

Culture, Rehabilitation, and Facial Birth Defects: International Case Studies

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Responses to birth defects are influenced by their cultural and social context. Two multicultural societies, Israel and Nigeria, are reviewed for attitudes toward birth defects. Israel is a developed society where cultural and national origin affect utilization of health services. Differences between Western Jews, Oriental Jews, and Arabs exist in their explanations of etiology and their attitudes toward rehabilitation and community participation. Nigeria is a developing nation with limited health resources. Facial birth defects are stigmatized, infanticide remains a practice, and attitudinal barriers to the development of rehabilitation resources exist. The economic, demographic, and spiritual causes of infanticide are reviewed historically. The persistence of infanticide, though illegal, is discussed relative to issues facing the response of Western medicine to seriously afflicted newborns as well as prenatal genetic diagnosis. The importance of culture as a variable in cleft lip and palate research is stressed.

The success of Western surgery has made possible the repair of many serious deformities, including once lethal birth defects. Recent court cases surrounding the "Baby Doe" phenomenon have raised basic ethical dilemmas (President's Commission, 1983). Should all children with reparable defects receive surgery? When is the quality of life so compromised that a family might opt not to operate? Should this be a parental, medical, or judicial decision? The possibility of surgical correction of defects has forced Western physi-

cians to consider the meaning of infanticide. Prior to the development of scientific medicine, infants not equipped for survival often died on their own.

Medical activism has created a situation in which decisions may revolve around whether to withhold treatment or withdraw therapy when an infant is not likely to survive. Attempts are made to assess the ultimate quality of life, as well as its likelihood. Cultural mores and values provide the criteria for such decisions. In diverse multicultural societies different value systems may coexist and can result in controversy and debate over moral questions, as is currently occurring in the United States (Strain, 1983; Angell, 1983).

In societies lacking specialized surgical practice and in which medical options are limited, fewer children with life-threatening defects survive. In these settings, what happens to infants who have nonlethal defects, such as many facial anomalies? In some developing societies there are specialized surgical services, but these are dif-

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difficult to access and are treated as a scarce resource. Rationing and allocation decisions about these scarce resources reveals much about national priorities and social values.

In affluent societies with sufficient medical resources, basic and universal surgical care is often provided through socialized systems, health insurance programs, or other avenues of social welfare. This is not true in societies with limited resources, and raises the question of what happens when there is not enough medical care to go around, or when access to care falls along clear lines between the advantaged and the disadvantaged. Data from medical, anthropologic, and historical sources indicate that decisions about health resource distribution depend on social, cultural, and religious perspectives.

This paper considers the treatment or nontreatment of birth defects and handicaps and the allocation of rehabilitation resources in multicultural societies. Israel is examined as a developed nation comprised of profoundly different cultural groups. Nigeria is selected to represent a developing society with a scarcity of health resources and considerable cultural diversity.

ISRAEL

Israeli society is composed of numerous cultural and national groups, the largest of which are European Jews (Western origins), Oriental Jews (North African and Middle Eastern origins) and Arabs. The different cultures represent considerable variation in Israeli beliefs about disability and family life (Chigier, 1972). Judaism is the dominant ethic, and Israeli values and legal statutes are strongly influenced by Jewish history and theology. In Hebrew there is no word for infanticide, and reports indicate that it is largely unknown in Israeli society (Jakobovits, 1978).

Within Jewish groups, variation in attitudes toward the disabled reflect national origins. Jews of Oriental origin tend to understand disability in fatalistic terms (Palgi, 1962). Families of Iraqi background hold a child's handicap to be a curse

on the family, related to the sins of its members. Families of Moroccan and Yemenite origins hold the belief that a disability is caused by external forces (God's will, demons, "evil eye") and therefore the family is not shamed (Florian and Katz, 1983). Disability may be considered permanent and not amenable to medical rehabilitation. Thus, Oriental Jewish attitudes reflect a passive stance toward treatment. The disabled are pitied and perceived as inferior. They have problems finding spouses, and their conditions are seen as reflecting poorly on their future.

