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## Parent-Child Resilience in Cleft Lip or/and Palate Condition: A Review

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### Abstract

Cleft lip or/and palate is the most common cranio facial difference observed in today's times. Like any other difference from the 'norms', it is a challenge for the child as well as his/her family. Most researches have talked about the negative experiences of the parents and children suffering from the cleft condition. Gradually in the past decade, the focus has begun to shift to the positive aspects of the difference being assessed using the concept of resilience. Hence, the present article aims to organize the factors contributing to positive psychosocial adjustment and resilience in parent-child dyad experiencing the cleft condition in the form of a review. Using studies carried out in the fields of psychology and dentistry, a review has been formulated. The article brings to light the need for integrating the contributonal perspective of difference in the research and apply it in the therapeutic domains for the professionals dealing with orofacial clefts.

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A difference compared to the general 'norms' is a challenging condition always. A child born with a different craniofacial condition has potential consequences for facial appearance, dental development and speech. The consequences occur because the society places excessive importance on outward appearance, making it a qualifying criterion for social acceptability.<sup>1</sup> At the same time, there are various disturbances of dentition and growth. The corresponding treatment course is complex, spanning childhood, adolescence and at times adulthood too. Thus, individuals with a craniofacial difference and their families are at a risk of facing difficulties in their psychological, social and emotional adjustment. Orofacial cleft refers to an opening in the lip or roof of the mouth caused when embryonic development gets arrested in the first trimester.<sup>2</sup> It may involve one or both sides of the lip or/and palate that is it may be unilateral or bilateral respectively. It may involve only the soft palate or both the soft and hard palate that is it may be incomplete or complete respectively. The visibility of the cleft condition apart from the internal complications results in negative self perceptions and difficulties in social interactions.

The thought processes contain fear of negative social evaluation, negative emotions of social anxiety, unfavourable self perceptions, lowered self esteem and unfavourable body image.<sup>3</sup>

One's attitudes and beliefs regarding appearance are either determined by the importance of appearance in one's life or the importance placed by the individual on appearance. For some individuals, appearance may have an effect to the point that it forms a part of their day to day life. On the other hand, for some, it may play a cardinal role in their self concept. Physical appearance as a part of body image affects the individual's self esteem with a positive body image associated with higher self esteem.<sup>4</sup> Low self esteem consequently can act as a risk factor for psychopathology according to the vulnerability model.<sup>5</sup> But at the same time some individuals born with a craniofacial condition show positive psychosocial adjustment and self perception.<sup>6</sup>

A significant risk or adversity can thus trigger a dynamic process of positive adaptation referred to as resilience.<sup>7,8</sup> Whether a person develops

resilience or not depends on social, cognitive and emotional processes within the individual and between individuals, as well as the social context.<sup>7,9</sup> A risk can be a single event or even a sequence of stressful experiences like chronic health conditions in children. Positive adjustment may occur in some domains but other developmental outcomes may be problematic.<sup>7</sup> Even Rumsey (2002)<sup>10</sup> stated that some individuals are able to find some ways of effective coping, placing their visible difference in the background. Broder (2001)<sup>11</sup> and Kapp-Simon and Gaither (2009)<sup>12</sup> have tried to incorporate the models of resilience in investigating coping in cleft conditions as an essential area needing exploration.

Still resilience as a concept in the cleft conditions is a relatively less explored area. Most researches reviewed have talked about the impact of the cleft condition on the quality of life and psychosocial adjustment separately for parents and children. The resilience aspect has been included as only a part of the research findings. Hence the present article is an attempt to present the way researchers have conceptualized resilience in children born with cleft lip and/or palate and their parents. The present review talks about the factors that promote or show the presence of resilience in parents and children with cleft conditions.

