outcomes, are poor predictors of overall adjustment (see Clarke et al., 2013). Rather, it is subjective factors, such as personality characteristics and thought processes, which have the most significant bearing on outcomes. Previous research has also highlighted the significance to patients of positive healthcare experiences, emphasizing the importance of an integral patient-centered approach (see Feragen & Stock, 2017 for a review). Supporting patients and their families to adapt to and overcome the challenges associated with craniofacial conditions is therefore crucial in the facilitation of adjustment, and all medical providers share a responsibility and opportunity to promote positive psychosocial outcomes. Applied psychological research and clinical experience can provide rich insight into the factors that can help or hinder adjustment and offer suggestions for medical providers in practice.

Drawing upon the psychosocial literature and clinical expertise from six centers, this manuscript outlines the nature, prevalence, and variation in psychosocial issues across developmental phases and how these issues can be addressed using a patient-centered multidisciplinary approach. Topics include how to facilitate psychological adjustment in parents, address teasing and bullying, promote academic

achievement, support informed medical decision-making, handle periods of transition, and use available screening measures to assess and monitor patients' wellbeing. The aims of this paper are to improve medical providers' knowledge of psychosocial issues relevant to patients with craniofacial anomalies (CFAs) across the treatment pathway and to offer practical guidance to medical providers in how to monitor and address psychosocial issues. A summary of recommendations is provided in Table 1. Additional resources are provided in Tables 2 and 3.

Parent and Family Adjustment

Importance of the Diagnostic Experience

The promotion of positive psychosocial outcomes in patients and families impacted by CFAs starts as soon as parents are informed about their child's diagnosis, referred to here as the diagnostic experience. The importance of not only what is said but also the way in which this information is conveyed should not be minimized. When reflecting on their diagnostic experience, parents of children with CFAs have consistently expressed several main themes (see Nelson et al., 2012 for a review). First, parents indicated a preference to be counseled about their child's diagnosis as soon as possible, in both verbal and written form. Parents have also reported a need for reassurance that their child's condition is not their fault, as well as for providers to identify which test results are unremarkable. Finally, providers can connect parents with family support organizations, though not all parents will be interested in this opportunity (Byrnes et al., 2003). Parents also identified a desire for medical providers involved in the diagnostic experience to show both empathy and confidence, as well as convey a willingness to try to help parents feel better (Byrnes et al., 2003).

Medical providers can begin to facilitate positive parental adjustment to their child's diagnosis by asking what specific questions they have or what areas they are most concerned about. Additionally, checking in with parents throughout the diagnostic experience to assess understanding, information preferences, and emotional reactions may be helpful. Finally, ending the diagnostic conversation with a clear plan for how parents can obtain additional information may help facilitate positive parental coping.

Timing of Diagnosis

There are advantages and disadvantages to diagnosis occurring prenatally and after birth. Parents who received the diagnosis prenatally often report this allowed for increased understanding of their child's feeding needs, as well as increased preparation for the birth. However, this may also lead to new concerns about "what else" may be found, a question which often remains unanswered until after birth. Parents with prenatal knowledge of their child's condition may struggle to envision what their baby will look like and may experience concerns about bonding with their child. Conversely, parents who receive the diagnosis after birth may experience less uncertainty but have the added challenge of processing the diagnosis and seeking treatment while still recovering from the birth and navigating the first days of parenthood (Davalbhakta & Hall, 2000).

Given these considerations, it may be helpful for medical providers to frame information in the context of the timing of diagnosis. Additionally, medical providers not involved in the diagnostic experience may find it helpful to inquire about what that experience was like for parents. While it is the hope that every parent has a positive diagnostic experience, parents may experience ongoing coping difficulties if this was not the case. Processing this experience can help medical providers understand how the condition is viewed by the family and presents an opportunity to remedy any lasting psychosocial impact.

Parental Coping

No matter when the diagnostic experience occurs, parents often report a range of emotions and most report high levels of positive adjustment and stress-related growth over time (see Nelson et al., 2012 for a review). Social support, effective coping strategies, and acceptance are all predictive of family adjustment. Additionally, financial resources and availability of a trusted confidant can positively impact maternal wellbeing and overall family coping. Medical providers treating children with CFAs are therefore encouraged to inquire about various aspects of parents' wellbeing. Themes of blame and isolation may be warning signs that a family is more at risk of difficulties. Identifying these difficulties allows for the connection of parents with appropriate support resources to address challenges and establish more adaptive ways of coping.

