**Pediatric Medical Traumatic Stress in Individuals with Craniofacial Conditions**

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**Abstract**

Purpose: This article reviews the literature focused on the psychological effects of craniofacial care for patients and their families. It provides an overview of pediatric medical traumatic stress associated with craniofacial conditions and related care along with a review of its risk and protective factors. Findings from studies of pediatric medical traumatic stress in craniofacial populations are also reviewed.

Conclusion: The article concludes with strategies for identifying, addressing, and preventing medical traumatic stress in the context of craniofacial care. Specific implications for speech language pathologists are also shared with respect to ways of minimizing risks for medical traumatic stress in craniofacial care. Future directions are also delineated and include strategies to improve screening and support for patients with craniofacial conditions and their families, along with the development of interventions aimed at increasing resilience.

*Key Words*: Craniofacial conditions, medical traumatic stress, resilience, treatment

Craniofacial conditions are among the most common congenital diagnoses in the world and can occur either in isolation or as part of a syndrome.(Dixon et al., 2011; Seto-Salvia & Stanier, 2014). Cleft lip with or without cleft palate (CL/P) is the most prevalent craniofacial condition and affects one in every 1000 to 1500 live births globally (Salari et al., 2021). Other common craniofacial conditions include premature fusion of the skull sutures (craniosynostosis) and underdevelopment of the jaw and/or ear (pharyngeal arch disorders), which are diagnosed in 1:2,500 (Shlobin et al., 2022) and 1:6,000 (Hennekam et al., 2010) live births, respectively. Another common diagnosis that can include a cleft palate is 22q11.2 deletion syndrome, which occurs in 1 in every 2,148 births (Blagojevic et al., 2021).

Craniofacial conditions can be associated with a range of functional and aesthetic concerns which can impact quality of life and psychosocial functioning. For example, anatomic abnormalities of the palate, jaw, and occlusion can result in reduced speech intelligibility and affect communication and social interactions (Losee & Kirschner, 2016). Similarly, the visible differences in appearance that are common in craniofacial conditions can negatively impact self-perceptions and increase risks for negative social attention and bullying (Alansari et al., 2014; Rumsey & Harcourt, 2007; Strauss et al., 2007). Families are also at risk for psychosocial concerns, which can include caregiver distress (e.g., grief, anxiety) related to the child’s health and condition-related psychosocial risks (e.g., worries about future peer acceptance and teasing related to the child’s differences) (Berger & Dalton, 2011; Despars et al., 2011; Stock & Rumsey, 2015; Stock et al., 2016). Additionally, surgeries, ongoing medical evaluations and therapies often result in substantial time and financial burdens, particularly when families must travel significant distances to access care (Cassell et al., 2013; Cassell et al., 2014; Long, 2016). Negative effects on caregiver psychosocial adjustment (Nidey et al., 2016; Stock, Costa, et al., 2020) can impact child adjustment during preschool and school-age years (Pope, Tillman, & Snyder, 2005; van Dalen et al., 2021; Wolodiger & Pope, 2019).

Children with craniofacial conditions are ideally treated by interdisciplinary teams (American Cleft Palate-Craniofacial Association, 2018). Care frequently begins in infancy and continues throughout adolescence and young adulthood. Treatment protocols typically include longitudinal evaluations and staged surgical procedures to address both form (aesthetics) and function. Significant variation exists in the number of surgical procedures children with craniofacial conditions receive owing to individual needs and variation in team protocols (Semb et al., 2005).As an example, most protocols for CL/P include the following 4 standard surgeries: cleft lip surgery, cleft palate repair, placement of tympanostomy tubes, and an alveolar bone graft. However, it is not uncommon for children born in the U.S. to have greater than 8 cleft-related surgeries by early adulthood, including lip or nasal revisions, secondary palate procedures to address velopharyngeal insufficiency or palatal fistula, and jaw surgery to address malocclusion (McIntyre et al., 2016; Losee & Kirschner, 2016). These children often receive other interventions, including pre-surgical orthopedics, extended or repeated orthodontic treatment, and speech therapy which can add to their overall burden of care (Losee & Kirschner, 2016).

