

Psychological aspects of cleft lip and palate

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SUMMARY In addition to the influences of family dynamics, educational and vocational factors on the social development and rehabilitation of CLP patients, psychological problems, such as lowered self-esteem and difficulties during social interaction, are also experienced by CLP individuals. As only 20 per cent of cleft teams world-wide carry out a psychological assessment for their patients, it is likely that the prevalence of psychological problems is higher than the literature suggests. To maximize the chances of a positive outcome in the care of cleft affected individuals, CLP patients who are concerned about their appearance or who experience psychosocial problems need to be identified by cleft teams. Interventions, such as counselling or social interaction skills training, should be offered in order that the patient's self-esteem and social self-confidence can be increased.

Current research surrounding patient and parent satisfaction with cleft care suffers from several areas of methodological weakness.

Introduction

Cleft lip and palate (CLP) is the most commonly occurring craniofacial developmental abnormality, affecting one in seven hundred live births (Coupland and Coupland, 1988; Gregg *et al.*, 1994). The incidence of cleft lip and palate anomalies varies according to race, gender and cleft type, being more common among Indian and Oriental populations (2.3 per thousand total clefts) and least common among Afro-Caribbean groups (0.6 per thousand total clefts; Gorlin *et al.*, 1971).

Following the birth of a baby with a cleft anomaly, primary corrective surgery is usually performed within the first few months of life. In the United Kingdom lip repairs are performed usually at around 3 months, with the cleft palate repair following at 6 months (Roberts-Harry and Sandy, 1992). Existing multi-speciality care is primarily aimed at physical rehabilitation, with the psychological issues of care often being neglected. The parents' and patients' perceptions and needs are a critical component of eventual outcome, yet they are frequently overlooked (Broder *et al.*, 1992).

Psychological factors in the rehabilitation of CLP affected individuals

The family environment is an important factor in the rehabilitation of a child with a facial cleft. The attitudes, expectations and degree of support shown by parents are likely to have an enormous influence on a child's perception of their cleft impairment (Bull and Rumsey, 1988; Lansdown *et al.*, 1991). The parents' feelings about their child's cleft defect are thought to be paramount in developing the child's self-esteem (Schonfeld, 1969; Broder *et al.*, 1992). The birth of a baby with a cleft anomaly is rarely predicted, despite the use of ultrasound scanning techniques, so the expectation is always for a normal birth. The initial emotional reactions from parents can be those of shock, confusion, grief, and guilt, although these are not necessarily universal (Slutsky, 1969; Clifford, 1973; Shakespeare, 1975; Bradbury, 1993). Families rarely discuss the cleft anomaly and often the issues surrounding the child's cleft may only surface during visits to the cleft care team (Clifford, 1987). The parents may experience a mental crisis that is handled according to their own character strengths and weaknesses.

These reactions in part depend on the parents' previous background, existing ability to cope with stress and personal philosophy of living (McWilliams, 1982). The baby's facial appearance may interfere with early mother child bonding (Field and Vegha-Lahr, 1984) which is thought to be an important determinant of personality and adjustment in adult life (Clifford, 1973). There is, however, no evidence that this bonding is always affected. Subsequent to the neonatal period, mothers of babies with CLP express more concern and anxiety about their baby than mothers of non-cleft babies (Spriestersbach, 1973). Similarly, mothers of babies with a cleft find they experience a higher degree of personal stress and family conflict, with less family cohesiveness compared with families of non-cleft babies (Ramstad *et al.*, 1995).

Parents of children with clefts report their offspring to be more shy and socially inhibited compared with non-cleft children. As a result, parents may be more tolerant of misbehaviour in their child (Tobiasen and Hiebert, 1984). Some parents of facially disfigured children are not only over protective and likely to spoil their child (Knudson-Cooper, 1981), but they are also more prone to experiencing stress, anxiety and depression themselves (Broder and Strauss, 1991). How parents deal with their child's cleft may vary from total denial of psychological problems within themselves or their child, to pre-occupation with their child's perceived problems (Broder and Strauss, 1989). Increasing a child's social skills, educational, and sporting achievements may compensate both parent and child for the problems experienced as a result of the child's appearance (Bernstein, 1976). This compensation provides a valuable means for the family to cope with the cleft anomaly and provides a mechanism of promoting self-esteem within the family (Lefebvre and Arndt, 1988).