Sibling Coping

Siblings of children with CFAs are an often overlooked group, and it is important to ensure their psychosocial functioning is addressed. Stock, Stoneman and colleagues (2016) found that the presence of a CFA can intensify the bond between siblings. While largely positive, this can also have a negative impact, such as the affected child relying too much on their siblings for support, and siblings engaging in arguments or physical fights to protect the affected child. Families impacted by CFAs may also experience increased competitiveness for attention among siblings and anxiety in siblings regarding the child's medical condition (Stock, Stoneman et al., 2016). Education about the condition and being involved in the family's efforts to cope may lessen these reports of anxiety, yet parents often report needing help to explain the condition to their non-affected children.

Given the potential psychosocial impact on siblings, medical providers should inquire as to how siblings are coping, involve the sibling in care to the extent that they desire and is developmentally appropriate, and involve other clinical support personnel (e.g., social work, child life, psychology) as indicated. It is also important to ensure that siblings know how to answer any questions they receive about the affected child's diagnosis and are prepared for surgeries that will change the appearance of the child.

Social Concerns

Prevalence and Impact of Teasing

Teasing can encompass direct or indirect verbal, relational (e.g., exclusion from social activities), or physical bullying. However, most teasing is verbal, such as name calling. Teasing is important to address, not only for the immediate distress it can cause, but also due to the potential for negative adult adjustment. In the general US population, 35% of youth reported being bullied (Modecki et al., 2014), and children with chronic conditions are as much as five times more likely to experience teasing than their peers (Pinquart, 2017). Among EuroCleft centers, 74% of children reported teasing, predominantly focused on facial appearance, with the highest rates reported among those between the ages of 8 and 11 (Semb et al., 2005).

Due to the frequency of teasing among craniofacial populations and concerns reported by parents from a young age, teasing is important to address in team care. While psychologists or social workers can screen for teasing and related concerns, not all teams have embedded psychosocial providers. All medical providers can link families to social skills groups, camp programs, anti-bullying programs, and/or refer to mental health specialists to address ongoing concerns. In addition, demonstrating empathy and consistent reinforcement of information across disciplines can be helpful.

Use of Neutral and Descriptive Language

One strategy medical providers can routinely follow to support a positive self-image in patients is the use of neutral and descriptive language when discussing diagnoses and treatment, since medical terminology can have potentially stigmatizing interpretations. In line with using person-first language as encouraged by the American Cleft Palate-Craniofacial Association (ACPA), medical providers can avoid terms with negative connotations, such as "defect", "malformation", "abnormality", "disfigurement", and "deformation". Neutral terms can be used while retaining the meaning and precision needed (e.g. replacing "birth defect" with "congenital diagnosis"). Providing a description of a medical term can also make information more accessible for children and families (e.g. explaining "alveolar ridge defect" as an "opening in the bone in the gum line"). Similarly, replacing lip/palate "repair" with "surgery", and saying "close" rather than "fix" remains accurate without unintentionally implying that a child is somehow "broken". Families and children often mirror the language used by their medical providers, and this subtle shift can positively impact their identity development.

Responding to Questions and Comments

Simple descriptive language is also important when coaching patients and families about how to explain diagnoses and respond to questions, which can be misinterpreted as having a negative or teasing intent. Preparing families for the likelihood that most people will be unfamiliar with CFAs and may ask questions out of curiosity can assist families in having a more positive interpretation of these situations. Starting with the prenatal consultation or infant visit, medical providers can teach families to practice a response that describes the diagnosis, provides reassurance, and changes the subject (see Clarke et al., 2013). Responses

should be given while demonstrating confident nonverbal communication, including a friendly tone of voice, eye contact, and good posture while smiling (Clarke et al., 2013). A response for a sibling questioned by a peer at the park might be "My brother was born with his lip and the top of his mouth open. The doctors closed it and he's doing great. I'll race you to the swings!" A kindergarten child with anotia might respond "I was born without this ear and I can hear you really well with my hearing aid. I like your backpack – where did you get it?" An elementary school child questioned about their speech could respond "I was born with my lip and the top of my mouth open. It's closed now and I'm practicing some sounds in speech therapy. What do you think will be on the history quiz tomorrow?" Medical providers should encourage families to generate responses and role-play using confident nonverbal communication.