Research on children with special healthcare needs demonstrates that treatment demands involving ongoing medical monitoring, hospitalizations, surgeries, and other interventions can adversely affect the psychological well-being of the child, caregivers, siblings, and extended family (Christofferson et al., 2020; Dewan et al., 2023; Pinquart, 2017; Stanzel & Sierau, 2021). While intermittent mild to moderate levels of physical and emotional distress can be viewed as ‘typical’ responses to abnormal situations, chronic distress may be associated with pediatric medical traumatic stress (PMTS) (Lim et al., 2019; Pinquart, 2017; Price et al., 2015).

According to the National Child Traumatic Stress Network, PMTS is defined as “psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences” (National Child Traumatic Stress Network, 2022). PMTS is a broad, inclusive term that is used to describe a continuum of post-traumatic stress symptoms such as intrusive thoughts about the diagnosis and/or its treatment; feeling distressed by these thoughts or reminders; nightmares; avoidance of thinking or talking about the experience; and hyper-arousal including irritability, problems concentrating, or feeling on edge (National Child Traumatic Stress Network, 2022). In some instances, these symptoms may be severe enough to meet formal diagnostic criteria for post-traumatic stress disorder (PTSD). A formal diagnosis of PTSD can be made when arousal, avoidance, and re-experiencing symptoms persist for longer than a month after the exposure to the medical traumatic event(s) and cause clinically significant distress or impairment in day-to-day functioning (American Psychiatric Association, 2022). PMTS also encompasses post-traumatic stress symptoms that may be less severe or occur less frequently than required for a formal PTSD diagnosis but nonetheless can have a potentially detrimental impact on children and/or their families (Kazak et al., 2005).

Post-traumatic stress symptoms associated with PMTS can occur if the healthcare experience involved pain, significant illness or threat to life, invasive or distressing treatment procedures, or was perceived of by the child and/or caregivers to be frightening or overwhelming (De Young et al., 2021; Kassam-Adams et al., 2013; Kazak et al., 2005; DeYoung et al., 2021).PMTS can persist through adulthood for individuals who experience traumatic medical experiences at a young age (see Kazak et al., 2005 for a review). Given that individuals with craniofacial conditions and their families often experience intensive and painful medical and surgical interventions throughout infancy, childhood, and adolescence, it is increasingly important to understand risks for PMTS in this population. While the burden of care associated with craniofacial conditions has been explored (e.g., Cassell et al., 2013; Cassell et al., 2014; Long, 2016), considerably less attention has been paid to the psychological effects of craniofacial care on patients and their families.

This paper reviews the psychological impacts of craniofacial care on patient and caregiver well-being, with additional exploration of PMTS, including risk and protective factors. This review highlights the importance of further work on PMTS in craniofacial settings, and offers discussion of clinical implications, with an emphasis on the role of speech and language pathologists and other health care providers in preventing and identifying PMTS. In this review, we primarily focus on PMTS through adolescence although we acknowledge that medical experiences can be associated with traumatic stress reactions in adults (e.g., Righy et al., 2019) and that PMTS can persist through adulthood for individuals who experience traumatic medical experiences at a young age (e.g., Kazak et al., 2005).