### **Decoding resilience in parents**

A diagnosis of a cleft lip and/or palate condition either antenatally or postnatally can be an unexpected outcome for an adult who at the stage of becoming a parent. The pressure on the family system may increase and disrupt the parents' ability to adapt to the novel situation<sup>13</sup> or may sometimes lead to a positive reappraisal.<sup>14,15</sup> The findings of the impact on parents by different researchers are quite varied. The factors promoting resilience in parents are listed:

**Acceptance of difference-** Strauss (2007)<sup>16</sup> showed that individuals with cleft conditions when they accept their condition are better capable of showing resilience. Parents with cleft conditions having had an experience of their own are better able to adjust to their child's cleft as they have themselves learnt to accept the feeling of being different. Cochrane and Slade (1999)<sup>17</sup> in their study on 51 adults concluded that personal appraisal of having a cleft and a different appearance influences the emotional well being. The emphasis of the medical field on the aesthetics of the outcomes of surgeries is not sufficient henceforth according to the investigators. Learning from their own experience as parents with cleft conditions themselves, has been found to be resulting in greater resilience in some adults with a cleft condition. Appreciation of positive outcomes led

the parents to feel less anxious about their children's future than parents with no such experience.<sup>6,17</sup> Successful coping with their own condition helps parents born with a cleft to feel more confident of knowing that they have already survived the process. Consequently parents develop an internal model of successful coping to draw from in case their own children have a cleft. Patel and Ross (2003)<sup>18</sup> investigated the perceptions of 20 South African adults with repaired cleft lip, cleft palate or both through an exploratory descriptive, qualitative research design. The participants of the study perceived their speech to be intelligible, not noticing the nasality problems often as per Witzel (1995).<sup>19</sup> Thus, the determination and ability to cope with adversity increases with the prior experience of the associated challenges and rewards. Parents are enabled to see the positives of the situation more referred to as the post traumatic growth.<sup>17,18</sup>

**Level of social support-** Social support is a well established factor that helps an individual to deal with a crisis more effectively. Baker *et al.* (2009)<sup>14</sup> found that less social support was associated with poorer family functioning and psychological health resulting in poor adjustment. They investigated the parental coping techniques and social support along with their adjustment levels and psychological distress. They found that parents with children born with a cleft condition reported positive outcomes from having a child with a cleft condition. Parents experienced personal growth, increased sensitivity, which henceforth formed the basis of a better psychosocial adjustment of the child. Similar findings were reported by Krueckeberg and Kapp-Simon (1993),<sup>20</sup> Campis, DeMaso and Twente (1995),<sup>21</sup> Endriga, Jordan and Speltz (2003),<sup>22</sup> Pope, Tillman and Snyder (2005).<sup>23</sup> Social support brings greater feelings of belongingness, self esteem, a more optimistic perspective and a greater sense of feeling valued. Sank, Berk and Cooper (2003)<sup>24</sup> found no differences in the social support of parents of children with a cleft condition in comparison to a no cleft group. The protective aspect of social support in managing the major turning points in one's lives has also been highlighted by King and Sanares (2003)<sup>25</sup>

**Availability of information-** Parents desire information about feeding, any treatment including surgeries or a developmental delay. Factors associated with clefting including the ones that are normal and the ones that are abnormal, the results of the child's examination including the muscle tone are also some queries of the parents.<sup>26-29</sup> A more accurate and sensitive description of the deformity in the child with reassurance from the health professionals that it was not the parental fault or the child was not in pain, gives a lot of relief to the

parents.<sup>27</sup> Dar, Winter and Tal (1974)<sup>30</sup> emphasised how essential it was for the treatment team to address the feelings of possible embarrassment that would result in parents on introducing the newborn. Questions with regards to the etiology of the deformity, duration of cranio facial care and risk for future pregnancies were the issues of concern for the parents. Pelchat *et al.* (1999)<sup>31</sup> conducted a study on 43 parents of children with cleft and 31 parents of children with down syndrome. The researchers compared the efficacy of an intervention program aiming to improve the parental adaptation to child's condition. They found parents to be reporting better adaptation when they were provided the intervention and even after follow up, the effect persisted.<sup>32</sup>

**Parental attitudes-** Parents' attitudes towards the cleft condition and their parenting style have a role to play in the dynamics of the parent and child. Researchers<sup>22,33</sup> have found factors like mothers acknowledging the stress of the situation of their child having a cleft, being with their role as parents and believing that they are able to meet the needs of the child with cleft, to be important. Ability to nurture children in a way facilitating healthy attachment during early childhood, better emotional self regulation during preschool years and lesser behavioral problems during elementary school, gets promoted. Better social skills as well as adjustment with greater self confidence in primary grades was found in children whose mothers had greater parenting confidence and less stress. A caring, nurturing parent with a socio economic status advantage according to Steele, Forehand, Armistead, Morse, Simon and Clark (1999)<sup>34</sup> are the family characteristics associated with a resilient child. Power and Shanks (1989)<sup>35</sup> consider the socialiser role models served by parents, provides children with support and structure, enhancing the ability of the child to thrive. Parent and child relationship changes with age and changing developmental demands. Pope and Ward (1997)<sup>36</sup> found better social competence of adolescents when parenting style was characterized by less worry about child's friendship and active encouragement of the efforts of the child to engage with the peers.