Medical providers can also assist families by reframing teasing from being centered on the patient to clarifying that people who engage in teasing are demonstrating they have problems of their own through their negative behavior. This step is important so patients do not internalize blame for other's behavior. Family members can encourage children to practice independent coping skills, while team providers can acknowledge that parents will want to protect their children. Other responses could include active ignoring with confident nonverbal communication, leaving the situation, seeking out friends' support, telling the person to stop, using friendly humor, and/or getting help from an appropriate adult (Clarke et al., 2013). In cases when teasing persists or there is physical risk, children should be coached to tell a trusted adult immediately. When schools are not responsive to child and family concerns, teams can assist in advocating for patient rights with school systems.

Cyberbullying

Cyberbullying is reported by about 15% of the population through a variety of online platforms (Modecki et al., 2014) and should also be screened for and addressed in craniofacial visits. Medical providers can help families develop monitoring plans for their children's online presence. Accounts can be deleted, users blocked, and content removed by contacting platform administrators or advocacy pages. Many US states utilize school systems to respond to cyberbullying, but law enforcement involvement may be needed in cases of harassment or physical threats.

School Issues

Cognitive and Academic Outcomes

Children with CFAs may experience health and treatment-related challenges that impact their school experiences, including absences, developmental delays, learning disabilities, hearing impairment, fine and gross motor difficulties, and other mood and behavior concerns (see Richman et al., 2012 for a review). Studies have demonstrated that while children with CFAs exhibit an overall average range of intelligence, they may be at increased risk for cognitive and behavioral deficits associated with lower school achievement and increased need for academic support (Richman et al., 2012). Children with complex CFAs and syndromes are often at increased risk for learning issues, in addition to any difficulties with social functioning due to differences in appearance, communication deficits, or other medical factors (Feragen & Stock, 2014). A thorough understanding of these risks and available resources is critical to ensuring optimal performance in the school setting.

Assessment

Ongoing assessment of school functioning is critical to optimizing children's educational experience. Rather than asking "How's school?" or taking a parent report at face value, asking more targeted questions provides a better understanding of child's school functioning. Medical providers are encouraged to ask about children's type of school setting and classroom, strengths and challenges in school, academic performance, and formalized learning support plan, as well as impressions of the quality and quantity of supports provided. Depending on family report or team recommendations, additional evaluation and school support services may be warranted.

There are three primary types of testing that may be recommended. Though the tests have considerable overlap, they each evaluate unique areas of concern. For issues related to academic progress at school, psychoeducational testing is essential. This is typically performed within the school district, often by a school psychologist. Psychoeducational testing assesses academic areas and may identify learning disabilities or needs for classroom accommodations. For children with more complex problems,

neuropsychological evaluation may be indicated. Neuropsychological testing assesses brain/behavior relationships, including memory, language, visual perceptual skills, fine motor skills, attention, and executive function. For children whose school performance is affected by emotional or behavioral functioning, as in the case of anxiety, mood or behavior disorders, psychological testing may be indicated.

School Support

Children in the US have a legal right to free and appropriate public education under federal law. The Individuals with Disabilities Education Act (IDEA) covers school-age children with 13 designated disabilities: specific learning disability, other health impairment (including ADHD), autism, emotional disturbance, visual impairment, deafness, hearing impairment, deaf-blindness, orthopedic impairment, intellectual disability, traumatic brain injury, and multiple disabilities. The child's disability must impact their educational performance and is addressed with a specialized Individualized Education Program (IEP). The law outlines the IEP process, including the team members, timelines and procedures for evaluation, determination of eligibility for services, writing and finalizing the IEP, implementation, annual review, and re-assessment every three years. Monitoring scholastic performance and ensuring an IEP is in place is particularly important for patients who may be transitioning between multiple schools. As a consistent and regular part of the child's life, medical providers play a key role in school communication.