**Psychological Impacts of Craniofacial Care**

From the point at which caregivers become aware that something may be different about their child’s physical health and/or appearance, they embark on a long treatment journey. Some families struggle to obtain a diagnosis, particularly in the case of rare craniofacial conditions, which can be highly stressful (Costa, Edwards, et al., 2022; Luquetti et al., 2018; Tierney et al., 2015). The diagnostic experience itself has been described as emotionally complex (Costa, Edwards, et al., 2022; Johns et al., 2023; Nelson et al., 2012) and exacerbated by distressing interactions with healthcare providers and/or a lack of reliable information (Costa, Edwards, et al., 2022; Kancherla et al., 2009; Nusbaum et al., 2008). Preparing and going through surgery often involves difficult decisions and conflicting emotions, parental fear about the risks involved, as well as the need to cope with potential post-surgical reactions in the child (Feragen, Rumsey, et al., 2017; P. A. Nelson et al., 2012; Zerpe et al., 2022). Over time, and despite a generally high level of satisfaction with healthcare, many caregivers report feeling overwhelmed by the burden and complexity of care. This can include the volume and coordination of appointments, travel, the impact of healthcare demands on caregivers’ finances and employment status, hospitalizations and the competing needs of other family members (Cassell et al., 2014; Costa, Edwards, et al., 2022; Luquetti et al., 2018). As a result of these treatment demands, parents of children with craniofacial conditions demonstrate increased levels of anxiety, depression, and stress (Costa, Edwards, et al., 2022; Pope et al., 2005; Stock, Costa, et al., 2020).

For children and adolescents with a craniofacial condition, treatment can be a core experience of growing up. Patients have described feeling like “objects on display” at large multidisciplinary clinics, with emotional reactions to these experiences ranging from “uncomfortable but manageable”, to “strong and overwhelming” (Feragen et al., 2019; Myhre et al., 2019). Ongoing medical monitoring can also highlight to children and adolescents that they are “different”, which can interfere with their need to “fit in” with their peers and to feel “normal” (Alansari et al., 2014; Havstam et al., 2011). The psychological processes involved in undergoing treatment, particularly for surgeries that will alter facial appearance, are complex and emotionally demanding, and adolescents may not always consider such treatments to be worthwhile (Cadogan & Bennun, 2011; Myhre et al., 2021). Some adolescents have indicated a desire to feel more involved in the treatment decision-making process and a need for support with the transition to adult care, while others find this responsibility burdensome and stressful (Hamilton et al., 2018; Matsunaka et al., 2020; Myhre et al., 2021). Minor and/or short-term difficulties related to craniofacial treatment may include difficulties sleeping and experiencing physical pain (Feragen, Semb, et al., 2017), as well as feeling nervous about, intimidated by and/or frightened of hospital appointments and interventions (Corcoran et al., 2021; Hall et al., 2012; Netherton et al., 2023).

Most patients will have completed their routine treatment by early adulthood, and studies suggest that most report a high level of satisfaction with treatment outcomes overall (Ardouin et al., 2021). Despite this, many patients report ongoing difficulties in adulthood, and express a desire for further treatment later in life (Alansari et al., 2014; Ardouin et al., 2021). While some adults may pursue additional treatment in the hope of improving aesthetic/functional outcomes and/or reducing psychological distress (Alansari et al., 2014; Costa, Ardouin, et al., 2022; Myhre et al., 2021), others feel conflicted about the risks and benefits involved, citing treatment fatigue, treatment anxiety and/or concerns about the treatment failing as reasons to avoid further intervention (Ardouin et al., 2021; Stock et al., 2023). Adults may also experience difficulties accessing appropriate care in adulthood, due to a lack of insurance coverage, a lack of awareness of what they are entitled to and/or a lack of appropriate referrals (Ardouin et al., 2021; Stock et al., 2023).

The treatment journey is typically viewed by those affected by craniofacial conditions and their families as being a long and fluctuating process (Hall et al., 2013). The psychological impacts of treatment are wide-ranging and continue throughout the lifespan, yet the ways in which individuals react to treatment are variable. While some caregivers and patients experience stress reactions to a mild degree and/or experience reactions which are restricted to the short-term, others may experience much more intense and/or longer-term distress, known as pediatric medical traumatic stress, or PMTS.

