

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

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26 **Abstract**

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

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

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

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52 Craniofacial conditions are among the most common congenital diagnoses in the world
53 and can occur either in isolation or as part of a syndrome.(Dixon et al., 2011; Seto-Salvia &
54 Stanier, 2014). Cleft lip with or without cleft palate (CL/P) is the most prevalent craniofacial
55 condition and affects one in every 1000 to 1500 live births globally (Salari et al., 2021). Other
56 common craniofacial conditions include premature fusion of the skull sutures (craniosynostosis)
57 and underdevelopment of the jaw and/or ear (pharyngeal arch disorders), which are diagnosed in
58 1:2,500 (Shlobin et al., 2022) and 1:6,000 (Hennekam et al., 2010) live births, respectively.
59 Another common diagnosis that can include a cleft palate is 22q11.2 deletion syndrome, which
60 occurs in 1 in every 2,148 births (Blagojevic et al., 2021).

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

75 2020) can impact child adjustment during preschool and school-age years (Pope, Tillman, &
76 Snyder, 2005; van Dalen et al., 2021; Wolodiger & Pope, 2019).

77 Children with craniofacial conditions are ideally treated by interdisciplinary teams
78 (American Cleft Palate-Craniofacial Association, 2018). Care frequently begins in
79 infancy and continues throughout adolescence and young adulthood. Treatment protocols
80 typically include longitudinal evaluations and staged surgical procedures to address both
81 form (aesthetics) and function. Significant variation exists in the number of surgical
82 procedures children with craniofacial conditions receive owing to individual needs and
83 variation in team protocols (Semb et al., 2005). As an example, most protocols for CL/P
84 include the following 4 standard surgeries: cleft lip surgery, cleft palate repair, placement
85 of tympanostomy tubes, and an alveolar bone graft. However, it is not uncommon for
86 children born in the U.S. to have greater than 8 cleft-related surgeries by early adulthood,
87 including lip or nasal revisions, secondary palate procedures to address velopharyngeal
88 insufficiency or palatal fistula, and jaw surgery to address malocclusion (McIntyre et al.,
89 2016; Losee & Kirschner, 2016). These children often receive other interventions,
90 including pre-surgical orthopedics, extended or repeated orthodontic treatment, and
91 speech therapy which can add to their overall burden of care (Losee & Kirschner, 2016).

92 Research on children with special healthcare needs demonstrates that treatment
93 demands involving ongoing medical monitoring, hospitalizations, surgeries, and other
94 interventions can adversely affect the psychological well-being of the child, caregivers,
95 siblings, and extended family (Christofferson et al., 2020; Dewan et al., 2023; Pinquart,
96 2017; Stanzel & Sierau, 2021). While intermittent mild to moderate levels of physical
97 and emotional distress can be viewed as ‘typical’ responses to abnormal situations,

98 chronic distress may be associated with pediatric medical traumatic stress (PMTS) (Lim
99 et al., 2019; Piquart, 2017; Price et al., 2015).

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

117 Post-traumatic stress symptoms associated with PMTS can occur if the healthcare
118 experience involved pain, significant illness or threat to life, invasive or distressing
119 treatment procedures, or was perceived of by the child and/or caregivers to be frightening
120 or overwhelming (De Young et al., 2021; Kassam-Adams et al., 2013; Kazak et al., 2005;

121 DeYoung et al., 2021). PMTS can persist through adulthood for individuals who
122 experience traumatic medical experiences at a young age (see Kazak et al., 2005 for a
123 review). Given that individuals with craniofacial conditions and their families often
124 experience intensive and painful medical and surgical interventions throughout infancy,
125 childhood, and adolescence, it is increasingly important to understand risks for PMTS in
126 this population. While the burden of care associated with craniofacial conditions has been
127 explored (e.g., Cassell et al., 2013; Cassell et al., 2014; Long, 2016), considerably less
128 attention has been paid to the psychological effects of craniofacial care on patients and
129 their families.