Another federal law is Section 504 of the Rehabilitation Act of 1973, which protects the educational rights of individuals with a physical or mental condition that affects their functioning in a major life activity, such as hearing, seeing, speaking, learning, and self-care. A 504 Plan is developed so a child with a disability receiving federally-funded education has the accommodations for their academic progress. These plans are typically created by teachers, parents, and principals. Unlike an IEP, there is no standardized 504 Plan format or timeline for re-evaluation, though many schools create a written document that is re-assessed periodically.

Examples of services that may be a part of an IEP and/or 504 plan can include pull-in or push-out learning support, full-time special education classroom, reduced workload, speech therapy, hearing support (e.g., preferential seating, FM system), vision support (e.g., preferential seating, large print, audio books),

physical therapy, mobility, and accessibility, occupational therapy for support with handwriting or functional independence, testing accommodations (e.g., additional time, quiet testing room, oral exams), nursing support, or behavioral support (e.g., 1:1 aide, counseling, behavioral plans).

The types, quality, quantity, and setting of services can vary greatly depending on the child's needs and their educational setting. Public schools receiving federal funding are legally required to provide educational support services, while students in private or parochial schools may face challenges accessing services depending on the school's resources. Medical providers therefore play a critical role in advocating for patients' rights to educational services. During routine team evaluations, the team psychologist, social worker, or other psychosocial provider should assess the child's level of educational functioning, including whether the child has an IEP or 504 Plan and what services are covered. It can be beneficial to have multidisciplinary teams document the need for services in the school setting, to provide letters of medical necessity, and to support families as they advocate for school services.

Treatment Decision-Making

Social Determinants of Health

When a family enters the world of medical treatment, they are changed. Psychosocial assessment therefore includes collecting information and developing a general sense of how a family sees the world early on to build an understanding of how the family responds to challenges. The basics of a psychosocial assessment often focus on the social determinants of health (SDH). The World Health Organization defines SDH as: "the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. SDH are mostly responsible for health inequities; the unfair and avoidable differences in health status seen within and between countries." Medical providers need to balance family SDH information with the details of their patient's treatment. Medical providers are encouraged to incorporate their understanding of patient's SDH into their treatment recommendations along with patient and family expectations of outcomes, which can vary from changes in function to perceptions of appearance.

Assessing Readiness for Surgery

In addition to surgeries aimed at improving function, teams have to consider suitability for surgeries which alter appearance. As the decision for a newborn's primary lip closure is made by the parents/legal guardians, medical providers need to provide families with information on the risks and benefits of the surgery, in addition to assessing parental expectations, anxiety, and coping strategies. For most families, it is generally understood that the risks involved with anesthesia and surgery are less than the anticipated benefits of decreased facial difference, increased functionality, and improved quality of life.

As patients grow older, however, their own perspective of their appearance needs to be central. In addition to framing the surgery as a way to decrease facial difference and prevent or reduce bullying, medical providers need to assess the patient's broader environment. That is, teams need to help assess if bullying can be addressed solely through surgery. Medical providers need to learn more about the origin of the problem and ensure that other interventions, such as counseling and collaboration with the school, are being implemented. Medical providers must remember that each surgery introduces physical risks, and patients' surgical motivations and expectations have to be carefully weighted (see Aspinall, 2010 for a review).

Part of the psychosocial assessment performed when a surgery is recommended is determining if the patient and their family actually identify a problem to be treated. A key concern is that a surgery will be sought solely to prevent anticipated future bullying. If this is the framework, the motivation may be based on fear, and may reflect unrealistic expectations of social situations that are part of typical childhood and adolescence. If the medical team's impression is that the patient does not perceive a concern or that parental perspectives are unrealistic, then the weighing of risks and benefits may need to be revisited.

Treatment Burden

Another part of receiving medical treatment is the ongoing burden of care, which can vary widely. Private insurance often has gaps in coverage, leaving leftover costs to be paid by families. Extended parental absence from work is protected by the Family Medical Leave Act, but there is no mandate that time off for regular clinic visits is paid or excused. Families also have bills from the child's birth, child care, and lost wages. Adding a child to parental insurance can also be costly. There are situations in which insurance

coverage may be lost when one parent decides to stay at home. Other financial costs to the family are related to the time spent and distance traveled to access care. Families may struggle to find transport or money for gas, and potentially, local lodging if traveling from a distance. Other important considerations are the educational and social consequences for the patient for missing school and extracurricular activities. Families may miss important family gatherings, and many patients sacrifice their school holidays for treatment on more than one occasion. At the time when treatment recommendations are being processed by patients and families, it is therefore extremely helpful if medical providers already have a full understanding of the context in which a family's decisions are made.