**Pediatric Medical Traumatic Stress**

According to research carried out in the broader pediatric population, approximately 16% to 28% of pediatric patients experience PMTS (Forgey & Bursch, 2013; Judge et al., 2002; Rennick et al., 2002; Rennick & Rashotte, 2009). A recent systematic review and meta-analysis of post-traumatic stress reactions in pediatric surgery populations found that the prevalence of PTSD in children was 16%, with a rate of 23% identified among parents (Turgoose et al., 2021). Studies in populations who have required intensive care, surgeries, oncology care, treatment related to a motor vehicle accident, and those with chronic disease demonstrate that PMTS negatively impacts children’s emotional well-being (Ari et al., 2019) and medical treatment adherence after discharge (Shemesh et al., 2000). Children experiencing anxiety and depression are three times less likely to adhere to their medical care (DiMatteo et al., 2000). Moreover, children with significant medical histories may avoid engaging in follow-up treatments as a way of managing traumatic stress symptoms (Kazak et al., 2005; Shemesh et al., 2000). Avoidance coping strategies may inadvertently maintain PMTS over time (Marsac et al., 2017), with some pediatric populations experiencing posttraumatic stress symptoms for up to a year after discharge (De Young et al., 2012; Kassam-Adams et al., 2013).

There are multiple risk factors that have been reported in the general pediatric literature that make a child more susceptible to PMTS including: younger child age (De Young et al., 2021; Kahana et al., 2006); experiencing emotional distress or anxiety (Kassam-Adams et al., 2005; Winston et al., 2003); a decreased perception of personal safety (Forgey & Bursch, 2013) and greater perception of the condition or procedure’s severity or life threat (Christian-Brandt et al., 2019; Turgoose et al., 2021); feelings of loss of control and helplessness (Judge et al., 2002); parental emotional responses and distress (Ari et al., 2018; Rennick et al., 2002); multiple incidences of hospitalization (Rennick & Rashotte, 2009); longer length of stay in intensive care units (Connolly et al., 2004);family dysfunction (Kazak et al., 2005); and invasive medical interventions (Keppel-Benson et al., 2002; Rennick & Rashotte, 2009) such as surgery (Stanzel & Sierau, 2021; Turgoose et al., 2021). While some of these risks may be more likely to occur in the context of an inpatient hospitalization, any procedure could pose risks for PMTS for children and their caregivers, even if healthcare providers deem the procedure to be ‘minor.’ The child and/or caregivers’ perceptions of the procedure and related experiences (e.g., pain and distress) are key to understanding risks for PMTS (Christian-Brandt et al., 2019).

**PMTS and Craniofacial Care**

Craniofacial care often involves surgical and non-surgical procedures, some of which can be provided on an outpatient basis, while others may require hospitalization. As reviewed above, craniofacial care can be associated with a range of stressors for both children and their families. To date, only a handful of studies have explicitly investigated PMTS in individuals with craniofacial conditions and their families. Some of these studies have attempted to measure PMTS specifically and have used standardized screening tools, while others have identified the potential presence of PMTS symptoms within the context of a wider research program. In one study, mothers of infants born with CL/P in Switzerland reported significantly more posttraumatic stress symptoms than mothers in the control group (Despars et al., 2011), as measured by the Impact of Event Scale (Horowitz et al., 1979). A qualitative study conducted in Norway with a large number of parents of children with rare craniofacial conditions also highlighted potential symptoms of PMTS, including feelings of powerlessness in the context of craniofacial treatment, fear surrounding the uncertainty of treatment, and a heavy weight of responsibility regarding the need to advocate for their child in treatment settings (Feragen et al., 2020). These experiences were qualitatively reported to result in acute physiological reactions, physical burnout, and a significant emotional toll impacting the whole family, all of which resided many years after the birth of their child.

Another recent quantitative study investigated the prevalence and impact of PMTS in a sample of 45 caregivers of children with craniofacial conditions (mean age 7.7 years) and found that 14% of parents met lifetime criteria for PTSD, with the majority reporting potentially traumatic medical care experiences for their child including hospitalization in the intensive care unit and feeling unprepared for their child’s surgeries (Umbaugh et al., 2023). On a validated measure of child PTSD symptoms (Child Stress Disorders Checklist), parent ratings for children with craniofacial conditions were significantly lower than those reported for pediatric burn patients but nearly equivalent to those for children who had congenital heart conditions or who had been in accidents or hospitalized for injuries or serious illnesses (DeMaso et al., 2017; Saxe et al., 2003). Further, parent and child PTSD symptoms were significantly correlated, highlighting the need for family-based screening and interventions to address PMTS in craniofacial populations (Umbaugh et al., 2023).