**Positive coping and outlook-** The way the an individual perceives and handles a problem situation influences his/her quality of life. Baker *et al.* (2009)<sup>14</sup> studied 103 British parents of children with cleft using instruments like Coping Response Inventory and Stress Related Growth Scale. They found a high degree of positive coping and optimism especially in parents whose children had more severe cleft conditions. Cognitive or problem focused strategies like discussing the needs of the child with the school staff, formulating ways to help child establish

friendships and handle teasing were some of the positive coping strategies.<sup>37</sup> Strauss (2001),<sup>38</sup> Johansson and Ringsberg (2004)<sup>39</sup> and Klein *et al* (2006)<sup>37</sup> reported some emotion focused strategies like maintaining a hopeful attitude for the future, confidence on one's own competence as a parent to be helpful as well. Parents were also able to identify the rewarding aspects of caring for a child with a cleft. Recognition of their own personal strengths, stronger relationships, appreciation of diversity, others' good intentions, tolerance, a sense of community and optimistic thoughts were the associated rewards.<sup>6,37,40</sup> The parents also report their ability to identify the strengths of the child including a determined attitude, perseverance and sociability.<sup>37</sup> Such have been the mixed findings that Eisermann (2001)<sup>6</sup> in his research found parents not wanting to get their child's cleft removed even if given the opportunity, a finding also reported by Juneja and Juneja (2014).<sup>15</sup> Baker *et al.* (2009)<sup>14</sup> in their study also found parents to be reporting positive outcomes co-occurring with negative ones. The positive impact included better understanding of their own selves and treatment of others, greater personal strength and optimism, more effective self regulation of emotions, greater sense of belongingness and religiousness. The positive effect was in line with the stress related growth reported by Schaefer and Moos (1992).<sup>41</sup> Approach oriented coping in terms of social support, problem solving, logical analysis and positive appraisal rather than avoidance oriented coping like cognitive avoidance, acceptance, alternative rewards and emotional discharge have been found to be associated with good adjustment to stressful life events.<sup>42</sup>

With regards to children suffering from an orofacial cleft, the factors facilitation adjustment and resilience are enlisted:

### **Decoding resilience in children**

**Physical characteristics of difference-** the subjective perception of the noticeability of the difference plays a major role in predicting the psychological and body image disturbance. The assessment of a detached observer or clinician does not suffice.<sup>1,43</sup> The self perception henceforth predicts the degree of depression and/or anxiety, satisfaction with appearance and the subjective experience of the child whether he/she was being teased. Feragen *et al.* (2009)<sup>1</sup> in their cross sectional study of 268 treated children in the 10 year old age group, born from 1992 to 1997 investigated the self reported social experience and psychosocial resilience of the children born with a cleft. By the analysis of responses on the some standardized questionnaires, they found that cleft visibility was not associated with a greater level of distress. No gender differences too with regards to resilience

were observed. Lower reported teasing by children could also be attributed to the child's self perceptions about the other people's reactions, which might be colored by the psychological deficits or assets of the children.<sup>44</sup> There also could be external factors that buffer the interpretation of the potentially negative experiences in social interactions.<sup>45</sup> A secure child interprets teasing as simple question or curiosity making attribution process important in interpreting social encounters.<sup>46</sup> In their review of understanding the adjustment process to acquired or congenital disfiguring conditions, they emphasized the way people with difference interpreted their selves. Self interpretation was found to be based on underlying cognitive self schemas and the social interaction contexts. Moss and Carr (2004)<sup>47</sup> and Rumsey and Harcourt (2005)<sup>48</sup> state that resilient children place less importance on others' evaluation of their appearance, facilitating better adjustment. The resilient children might accept themselves the way they are or may play down the importance attached to a visible difference in their facial appearance. The acceptance enables them to keep their own self perceptions untouched. They remain protected henceforth from the stares and opinions of other people. At the same time, resilient children and parents might reflect more about the consequences and meaning of appearance in life.<sup>49</sup>