Transition

Barriers to Transition

Within healthcare, transition is defined as the purposeful, planned movement of young adults with chronic conditions from child-centered to adult-oriented health-care systems (Blum et al., 1993). Successful transition requires learning and practicing skills during adolescence that result in improved self-management in adulthood. Craniofacial team care is therefore critical in the facilitation of healthcare transition. Unfortunately, there are multiple potential barriers to transition, including poor understanding of the transition process, lack of preparation, and a lack of dedicated transition staff to advocate for patients. In addition, patients and families may experience anxiety and have unrealistic expectations of self-management skills, particularly when transition timing is based on age rather than readiness. In most settings, there are systemic differences in pediatric and adult medicine and often a dramatic decrease in resources and insurance coverage. In light of these barriers, adolescents with chronic conditions are generally not referred in a timely or systematic manner to providers who can offer primary and specialty care (Betz, 1998).

Transition Assessment and Support

Adolescence, independent of health status, is a process of transition, but a medical diagnosis adds to its complexity and importance. Puberty, autonomy, personal identity, sexuality, education, and vocational

choices may all be influenced by the condition. Additionally, pain, medical stressors, appearance concerns, and perceived prognosis can present additional challenges and may contribute to unmet needs in adulthood (Blum et al., 1993). Continuous assessment and support of transition readiness can be incorporated throughout the continuum of comprehensive craniofacial care. In infancy, medical providers can encourage familial record-keeping of medical and early intervention services. In early childhood, caregivers and medical providers can teach children basics about their diagnosis and healthcare needs and model active participation in their care. During the school years, caregivers can encourage children to practice direct interaction with their medical providers. School-age patients should also be encouraged to participate in planning decisions about their care, such as timing surgeries around their academic and extracurricular activities.

Transition support for adolescents should begin with the assessment of the patient's perception and knowledge of their diagnosis and treatment plan. Patients should be encouraged to proactively participate in their care visits by prompting them to ask questions and practice taking notes about their treatment plan. They can also be assisted with tracking their health history, such as reviewing past team recommendations or by creating a health passport or care binder. Adolescent patients can also be encouraged to schedule their own appointments and follow-up care. Promoting adherence, particularly for orthodontic and orthognathic surgery preparation, is vital at this age.

In young adulthood, patients should be supported to identify suitable adult medical providers and should have access to staff who can help review adult healthcare coverage options. Additional strategies that are useful with transition planning at this stage include discussion of educational and professional goals, considering educational services and supports beyond high school graduation, exploring college student disabilities services and resources, and referrals to government-based agencies for job training and placement. It is also important to discuss and assist in completion of Advance Healthcare Directives within the family context so that parents can understand the transfer of legal rights to their adult children. For patients with intellectual disability or significant cognitive delays, medical providers should address the possible need for a legal agreement allowing family members to retain the right to make healthcare and life

decisions. In such cases, patients may also qualify for additional community or government assistance, such as Social Security Disability.

Screening Tools

Standards of Care

Due to the known psychosocial risks associated with CFAs, the ACPA Parameters for Evaluation and Treatment (see ACPA, 2018) recommends routine psychosocial screenings beginning in infancy and continuing through discharge. Additionally, the ACPA Commission on Approval for Teams recommends that social workers and/or psychologists are embedded in teams, or at least that referrals to these professionals are made, to address the psychosocial needs of patients and their families (see ACPA, 2016). Screenings can also be conducted by professionals from a variety of disciplines, including nursing and pediatrics.

