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PSYCHOSOCIAL ISSUES SURROUNDING CLEFT LIP AND PALATE

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INTRODUCTION

Health care practitioners working with clients with craniofacial anomalies (CFAs) such as cleft lip and/or palate are acutely aware of the many psychosocial stressors that confront these people and their families. However, "less widely known are the specific psychological and social sequelae of these disorders and interventions designed to optimise the psychosocial adjustment of individuals with CFAs" (Pope & Speltz 1997:371).

A cleft is an elongated opening, usually resulting from the failure of parts of the oral cavity to fuse or merge early in the first trimester of prenatal development. The failure to fuse may involve only the lip, only the palate, or a combination of the two. While most clefts result from the interaction of genetics and environment, some clefts are associated with other congenital malformations, some of which occur predictably together and are classified as syndromes, for example, Treacher Collins Syndrome, Pierre Robin Syndrome and Apert Syndrome (McWilliams & Witzel 1994:442).

Cleft lip and palate represent the second most frequently occurring congenital deformity (after clubfoot). Males are more often affected than females and are more likely to have a bilateral cleft (Woolf 1971). According to the Birth Defects Surveillance Systems (BDSS) Report published by the South African Department of Health, there were 113 reported cases of cleft palate, i.e. 2.3 per 10 000 live births, and 180 reported cases of cleft lip, i.e. 3.6 per 10 000 live births during the period 1989 to 1996 (BDSS Report 1996/1997). Areas covered by the BDSS included Soweto, East London, Bloemfontein, Durban, Chatsworth, Umlazi, Cape Town, Worcester, Pretoria, Shongwe Mission and Kabokweni. According to Venter *et al.* (1995), within the rural areas 3.9 cases of cleft palate per 10 000 live births were reported among rural African neonates for the period 1989 to 1992.

The baby with structural problems of the oral cavity has been found to be at an increased risk for the development of problems in developing speech and language (McWilliams & Witzel 1994). The presence of anatomical malformations of the head and neck also increases the risk for all forms of hearing impairment (McWilliams & Witzel 1994). Moreover, Broder (1997:404) maintains that on the basis of cross-sectional investigations, "... it is generally accepted that individuals with craniofacial anomalies (CFAs) such as clefts are at risk for impaired psychological adjustment, diminished social skills, delayed cognitive status, and potentially low parental acceptance". When considering the psychosocial issues surrounding cleft lip and/ or palate, it is often helpful to consider the particular issues likely to take precedence at different stages of the life cycle.

THE PRENATAL PERIOD AND EARLY INFANCY

The advent of new medical technology has made it possible in some cases to diagnose facial malformations even before the birth of the child (McWilliams 1997). However, whether parents learn about the diagnosis during the pre- or postnatal period, they generally tend to experience great emotional upheaval, including feelings of disappointment, grief and shock. These feelings are poignantly illustrated in the words of a mother of an infant with a bilateral cleft lip and

palate: *"As an expectant parent, I was filled with feelings of excitement, anticipation and joy. What a happy time this was and what a tremendous disappointment when I found out he was born less than perfect. I felt no love for this baby. I felt nothing ..."* (Andrews & Andrews 1990). Yet, despite these initial feelings, most parents usually recover fairly quickly and come to accept their baby and the cleft. Parents vary in their ability to cope with this particular problem just as they vary in the way they cope with all problems. Some cope well from the beginning, while a few never accommodate or come to an acceptance of the problem. Ability to cope seems to depend on previous knowledge of clefting; individual stability; family unity, support received during the initial period of diagnosis; and the severity of the cleft, i.e. whether both lip and palate are involved or only the palate. Also, malformations vary in severity, and the newborn infant's "attractiveness" index is usually negatively affected as the facial disfigurement increases (Slade, Bishop & Jowett 1995). However, there does not seem to be a one-to-one relationship between severity of the cleft and parental distress.

Similarly, while some children with clefts have severe emotional problems, others never develop any problems of this nature. In fact, there does not appear to be any research evidence to suggest that these children are any more likely or less likely to be emotionally disturbed than other children. Hence, counsellors need to be sensitive to parents and the ways they interact with their children.