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

140 **Psychological Impacts of Craniofacial Care**

141 From the point at which caregivers become aware that something may be different
142 about their child's physical health and/or appearance, they embark on a long treatment
143 journey. Some families struggle to obtain a diagnosis, particularly in the case of rare

144 craniofacial conditions, which can be highly stressful (Costa, Edwards, et al., 2022;
145 Luquetti et al., 2018; Tierney et al., 2015). The diagnostic experience itself has been
146 described as emotionally complex (Costa, Edwards, et al., 2022; Johns et al., 2023;
147 Nelson et al., 2012) and exacerbated by distressing interactions with healthcare providers
148 and/or a lack of reliable information (Costa, Edwards, et al., 2022; Kancherla et al., 2009;
149 Nusbaum et al., 2008). Preparing and going through surgery often involves difficult
150 decisions and conflicting emotions, parental fear about the risks involved, as well as the
151 need to cope with potential post-surgical reactions in the child (Feragen, Rumsey, et al.,
152 2017; P. A. Nelson et al., 2012; Zerpe et al., 2022). Over time, and despite a generally
153 high level of satisfaction with healthcare, many caregivers report feeling overwhelmed by
154 the burden and complexity of care. This can include the volume and coordination of
155 appointments, travel, the impact of healthcare demands on caregivers' finances and
156 employment status, hospitalizations and the competing needs of other family members
157 (Cassell et al., 2014; Costa, Edwards, et al., 2022; Luquetti et al., 2018). As a result of
158 these treatment demands, parents of children with craniofacial conditions demonstrate
159 increased levels of anxiety, depression, and stress (Costa, Edwards, et al., 2022; Pope et
160 al., 2005; Stock, Costa, et al., 2020).

161 For children and adolescents with a craniofacial condition, treatment can be a core
162 experience of growing up. Patients have described feeling like “objects on display” at
163 large multidisciplinary clinics, with emotional reactions to these experiences ranging
164 from “uncomfortable but manageable”, to “strong and overwhelming” (Feragen et al.,
165 2019; Myhre et al., 2019). Ongoing medical monitoring can also highlight to children and
166 adolescents that they are “different”, which can interfere with their need to “fit in” with

167 their peers and to feel “normal” (Alansari et al., 2014; Havstam et al., 2011). The
168 psychological processes involved in undergoing treatment, particularly for surgeries that
169 will alter facial appearance, are complex and emotionally demanding, and adolescents
170 may not always consider such treatments to be worthwhile (Cadogan & Bennun, 2011;
171 Myhre et al., 2021). Some adolescents have indicated a desire to feel more involved in
172 the treatment decision-making process and a need for support with the transition to adult
173 care, while others find this responsibility burdensome and stressful (Hamilton et al.,
174 2018; Matsunaka et al., 2020; Myhre et al., 2021). Minor and/or short-term difficulties
175 related to craniofacial treatment may include difficulties sleeping and experiencing
176 physical pain (Feragen, Semb, et al., 2017), as well as feeling nervous about, intimidated
177 by and/or frightened of hospital appointments and interventions (Corcoran et al., 2021;
178 Hall et al., 2012; Netherton et al., 2023).

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

190 what they are entitled to and/or a lack of appropriate referrals (Ardouin et al., 2021; Stock
191 et al., 2023).

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

200 **Pediatric Medical Traumatic Stress**

201 According to research carried out in the broader pediatric population, approximately
202 16% to 28% of pediatric patients experience PMTS (Forgey & Bursch, 2013; Judge et al.,
203 2002; Rennick et al., 2002; Rennick & Rashotte, 2009). A recent systematic review and
204 meta-analysis of post-traumatic stress reactions in pediatric surgery populations found
205 that the prevalence of PTSD in children was 16%, with a rate of 23% identified among
206 parents (Turgoose et al., 2021). Studies in populations who have required intensive care,
207 surgeries, oncology care, treatment related to a motor vehicle accident, and those with
208 chronic disease demonstrate that PMTS negatively impacts children's emotional well-
209 being (Ari et al., 2019) and medical treatment adherence after discharge (Shemesh et al.,
210 2000). Children experiencing anxiety and depression are three times less likely to adhere
211 to their medical care (DiMatteo et al., 2000). Moreover, children with significant medical
212 histories may avoid engaging in follow-up treatments as a way of managing traumatic