Oriental Jews have been often characterized as holding markedly different sociomedical beliefs from those of Western Jews. As a group the Oriental Jews have lower educational and socioeconomic levels, and there is some evidence that as educational attainment rises, attitudes toward the disabled become more positive (Florian, 1977), and cultural differences are less salient. Western Jews tend to see defects as remediable through medical attention, and expect those affected to integrate themselves into the normal community and its social life as much as possible. These parents usually give medical explanations for a disability. The family does not perceive itself as shamed, and a value is placed on normalization and social integration.

The Arab community in Israel includes several religious minority populations, but it is predominantly Moslem. Islamic beliefs support a fatalistic and spiritual explanation for a disability. Those affected are seen as physically and spiritually deficient (Haz, 1970; Hamza, 1964). Jewish and Arab high school students of similar socioeconomic background hold significantly different attitudes about the disabled (Florian, 1977), with Arabs being more negative. Students of either Arab or Jewish background who considered themselves religious had more negative views about the disabled than did those who stated that they were less religious. It is difficult to separate cultural and religious factors, and in several of the studies reviewed, sex, economic levels, and contact with the disabled significantly modified the

effects of cultural origin.

Differences in attitudes were reflected in varied coping behaviors in families with a disabled child (Florian and Shurka, 1981). Arab parents are more likely to sell family property to address economic difficulties related to a child's medical problems. Jewish parents are more likely to send a mother to work or have a father take on additional work. Arab parents tended to rely on their extended family to solicit community assistance and services, while Jews took more individual initiatives. Arab families felt more deprivation due to their child's problems and had a stronger need for aid. This meant that Arabs were more interested in participating in groups for parents of disabled children. Florian and Shurka speculated that Jewish parents preferred interaction with parents of normal children, rather than defining their social contacts by their child's problems.

Cultural and social values dealing with disability also appear to relate to family organizational patterns. Traditional, patriarchal Arab or Jewish families see a disabled child as a family shame, and perceive their role as sheltering and protecting the child. Jewish families that are nuclear and modern in organization encourage a child's independence and appear to generate higher expectations for ultimate performance.

Differences in cultural practices and understandings evidently have a profound impact on the Israeli rehabilitation process. Israel has an unusually high per capita use of medical services (14 visits per year as opposed to 4.7 visits per year in the United States). There are many doctors (260/100,000 population) in Israel and care is readily accessible, with a network of 2000 neighborhood primary care clinics and four medical schools with affiliated teaching hospitals (Greenberg, 1983). In Israel, the availability of care assures the possibility of treatment, and cultural origin determines how resources are utilized. In this respect it is similar to other relatively developed nations including the United States, where cultural, social, and ethnic factors strongly influence care-seeking behaviors and attitudes toward the disabled.

NIGERIA

Nigeria is the largest of the West African coastal nations and its population of 82,396,000 (July, 1982) is divided into more than 250 tribal groups of which the Hausa, Fulani, Yoruba, and Ibo comprise the majority.

In Nigeria, a rehabilitation infrastructure has only begun to emerge. Infectious and parasitic diseases are the major health problems, and attention has recently been turned to the welfare of the handicapped. In a series of Nigerian case studies (Oyemade and Olugbile, 1981) it is apparent that even a minor physical handicap means assured poverty. Begging, which is seen as the means of economic survival for the handicapped, begins when the child is very young. A disfigured child is held to represent the family's social position and is regarded with shame. In one case, both mother and child were forced out of the matrimonial home due to the child's condition. In another case, the family's misfortunes were attributed to witchcraft, and medical treatment was sought only from herbalists. That many Nigerians practice the Islamic faith assures that street beggars will receive freely-given alms. Medical insurance exists only for those injured at work. The number of handicapped persons is reported to be increasing. This increase is attributed to the increasing number of children surviving with birth defects and an increased number of automobile accidents.