**Temperament-** Attributes of personality act as mediating factors that enhance or inhibit the adjustment of an individual to an illness.<sup>50,51</sup> A central quality of an individual is temperament.<sup>52</sup> A more even tempered child who tolerates surgeries with less distress is less likely to be disturbed by questions about the scarring from the cleft. The easy going positive natured children hence are less likely to be teased by their peers or view teasing as a problem in other children.<sup>53</sup> Endriga et al. (2003)<sup>22</sup> studied the aspect of emotion self regulation and its relationship to future adjustment in 83 five year old children with cleft conditions and a control group. They found the cleft group to be displaying lesser disappointment than children in comparison group. The lower levels of disappointment were predicted to be acting as a protective factor for children with clefts. The effect of early stress on development acted as a buffer restricting behavioral and emotional problems in future. Kapp-Simon (2006)<sup>54</sup> talked about the characteristics intrinsic to the child like temperament and intelligence to be contributing to the global well being of the child suffering from the cleft.

**Social acceptance-** The social reactions influence an individual's view about the self and the world to a certain extent. Researchers<sup>55-58</sup> found children with cleft conditions having an above average self

concept compared with test norms or at least lying in the average range. It was attributed to them having many friends to play than wanting to play alone as expected due to avoidance and fear of embarrassment of their physical appearance. Thus peer acceptance resulted in children having average or above average self perception. Maternal acceptance as well as maternal teaching during parent-child interactions resulted in a healthy and functional global self concept. Adolescents rely on their families to compensate for the lack of peer relationships. Healthy parent-child relationships become essential to the growing personality of the adolescent than the overprotectiveness of the parents. Support from parents buffers the child's potentially negative experiences with the social world.<sup>59,37</sup> If the parents were able to handle their difficulties, the adolescents began to perceive themselves as more understanding of others.<sup>60</sup> The children with parental support do not integrate the negative social reaction of people into their own self perception. The development of an identity of being negatively different is therefore avoided. The positive affectivity in the social support protects against the negative impact of negative emotional experiences too.<sup>61</sup> Emmons and McCullough (2003)<sup>62</sup> found that a grateful response to life circumstances was an adaptive psychological technique in which everyday experiences are interpreted positively. Although youth may not have learned the required coping skill to have a positive sense of self, they might not have achieved the level of maturity to report that the facial difference has helped them, resilience nevertheless was seen in the adolescents. Feelings of closeness and intimacy provided by friendships results in feelings of being socially accepted, lowering the emotional distress. The trust, approval and reciprocity characterizing friendship makes the individual feel more attractive and protects against emotional distress.<sup>63</sup>

**Social Skills-** The skills of an individual to maintain interpersonal relationships determines the social life of an individual. Kapp-Simon, Simon and Kristovich (1992)<sup>64</sup> studied 45 young adolescents with cranio facial anomalies to examine the relationships between their self perception, social skills, overall adjustment and social inhibition. A higher level of adjustment was seen in children who displayed better social skills and social behaviors. The child's own feelings about their appearance, perception of school performance or even their own sense of self worth were not the only determinants. Eiserman (2001)<sup>6</sup> in a pilot study on 11 parents of children and 11 affected adults with cranio facial differences, using a qualitative and quantitative methodology, asked the participants to reflect on their experiences. He found positive outcomes with regards to the communication skills, service to

others, observational skills, inner strength, abilities to question the society, a valued social circle and perceptions of being normal because of the difference. The findings were explained in terms of an unusual attribute believed to be absent in the so called 'normal' population, which is hence a positive and functional aspect. Half of the participants did not even wish to eliminate the experience of the facial difference if given an option. Strauss *et al.* (2007)<sup>16</sup> also concluded the significance of social skills while studying stigma experiences of adolescents with congenital and acquired facial differences.

Apart from the factors discussed, extrafamilial factors like enrolling in prosocial organizations, effective schools, supportive teachers to provide instructions and attachment with prosocial adults like religious leaders are found to be associated with resiliency as well.<sup>11</sup>

### Conclusion

Although the review is limited by the research studies available to the authors, it tries to coherently present factors promoting positive psychosocial adjustment and resilience in both parents and children at one place. Integrating perspectives from different fields, it emphasizes the need to broaden the research horizons and consider the so called disability as a difference that has a uniqueness of its own.

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