213 stress symptoms (Kazak et al., 2005; Shemesh et al., 2000). Avoidance coping strategies
214 may inadvertently maintain PMTS over time (Marsac et al., 2017), with some pediatric
215 populations experiencing posttraumatic stress symptoms for up to a year after discharge
216 (De Young et al., 2012; Kassam-Adams et al., 2013).

217 There are multiple risk factors that have been reported in the general pediatric
218 literature that make a child more susceptible to PMTS including: younger child age (De
219 Young et al., 2021; Kahana et al., 2006); experiencing emotional distress or anxiety
220 (Kassam-Adams et al., 2005; Winston et al., 2003); a decreased perception of personal
221 safety (Forgey & Bursch, 2013) and greater perception of the condition or procedure's
222 severity or life threat (Christian-Brandt et al., 2019; Turgoose et al., 2021); feelings of
223 loss of control and helplessness (Judge et al., 2002); parental emotional responses and
224 distress (Ari et al., 2018; Rennick et al., 2002); multiple incidences of hospitalization
225 (Rennick & Rashotte, 2009); longer length of stay in intensive care units (Connolly et al.,
226 2004); family dysfunction (Kazak et al., 2005); and invasive medical interventions
227 (Keppel-Benson et al., 2002; Rennick & Rashotte, 2009) such as surgery (Stanzel &
228 Sierau, 2021; Turgoose et al., 2021). While some of these risks may be more likely to
229 occur in the context of an inpatient hospitalization, any procedure could pose risks for
230 PMTS for children and their caregivers, even if healthcare providers deem the procedure
231 to be 'minor.' The child and/or caregivers' perceptions of the procedure and related
232 experiences (e.g., pain and distress) are key to understanding risks for PMTS (Christian-
233 Brandt et al., 2019).

234 **PMTS and Craniofacial Care**

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

253 Another recent quantitative study investigated the prevalence and impact of PMTS in
254 a sample of 45 caregivers of children with craniofacial conditions (mean age 7.7 years)
255 and found that 14% of parents met lifetime criteria for PTSD, with the majority reporting
256 potentially traumatic medical care experiences for their child including hospitalization in
257 the intensive care unit and feeling unprepared for their child's surgeries (Umbaugh et al.,

258 2023). On a validated measure of child PTSD symptoms (Child Stress Disorders
259 Checklist), parent ratings for children with craniofacial conditions were significantly
260 lower than those reported for pediatric burn patients but nearly equivalent to those for
261 children who had congenital heart conditions or who had been in accidents or
262 hospitalized for injuries or serious illnesses (DeMaso et al., 2017; Saxe et al., 2003).
263 Further, parent and child PTSD symptoms were significantly correlated, highlighting the
264 need for family-based screening and interventions to address PMTS in craniofacial
265 populations (Umbaugh et al., 2023).

266 Three additional studies of PMTS have investigated symptoms in children,
267 adolescents, and adults with craniofacial conditions. In a study of five-year-old children
268 with unilateral CLP across five countries, 2% of children had major or long-lasting
269 difficulties in response to treatment experiences, according to a survey item that assessed
270 parent-reported observations of their child's coping and response to aspects of their
271 overall cleft treatment (Feragen, Semb, et al., 2017). These difficulties included
272 significant sleep problems, health-related or behavioral changes and/or a high level of
273 anxiety impacting on future treatment plans and/or daily functioning. When queried about
274 their child's response to surgery, 7% to 11.5% of the children were described by parents
275 as experiencing major difficulties. Most parents reported that their children coped well
276 with speech therapy, although 6% to 31.3% had minor treatment-related problems such as
277 anxiety that could affect their child's response to speech therapy (Feragen, Semb, et al.,
278 2017). In a comprehensive mixed-methods study by Riklin and colleagues (2020), 50
279 percent of adolescents met the threshold for posttraumatic stress disorder. Finally, a
280 recent online survey study of adults with craniofacial conditions (N = 34) reported a wide