Children with CLP may find their mothers exert psychological control and are more intrusive than children with other congenital facial anomalies or non-cleft children (Richman and Harper, 1978). Facially disfigured children may detect negative reactions from their parents at an early age, but fortunately children also discern that their parents take pride in them despite

any family anxieties and stresses during their upbringing (Kok and Solman, 1995).

There are few studies on family issues alone and those findings which have been published are usually secondary and coincidental to the main research questions. As an example, Lefebvre and Munro (1978) found 12 per cent of parents of CLP children were separated or divorced and 6 per cent were suffering from mental ill-health problems. The authors' inclusion of seemingly peripheral statistics infers that marital discord is a result of family stress surrounding their disfigured child, although the issue is not explored further. Winick (1967) suggests that as many as 50 per cent of marriages fail where a baby has serious congenital problems. The divorce rate amongst adult CLP-affected individuals (14 per cent) approximates that of their non-cleft siblings (12 per cent), but is lower than non-cleft controls (18 per cent; Peter and Chinsky, 1974). Approximately half of divorced individuals (including those with CLP) later remarry (Peter and Chinsky, 1974).

Stigma experienced by cleft lip and palate affected individuals

An individual's perception of their facial attractiveness and their ability to communicate verbally has an important influence upon an individual's psychological well-being (Goffman 1968; Fitts, 1972; Kapp-Simon, 1979). How we perceive ourselves is influenced by how others respond to us socially. A negative response from outsiders, actual or perceived, may adversely affect our own self-image (Videbeck, 1960; Goffman, 1968; Charon, 1979). The links between physical attractiveness, and the likelihood of personal achievement and social acceptability are now well established. Even amongst children as young as three years, attractive children are more accepted as peers (Dion *et al.*, 1972; Dion, 1973). Amongst adults, positive personality characteristics are more frequently attributed to attractive people compared with the unattractive (Dion, 1973; Bull and David, 1986). Attractive adults also tend to be more socially skilled (Goldman and Lewis, 1977). These links between physical beauty and social acceptability underline the

potential disadvantages for CLP affected individuals who may have an abnormal facial appearance (Bull and Rumsey, 1988).

Social interactions

An imperfect appearance may initiate overt teasing, bullying and unwanted questioning. Social responses may also take the form of more subtle changes in normal patterns of verbal and non-verbal interaction such as facial expression (Bull, 1990). These unfavourable social responses are the result of stigma, where outsiders subconsciously judge an individual negatively because of their imperfect appearance. The unfavourable social responses may be interpreted as a form of social unacceptability which may reduce feelings of self-worth within the individual (Bernstein, 1976; Lefebvre and Munro, 1978; Macgregor, 1982; Bull and Rumsey, 1988; Bull, 1990). An individual with a disfigurement may be at risk of developing psychological problems if feelings of self-worth are consistently low (Spriestersbach, 1973).

Social rejection from outsiders is predicted and noticed by people with CLP (Lefebvre and Munro, 1978; Rumsey and Bull, 1986). Fearful anticipation of these antisocial responses within any disfigured individual will affect how they function socially. These fears may result in psychosocial adjustment problems (Shaw, 1981, 1986) because unfavourable responses are recalled at the next encounter (Bernstein, 1976; Macgregor, 1982).

Characteristics other than the direct visual impact of the cleft may also influence the degree of stigmatism experienced. For instance, the ability with which a CLP affected individual is perceived to be handling their imperfect appearance can favourably alter an outsider's judgement of the individual (Stricker *et al.*, 1979). Broder and Strauss (1989) have demonstrated that it is not only individuals with 'visible' cleft defects who feel they are under scrutiny by the public, but also those with 'invisible' defects (cleft palate only) who may feel self-conscious. There is some speculation that milder disfigurements cause as much, if not more, anxiety than severe disfigurements (Lansdown *et al.*, 1991). The

social response towards individuals with milder defects is less predictable than that towards severely disfigured individuals. It is the unpredictability of the social response that is thought to raise anxiety levels (Epsteen, 1958; Macgregor, 1970; Lansdown *et al.*, 1991). CLP affected individuals who are dissatisfied with or who are unrealistic about their appearance need to be identified. Once found, these individuals 'at risk' for developing low self-esteem, could be offered some social skills training to improve their self-confidence and increase their self-esteem (Rumsey *et al.*, 1986; Kapp-Simon, 1995). This routine psychological assessment of individuals with CLP is likely to contribute to a more complete rehabilitation (Broder and Strauss, 1989; Kapp-Simon *et al.*, 1992; Bradbury, 1993).