In an interview survey (Okunade, 1981) in four Western Nigerian communities, public attitudes were least favorable toward visual handicaps, followed by physical disabilities. An auditory handicap was better tolerated. Small percentages of interviewers felt children with handicaps should not be allowed to live. In terms of social participation, the more Westernized the community, the less accepting it was of a disability. In this survey, more than 60 percent of respondents in the most modern site felt that a child with a physical handicap should not be reared by his or her parents with other siblings. Respondents in traditional settings displayed more

social accommodation and wanted such children to remain in their family context. In an elite modern community, less than 20 percent of the respondents believed that supernatural forces caused handicaps. Traditional groups found this explanation more acceptable and were much more likely to seek care from a spiritual church (Aladura) or a traditional healer.

A review of facial clefts in Nigeria (Olusami and Adekunle, 1970) reported that it was difficult to obtain a family history of congenital anomalies since they were generally denied. The authors stated that "the bad practice of encouraging congenitally malformed babies to die has not completely disappeared and the traditional Western Nigerian method of feeding a baby will almost certainly kill a child with a cleft palate". According to traditional Yoruba feeding practice, the baby lies prone in the mother's lap while the mother's hand is cupped over the baby's mouth, her fingers partially occluding his nostrils, and food is poured into her cupped hand and from there into the baby's mouth. Gupta (1969) in his study of Nigerian birth deformities speculated that the reported incidence was probably low because "the attitude of African society towards the malformed child is responsible for the relatively small proportion of these seen in hospital practice". He stated that such children were a "bad omen to the family" and were "concealed or neglected". In a study of birth practices among the Bariba tribe of Benin, West Africa, it was found that midwives were charged with detection of witchcraft. They identified "witch babies" as those with breech presentations, natal teeth, or birth defects. Infanticide was sometimes deemed necessary in these births (Sargent, 1982). Cervenka (1984) speculated that few West Africans with clefts reach adulthood, and he believed that this was the reason that the Fon tribe of West Africa would treat an adult face mask with an unrepaired cleft as a "public amusement" and a novelty.

In a small study (Ojofeitimi and Oyeso, 1980) of a Nigerian day school for the handicapped, 61.5 percent of the children had clinical signs of malnutrition.

Each mother was interviewed regarding her child's growth. More than three-quarters of them expressed satisfaction. Fewer than one-third found their children a source of joy, and more than two-thirds found them an embarrassment. These children were largely seen as unable to provide support for their parents in their old age. The authors concluded that "ignorance as to the causes of handicapping conditions coupled with poor attitudes and low expectations are the major factors contributing to poor general care of these children". They also noted that in 1980 there were no child health or developmental centers in Nigeria. Okafor (1984) points out that Nigeria, because of its oil wealth, is not a poor country when compared to other nations, but its population, growth, and planning problems cause difficulties in the delivery of health services. The construction of centralized general hospitals in urban areas serves to deny care to large rural populations because of inadequate transportation and problems with accessibility and cost. The lack of health and economic resources, coupled with religious or attitudinal barriers or both, may inhibit the elaboration of rehabilitative services in Nigeria.

INFANTICIDE

Infanticide is considered a cruel and primitive practice by most Westerners. It is assumed to be a vestige of tribal custom or a practice of uncivilized peoples. Infanticide has been practiced by many cultures around the world, at every degree of sophistication. It has served social and economic needs and has often been practiced as a means of limiting family size (Williamson, 1978). It has been difficult to study infanticide because such deaths are rarely reported; when reported, they are usually listed as stillbirths or accidents. Even in societies that officially deny the existence of infanticide, other signs such as a disproportion in the childhood ratio between males and females may suggest otherwise (Divale and Harris, 1976). In some cultures the line between infanticide and abortion is not clear, especially when a fe-

tus is disrupted in the late stages of pregnancy. Societies such as Eskimo, Fiji Islander, Western Indian (high caste), and Imperial Chinese preferred male children and utilized infanticide, not abortion, to select males for survival.