Currently, there are no standards for conducting assessments and how and when they are conducted varies considerably between and even within teams. There are often issues with resources and funding, which can make it difficult to provide screenings for all families at every visit. Assessment of psychosocial risk factors in a systematic manner has also been hampered by a lack of craniofacial-specific screening instruments and by time constraints or lengthy scoring protocols required for some measures. Given these barriers, many teams rely upon an interview-based approach to screen for psychosocial concerns. In this instance, the team social worker or psychologist conducts a brief interview with families to assess for a variety of risks and tailors the interview content based on the child's age, diagnosis, and other relevant factors (e.g., new versus established patient). Interviews typically involve caregivers and increasingly involve the child as they grow and develop. However, this mode of screening may not be feasible for teams whose access to psychosocial specialists are referral-based.

Recently, much work has been done to identify instruments that can be used to assess psychosocial outcomes of craniofacial care, many of which are also appropriate to use for clinical audit and/or screening purposes. Table 3 provides an overview of the content areas and instruments that have been used in

craniofacial populations to assess domains of functioning. The instruments featured here have been recommended by Americleft (see Crerand et al., 2017), the International Consortium for Health Outcomes Measurement (see Allori et al., 2017), and the ACPA Global Task Force for Holistic Outcomes (see Stock, Hammond et al., 2016). Cost, length, availability of parent and self-report versions, multiple languages, and psychometric properties (reliability and validity) were all factors in selecting these instruments. Consideration was also given to identifying instruments that assess both craniofacial-specific and general psychosocial concerns.

Practical Aspects of Screening

There are several practical aspects that need to be considered when selecting a screening approach, including which domains of functioning are deemed most critical to assess (e.g., caregiver mental health in parents of new babies; parent and patient perceptions of psychosocial functioning in childhood and adolescence). Second, consideration needs to be paid to how screening will be integrated into a clinic visit (e.g. who administers, scores, and enters data and where data is stored). A related concern pertains to management of any acute safety concerns (e.g., self-harm or abuse) that could be identified by an instrument. Medical providers should ensure that a plan is in place to manage such crises. Time is also a significant consideration, for example, when will parents or children be asked to complete these instruments? Will questionnaires be administered electronically or on paper? How will the added time affect clinic flow? Finally, while some instruments are free, others may have annual licensing fees and/or scoring programs which need to be purchased.

Examples of Screening Measures

Table 3 provides an overview of screening instruments recommended for use in craniofacial populations to assess quality of life, emotional and behavioral functioning, and competence. These include the Edinburgh Postnatal Depression Scale (EPDS; Cox, et al., 1987), which has been recently successfully integrated into assessments of infants presented for craniofacial treatment; the Pediatric Quality of Life Inventory (PedsQL; Varni, et al., 2001); Patient-Reported Outcomes Measurement System (PROMIS; Ader, 2007); Child Behavior Checklist (CBCL; Achenbach and Rescorla, 2001); and Strengths and Difficulties

Questionnaire (SDQ; Goodman, 2007). Additionally, two newly developed craniofacial-specific instruments that can be used for screening purposes have been proposed, including the Psychosocial Assessment Tool-Craniofacial Version (PAT-CV; Crerand, et al., 2018) and the CLEFT-Q; Klassen et al., 2018), both of which have been recently established as psychometrically sound and clinically useful.

Conclusions

This paper has drawn upon available literature and clinical expertise to outline key psychosocial issues across developmental phases and to offer guidance to medical providers as to how these issues can be addressed using a patient-centered multidisciplinary approach. A number of practical suggestions have been made. First, it is imperative to communicate treatment plans as clearly, consistently, and sensitively as possible. It can be difficult for patients and families to process and retain information when they are feeling stressed or overwhelmed. It is therefore important not to hurry them and to repeat information if necessary. It is essential for providers to be empathic, to listen to and normalize patients' and families' concerns, and to take those concerns seriously. The use of neutral or descriptive language and the avoidance of negative connotations are also important considerations.

Second, medical providers have a valuable opportunity to empower their patients and families. By supporting care coordination and providing referrals to other health professionals and organizations, providers can enable patients and families to be better informed and to take more control of their care. Encouraging patients to use confident and assertive verbal and non-verbal communication to address any teasing, comments, and questions positively can help to improve social interactions, avoid unnecessary confrontation, and improve patients' confidence in social situations. In addition, medical providers can support patients before, during, and after key transition periods to ensure patients are prepared and can utilize positive coping strategies. The facilitation of authentic shared decision-making between clinicians, patients, and families is crucial so that patients feel their voice has been heard and to avoid creating an unnecessary burden of care.

