

Biopsychosocial Issues in Cleft Lip and Palate

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IMPACT OF CLEFT LIP AND/OR CLEFT PALATE DIAGNOSIS BEGINS AT NOTIFICATION

The Centers for Disease Control and Prevention estimates that annually in the United States about 4,400 babies are born with a cleft lip that may or may not also include a cleft palate (Parker et al., 2010). Cleft lip and/or cleft palate can affect a newborn's daily functioning with regard to feeding and hearing. Having cleft can also impact the long-term outcomes of a child with regard to speech intelligibility (John, Sell, Sweeney, Harding-Bell, & Williams, 2006). As a result, surgical repairs start early in life.

With the use of modern technology during pregnancy, the presence of cleft lip often can be observed through the use of routine ultrasound or sonogram. Fourteen percent to 28% of pregnancies with the presence of cleft are diagnosed during pregnancy (Jones, 2002; Robbins et al., 2010). Researchers indicate that with the use of three-dimensional sonography a more accurate diagnosis of craniofacial malformations is possible (Platt, DeVore, & Pretorius, 2006). Other researchers report that three- and four-dimensional ultrasound imaging are sources of more exacting evaluations of the presence of cleft (Rotten & Levaillant, 2004). Mothers who are able to obtain prenatal care receive an ultrasound or sonogram that allows the physician to observe the fetus and often identify medical conditions. As a result, it is important to note that the impacts of a cleft diagnosis do not always begin at birth (at the sight of a baby); they can begin antenatally during the second trimester.

When diagnosis of a baby having the make-up supporting cleft lip occurs, education regarding the disorder and its impacts ideally would begin immediately. This is why it is important to have a multidisciplinary team who can address the genetic, environmental, medical, psychological, and social aspects of a cleft diagnosis. A study shows that because a cleft diagnosis can have emotionally distressing impacts on a family, the timing of a cleft diagnosis may be important as it provides advance opportunity for families

to gain knowledge, receive counseling about care and feeding needs, develop a plan for child care, and address employment issues before birth (Robbins et al., 2010).

WHAT TO LOOK FOR: THE IMPORTANCE OF BIOPSYCHOSOCIAL ASSESSMENTS

The cause of cleft lip and/or cleft palate is complex and viewed to be the result of both genetic and environmental factors and exposures (Stainer & Moore, 2004). Therefore, a component of these birth defects has *biological* origins. The location of the cleft and the visual appearance of a child can affect parents' perceptions of success for their child as well as a child's self-image, which can have *psychological* impacts. It is also possible that the presence of scarring or speech delays may require a child to learn how to navigate *social* interactions at school and among peers. The role of the psychologist and/or social worker on the medical team is to provide a safe space for families to verbalize their range of emotions, normalize those reactions, and provide supportive counseling in the moment. These acts of empathy can occur simultaneously during completion of a biopsychosocial assessment in an attempt to meet families at their point of need.

If we focus only on the diagnosis or illness, we miss an opportunity. Although the diagnosis is hugely important, as it has become the most prominent family issue to be addressed, it is the tip of the iceberg above the waterline. Every family system has strengths or resiliencies and every family system has areas for improvement or vulnerabilities. Some family systems have more aspects that fall in one column than the other. While the genesis of this argument stems from focusing on abusive family systems, the implicit message of the model can apply to any family system (Trepper & Barrett, 1989).

Because a cleft lip and/or palate diagnosis has biological origins, it is essential to assess the possible origins. The genetics counselor or social worker explores the biological history of families with them to assess for predispositions and to potentially identify environmental patterns. Sometimes, the verbalization of others in the extended family having a cleft diagnosis helps reduce anxiety and thoughts that perhaps there is something the parents could have done differently. The remainder of the biopsychological assessment is intended to ask specific and intentional questions to identify strengths within the individual, family, and social aspects of their lives, and to assist families

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with identifying and understanding their reactions to stress, anxiety, and conflict. This is done by learning about a range of topics, including relationships, employment status, the availability and reliability of transportation, the presence of a support system, the presence of other children in the home, and a wide array of other information. Depending on the responses to these questions, the family may be able to better understand patterns, incorporate cultural norms, draw strength and hope from religious and/or spiritual practices, and identify members of their support system that can assist them during upcoming medical procedures and follow-up. The responses may also reveal financial concerns, marital issues, lack of support, unreliable transportation to medical appointments, lapses in health insurance, and a host of other life stressors that have been ongoing risk factors and impacts on the family unit—even before the diagnosis of cleft lip.

The completion of the biopsychosocial can reveal how parental reactions may influence the child's perception of having a cleft diagnosis. The psychologist, social worker, and genetic counselor's roles are to be liaisons between families and the relevant members of the medical team to assist with advocating for the needs of the patient and the family.

DIAGNOSIS CAN BE THE STRAW OR THE GLUE

It is within a normal range of emotions for the reactions to learning of a diagnosis of any chronic condition or severe illness to be denial, fear, anxiety, and/or depression. It is also possible for behavioral issues to develop among children and adolescents. Similar results have been observed in several longitudinal, cross-sectional, or retrospective studies (Hunt, Burden, Hepper, & Johnston, 2005). Studies also show that caregivers report greater stress associated with parenting a child with a chronic condition than those parenting a child without a chronic illness (Cousino & Hazen, 2013).