Three additional studies of PMTS have investigated symptoms in children, adolescents, and adults with craniofacial conditions. In a study of five-year-old children with unilateral CLP across five countries, 2% of children had major or long-lasting difficulties in response to treatment experiences, according to a survey item that assessed parent-reported observations of their child’s coping and response to aspects of their overall cleft treatment (Feragen, Semb, et al., 2017). These difficulties included significant sleep problems, health-related or behavioral changes and/or a high level of anxiety impacting on future treatment plans and/or daily functioning. When queried about their child’s response to surgery, 7% to 11.5% of the children were described by parents as experiencing major difficulties. Most parents reported that their children coped well with speech therapy, although 6% to 31.3% had minor treatment-related problems such as anxiety that could affect their child’s response to speech therapy (Feragen, Semb, et al., 2017). In a comprehensive mixed-methods study by Riklin and colleagues (2020), 50 percent of adolescents met the threshold for posttraumatic stress disorder. Finally, a recent online survey study of adults with craniofacial conditions (N = 34) reported a wide range of potentially traumatic medical experiences (e.g., hospitalization in the ICU, exposure to frightening sounds and sights in the hospital, and lengthy hospital stays). Twenty-one percent of participants met the lifetime criteria for PTSD (McClinchie et al., 2023).

Interestingly, positive impacts have also been reported in relationship to difficult treatment experiences, including enhanced resilience and personal growth, consistent with findings from other studies of chronic and acute conditions (Hilliard et al., 2015; van der Laan et al., 2023). For example, caregivers of children with rare craniofacial conditions reported feeling more empathetic, appreciative, accepting, and self-confident in their parenting as a result of their experiences (Feragen et al., 2020). Similarly, in their mixed methods study of adolescents with craniofacial conditions, Riklin et al. (2020) observed both higher resilience scores and higher PTSD symptoms in their sample, with qualitative responses indicating that receiving social support from peers and family, taking pride in their differences, reflecting on how they have overcome past challenges, and focusing on aspects of their lives that they can control supported resilience.

Although in its infancy, the current literature suggests that care experiences can be significant stressors for children with craniofacial conditions and their families, with the potential for detrimental long-term psychosocial effects, including the development of PMTS. There is a critical need to further investigate this phenomenon. Whether patients’ and parents’ stress reactions to craniofacial treatment can be considered mild and/or short-term, or more severe and impactful in the longer-term, there is a clear need to identify those at risk of/who are experiencing psychological distress, and to explore ways of intervening, and of preventing further instances of PMTS across the lifespan. Further, future research should address methodological limitations present in some studies of PMTS by utilizing longitudinal designs; providing clear definitions of the constructs under study; characterizing PMTS symptoms clearly to facilitate comparison with other studies; and using validated measures of traumatic stress. Future work is also needed to better understand and cultivate resilience in the context of craniofacial-related stressors.

**Implications for Clinical Care**

The psychological impact of numerous surgical interventions, hospitalizations, and continuous medical monitoring highlight the importance for psychological screening and intervention efforts for individuals with craniofacial conditions. Psychosocial support and screenings should be a standard practice in craniofacial care (American Cleft Palate-Craniofacial Association, 2018) to aid in both the education and preparation of children with craniofacial conditions and their families for potentially stressful medical care experiences. However, access to social workers and psychologists varies greatly across craniofacial teams. While some teams have embedded psychosocial providers, others only have access to psychosocial services on a referral basis (e.g., Hood et al., 2011). These differences in care practices may affect awareness of PMTS and more generally, of psychosocial risks associated with craniofacial conditions and their management.