Speech

Concerns regarding speech are thought to be less significant than appearance in contributing to low self-esteem amongst cleft affected individuals (Richman, 1983). Little else is known about the opinions of cleft lip and palate patients regarding their speech, and where opinions are sought, the majority are largely satisfied with this aspect. One study, however (Strauss *et al.*, 1988), reported that 28 per cent (a significant minority), judged themselves to be either moderately intelligible or else not understood at all. Parents and children fail to agree on satisfaction with speech. This is important because speech ranks highly in aspects which are likely to attract teasing (Thomas *et al.*, 1997; Turner *et al.*, 1997). If parents fail to agree with the child on how severe the speech problem is then they may not recognize a cause of significant distress.

Incidence of psychosocial problems

There appear to be no guidelines as to the level of psychosocial problems in CLP affected individuals who need psychiatric referral. In some studies, where the occurrence of psychological problems is not the main research issue, a patient's psychological well-being is defined according to psychometric tests only (Kapp-Simon, 1979, 1986; Broder and Strauss, 1989).

Based on examinations carried out by mental health professionals, 56 per cent of patients with clefts have problems warranting a psychosocial referral (Broder and Strauss, 1991). The incidence increases with age (6–12 years 62 per cent, 12–18 years 72 per cent) (Broder and Strauss, 1991). Problems are more frequently found among males (69 per cent) than females (42 per cent; Broder and Strauss, 1991). These figures seem high but this includes behavioural, cognitive, emotional and family problems. There is salutary preliminary evidence which suggests the suicide rate in adult individuals with a cleft lip is twice that of the normal population (Herskind *et al.*, 1993).

Where direct comparisons of psychosocial adjustment between different age groups are made, 'poor adjustment' in young patients is often expressed outwardly as antisocial behaviour. Older patients are more likely to internalize their problems and experience more anxiety and depression (Pertschuk and Whitaker, 1982; Pillemer and Cook, 1989). Sigelman and Singleton (1986) postulate that psychological problems increase with age because of an increased sensitivity towards physical impairment from non-cleft subjects. Alternative reasons could be that younger patients are better at denying their problems or that appearance is of less perceived importance in young children compared with adolescents. The differences observed between age groups could also simply reflect variation in the methods used for measuring psychological adjustment. Finally, younger children have relatively stable friendship groups whereas adolescents are constantly forming new relationships, which may account for any increase in problems (Clifford, 1987).

Whatever the mechanism for this observed increase in psychosocial maladjustment with age, there are important implications for the timing of any surgery for cleft affected patients. It is suggested that surgical procedures are less psychologically traumatic if performed at an early age or as needs arise (Macgregor, 1982; Pertschuk and Whitaker, 1982). However, cleft lip and palate surgery (other than primary lip, palate, and alveolar repair) should ideally be minimal until growth in the facial region has reached

adult levels because scarring, as a result of the surgery, restricts mid-facial growth (Ross, 1987; Mars and Houston, 1990; Semb, 1991). The greater the extent and number of surgical procedures then the greater the facial growth restriction (Ross, 1987). Clearly, this is an area of potential conflict for cleft care teams whose patients' psychosocial development would, in theory, benefit from corrective surgical procedures being carried out during growth. Conflicts such as this underline the need for detailed case discussion between different specialists within a cleft lip and palate team as well as the immediate family (Field and Vegha-Lahr, 1984; Canady, 1995).

Educational and vocational issues

Cleft-affected children experience increased frequency of speech and learning problems (Lefebvre and Arndt, 1988), as well as lower IQ scores for verbal and language deficiency compared with normative data (Richman and Eliason, 1983). These problems are compounded by teachers who frequently underestimate a child's intellectual ability (Dion, 1973; Richman, 1978). Despite the apparent disadvantages encountered by individuals with CLP during school education, one study has reported that a significantly higher proportion achieve a job status within the higher professional, managerial and skilled trade groups, compared with the non-cleft population. However, other studies suggest CLP affected individuals have an overall lower socio-economic status compared with non-cleft patients (Broder and Strauss, 1991), although their job satisfaction is high (Clifford *et al.*, 1972).