281 range of potentially traumatic medical experiences (e.g., hospitalization in the ICU,
282 exposure to frightening sounds and sights in the hospital, and lengthy hospital stays).
283 Twenty-one percent of participants met the lifetime criteria for PTSD (McClinchie et al.,
284 2023).

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

296 Although in its infancy, the current literature suggests that care experiences can be
297 significant stressors for children with craniofacial conditions and their families, with the
298 potential for detrimental long-term psychosocial effects, including the development of
299 PMTS. There is a critical need to further investigate this phenomenon. Whether patients'
300 and parents' stress reactions to craniofacial treatment can be considered mild and/or
301 short-term, or more severe and impactful in the longer-term, there is a clear need to
302 identify those at risk of/who are experiencing psychological distress, and to explore ways
303 of intervening, and of preventing further instances of PMTS across the lifespan. Further,

304 future research should address methodological limitations present in some studies of
305 PMTS by utilizing longitudinal designs; providing clear definitions of the constructs
306 under study; characterizing PMTS symptoms clearly to facilitate comparison with other
307 studies; and using validated measures of traumatic stress. Future work is also needed to
308 better understand and cultivate resilience in the context of craniofacial-related stressors.

309 **Implications for Clinical Care**

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

321 The findings reported in the context of this review highlight the need for trauma-
322 informed care practices to be incorporated into all aspects of craniofacial care, including
323 interdisciplinary team appointments, exams, procedures, surgeries, and hospitalizations.
324 Providing children and adolescents with craniofacial conditions psychosocial support could
325 protect against PMTS and support adaptive coping with medical care and related stressors into
326 adulthood. The emerging research about PMTS in craniofacial populations also points towards

327 routine traumatic stress symptom screening along with other mental health risks, including
328 anxiety and depression.

329 **Trauma-Informed Care Practices**

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

342 Trauma-informed care practices include providing children with a sense of choice and
343 control in the context of their care. Examples include obtaining age-appropriate assent from
344 patients for procedures, offering brief, developmentally appropriate, neutral descriptions of
345 treatment plans and procedures (Stock, Marik, et al., 2020). It can be helpful to engage patients
346 and families in conversations about how health care providers may help the child deal with
347 potential triggers due to prior negative care experiences. Further, providers can assist patients
348 and caregivers with approaches to help the child cope with a procedure or hospital stay (e.g.,
349 listening to music, watching a movie, having caregivers present), what parts of the procedure are

350 likely to cause distress, and what could make the procedure or hospital stay more tolerable. Other
351 strategies that enhance choice and control can include selecting which part of an exam to do first
352 or second as appropriate and identifying comfort items that they can bring to the hospital with
353 them prior to surgery or a planned admission.

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

364 Further, adequate preparation for surgical procedures and facilitation of adaptive coping
365 strategies during inpatient stays can also reduce risks for PMTS. For example, families (and
366 children as age appropriate) can be informed about common side effects of surgery (e.g., facial
367 swelling, anticipated difficulties with eating or talking) and problem-solve about ways to cope in
368 advance of the procedure (e.g., identifying preferred soft foods, having a pen/paper available or
369 use of a tablet or phone to communicate). While postoperative care often involves activity,
370 dietary, and other types of restrictions, patients and families may benefit from reminders about
371 what they can still do during this time and to make a schedule of enjoyable activities (e.g.,
372 making a list of movies to watch). Finally, an important part of trauma-informed care involves

373 minimizing the time that caregivers and children are separated from each other, particularly
374 during times of high anxiety. For example, some pediatric hospitals will permit caregivers to
375 escort their child to the operating room to minimize distress and have the caregiver present while
376 the child is awakening from anesthesia postoperatively. Integrating the patient and family's input
377 into the care plan and validating their concerns and feelings can build trust and help mitigate
378 distress, even in the face of traumatic experiences (Dewan et al., 2023).

