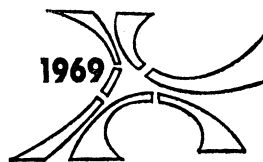


Maternal Reaction and Adjustment to Birth and Care of Cleft Palate Child



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The human organism cannot be considered as an isolated specimen in a hermetically sealed environment. Rather he must be perceived as an integral part of the wider milieu from which he stems and in which he lives. The individual's long past, to which he has become heir by transmission of hereditary traits and the external environment in which he must live, exerts its inexorable influence on man, demanding an increasing capacity for adaptation. The individual lives and thrives and adapts his physiologic resources not only to the physical universe about him but to the shifting requirements of the interpersonal and social relationships in his environment. In addition to the physiologic organ equilibrium which individuals must maintain, patients have families, and that family must maintain an equilibrium within itself and towards its environment.

In both clinical and research literature on physical disabilities (1, 5), there is general agreement on the psychosocial component to the problems of the physically disabled. Indeed, from a rehabilitation point of view, these problems may transcend in importance the actual physical disability or handicap. This should not be surprising in view of the generally negative response to atypical physical functioning and the highly positive values placed in our culture upon adequate physical functioning. In view of this obvious nature of the disability, the psychosocial consequences of a cleft lip and/or palate should be especially significant.

All medical care and practice is aimed primarily at returning to or achieving an optimum state of health so that the patient can function as an effective member of his family and community. In this sense, the primary function of medicine is a social one and, as such, must concern itself with the social component of illness or rehabilitation. With the multiplication of ingenious mechanical devices for restoring impaired functionings and with the development of elaborate educational and

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TABLE 1. Description of sample.

<i>group</i>	<i>age in months</i>		<i>sex</i>		<i>residence</i>		<i>socioeconomic class</i>				
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>F</i>	<i>ru- ral</i>	<i>ur- ban</i>	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
cleft lip and palate (N = 34)	130.41	28.79	27	7	22	12	4	2	4	15	9
cleft palate only (N = 32)	122.25	25.98	19	13	17	15	1	1	2	17	11

training methods for teaching compensatory skills, the X factor of human nature becomes an even more challenging problem to rehabilitation specialists. With the understanding of the emotional and social aspects of illness, a fuller recognition of the patient as a social functioning person has more securely linked the work of the physician and the social worker.

Social service at the Lancaster Cleft Palate Clinic came into being in response to the need to work with parents and patients in handling their initial feelings and anxieties as a way of supporting dental and speech therapy and buttressing treatment goals. The high value placed by our society upon physical attractiveness would make the disability of a cleft lip especially potent and the premium placed on verbal communication and adequate speech would further suggest that the speech-handicapped individual with a cleft palate has profound psychosocial sequelae. The individual with these disabilities would have to contend with problems arising from both cosmetic and communication difficulties.

A bilevel research program was undertaken by the clinic: a longitudinal study of cleft children from birth through seven years of age; and a family study (completed) involving cleft palate children and, as a control group, their siblings between seven and fourteen years of age. Families were selected on the basis of the following criteria: a) active patients at the Lancaster Cleft Palate Clinic, b) living within a 150 mile radius of the clinic, c) cleft child was between 7 and 14 years of age, d) there was a noncleft child in the home within the same age range, and e) patient lived with the mother or mother and father. Of the 78 families fulfilling the criteria, 12 were eliminated due to a lack of cooperation, race, a unique subcultural background, and a condition of the child that would have contaminated psychological testing. Sex of the cleft child, the age of the cleft child at the time of the interview, classification of place of residence and socioeconomic class (3) are reported in Table 1. With the exception of socioeconomic class, in which *N*s were too small for statistical analysis, there were no significant differences between the cleft lip and palate and the palate only groups on the aforementioned characteristics.

Mothers were seen for a structured interview designed¹ to elicit attitudes, impressions, and anxieties to the birth and early care of her child. Responses to these structured interviews were tallied separately for the cleft lip and palate and palate only groups. Differences were tested between percentages in each response category by means of a critical ratio. All differences to be reported between groups were significant at the .05 level.

Our experience with mothers of 66 study families has shown, not surprisingly, that 80% of the mothers reported that they reacted to the birth of a congenitally deformed child with strong feelings of shock, hurt, disappointment, helpless resentment, and, in some cases, hysteria. They have lost the perfect baby nurtured in their imagination and have received instead a damaged child (6). Most mothers recover from this painful birth reaction within a short time, come to view the deformity without guilt, and muster inner strength to handle it as a realistic problem. 79% of the mothers reported that it was their own strength and ability that was the most effective single factor in successfully managing their child.