Patient and parent satisfaction with cleft care outcome

Self-perception of the cleft anomaly is an important contributor to a CLP affected individual's self-esteem and psychosocial adjustment (Videbeck, 1960; Fitts, 1972; Strauss *et al.*, 1988). Enhancement of patients' self-esteem and parental acceptance of their child's cleft are therefore important goals for craniofacial teams (Schonfeld, 1969). Only a few studies have

examined levels of patient satisfaction as a measure of cleft care outcome (Lefebvre and Munro, 1978; Richman *et al.*, 1985; Strauss *et al.*, 1988; Noar, 1991; Broder *et al.*, 1992).

Satisfaction with surgical results

Surgery for disfigurement usually results in increased self-esteem, self-confidence, and satisfaction with appearance, irrespective of whether an objective improvement is noticed by independent observers (Lefebvre and Munro, 1978). The majority of disfigured patients report high levels of satisfaction with their surgical results (Clifford *et al.*, 1972; Strauss *et al.*, 1988; Noar, 1991; Broder *et al.*, 1992). This level of expressed satisfaction may be attributable to a need for families to justify their emotional, and sometimes financial investment in treatment (Broder and Richman, 1987). Unrealistically high expectations for surgical improvement end in dissatisfaction with post-surgical results so families should be counselled extensively pre-operatively to identify cases where this may be a problem (Macgregor, 1971; Canady, 1995). Dissatisfaction may also occur when parents feel they are being pressured into agreeing to surgery for their child during a period when they are denying to themselves that their child is disfigured or in need of treatment. If parents deny to themselves that their child is disfigured, there are probably no benefits to be gained from surgical intervention (Berscheid and Gangestad, 1982).

Although the majority of cleft affected individuals are reportedly very satisfied with their overall appearance, their cleft-related facial features such as lip scars, are often the focus for dissatisfaction (Richman *et al.*, 1985; Strauss *et al.*, 1988; Noar, 1991). Parents consistently report more disappointment in their child's facial appearance than their children, irrespective of cleft type (Broder *et al.*, 1992). These differences may be due to under-reporting of concerns by children who may be reticent about expressing disappointment whilst in the presence of their parents and specialists (Broder *et al.*, 1992). Recently, it was demonstrated that in different age groups (10-, 15-, and 20-year-olds) it is the 15-year-olds who disagree most with their

parents about their overall facial appearance. They expressed most dissatisfaction with the appearance of their lips and teeth (Thomas *et al.*, 1997; Turner *et al.*, 1997).

Parents of girls perceive their children to be more concerned about their appearance than parents of boys (Broder *et al.*, 1992). There are conflicting data surrounding gender differences in satisfaction with cleft care. Some studies report that females with clefts are more dissatisfied with appearance than males (Berscheid and Gangestad, 1982; Broder and Strauss, 1989). Others suggest that males and females have similar levels of satisfaction (Broder *et al.*, 1992).

Methodological weaknesses within current cleft psychology research

The challenge of psychometric testing is to identify ways in which subjective experiences of patients can be made objective. It is, however, difficult to identify how people think and react to facial disfigurement. In order to address these questions complex statistical tools are needed to isolate and identify the underlying structure of an individual's perceptions. It would be naive to assume that psychometric tests alone can identify adversity in experience of cleft lip and palate. These tests are important in the treatment of these patients, but cannot be used in isolation. In the last 25 years there have been advances in the quality of study design used to investigate psychosocial issues. Prior to the 1970s, studies were, at best, theoretically speculative. Case reports were common with no solid data to substantiate claims (Stricker, 1970). Comparison between studies was impossible due to lack of agreement amongst researchers on methodology and sampling (Bradbury, 1993). Clifford (1988) suggested that this had resulted in 'conceptually naive attempts to describe a set of patients sharing the same anomaly in familiar psychological terms'. Investigative links between physical appearance and the individual's psychosocial functioning are difficult because although facial appearance can be measured in terms of 'impairment' (Tobiasen and Hiebert, 1993) and, to some extent, 'attractiveness' (Howells and Shaw, 1985; Roberts-Harry *et al.*, 1992), it is impossible to measure the