McWilliams, Morris and Shelton (1990) cite an earlier study by Weachter (1959) in which parents were asked to list their major concerns about their children who had clefts. In order of frequency they mentioned the following concerns: (1) appearance; (2) immediacy of surgery; (3) speech; (4) feeding; (5) reactions of the other parent; (6) responses of brothers and sisters; (7) reactions of other family members and friends; (8) mental development; (9) finances; and (10) the possibility of recurrence in future children. Four decades later these concerns are still encountered. They are also not static and change as the child grows and develops.

As parents are gradually able to move beyond their initial shock and grief, counselling can be expanded to help them ask questions, begin to plan their child's treatment, understand the role of the various team members, and acquire the knowledge and skills needed to care for their infant. At this point it is often helpful for mothers and fathers to meet other parents via cleft palate associations and to visit clinics where they can come into contact with children who have been treated for similar birth defects (McWilliams 1997).

The earlier parents are given an opportunity to discuss their fears and concerns surrounding the facial anomaly, the more quickly they are likely to accept the situation and to bond with an infant who is remarkably different from the perfect child they had dreamed of. However, early acceptance is not without difficulty for some parents. Hence, counselling is of crucial importance as the development of parent-child attachments may, in part, influence the nature of the child's psychological adjustment in later years. It can be particularly helpful if the professional counsellor or another parent of a child with a cleft demonstrates positive responses to the baby. Holding and looking at the infant while engaging in baby talk and commenting on the infant's other features can help parents to see beyond the facial disfigurement and respond to their *baby* rather than to the birth defect. They also need to be encouraged to vocalise and endeavour to stimulate the baby's speech and language development. In this way one can hopefully prevent the kind of interaction noted by Field and Vega-Lahr (1984) in which mothers of children with craniofacial defects smiled and vocalised to their infants less frequently than did mothers of unimpaired babies.

Other concerns that need to be addressed during this period relate to surgery. Among the first questions that parents usually ask is whether or not the condition can be corrected. Although the

entire treatment team is involved at this stage, the surgeon usually assumes primary responsibility for determining the timing of surgical procedures, and explaining to parents the details of surgery and its aftermath. While being compassionate and optimistic, it is important that counsellors avoid assuring parents that there will be no lip scar after surgery. Also, parents may harbour ambivalent feelings regarding surgery. For example, they may want to have the defect repaired but at the same time they may fear that the child might die or be harmed in the process. They may also be concerned about feeding the baby after surgery and may have problems accepting the idea of hospitalisation. The support of a professional counsellor or another parent during and after surgery is therefore of crucial importance.

With regard to feeding, it may be difficult to breastfeed babies with clefts. Feeding often takes a long time and the infant may become restless when it is unable to suck sufficient milk. Inadequate weight gain on the part of the infant can also be a source of anxiety for the parents. Parental concern about feeding and poor weight gain, coupled with the awareness of discomfort on the part of the infant, can in turn interfere with the development of the mother-child relationship. According to Speltz *et al.* (1994), mothers of infants with clefts have been found to be less positively interactive with their infants, not because of the child's unattractiveness, but due to the many difficulties experienced during the feeding process. Consequently, less smiling and feeding cues and reduced responsiveness have been noted on the part of both the infant and mother. Frequent hospitalisation to repair the craniofacial abnormality and facilitate feeding can also potentially hamper the development of a good mother-child relationship. A further point with regard to feeding problems is that they can also hinder speech development. Oliver and Jones (1997) administered a postal questionnaire to a group of 100 parents of children born with clefts in South East Wales and found that, prior to birth, the majority of mothers intended to breastfeed their children, but after birth, the majority bottle fed their infants. First-time mothers were less critical of the service provided to assist with feeding than were mothers whose children had elder siblings. These researchers stress the need for good-quality feeding advice for parents of children born with orofacial clefts both in hospital and following discharge.

