ATTITUDES AND BELIEFS REGARDING OROFACIAL CLEFT DEFORMITIES IN NEPAL

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ABSTRACT

The parents of 56 cleft lip and palate patients were interviewed to determine their attitudes and beliefs as well as community attitudes towards cleft deformity. Acceptance of the child was high among the parents (89%) but low in the community (45%). Superstitious beliefs regarding the cause of the deformity were noted in only 36% of parents. We conclude that parents of children with cleft deformity in western Nepal have generally good attitudes towards cleft deformity and mostly reasonable beliefs regarding causes.

Key Words: Cleft lip and palate, attitudes, beliefs, acceptance.

INTRODUCTION

Cleft lip and palate is a common congenital deformity in the west and may be even more common in many Asian countries, including Nepal and India. Late repair of the defect is common in Nepal,¹ and as such these children often have to interact in their community for several years prior to correction. Social acceptance of children with this deformity is important to the child's overall development, as rejection or poor acceptance by family or peers is likely to lead to a low self-esteem in these children. Psychosocial variables have been shown to influence the physical growth of children with cleft deformity, implying that improved parental and community acceptance may improve the child's overall growth as well.² This decreased acceptance of children with cleft defect has been shown to have a negative influence on the child's self-esteem and psychological development up until the teen years.³ Intervention with simple counselling sessions has been demonstrated to lead to a prolonged improvement in parental adaptation to the cleft deformity.^{4,5} For this counselling to be effective it must be directed at the specific belief systems of the individuals involved.

Superstitious beliefs regarding the cause and means of prevention of the cleft deformity vary widely between different countries.^{5,6,7,8}

It is likely that the parental perception of the cause of the defect will influence their attitude towards the defect and therefore their acceptance of the child. It is therefore important to determine the prevalent beliefs in a given society in order to know how to provide effective counselling to the parents. The counsellor will then be more aware of the particular beliefs or attitudes that may require attention in the counselling sessions.

In this study the family and community attitudes towards cleft patients were assessed. Perceptions of the cause and means of prevention of the defect by parents of cleft children were also assessed.

METHODS

This cross-sectional survey was carried out at the Western Regional Hospital, Pokhara, Nepal, which is the referral center for the central area of Nepal. All patients presenting to the Departments of Speech Therapy and Surgery with a diagnosis of cleft lip and/or palate between April 1999 and Sept 1999 were included in the study. The father or mother of each patient was interviewed by one author (SBK) using a questionnaire (reproduced in part in Table I). Both pre-operative and post-operative patients were included. Three patients were excluded, as their parents were unavailable. A total of 53 patients were included in the study.

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RESULTS

There were 39 male and 14 female patients. 17 patients had an isolated cleft lip, 6 an isolated cleft palate and 30 had a combined cleft lip and palate. 39 patients had already been operated on or had their operation during the study period, and 14 were still awaiting surgery.

Regarding attitudes, in 47(89%) of the families the cleft child was accepted as a normal family member. The child was significantly ostracized in only 4 families (8%) and mild neglect occurred in 2 families (4%). However in the community the child was treated as normal in only 24 cases (45%), while 19 children were ostracized (36%) and 10 experienced mild neglect. Perceptions of the causes of the defect are summarized in Table II. Eight (15%) of the parents reported the belief of either themselves or the community that something sinful that they had done during pregnancy had caused the defect, such as doing something harmful to another person. Only 11 (21%) reported other superstitious beliefs regarding the cause of the defect, such as thunder or solar eclipse occurring at key times during the pregnancy. The opinion of the parents of what could be done to prevent the deformity are presented in Table III, with only 2 parents (4%) reporting superstitious beliefs. No parent reported consulting jhankris (witch doctors) prior to coming to the hospital.

DISCUSSION

This study found that a large majority of parents in western Nepal had a healthy supportive relationship with their cleft children. This is in contrast to a study in Nigeria where it was found that six out of ten mothers were withdrawn in their relationship with their child with an unclosed cleft lip.⁶ There may be a bias in that parents may tend to underreport their own poor attitudes. Many of these parents had been exposed to other cleft children as well as cleft health care specialists, and as such may have developed more tolerant attitudes. Even in developed countries with early expert counselling available, parents of cleft children score low on testing of positive affect and high on anxiety testing.⁹ In Japan 13.5% of mothers of cleft children deny the existence of the child as a human.¹⁰ Studies in Czechoslovakia, Japan and Great Britain have shown that 70-75% of parents of cleft children were shocked at the time of birth by the discovery, and many reported subsequent depression, social avoidance and feelings of guilt.^{3,9,10} Early counselling has been shown to largely alleviate many of the parents' concerns, especially when they realize that the defect is surgically correctable.¹¹ While our study measured acceptance some years after birth, it appears that in Nepal mothers are eventually able to come to terms with their child's deformity. This is an important finding, because psychosocial variables have been shown to influence early infant physical growth,² and poor maternal