Finally, every member of the multidisciplinary craniofacial team can help to identify those patients and families who may be struggling, and who may benefit from additional support. The routine use of

appropriate screening measures to assess and monitor psychosocial issues can assist in this endeavor, and resulting data can help medical providers to build a case for an increase in psychosocial resources. Having an agreed upon multidisciplinary team plan in place will help to address any issues that arise.

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Table 1: Summary of Recommendations

Area of Concern	Recommendations
Parent and Family Adjustment	• Counsel parents about their child's diagnosis as soon as possible, in both verbal and written form • Provide reassurance that their child's condition is not their fault • Ask parents what they are most concerned about and whether they have any specific questions • Assess parents' experiences, understanding, information preferences, and emotional reactions throughout the diagnostic process • Frame information in the context of the timing of the diagnosis • Offer to connect parents with support organizations and provide a clear plan for how parents can obtain additional information • Show empathy, consistency of information, and confidence • Continue to assess key aspects of parental wellbeing over time and known risk factors for distress • Educate and involve siblings in the healthcare process where possible
Social Concerns	• Link families to social skills groups, camp programs, anti-bullying programs, and/or refer to mental health specialists • Use person-first language • Utilise neutral and descriptive terminology when discussing diagnoses and treatment • Teach families to practice confident verbal and nonverbal communication to address unwanted questions or comments • Reframe staring and questions as curiosity, rather than a threat, and refocus teasing/bullying on the individual carrying out the teasing • Advocate for patient rights within the school system if schools are not responding effectively to social concerns • Support families to monitor their child's online presence to minimise the risk of cyberbullying
School Issues	• Comprehensively inquire about key aspects of the child's school experiences • Ensure that psychoeducational, neuropsychological, and emotional and behavioural assessments are conducted as indicated • Communicate with schools to ensure that scholastic performance is being monitored appropriately, and that there is an Individualized Education Program and/or 504 Plan in place as needed • Advocate for patients' rights to effective educational services
Treatment Decision-Making	• Incorporate an understanding of social determinants of health in treatment recommendations • Provide information on the risks and benefits of surgery and balance these carefully with patients' and parents' motivations and expectations • Assess patients' and parents' level of anxiety and available coping strategies • Assess the burden of treatment when making medical decisions, including insurance coverage, work and school absences, and social impacts

Transition	• Encourage parental record-keeping of medical and intervention services in infancy
	• In early childhood, provide patients with basic information about their condition and healthcare needs, and model active participation
	• Support school-age patients to directly interact with medical providers and encourage them to participate in treatment decision-making
	• Encourage adolescents to track their health history and schedule their own appointments, in addition to promoting treatment adherence
	• Support young adults with the transition to adult care, including the identification of suitable medical providers and a review of healthcare coverage options
	• Assist in the completion of Advance Healthcare Directives to transfer legal rights from parents to adult patients
	• Refer patients and parents to additional community and/or government assistance where indicated
Screening Tools	• Become familiar with standards of care
	• Refer patients and families to psychosocial specialists where possible
	• Utilise recommended screening tools in the routine assessment of psychosocial aspects of care

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Table 2: Additional Resources