McWilliams (1997) emphasises that it is important for parents to understand that feeding problems are usually the result of a mechanical failure of the oral mechanism and not because of poor parenting. It is therefore advisable to teach parents how to feed the baby as simply and normally as possible. For example, one can show parents how to hold the infant in a sitting position, using a cross-cut nipple rather than one with an enlarged hole that delivers the liquid too quickly. They can also be advised to use a soft plastic bottle which enables pressure to be gently applied to assist the baby in drinking the milk. Parents who are able to feed their infants successfully tend to feel more confident of their parenting skills. A few mothers who are intensely motivated to breastfeed their babies may be able to do so, particularly if the infant has only a minor defect. Still others are able to accept the idea of feeding breastmilk expressed into a bottle (McWilliams 1997).

In view of the fact that Cohen (1991) identified 342 syndromes associated with clefting, many children with clefts are at an increased risk for additional abnormalities. If other congenital defects are diagnosed, the appropriate genetic counselling needs to be provided.

Another area of concern during infancy is the presence of ear disease. Ear disease is often associated with mild conductive hearing losses which, if left untreated, can cause hearing loss. The speech and hearing therapist needs to collaborate closely with the paediatrician and otolaryngologist in the treatment of ear infections and to follow-up on the baby over an extended period (McWilliams 1997).

A final issue during infancy, revolves around speech and language development. Although approximately 75% of children with clefts do not develop permanent significant speech problems, McWilliams, Morris and Shelton (1990) advise speech-language pathologists to gently guide the parents to be good language and speech stimulators.

CHILDHOOD

During early childhood, parents and children have to be prepared for further hospitalisation and surgery. In addition, approximately 25% of children with clefts have associated developmental problems. For example, Strauss and Broder (1993) found that 10.1% of their sample of 553 subjects with clefts presented with varying degrees of mental retardation, usually moderate in nature, whereas 13.9% had learning disabilities. It is therefore important that counselling not only focus on the cleft and other facial attributes to the exclusion of developmental aspects. In such cases referral for developmental assessments may be needed.

Although children with cleft palates are not typically emotionally maladjusted, they may experience some problems related to social acceptance. For example, McWilliams *et al.* (1990) cite a study by Kapp-Simon (1986), who administered personality scales to a sample of children with clefts and found that they perceived themselves to be less acceptable than their peers, more likely to require assistance, and more frequently experienced feelings of sadness and anger.

Tobiason (1987) found that faces with clefts were rated by other children as less friendly, less likely to be chosen as friends, less intelligent and less good-looking. These ratings were not related to age or gender. On the basis of these findings, Tobiason concluded that "facial deformity may be a central cue for social stereotyping, because facial deformity may be seen as ugly and ugly as bad" (cited in McWilliams 1997).

MacGregor (1961 in McWilliams *et al.* 1990) concluded that the majority of the 115 individuals she interviewed were dismayed by their own mirror images and "saw their handicaps reflected in the reaction of others towards them". The people interviewed reported staring, passing of remarks, questioning, pity, rejection, ridicule, whispering, nicknames and discrimination. Such responses were reported to make them feel "self-conscious" and "unhappy". The majority of individuals whom MacGregor interviewed also reported suffering from feelings of inferiority, frustration, preoccupation with the deformity, hypersensitivity, anxiety, hostility, paranoia and wanting to withdraw from social activities.

More recently, in 1997 Pope and Ward investigated the psychosocial adjustment related to self-perceived facial appearance of 21 pre-adolescents with craniofacial abnormalities, via self-report and parent-report questionnaires. Dissatisfaction with facial appearance was associated with peer relationship problems and low global self-esteem.

Group therapy for parents is particularly effective because it allows them to freely exchange feelings, information, ideas for handling sensitive issues, concerns about child rearing practices, and questions about speech and language. Through the provision of emotional support, parents are encouraged to be accepting of the situation so that their children grow up with strong self-images, confident attitudes and objective information about the disorder and its treatment.

In counselling children, it is important to let them know that the problems they have are not shameful but are shared by many others. Small, cuddly teddy bears with stitched lips can also be helpful as children can relate to these toys. Such toys can become part of the share-and-tell periods at preschool and can help other children in this age group to become acquainted with individual differences (McWilliams 1997). A joint session with preschool staff, parents and

counsellor can help to alleviate parental concern that other children will tease their son or daughter about the lip scar, distorted facial features or deviant speech.

