

Parental Needs and Professional Responses: A Parental Perspective

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Parental needs are discussed as they have been revealed during a six-year period in a Boston *parents' group*, Prescription Parents, Inc. In addition, *professional responses* at various stressful periods during *cleft palate* rehabilitation are examined and certain responses suggested. Emphasis is given to the *professional-parent partnership* in developing the child's *self-image* and also to the relationship between professionals and the patient, particularly from age six through adolescence. The role of the peer group as it interacts with the home environment is also stressed. Specific suggestions are offered concerning the influence of a parents' group and the specific services such groups can provide.

Introduction

Parents of children born with cleft lip and/or cleft palate are heterogenous and present a variety of ethnic, religious, cultural, and socio-economic backgrounds, all of which influence their responses and needs when they are confronted with the problems surrounding the birth of children with these defects. In addition, the severity of the cleft, together with the immediate impact and the long-range effects, may influence the parents' perceptions, reactions, and needs.

This paper reflects parental perspectives gained through experience with Prescription Parents, Inc. (Boston) during the past six years. Although parents who choose to join a parents' group may not be representative of *all* parents, they do provide some insight into the nature of parental concerns at different stages in the habilitative process. This paper is based upon two premises: (1) The needs of parents vary along a continuum. (2) Parents' needs change during the treatment period and tend to be most evident during times of stress. These include such times as the birth, the initial hospitalization, the beginnings of formal speech, entry into school, and the child's pre-adolescent and adolescent years.

PARENT-PROFESSIONAL RELATIONSHIP. In

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general, the parent looks to the professionals for information, reassurance, and effective coordination of the various disciplines involved in cleft lip/palate treatment. In order for professionals to respond effectively, they must help parents deal with relatives, friends, teachers, the financial strain, the emotional adjustment, the emerging of the child's self-image, and his adjustment to his problems.

NEWBORN PERIOD. In discussing parental needs, much time is usually spent on the newborn period and necessarily so. Since most parents are unprepared for the birth of a child with a cleft and are not familiar with the defect, the manner in which the obstetrician or pediatrician first presents the infant and the defect to the new parents is of utmost importance. Probably the most difficult aspect of helping new parents is to evaluate their response to both the trauma of birth and to the cleft and then to offer appropriate professional responses.

Most parents in our group reported that they felt saddened, confused, and anxious. Some reported that they cried easily, felt withdrawn, or were angry. All of these responses are reactions well within normal limits following the birth of any infant, and may be exacerbated when the child has a problem. Parents need to understand that crying, sadness, and fear are *normal*. Too often they are told not to cry or not to worry, as if these reactions were abnormal.

Parents take their cues from the profession-

als around them. A reluctance to discuss the defect and the parents' reactions openly may magnify the severity of the infant's problem and its implications in the parents' minds. They need time to talk, to learn about the defect, and to adjust. When professionals tell them not to feel guilty, not to feel lonely, etc., they seem to be suggesting to the parents what they *should* be experiencing.

To accomplish this "healing" we suggest that the professional listen to the feelings that the parent may be able to articulate and to the problems he outlines. He may have concerns about telling relatives, displaying the baby in public, finances, surgery, or future problems. A study by Skipper and Leonard (1968) indicates that one of the most stressful situations for a patient is to be isolated without expressive interaction with the staff. This isolation has been reported by mothers from our group. Immediately following the birth of the baby many felt that the nursing staff performed the routine functions of care but were uncomfortable listening to parents talk about their feelings. Stenko (1973) similarly reports that the post-partum separation of mothers from their babies with birth defects intensified an already stressful situation. For example, babies were kept in a special nursery and were not allowed on the floor when other babies were brought to their mothers, or they were transferred to another hospital altogether. Such events tend to magnify the defect in the parents' eyes and to prevent the mother from feeding, cuddling, and adjusting to her baby.

When talking with parents, we recommend that the professional: (1) listen; (2) offer positive comments regarding the *total* baby; (3) help the parent to understand his/her importance in the baby's habilitation; (4) make the parents feel confident in feeding and caring for the baby; (5) encourage the parents to express their feelings; (6) indicate continuing support when the infant is discharged; and (7) clarify the plan of care to them.

Although professionals may be well-intentioned when they tell parents, "Everything will be all right," or "Don't worry about that," many parents resent these comments even though they may realize their truth later. Even if questions arise about the effect of the defect on speech or on the eruption of teeth, it is preferable to answer honestly, without

overwhelming the parent with too much information, rather than to put off the question only to allow parents' imaginations to run rampant.