Area of Concern	Resources
Parent and Family Adjustment	Sibling resources: https://www.siblingsupport.org/sibshops Books: *What about me? When Brothers and sisters get sick* Alex Peterkin *Anna's Special Present* Yoriko Tsutsui *Our new baby needs special help* Gail Klayman *When Molly was in the Hospital: A Book for Brothers and Sisters of Hospitalized Children* Debbie Duncan *The Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs* Don Meyer *Views from Our Shoes: Growing up with a Brother or Sister with Special Needs* Don Meyer *Special Brothers and Sisters: Stories and Tips for Siblings of Children with Special Needs, Disability or Serious Illness* Monica McCaffrey and Annette Hames *The Other Kid: A Draw It Out Guidebook for Kids Dealing with A Special Needs Sibling* Lorraine Donlon
Social Concerns	Help with Social Situations. (Heppner et al., 2018). ACPA Family Resources: www.cleftline.org Tools to handle questions and teasing. (Kammerer Quayle, 2001). *Burn Support News*. Grand Rapids, MI: Phoenix Society for Burn Survivors. School-based/classroom bullying prevention programs: www.stopbullying.gov Reporting cyberbullying: www.cyberbullying.us/report
School Issues	Learning Disabilities Association of America: www.ldaamerica.org International Dyslexia Association: www.dyslexiaida.org Learning and attention disorders: www.understood.org Education Law Center: www.edlawcenter.org US Department of Education: www2.ed.gov/about/offices/list/ocr
Treatment Decision-Making	ACPA treatment and care booklets: https://cleftline.org/family-resources/booklets-fact-sheets CCAKids fact sheets: https://ccakids.org/wp-content/uploads/2017/09/one-sheet_helpingyourchild.pdf and https://ccakids.org/wp-content/uploads/2017/09/one-sheet_before-aftersurgery.pdf
Transition	Health passport (Wolfstadt et al., 2011): www.sickkids.ca/myhealthpassport Transition Readiness Assessment Questionnaire (Wood et al. 2014): www.rheumatology.org/Portals/0/Files/Transition-Readiness-Assessment-Questionnaire.pdf Transition Timeline for Children and Adolescents with Special Health Care Needs (Kinsman, 2002): www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/TransitionTimeline-ChronicIllnessAndPhysicalDisability.pdf
Screening Tools	See Table 3

Table 3: Screening Instruments for Use in Craniofacial Populations

Measure	Description	# Items	Versions	Cost	How to Obtain
General Population Instruments					
Edinburgh Postnatal Depression Scale[1]	Screen for postpartum depression symptoms, which can impact attachment and infant bonding	10 items	Parent-report	Free	Published in Cox et al., 1987
Pediatric Quality of Life Inventory (PedsQL 4.0)[1-3]	Assessment of health-related quality of life related to physical, emotional, social, and school functioning; a family impact module (FIM) is also available to measure impact of pediatric chronic health conditions on families	23 items (PedsQL); 36 items (FIM)	Parent- (2+ y) and child-report (5 y+)	License fee depending on use (e.g., funded research)	http://www.pedsql.org
Patient-Reported Outcomes Measurement Information System (PROMIS)[1,2]	Person-centered measures that evaluate physical, mental, and social health (e.g., anxiety, depression, stigma)	Differ depending on content area being assessed	Parent-proxy (5-17 y) and child report (8-17 y)	Free	http://www.healthmeasures.net/explore-measurement-systems/promis
Child Behavior Checklist and Youth Self-Report[1,2]	Assessment of children's externalizing problems (e.g., noncompliant, disruptive), internalizing problems (e.g., withdrawn, anxious), and competence (e.g., school, activities, social)	118 items	Parent-report (CBCL 1.5 y+) and child-report (YSR 11 y+)	Scoring program and license fee	http://www.aseba.org
Strengths and Difficulties Questionnaire[3]	Screening instrument to assess positive and negative attributes in several domain including emotional symptoms, conduct problems, and hyperactivity/inattention	25 items	Parent-report and child-report (11 y+)	Free	http://www.sdqinfo.com
Craniofacial-Specific Instruments					
Psychosocial Assessment Tool-Craniofacial Version (PAT-CV)[1,2]	Brief screener of psychosocial risk in 8 domains, including family structure and resources, social support, and child and family problems; the PAT-CV was adapted for the craniofacial population with relevant questions about speech, hearing, vision, teasing, appearance concerns, and social problems; families are classified into three risk categories—universal, targeted, or clinical	84 items	Parent-report	License fee required	http://psychosocialassessmenttool.org

| CLEFT-Q[1,2] | Instrument for patients with CL/P to evaluate outcomes related to satisfaction with appearance (cleft lip scar, face, jaws, lips, nose, nostrils, and teeth), health-related quality of life (psychological, school, social, speech-related), and facial function (eating/drinking, speech) | 119 items; individual subscales may also be administered | Patient-report (8-29 y) | Free | https://www.flintbox.com/public/project/31280 |

[1]Endorsed by Americleft (Crerand, et al., 2017); [2] Endorsed by ICHOM (Allori, et al., 2017); [3] Endorsed by the

ACPA Global Task Force for Holistic Outcomes (see Stock, Hammond et al., 2016).