379 **Screening and Intervention**

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

388 Screening and assessment can include use of clinical interviewing as well as use of
389 screening instruments such as the Psychosocial Assessment Tool-Craniofacial Version (PAT-
390 CV), a caregiver-report screening tool which can help identify a family's areas of risk and
391 resilience, including exposures to non-medical traumas (e.g., abuse, domestic violence), child
392 and caregiver mental health problems (e.g., anxiety, depression), family resources, social
393 support, and caregiver beliefs about coping with the child's condition and care (Crerand et al.,
394 2018). The PAT-CV was adapted from the Psychosocial Assessment Tool (PAT), a tool
395 originally developed for psychosocial risk screening in pediatric oncology populations (Kazak et

396 al., 2001; Pai et al., 2008). The PAT was informed by the Pediatric Psychosocial Preventative
397 Health Model (Kazak, 2006), a framework for screening and intervention in the context of
398 pediatric healthcare. This model purports that most families of children who experience either an
399 acute, chronic, or potentially life-threatening condition will experience some normative distress
400 and will cope effectively with the provision of general support and information from the care
401 team. Some families may experience more significant distress and may have other family risk
402 factors (e.g., pre-existing caregiver or child mental health problems, past exposure to trauma)
403 which may increase the likelihood of distress and require targeted interventions to address
404 specific symptoms or concerns. Finally, some families may exhibit multiple psychosocial risks
405 (e.g., limited access to social support or financial resources, caregiver and child problems) which
406 may place them at risk for persistent and escalating distress (Kazak, 2006). The PAT-CV takes
407 approximately 10 minutes to complete and has been integrated into some craniofacial teams to
408 identify patients and families who require psychosocial support (Crerand et al., 2022).

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

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

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

441 conditions is warranted, as this intervention shows promise in mitigating craniofacial care-related
442 stressors and related impacts on psychosocial functioning and facilitating resilience.

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

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

459 Once speech therapy has started, symptoms of PMTS may manifest in negative
460 interactions with providers, treatment anxiety, inconsistent adherence, and low motivation.
461 Clarifying child and family goals and expectations for speech therapy at the outset provides an
462 opportunity to build motivation about the steps they need to take to achieve their goals and may
463 prevent later disappointment with therapy. SLPs can discuss their role within the context of the

464 overall craniofacial treatment plan with the intent to match the speech goals of the child and
465 family, while being transparent about the possible need for future surgical intervention.
466 Discussions about future surgeries should reinforce the joint decision making of the team and
467 family together and include time to prepare for surgery. Strategies used during therapy that are
468 familiar to SLPs can be augmented by additional praise for effort, creating choices to reinforce
469 child control, empathic listening with validation of the difficulties they've experienced, use of
470 play and rewards, and frequent clarification of concerns or misunderstandings.

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

483 **Conclusions and Future Directions**

484 Craniofacial conditions and related treatments may result in stress for patients and their
485 families and can negatively affect psychosocial adjustment. In some instances, medical care
486 practices and experiences can be traumatic for patients and their families, with a growing body of

487 literature identifying symptoms of traumatic stress in craniofacial populations. Additional
488 research is indicated to document the effects of craniofacial care particularly on patient and
489 family well-being, along with the long-term psychological impacts of care (both positive and
490 negative) which may become more salient during adolescence and adulthood. More studies are
491 needed to better understand and characterize PMTS in craniofacial populations and identify
492 specific risk and protective factors and the impact craniofacial care has on psychosocial
493 adjustment. Future work is also needed to develop and integrate trauma-informed care practices,
494 screening protocols, and interventions to address stress and coping in the context of craniofacial
495 care.

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