Kapp-Simon and McGuire (1997) compared the social interaction skills of children with craniofacial conditions (CFCs) with non-affected peers in the naturalistic setting of a school lunch room. They found that a significant number of children with CFCs were often at the periphery of the group, and tended to be observers rather than participants in conversation.

A finding from various case studies which is even more alarming is the fact that in late childhood the personality responses to a deformity may be incorporated as an integral part of the personality, so that even after the defect is repaired, the child may continue to behave as if it is still present. These findings underscore the need for children with clefts and their parents to receive help and support in dealing with these problems.

While there is no evidence of a "cleft-palate personality", those with clefts and other structural abnormalities affecting the head and face are often subject to unique problems imposed by a society that penalises differences.

McWilliams and Witzel (1994:439-440) list the following myths surrounding cleft palate:

Myth: Facial disfigurement and palatal clefts are G-d's punishment for parental sins.

Reality: Most clefts result from the interaction of genetics and environment.

Myth: Cleft palates occur because of "marking", for example, a pregnant woman who sees blood running down the upper lip of a suicide victim.

Reality: Prenatal experiences of this type have nothing to do with the baby's facial features.

Myth: The deformity was caused by poor obstetrics.

Reality: A cleft results from an alteration in embryogenesis between the 6th and 12th weeks of pregnancy. It cannot be caused by faulty obstetrical practices.

Myth: Children with clefts are mentally retarded.

Reality: Only if clefts are accompanied by other abnormalities or if there is a cleft involving only the palate is there an increased risk for developmental problems, including mental retardation.

Myth: The severity of the facial deformity is an index of mental abilities.

Reality: It is impossible to predict intelligence from facial appearance.

Myth: Children with clefts of the palate only are brighter than children with clefts of the lip and palate, and brighter even than children without clefts.

Reality: There is no support at all for this view.

Myth: Most speech problems associated with cleft palates can be corrected by speech therapy.

Reality: Many such problems are not treatable by behavioural means alone. In most cases maxillo-facial and dental surgery is also needed.

Myth: There is a typical "cleft personality".

Reality: While people with clefts must make obvious adjustments, they have a range of personalities just as people in general have.

The influence of some of these beliefs has been subjected to empirical research. For example, in 1978 Richman explored the effect of facial disfigurement on teachers' perceptions of ability in children with clefts. The main findings were as follows: (i) Teachers rated the children with minimal facial disfigurement more accurately than they did those with more severe deficits; (ii) The potential of children with noticeable facial disfigurement and below average intelligence was under-estimated; (iii) The abilities of children with noticeable facial disfigurement and above average intelligence were also under-estimated. These findings have important implications for children with cleft palates in terms of the "Pygmalion Effect", as such beliefs can become self-fulfilling prophecies.

In another study Blood and Hyman (1977) investigated the effect of nasal resonance, which is a common quality of cleft palate speech, on the impressions of listeners. As the hypernasal voice quality of the speaker increased, children responded more and more negatively to the speaker. The researchers concluded that during adjustment to school, children with clefts may face judgement, ridicule and rejection from their peers which could exert a negative impact on their social development. However, different findings were obtained in a more recent study by Berry *et al*. (1997), who asked 20 sixth-grade students to rate personality characteristics of 20 repaired cleft children and 16 control children based on audiotapes of speech samples. They found that in the absence of visual input, there were no significant differences between the ratings for the cleft palate sample and the control group.

These studies underscore the need for counsellors of school-age children to explore school experiences and take appropriate steps to modify the classroom environment where necessary. This approach may involve individual work with involved teachers, continuing education of teachers in general, and awareness programmes for children who do not have clefts to learn to understand and accept differences in others.

THE TEEN YEARS

Teenagers represent a heterogeneous group and experience the normal changes which accompany adolescence, such as the need to cope with rapid physical changes, assert their independence from their parents, and be like everyone else. However, among teenagers who have been born with clefts there may be curiosity about as well as fears regarding the nature and causes of their birth defects and the chances of having similarly affected offspring.