Written Information. Most of the parents who join our group when their infant is a newborn express a desire for printed materials. As indicated by Walesky-Rainbow and Morris (1978), misunderstanding and misinformation at this time is devastating in that parents may carry the impressions with them for a long time. Particular care should be given in discussing the timing of surgery in the knowledge that anxious parents tend to hang onto every word. Parents need adequate information to reply to relatives and neighbors carrying old wives' tales about the causes and results of these defects. Particularly important here is some basic information on genetics appropriate for laymen. Professionals must exercise care in guiding parents to those materials or portions of materials which are relevant to their child's condition and treatment.

Several specialists in Boston have written pamphlets for parents of newborns, and Prescription Parents, Inc., has prepared a newborn packet which contains information written by professionals. It also includes a publication entitled "Caring for Your Newborn with Cleft Lip and Cleft Palate" written by parents exclusively for parents of newborns. It requires sensitivity by professionals to choose those publications which are appropriate for individual parents, and it is helpful if they are willing and able to discuss such materials after the parents have read them.

INITIAL SURGERY. Parents seem to have ambivalent feelings about the initial surgery. While they look forward anxiously to having the child's defect(s) repaired, they are nervous about hospital procedures, the baby's discomfort, and the outcome of the surgery. Parental needs at this time will determine the nature of the information they require and will influence their expectations regarding the surgical outcome. Parents need to understand a simplified version of the surgical procedure and the range of expected outcomes.

Siblings at home will feel the pressure of the hospitalization, and simple explanations by parents to them will help the other children in the family to deflect their anxieties about themselves. Specifically, parents should be given information about routine hospital pro-

cedures that might frighten those not familiar with them: a mist tent, the presence of an intravenous feeder, arm restraints, etc. only increase stress when these are not expected. It is clear from the study by Skipper and Leonard (1968) that mothers who were well-informed about their children's operations "suffered less stress" than the control group who were given no information. This confidence would seem to be reassuring to siblings at home who might be alarmed by parents who displayed confusion and fear about the infant's future experiences. In addition, knowledgeable parents can sometimes complement professional care. They may see hospital procedures from a different perspective and thus be able to suggest ways in which they can be helpful to the staff and can participate positively in the post-surgical care.

Parents are, of course, most concerned with what the results of the surgery will be. They want to hear that all will be well and that the surgery is a cure-all for the child's defect. This attitude is normal; however, unless the surgeon is realistic with the parents, setting expectations that are too high inevitably leads to disappointment. Some parents mistakenly believe that initial surgery is the end of the treatment. They are confused and disappointed when they hear that additional surgery, dental care, speech pathology, ear care, and other services are necessary. They may mistakenly impart their attitudes to their small child. When the child finds that his/her treatment is not complete, his/her trust in the parent and in professional people is undermined. From the beginning, the parent should understand that the care is long-term. Carefully written materials can reinforce accurate information provided it is applicable to the child in question. Much available material is outdated and misleading and may serve to confuse and frighten parents. More good information is badly needed.

Transition to the Pre-School Years. During the neonatal period, the professional should help the parent adjust to the baby, develop a realistic attitude toward the defect(s), and become a partner with the professional team in the psychological, language, and speech development of the growing child. Since the pressure of feeding and impending surgery soon fade, we find that parents have less need

for group involvement during the pre-school years and tend to focus less on the defect, probably a healthy step. The danger here, however, is that parents may lapse into an "all is well" attitude and fail to be sensitive to such things as ear problems and to their role in language and speech development. In addition to counselling by the team, specific guidance such as that published by Amundsen (no date) can be helpful to parents of small children. Although some children with clefts may require no speech therapy, the guidelines outlined by Amundsen offer specific suggestions for language stimulation in the home. The guideposts for cues to potential hearing problems are also useful. The booklet is helpful to all parents of toddlers, not just those with potential speech and language problems.

Specialists should explain to the parents the importance of the child's self-image and specific ways in which they can guide their children to an acceptance of their self-worth. It is Bershied and Walster's (1974) hypothesis that a poor self-image developed during the pre-school and primary grade years can become a model for the child's personality development. In the light of this theory, the professional must be cautious about using the parent as the scapegoat if the child should have problems with adjustment later. Although some parents may deserve this criticism, the professional must be careful lest this generalization be applied to *all* parents whose children have adjustment problems.

During the pre-school years the parent should be sensitive to the child's development of his self-image and his understanding of his problem. Parents may need guidance in explaining to the child, in very simple terms, what happened to him/her and the need for various therapies. As soon as the child is old enough to be questioned by playmates and peers, he should be armed with some simple kind of explanation of his condition. Other parents can be helpful here. Bershied and Walster (1974) report that, even in the pre-school years, children's acceptance by peers is influenced by physical attractiveness. The study indicates that the child's self-concept is largely a function of his social relations. In their report, unattractive children were perceived by peers as aggressive and less self-

directed than attractive peers. The study also indicated that adults' perception of unattractive adults yielded the same results.