The findings reported in the context of this review highlight the need for trauma-informed care practices to be incorporated into all aspects of craniofacial care, including interdisciplinary team appointments, exams, procedures, surgeries, and hospitalizations. Providing children and adolescents with craniofacial conditions psychosocial support could protect against PMTS and support adaptive coping with medical care and related stressors into adulthood. The emerging research about PMTS in craniofacial populations also points towards routine traumatic stress symptom screening along with other mental health risks, including anxiety and depression.

**Trauma-Informed Care Practices**

Clinically, risks for PMTS and distress may be reduced by implementing trauma-informed medical care practices, which recognize the potential traumatic impacts of procedures and related care on both children and their caregivers and incorporate this understanding into the medical team’s culture, procedures, and practices to reduce harm and other negative psychosocial impacts for both the child and family (Kassam-Adams & Butler, 2017). Trauma-informed care also recognizes that children and families may have prior exposures to trauma (e.g., historical exposure to abuse; injury; car accidents) that could also affect their medical care experiences and risks for PMTS (Kassam-Adams & Butler, 2017). The literature is sparse regarding the integration of trauma-informed care practices into craniofacial treatment, as is the case within pediatric healthcare more broadly (e.g., Marsac et al., 2016). Here, we describe some practices that can be helpful in reducing risks for distress and potentially, PMTS, in the context of craniofacial care.

Trauma-informed care practices include providing children with a sense of choice and control in the context of their care. Examples include obtaining age-appropriate assent from patients for procedures, offering brief, developmentally appropriate, neutral descriptions of treatment plans and procedures (Stock, Marik, et al., 2020). It can be helpful to engage patients and families in conversations about how health care providers may help the child deal with potential triggers due to prior negative care experiences. Further, providers can assist patients and caregivers with approaches to help the child cope with a procedure or hospital stay (e.g., listening to music, watching a movie, having caregivers present), what parts of the procedure are likely to cause distress, and what could make the procedure or hospital stay more tolerable. Other strategies that enhance choice and control can include selecting which part of an exam to do first or second as appropriate and identifying comfort items that they can bring to the hospital with them prior to surgery or a planned admission.

Trauma-informed care also includes appropriate management of pain, either through pharmacologic and/or non-pharmacologic means, along with appropriate support from caregivers (Kassam-Adams & Butler, 2017). For example, distraction strategies (e.g., having the child focus their attention on something other than the procedure or pain) can help reduce fear and distress effectively (McMurtry et al., 2010; Pillai Riddell et al., 2023), while some verbal statements such as “don’t worry” from caregivers or healthcare providers that are intended to be reassuring should be limited as they may worsen the child’s fear and distress (McMurtry et al., 2010). In contrast, truthful disclosures about possible experiences of pain or anxiety that may accompany a specific procedure, explained in appropriate language, have been shown to promote a child’s sense of participation and control (Hudson et al., 2019).

Further, adequate preparation for surgical procedures and facilitation of adaptive coping strategies during inpatient stays can also reduce risks for PMTS. For example, families (and children as age appropriate) can be informed about common side effects of surgery (e.g., facial swelling, anticipated difficulties with eating or talking) and problem-solve about ways to cope in advance of the procedure (e.g., identifying preferred soft foods, having a pen/paper available or use of a tablet or phone to communicate). While postoperative care often involves activity, dietary, and other types of restrictions, patients and families may benefit from reminders about what they can still do during this time and to make a schedule of enjoyable activities (e.g., making a list of movies to watch). Finally, an important part of trauma-informed care involves minimizing the time that caregivers and children are separated from each other, particularly during times of high anxiety. For example, some pediatric hospitals will permit caregivers to escort their child to the operating room to minimize distress and have the caregiver present while the child is awakening from anesthesia postoperatively. Integrating the patient and family’s input into the care plan and validating their concerns and feelings can build trust and help mitigate distress, even in the face of traumatic experiences (Dewan et al., 2023).