There is also "the reality of their differences and the realisation that there may be few remaining treatment options" (McWilliams 1997:283). Some surgical procedures may offer only minimal chances of improving speech or appearance. According to Noar (1991), several studies have shown that teenagers and young adults tend to generally be satisfied with their speech and appearance, but are usually less pleased with cleft-related characteristics such as noses, lips, profiles, teeth and speech. Thomas, Turner, Dowell and Sandy (1997) studied 111 patients with clefts whose ages ranged from 10 to 20 years, and found that those with visible impairments were more dissatisfied with their facial appearance than subjects with invisible impairments. Nevertheless, these young persons may be reluctant to undergo further surgery or may seek inappropriate forms of treatment. In such cases makeup artists can be used to teach the young person how to minimise remaining defects. As in other stages of the life cycle, counselling can help the adolescent to talk about such concerns. Support groups, genetic counselling, and career and educational planning are also important. In addition, role models of successful adults with clefts can demonstrate that there is life beyond the clinic.

ADULTHOOD

It is difficult to generalise about adults with clefts because so few studies are available on this group. Furthermore, many of the studies that are found in the literature tend to reflect the outcome of treatment conducted many years ago when medical technology was much less sophisticated than it is today. Nevertheless, some of the findings from these earlier studies are worth noting.

For example, Peter and Chinsky (1994) found that young adults with clefts attended college as frequently as a control group of peers without clefts. However, males with clefts were not as upwardly mobile in their jobs, they reported more feelings of job insecurity, and had lower income aspirations in comparison with their siblings and random controls (Peter, Chinsky & Fisher 1975). Despite the tentative nature of these findings, they highlight the need for vocational counselling during the teen years.

With regard to relationships with the opposite sex, Van Demark and Van Demark (1970) found that their subjects tended to go on dates less frequently than their peers, while Bjornsson and Agustdottir (1987) noted that subjects with clefts married less frequently and somewhat later than control subjects. Van Demark and Van Demark (1970) observed that the adults whom they studied seemed to be observers of life rather than participants, and preferred individual rather than group activities.

CONCLUSION

The many destructive myths surrounding congenital malformations of the face and oral cavity are often difficult to eradicate, and tend to plague the lives of individuals with clefts, their parents and families (McWilliams & Witzel 1994). The extra stresses posed by these stereotypes may be especially marked during the school years and may lead to withdrawal, altered interpersonal relationships and lowered self-esteem. A well-informed counsellor is often in a unique position to provide information that may modify some of these harmful beliefs and help to overcome these barriers to a full and satisfying life. Orthodontists, plastic, reconstructive and maxillo-facial surgeons fulfil a vital function in repairing the cleft lip/palate and associated physical structures, while speech therapists enable these persons to acquire communication skills. Social workers and psychologists can assist affected persons and their families to come to terms with the many psychosocial issues surrounding the experience of a cleft. In addition, support groups such as Cleftpals can help parents to cope with a child who is physically different. Other members of the craniofacial team include the paediatrician, otolaryngologist, dietician and geneticist. A final point is that with a combined team approach, involving all relevant parties, the prognosis for successful psychosocial development of the child with a cleft lip/palate would appear to be achievable in the majority of cases. Moreover, infants who begin life with strong support and guidance and have that extra assistance through adolescence, are more likely to enter adulthood with better psychosocial skills than those who struggle alone (McWilliams 1997).

REFERENCES

ANDREWS, JR & ANDREWS, MA 1990. **Family-based treatment in communication disorders: A systemic approach**. Dekalb: Janelle Publications Inc.

Birth Defects Surveillance Systems (BDSS) 1996/1997. Pretoria: Women's Health and Genetics, Department of Health.

BERRY, L; WITT, P; MARSH, J; PILGRIM, & EDER, R 1997. Personality attributions based on speech samples of children with repaired cleft palates. **Cleft Palate-Craniofacial Journal**, 34(5):385-389.

BLOOD, G & HYMAN, M 1977. Children's perception of nasal resonance. **Journal of Speech and Hearing Disorders**, 42:446-448.

BRODER, H 1997. Psychological research of children with craniofacial anomalies: Review, critique and implications for the future. **Cleft Palate-Craniofacial Journal**, 34(3):402-404.