PRIMARY GRADES. At this point, at the time of clinical visits and during hospitalizations, the professional should direct himself primarily to the child by asking him questions and carefully explaining procedures to him. He/she likewise needs to inform and help the parent understand the information since the child will turn to the parents at home for further clarification and reinforcement. It is clear from the recent study by Walesky-Rainbow and Morris (1978) that, not only do parents misunderstand information, but they do not adequately assess their children's understanding of the basic facts. Leonard and Skipper (1968) also report that children experience greater stress during hospitalization and following discharge if procedures are not clear to them beforehand.

At this time children may begin to resent keeping appointments partially because they may be dealing to some extent with peer pressure and teasing. Professionals should be sensitive to the child's needs by not reinforcing parental pressures on the child regarding appointment-keeping. The child may gain some feeling of control by missing one or two appointments. Also, professionals should be sensitive to the parents' feelings of hurt and frustration when their child comes home from school in tears as a result of teasing. Parents should be encouraged to talk with the child, to develop the child's feelings of self-worth, to encourage him/her to develop a particular talent, and to try to help him/her frame a response to peers. They must understand, however, that they cannot control the peer group, nor should they be encouraged to try. *All* children have to deal with a certain amount of peer pressure. According to Bershied and Walster (1974), children aged eight to ten see the face as the most important characteristic in a girl.

Professionals should be careful when evaluating anger, shyness, aggression, and similar expressions in a child. Although parental influence is of unquestionable importance, it is easy to ascribe these personality traits to parental inabilities and parental failures in helping a child develop self-esteem rather than to another source, the peer group. Particular

pressure may be exerted on the child if she/he has moved several times and has had to adjust to many groups of children who may tease or criticize. These experiences tend to make the child question his self-worth. In our group, adult members who were born with clefts have given parents some insights into coping with these problems and in helping these children to do so as well.

Professionals should realize that another pressure for parents is the cost of orthodontics and of other procedures which may come during the early school years. Parents' groups can lobby for improved financial programs, either public or private. Professionals might direct parents to investigate PL 94-142 as a resource for programs for children with special needs.

PRE-ADOLESCENCE, ADOLESCENCE, AND ADULTHOOD. Here another professional-patient dynamic interaction should occur. Previously the child placed somewhat implicit faith in the parent that the specialist performing the service was to be trusted. Now the patient needs more reassurance than just the parent's confidence, particularly where much of the treatment at this point involves cosmetics, an area of concern to teens anyway. Teens request more information than they often are presently receiving (Walesky-Rainbow and Morris, 1978). Since teens are sensitive about their bodies, they should have complete and accurate information, in layman's terms, about procedures and should be consulted about their feelings as to expectations and results. Particular care should be given to offer clear information on genetics when the patient is ready to receive it.

The specialist should help the parent to see the teenager and his/her problems in the proper perspective. Perspective at this time in life is difficult at best. The individual with a cleft may be so accustomed to a focus on his/her face and mouth that his/her perspective may be distorted beyond what is seen in teenagers generally. Parents should realize that teenagers are sensitive to appearance and that any particular child's set of experiences may make him super-sensitive unless efforts are made by parents, teachers, and specialists to develop his/her particular talents and to help him increase his personal strengths.

An additional problem relates to the length

of treatment. Members of our Medical Advisory Board and adult members with clefts have informed us that, after many years, both parent and patient are anxious for final discharge. Yet, the specialist must be careful to inform them that follow-up appointments should be kept, especially following cosmetic revision and restorative dentistry. We find that the referral mechanisms for some of our adult members have broken down, that they have nagging wishes for further improvements, but do not realize that additional help is possible. Also, the members report uncertainty about going ahead with further habilitative work in the fear that some earlier repairs might be jeopardized.

Conclusion

We wish to convey to professionals that most parents in our group are very much interested in helping their children. To develop their confidence in themselves as parents, from time to time they need to hear that they are doing a good job, even at the small tasks. Particularly in a stressful time they need to hear that, although the situation is difficult

to handle, the professional has confidence in them as parents and understands their concerns. Parents need to feel that they are playing an active part in helping their child. Even though a professional may see a parent as somewhat less than ideal, developing some dialogue may make a considerable difference in parenting. In any event, the parents should feel that they are part of the mainstream of parenting and not abnormal in their needs and expressions.

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