It has been previously reported (2) and logically assumed by many who work with cleft patients that the birth of a cleft lip and palate child creates a greater impact than the birth of a cleft palate only child. In our study, several significant differences were found between the two groups which tend to confirm this. In response to a question regarding feelings and thoughts at the birth of a cleft child, a greater percentage of cleft palate only mothers (19% vs. 3%) reported no effect or gave an avoidance response. Conversely 91% of the cleft lip and cleft palate mothers reported an emotional response. In addition, the mothers of cleft lip and cleft palate children were more likely to report that the birth of the child affected their marriage by bringing the parents closer together (32% vs. 9%). Mothers of cleft lip and palate children also appear to have needed greater acceptance and encouragement from others. 71% of these mothers indicated that this has been most helpful while only 47% of mothers of cleft palate only children indicated the same.

As we are aware from the beginning, the life experiences of the baby with a cleft lip and cleft palate are different from those of normal infants. Early stresses and anxieties in the mother stem from the feeding difficulty, oftentimes frustrating, non-pleasurable and anxiety-ridden. Interestingly, mothers of cleft palate only infants reported more anxiety around feeding and the baby choking, et cetera, than did mothers of cleft lip and palate infants. In addition, they were more worried about possible speech problems. More mothers of cleft lip and palate children reported anxieties about others' reactions during the first year of life while, after

¹Structured Interview designed by Charles C. Wirls, Ph.D., Chief Psychologist at the H. K. Cooper Institute for Research, Education and Rehabilitation of the Lancaster Cleft Palate Clinic, Lancaster, Pennsylvania.

the first year, more mothers of cleft palate only children indicated that they felt that others' reactions hindered. Explanation centers around the obvious anomaly presented by the cleft of the lip when parents have to face it very early. Cleft of the palate only is not visible to the "outside" in the beginning but becomes more obvious with the oncoming of speech—if uncorrected.

These mothers have many problems to cope with and they are in great need of professional support from the beginning of the post partum period. Mothers suffered most when, following delivery, information was delayed and the baby was not shown at the expected time. Although only 53% of the mothers learned of the defect at or immediately after delivery, 92% of the mothers indicated that this was the best time to be told. Mothers quickly sense that something is wrong and, as their anxiety mounts, they imagine things much worse than cleft palate or cleft lip. The duty of telling the parents of the defect falls to the physician. This is the usual procedure in most hospitals, although not too frequently it is overlooked in cases of undetected cleft palate alone or in some rural hospitals with no experience with cleft whatsoever. 99% of the mothers indicated that they wished to have learned of the defect from their attending physician while in actuality 71% did learn from the physician. Our mothers reported that they wished early, frank communication between the physicians and the parents: not only to explain the nature of the defect and the problems to be faced but also the successive procedures and rehabilitative measures and resources available to them. 76% of the mothers had no knowledge of what a cleft is prior to the birth. 44% of the mothers expressed no knowledge of cleft causes 7 to 14 years after the birth. The need for genetic counseling is most crucial. As the birth anxiety and trauma passes, other concerns take their place; speech, peer acceptance and school achievement.

The many clinic visits of the child and parents provide opportunity for continuous contact with total clinic services, enabling continuing pediatric, medical, dental, and speech surveillance and counseling. Parental participation and cooperation is essential if the best results are to be obtained for the child. The parents, particularly the mothers, are more of an emergency than the child, yet physicians will treat the child and not the parents (4). Current medical knowledge, facilities, and practice can meet required surgical, dental, and speech needs of the cleft infant. Much more emphasis is placed on the known—assuming that the concentration is on the patient—the affected one. In reality, the parents often feel themselves to be the affected ones.

One of the most impressive outcomes of the extensive contact with parents in our clinic is the revision of their attitudes toward the deformity, greater acceptance of the child's limitations, reduction of anxieties concerning the child's future, and increased understanding of, as well as cooperation in, the total clinical process.

Summary

Sixty-six mothers were seen for a social service structured interview designed to elicit attitudes, impressions and anxieties to the birth and early care of their cleft child. Responses to these structured interviews were tallied separately for the cleft lip and palate and palate only groups. 80% of the mothers reacted with strong feelings of shock, hurt, disappointment, helpless resentment, and, in some cases, hysteria, to the birth of their cleft child. Most mothers recover from the painful birth reaction within a short time, come to view the deformity without guilt, and muster inner strength to handle it as a realistic problem. The birth of a child with a cleft lip and palate creates a greater impact than the birth of a child with a cleft palate only. However, both types of mothers have many problems to cope with and are in great need of professional support and genetic counseling from the beginning of the post partum period. Frank information, explanation, and available resources should be offered parents by their physician right after delivery. Parents, particularly the mothers, are more of an emergency than the affected child and emphasis should be placed on treating the parents—the patient at that moment is the mother. Parental participation and cooperation is essential if the best results are to be obtained for the child.

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