thoughts of a disfigured person. Furthermore, people vary in their perception of their physical self-image and their emotional reactions to these perceptions (Richman *et al.*, 1988). Attempting to evaluate the thoughts and feelings of a disfigured individual is possible using standardized psychometric questionnaires that have been developed and validated by social scientists and psychologists. For example, the 'Piers Harris children's self-concept scale' is an objective measure consisting of 80 statements about the individual to which the respondent replies 'yes', or 'no' (Piers, 1969). However, opinion concerning the usefulness and applicability of different standardized measures varies widely amongst researchers in this field. Although such a questionnaire provides a basis for comparison this is only possible in a limited sense. Even when data have been obtained, problems exist concerning analysis. Behavioural scientists have investigated problems of analysis and interpretation over the last few years, sometimes advocating the use of complex statistical tools such as 'factor', and 'cluster' analyses (Stricker *et al.*, 1979). These analyses are more frequently used for market research purposes and are viewed sceptically by health care statisticians. Methods of analysing psychometric data therefore remain a controversial topic.

Future study designs

Many studies investigating psychological issues of cleft lip and palate use self-reported data (Harper and Richman, 1978; Kapp-Simon, 1979, 1986; Richman, 1983; Richman *et al.*, 1985; Strauss *et al.*, 1988; Broder and Strauss, 1989). To date these studies have only been cross-sectional for different age groups. In future longitudinal studies of subjects will be needed to investigate if intra-individual self-perception changes with age (Broder *et al.*, 1992). If cleft teams are to use patient questionnaire data as a measure of treatment outcome, then information regarding changes in self-perception with time will be needed using cleft and non-cleft populations (Broder and Strauss, 1991).

The opinions of patients' and parents' satisfaction with treatment are usually based on their

experiences from one centre (Lefebvre and Munro, 1978; Richman *et al.*, 1985; Strauss *et al.*, 1988; Broder *et al.*, 1992). To avoid biased responses from the subjects regarding satisfaction, their opinions should ideally be collected from several different cleft lip and palate centres using standardized data collection methods administered by independent examiners. Noar (1991) used data from five centres within London. Superficially, this represents a multi-centre study, but as only 28 patients responded, the sample size precludes any meaningful comparisons.

Problems with samples in cleft psychology studies

Despite CLP being relatively common compared with other craniofacial anomalies (Gorlin *et al.*, 1971) there is still a tendency to use small sample sizes (Richman *et al.*, 1985; Noar, 1991). This may be a reflection of the time consuming data collection required to complete psychometric assessments (Pertschuk and Whitaker, 1982). Alternatively, small sample sizes may reflect the problem of using only one centre with a limited catchment area for subjects. Some have used combined groups of different cleft anomalies in order to increase the sample size (Lefebvre and Munro, 1978; Richman *et al.*, 1985; Strauss *et al.*, 1988). The validity of results for 'satisfaction' with cleft outcome may be reduced if all cleft types are combined within the analysis. As an example, in Richman's study of self-reported speech concerns, no indication was given of the incidence of palatal and pharyngeal surgery within the sample (Richman, 1983). These subjects were combined with others who had received no palatal or pharyngeal surgery. As a result, their observations regarding speech concerns are likely to be over optimistic. Self-selection factors may skew a sample in those studies where subjects are asked to volunteer for assessment (Clifford *et al.*, 1972).

Additional methodological problems

Researchers rarely refer to the period of time over which investigations into satisfaction are undertaken. This should be taken into account,

as the success of procedures undertaken by cleft specialists may increase with their experience. This may have a bearing on how satisfied a patient is with, for example, a lip repair. Similarly, if responses to interview questions have been categorized by an interviewer over several years of data collection, it is possible that the reliability of the categorization procedure will drift with the interviewer's experience and enthusiasm. Strauss *et al.* (1988) collected data over 11 years, yet inter-examiner calibration and re-calibration were not undertaken during the study. Several other methodological problems also need to be addressed. Retrospective investigations asking for opinions on past treatment may be subject to recall and memory bias, especially where adults are involved (Clifford *et al.*, 1972). The expression of satisfaction from an adult regarding surgery undertaken during childhood may under- or over-estimate, childhood dissatisfaction. Using one standardized psychometric test for a sample with a large age range may reduce the sensitivity of the results because the test has to be modified to suit the different ages of the subjects. For example, one study (Lefebvre and Munro, 1978) examined subjects from ages 6 to 37 years using the same questionnaire. It may be more appropriate to analyse samples in their different age groups rather than combining all of the results for the sake of increasing sample size.

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