As a result of other life stressors impacting a family unit that may also be causing a range of emotions, it could be the case that learning of a cleft diagnosis during pregnancy or at birth could be the straw that breaks the emotional strength of a family unit, including such reactions as severing the emotional bonds of a couple or physical distancing in which a parent may leave the home to evade the responsibility of a child born with feeding, drinking, and breathing concerns. The presence of a cleft diagnosis and the need for ongoing medical appointments and surgical procedures could be the final straw leading an employer to no longer allow for a flexible work schedule and to demand the formal implementation of the Family Medical Leave Act, thereby requiring time taken off to be unpaid. It could be the final straw requiring one parent to resign from their employer to be caregiver to their child, causing financial stress on the family unit—either leading to one

breadwinner or becoming reliant on public assistance that may or may not be financially enough to sustain the family.

On the contrary, a cleft diagnosis could become the glue that binds parents and extended family members together for support and encouragement. The strengths and supports that were already present in the family system could be further called into action and incorporated into daily routine and schedules. For example, fathers may utilize paternity leave to be present to assist at feeding appointments to help learn how baby feeds best, extended family may move or live nearby, neighbors may pitch in to watch other children while parents complete necessary appointments and prepare for surgery, employers may be flexible and reduce hours to part-time, or religious or spiritual organizations may send food and resources to the home to assist.

INCREASED MEDICAL TEAM AWARENESS

The importance of completing the biopsychosocial assessment early in the new diagnosis is to not only learn of opportunities to support family members but to assist the medical team with understanding the various external and internal forces impacting the family unit. By understanding these stressors and strengths, the medical team can be more aware that there may be subtle nuisances in care and treatment that cause stress and anxiety for families. For example, clinic appointments at certain times of day may impact child care for other children, the availability of transportation, conflictual work expectations, and/or interfere with a parent's class schedule as attempts are made to obtain a higher education. There also may be opportunities to schedule appointments on the same day to lessen burden on the family unit. Increased awareness allows for greater flexibility and understanding that a diagnosis can be the tip of the iceberg for some families.

CONCLUSION

The presence of a diagnosis can become an added stressor for families. Families have preexisting strengths and areas for improvement even before learning of a diagnosis. There is hope that with a comprehensive team the necessary supports can be identified to assist a family through such an ordeal. Having a comprehensive cleft palate team is an essential part of the diagnosis, treatment, and sustaining of a family through a cleft diagnosis and cleft lip and/or palate repair. The presence of a comprehensive team allows for the addressing of the biopsychosocial issues that families inevitably bring to the medical experience, even before a diagnosis has been made.

REFERENCES

- Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology*, 38(8), 809–828.

- John, A., Sell, D., Sweeney, T., Harding-Bell, A., & Williams, A. (2006). The cleft audit protocol for speech-augmented: A validated and reliable measure for auditing cleft speech. *Cleft Palate-Craniofacial Journal*, 43(3), 272–288.
- Jones, M. C. (2002). Prenatal diagnosis of cleft lip and palate: Detection rates, accuracy of ultrasonography, associated anomalies, and strategies for counseling. *Cleft Palate-Craniofacial Journal*, 39(2), 169–173.
- Hunt, O., Burden, D., Hepper, P., & Johnston, C. (2005). The psychosocial effects of cleft lip and palate: A systemic review. *European Journal of Orthodontics*, 27, 274–285.
- Parker, S. E., Mai, C. T., Canfield, M. A., Richard, R., Wang, Y., & Meyer, R. E., et al.; for the National Birth Defects Prevention Network. (2010). Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Research (Part A): Clinical and Molecular Teratology*, 88, 1008–1016.
- Platt, L. D., DeVore, G. R., & Pretorius, D. H. (2006). Improving cleft palate/cleft lip antenatal diagnosis by 3-dimensional sonography: The “flipped face” view. *Journal of Ultrasound in Medicine*, 25(11), 1423–1430.
- Robbins, T. M., Damiano, P., Druschel, C. M., Hobbs, C. A., Romitti, P. A., & Austin, A. A., et al. (2010). Prenatal diagnosis of orofacial clefts: Association with maternal satisfaction, team care, and treatment outcomes. *Cleft Palate-Craniofacial Journal*, 47(5), 476–481.
- Rotten, D., & Levailant, J. M. (2004). Two- and three-dimensional sonographic assessment of the fetal face. 2. Analysis of cleft lip, alveolus and palate. *Ultrasound in Obstetrics and Gynecology*, 24(4), 402–411.
- Stanier, P., & Moore, G. E. (2004). Genetics of cleft lip and palate: Syndromic genes contribute to the incidence of non-syndromic clefts. *Human Molecular Genetics*, 13(Suppl. 1), R73–R81.
- Trepper, T., & Barrett, M. J. (1989). *Systemic treatment of incest: A therapeutic handbook*. New York: Brunner/Mazel.

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