**Screening and Intervention**

Screening for PMTS and related mental health impacts of craniofacial conditions and prompt referral for mental health treatment for those experiencing distress or PMTS are also warranted. Psychosocial providers who work with craniofacial teams can talk with children and their caregivers about their past treatment experiences and how these have affected their mental health and their feelings about future procedures, in addition to providing support and strategies to facilitate coping with medical care experiences. They can also advocate for trauma-informed care for patients by talking with the child’s treatment team members about their concerns, preferences, and needs for support before, during, and after procedures or hospital admissions.

Screening and assessment can include use of clinical interviewing as well as use of screening instruments such as the Psychosocial Assessment Tool-Craniofacial Version (PAT-CV), a caregiver-report screening tool which can help identify a family’s areas of risk and resilience, including exposures to non-medical traumas (e.g., abuse, domestic violence), child and caregiver mental health problems (e.g., anxiety, depression), family resources, social support, and caregiver beliefs about coping with the child’s condition and care (Crerand et al., 2018). The PAT-CV was adapted from the Psychosocial Assessment Tool (PAT), a tool originally developed for psychosocial risk screening in pediatric oncology populations (Kazak et al., 2001; Pai et al., 2008). The PAT was informed by the Pediatric Psychosocial Preventative Health Model (Kazak, 2006), a framework for screening and intervention in the context of pediatric healthcare. This model purports that most families of children who experience either an acute, chronic, or potentially life-threatening condition will experience some normative distress and will cope effectively with the provision of general support and information from the care team. Some families may experience more significant distress and may have other family risk factors (e.g., pre-existing caregiver or child mental health problems, past exposure to trauma) which may increase the likelihood of distress and require targeted interventions to address specific symptoms or concerns. Finally, some families may exhibit multiple psychosocial risks (e.g., limited access to social support or financial resources, caregiver and child problems) which may place them at risk for persistent and escalating distress (Kazak, 2006). The PAT-CV takes approximately 10 minutes to complete and has been integrated into some craniofacial teams to identify patients and families who require psychosocial support (Crerand et al., 2022).

While the PAT-CV does not currently include items that screen for traumatic stress symptoms specifically, other versions of the PAT (e.g., Pai et al., 2008) which were developed for children with potentially life-threatening conditions like cancer do include items about PTSD symptoms. Similarly, other measures can be utilized to identify patients and/or caregivers who are experiencing traumatic stress symptoms such as the Child Stress Disorders Checklist (Saxe et al., 2003) (a caregiver-report instrument of child PTSD symptoms) and the PTSD Checklist (PCL-5) (Weathers et al., 2013), a reliable and valid PTSD screening instrument for older adolescents and adults. Additional resources for trauma screening practices, recommended instruments, and education can be found through The National Child Traumatic Stress Network [https://www.nctsn.org].

Children and caregivers who present with symptoms of PMTS may benefit from psychotherapy, particularly approaches that utilize cognitive-behavioral interventions tailored to the child’s developmental stage and that incorporate caregivers as age appropriate (Christian-Brandt et al., 2019). For example, Trauma-Focused Cognitive Behavioral Therapy is an empirically supported intervention that focuses on teaching skills to improve emotion regulation, thoughts, behavior, trauma processing, communication and relationships (see Dorsey et al., 2017 for a review of evidence-based treatments for traumatic stress). The National Child Traumatic Stress Network has also developed fact sheets which provide descriptions of treatment approaches for PTSD and PMTS.

Additionally, interventions targeting resilience may also support healthy psychosocial adjustment and mitigate risks for distress and/or PMTS. In recent years, a resilience-focused intervention called Promoting Resilience in Stress Management (PRISM) has been developed and tested in other pediatric populations at risk for elevated stress (oncology and type 1 diabetes) (Rosenberg et al., 2015; Yi-Frazier et al., 2017), targeting both adolescents and caregivers. PRISM is designed to teach resilience-building skills (e.g., stress management strategies such as mindfulness; recognizing and challenging negative thought patterns; goal setting; and looking for positives and meaning in the context of stressful experiences (Yi-Frazier et al., 2017)). Findings from randomized controlled trials suggest PRISM improves distress, resilience, quality of life, and adherence (Rosenberg et al., 2019; Rosenberg et al., 2018), and was also shown to prevent the development of depression (Rosenberg et al., 2018). PRISM was recently piloted in caregivers of children with craniofacial conditions (Fladeboe et al., 2023) with evidence for acceptability and feasibility. Further study of PRISM in both parents and youth with craniofacial conditions is warranted, as this intervention shows promise in mitigating craniofacial care-related stressors and related impacts on psychosocial functioning and facilitating resilience.