COHEN, MM 1991. Syndrome delineation involving orofacial clefting. **Cleft Palate-Craniofacial Journal**, 28:119-120.

FIELD, T & VEGA-LAHR, N 1984. Early interactions between infants with cranio-facial anomalies and their mothers. **Infant Behavior**, 7:527-530.

KAPP-SIMON, KA & McGUIRE, D 1997. Observed social interaction patterns in adolescents with and without craniofacial conditions. **Cleft Palate-Craniofacial Journal**, 34(3):380-384.

McFARLANE, SC; FUJIKI, M & BRINTON, 1984. **Coping with communicative handicaps: Resources for the practising clinician**. California: College-Hill Press.

McWILLIAMS, BJ 1997. Cleft palate and other craniofacial disorders. **In**: CROWE, TA (ed) **Applications of counselling in speech-language pathology and audiology**. Baltimore: Williams & Wilkins.

McWILLIAMS, BJ; MORRIS, HL & SHELTON, RL 1990. **Cleft palate speech**. (2nd ed) Philadelphia: BC Decker Inc.

McWILLIAMS, BJ & WITZEL, MA 1994. Cleft palate. **In**: SHAMES, GH; WIIG, EH & SECORD, WA (eds). **Human Communication Disorders: An Introduction**. (4th ed) New York: Macmillan College Publishing Co.

NOAR, J 1991. Questionnaire survey of attitudes and concerns of patients with cleft lip and palate and their parents. **Cleft Palate-Craniofacial Journal**, 30:87-89.

OLIVER, R & JONES, G 1997. Neonatal feeding of infants born with cleft lip and/or palate: Parental perceptions of their experience in South Wales. **Cleft Palate-Craniofacial Journal**, 34(6):526-532.

PETER, J & CHINSKY, R 1974. Sociological aspects of cleft palate adults. II. Education. **Cleft Palate Journal**, 11:443-449.

PETER, J; CHINSKY, R & FISHER, M 1975. Sociological aspects of cleft palate adults. III. Vocational and economic aspects. **Cleft Palate Journal**, 12:193-199.

POPE, AW & SPELTZ, ML 1997. Research on psychosocial issues of children with craniofacial anomalies: Progress and challenges. **Cleft Palate-Craniofacial Journal**, 34(5):371-373.

POPE, A & WARD, J 1997. Self-perceived facial appearance and psychosocial adjustment in preadolescents with craniofacial anomalies. **Cleft Palate-Craniofacial Journal**, 34(3):396-401.

RICHMAN, L 1978. The effects of facial disfigurement on teacher's perceptions of abilities in cleft palate children. **Cleft Palate Journal**, 13:4-10.

SLADE, P; BISHOP, P & JOWETT, R 1995. Relationship between cleft severity and attractiveness of newborns with unrepaired clefts. **Cleft Palate-Craniofacial Journal**, 32:318-322.

SPELTZ, ML; GREENBERG, MT; ENDRIGA, MC & GALBRAITH, H 1994. Developmental approach to the psychology of craniofacial anomalies. **Cleft Palate-Craniofacial Journal**, 31:1.

STRAUSS, R & BRODER, 1993. Children with cleft lip/palate and mental retardation: A subpopulation of cleft-craniofacial team patients. **Cleft Palate-Craniofacial Journal**, 30:548-556.

THOMAS, P; TURNER, S; DOWELL, T & SANDY, J 1997. Satisfaction with facial appearance among subjects affected by a cleft. **Cleft Palate-Craniofacial Journal**, 34(3):226-231.

VAN DEMARK, D & DEMARK, A 1970. Speech and socio-vocational aspects of individuals with cleft palate. **Cleft Palate Journal**, 7:284-299.

VENTER, P; CHRISTIANSON, A; HUTAMO, C; MAKHURA, M & GERICKE, G 1995. **South African Medical Journal**, 85.

What you should know about cleft lip and palate. 1985. Pretoria: Genetic Services, Department of Health.

WOOLF, CM 1971. Congenital cleft lip: A genetic study of 469 propositi. **Journal of Medical Genetics**, 8:65-83.