Some cultures used infanticide to eliminate children with defects, or to avoid illegitimate births or motherless infants. In some societies multiple births were considered evidence of immorality and were dealt with by infanticide. Infanticide may also have served an economic and demographic purpose (Dickeman, 1975). Anthropologic evidence indicates that nomadic hunter populations spaced their children widely apart, using infanticide to assure the group's mobility. More sedentary agricultural groups maintained population levels matched to food and water resources. Other measures of population control included late marriage, war, celibacy, abortion, dangerous missions, and prolonged lactation. When large families represented an economic advantage, children survived. This was true among farming families in agricultural societies. Large numbers of births also served to assure survival of some children to adulthood. Acceptance of modern family-planning methods may be linked to economic development and to declines in numbers of infant deaths.

In Western Europe, infanticide was widespread in Greek and Roman times. The sixth commandment influenced Judeo-Christian thinking and was crucial in altering perceptions of infanticide (Williams, 1978). Historic evidence indicates that meaningful limits on large-scale infanticide in Western Europe did not occur until the late 1800s (Langer, 1974). Reports show that as late as the 1890s dead babies were still a common sight on London streets (Demaue, 1977).

The English grappled with the difficult problem of mothers who killed their own infants by passing a legal statute. The Infanticide Act of 1922, amended in 1938, found women who were involved in the death of a child under one year of age guilty of infanticide. This crime was treated

much more leniently than other forms of murder (Williams, 1978) and allowed for recognition of a psychological disturbance related to the birth. In the United States the problem is treated as second-degree murder, although the severe sentences imposed have often influenced juries to avoid convictions.

Infanticide may still be the hidden response to children with birth defects in some societies. Evidence of this practice, though difficult to come by, exists for contemporary China (Mosher, 1983) and Brazil (Sheper-Hughes, 1984). In both cases, American anthropologists conducted field investigations of birth and contraceptive behaviors, concluding that active infanticide and selective malnutrition are currently practiced, although they are not legally permissible. Infanticide is now universally held as a crime, and most societies have created social roles for defective children within community life.

Modern medicine undoubtedly has increased the potential survival of infants with defects. Genetic screening, prenatal diagnosis, and abortion may function to maintain an even incidence of genetic disease in a Western developed population, much as infanticide or infant mortality did in less developed settings.

IMPLICATIONS

The impact of cultural and social values on responses to birth defects, and in particular facial clefts, remains largely uninvestigated. The case studies presented explore the literature regarding resource allocation and attitudes in two societies. Other aspects of cultural life also affect children with facial clefts. The face as the initial presentation of self is central to social interaction and personal identity. Cultural norms of beauty affect perceptions of the face and determine whether blemishes will limit opportunity. They also affect the willingness to seek surgical care and the ability to follow through on recommendations.

In the United States, treatment is widely available for facial malformations. Melt-

ing-pot assumptions about the loss of ethnic and cultural values in the process of assimilation serve to distract Americans from the considerable cultural variations that occur. Evidence exists that cultural origins affect behaviors as widely varied as food choice (Kolasa, 1978) and pain perception (Zborowski, 1952). How do cultural and ethnic origin affect attitudes toward facial appearance? Are some groups more likely to seek medical care actively? Do cultural values downplay the importance of medical care in some groups? Does culture determine why a family may or may not return for recommended treatment and followup? Such uncertainty suggests that social and cultural variables should be included in studies of cleft lip and palate rehabilitation.

Cultural factors are also very important in the development of international programs that provide technical assistance and training. At the 1982 meeting of the American Cleft Palate Association, an international symposium (K. Salyer, Chairman) suggested that medical specialists in developed nations such as the United States become involved in training and technology transfer to Third world developing nations. It was suggested that such interactions could possibly be coordinated through national professional organizations such as the American Cleft Palate Association. In light of the cases presented in this paper, it is crucial that such endeavors remain highly cognizant of the social and cultural differences between nations. What is excellent treatment in one setting may be an inappropriate intervention in another. Cultural awareness is a powerful tool in understanding meanings and behaviors in others.

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