**Clinical Care Implications for Speech and Language Pathologists**

For speech language pathologists (SLPs), an understanding of the possible impact of PMTS on the children and their families can help in tailoring treatment. Including a few broad questions about their prior treatment experiences at the start of therapy can assist in establishing both rapport and therapy expectations, and provide indications of whether additional follow-up should be considered. Beyond gaining details of any past speech therapy, asking about how they feel their overall craniofacial care and surgeries have been for them along with anything they would have liked to change opens the conversation to understand their care experiences. For those children and families who report challenges in their care, it may be useful to spend some time addressing their concerns and linking them to appropriate support, such as case management for scheduling or insurance barriers, social work for a range of resources, psychology for adjustment concerns, and school districts for an Individualized Education Programs (IEP) and other services. The effects of PMTS may compound existing speech and language concerns to have a greater negative impact on social relationships, in which case SLPs may elect to highlight social pragmatics as part of therapy and help families identify activities to build social support, such as peer activities (e.g., sports, scouts) and formal support groups.

Once speech therapy has started, symptoms of PMTS may manifest in negative interactions with providers, treatment anxiety, inconsistent adherence, and low motivation. Clarifying child and family goals and expectations for speech therapy at the outset provides an opportunity to build motivation about the steps they need to take to achieve their goals and may prevent later disappointment with therapy. SLPs can discuss their role within the context of the overall craniofacial treatment plan with the intent to match the speech goals of the child and family, while being transparent about the possible need for future surgical intervention. Discussions about future surgeries should reinforce the joint decision making of the team and family together and include time to prepare for surgery. Strategies used during therapy that are familiar to SLPs can be augmented by additional praise for effort, creating choices to reinforce child control, empathic listening with validation of the difficulties they’ve experienced, use of play and rewards, and frequent clarification of concerns or misunderstandings.

In addition to speech therapy, nasopharyngoscopies (NPs) performed to inform treatment planning for velopharyngeal insufficiency are another opportunity for SLPs to be mindful of possible PMTS. The NP camera placement in a child’s nostril while producing speech samples may be a trigger for PMTS beyond baseline high anxiety reported by children and parents prior to a NP (Johns et al., 2020). SLPs can help address this anxiety with thorough preparation, including honest communication of sensations of pressure with low pain reported, and practicing coping strategies ahead of time (Johns et al., 2020). Including families in procedural education and helping them have adaptive behaviors prepared during the NP is important as children are responsive to their caregiver’s anxiety. Praise and reflecting on child and family experience after the NP can help them form a positive perspective of the NP. Pediatric hospitals often employ child life specialists, healthcare providers who have expertise in helping children cope with procedures, who may be able to assist with pre-NP preparation and coping during the NP.

 **Conclusions and Future Directions**

Craniofacial conditions and related treatments may result in stress for patients and their families and can negatively affect psychosocial adjustment. In some instances, medical care practices and experiences can be traumatic for patients and their families, with a growing body of literature identifying symptoms of traumatic stress in craniofacial populations. Additional research is indicated to document the effects of craniofacial care particularly on patient and family well-being, along with the long-term psychological impacts of care (both positive and negative) which may become more salient during adolescence and adulthood. More studies are needed to better understand and characterize PMTS in craniofacial populations and identify specific risk and protective factors and the impact craniofacial care has on psychosocial adjustment. Future work is also needed to develop and integrate trauma-informed care practices, screening protocols, and interventions to address stress and coping in the context of craniofacial care.

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