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Social Analysis of Cleft Lip and Palate Abnormality in Nigeria

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This study examined cleft lip and palate from the sociological point of view. It looked at the social aspects of a health issue by examining the social problems that may emanate from cleft lip/palate deformity. Questionnaires were administered in northern Nigeria to 32 patients between the ages of 10 and 60 who had been born with the defect. Oral interviews using the same set of questions were conducted with 18 patients with similar defects of cleft lip/palate deformity in southern Nigeria. The questionnaire method was preferred by the respondents in the north, whereas the respondents in the south preferred the interview method. Two case studies also were reviewed from the south as part of the methodology. The study revealed the predominance of the defect among the lowest income group within society. Because of the financial constraints involved in medical treatment, the defects were not attended to earlier in the patients' lives until dental surgeons offered free treatment. Stigmatization and discrimination were related by the respondents as a common experience. In northern Nigeria, 98% of the patients who were interviewed were of the Muslim faith and saw the defect as the will of God, so they accepted the stigma and discrimination as their fate. In southern Nigeria, witchcraft was basically seen as the cause of the defect. The need for public awareness is emphasized for early diagnosis and early treatment of the defect to enable those affected by it to live healthy and productive lives.

Keywords: *cleft lips, palate deformities, public awareness, social problems, stigmatization*

Introduction

Culture contributes to differences in medical care and the ways in which health is defined. It also can also influence the relative incidence of a disease or disorder (Schaefer, 2005). Researchers have found that diseases are rooted in the shared meanings of particular cultures. Culture also plays an important role in the widely shared concept of disease in Nigerian society. Nigerians believe that diseases are caused by natural, preternatural, and mystical/mysterious factors. Preternatural explanations are related to the belief in witchcraft (Erinohso, 2005). The belief in witchcraft is widespread and entrenched in Nigeria. Witches are believed to exist and are reputed to have powers to cause unrest of the mind and illness. Despite the recognition of the natural explanation of diseases, Nigerians often invoke sorcery, witchcraft, or cosmic forces as a plausible explanation for illness. According to Erinohso, regardless of educational or religious background, Nigerians are likely to attribute motor accidents or snakebites to preternatural or cosmic factors.

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The concept of beauty also is culture bound. Some cultures believe that being thin is beautiful, whereas others consider being fat as beautiful. In South Eastern Nigeria, among the Calabar people is the tradition of a fattening room for girls. Cultural beliefs and expectations about beauty and body shape prevent people who are regarded as ugly from advancing as rapidly as their abilities should permit. They are regarded as not conforming to the beauty myth; according to Goffman (1963), they may be viewed as "disfigured" or "strange" in appearance.

Stigma is described as permanently spoiled identity that prevents "competent or morally trustworthy" behaviour (Impression Management. 2000). Goffman (1963) defined three types of stigma, one of which one is defects of the body (e.g., facial scars). He suggested that society has attached a stigma to many forms of disability and deformity and that this stigma leads to prejudicial treatment. Therefore, the status of "disabled/deformed" carries a stigma. Stigma is socially constructed and varies across time and culture. Stigmatized individuals generally perceive others as evaluating them negatively, so they consequently develop coping strategies to manage their identities.

Throughout history and around the world, people with disabilities have been subjected to cruel and inhumane treatment. They have been viewed as subhuman creatures that are a menace to society (Schaefer, 2005). A review of studies of people with disabilities disclosed that most academic research on the subject has not differentiated gender, thereby perpetuating the view that a disability overrides other personal characteristics. Consequently, disability serves as a mast status. Discrimination against individuals who are disabled occurs around the world. In Nigeria, as in many other parts of the world, disabilities are classified into various categories.

Theoretical Approaches

The researchers examined the social problems and societal perceptions of cleft lip and palate deformities, the most common congenital abnormality affecting the head and neck region hat cannot be covered by clothing. The following sociological theoretical paradigms explain why health and medicine are social issues, as examined in this paper.

The symbolic-interaction paradigm and social conflict analysis were relevant to this study. The symbolic-interaction paradigm sees society less as a grand system than as a series of complex and changing realities. Health and medical care, therefore, are socially constructed by people through their everyday interactions. How we respond to illness is based on social definitions that may, or may not, square with medical facts. Health is seen as less of an objective fact than a negotiated outcome. The symbolic-interaction paradigm reveals that what people view as healthful or harmful may depend on factors that are not strictly speaking medical (Thomas, 2003).

The social conflict analysis points out the connection between health and social inequality; based on the model of Karl Marx, it ties medicine to the operation of capitalism. According to Thomas (2003), "Researchers have focused on three main issues, access to medical care, the effect of the profit motive, and the politics of medicine" (p. 39). Under access to medical care, health is seen as important to everyone, but by making health a commodity, capitalist societies allow health to follow wealth. The access problem is more serious in countries with no universal medical care system. According to Thomas, conflict theorists have argued that capitalism provides excellent health care for the rich, but not for the rest of the population.

Thomas (2003) reiterated that some social conflict analysts with profit motive issues have argued that the real problem is not access to medical care but the character of capitalist medicine itself. The profit motive turns physicians, hospitals, and the pharmaceutical industry into multibillion-dollar corporations. The quest for higher profits encourages unnecessary tests and an overreliance on drugs (Ehrenreich, 1978; Kaplan et al., 1985). Therefore, social conflict theorists have contended that most surgery reflects the financial interests of surgeons and hospitals as much as the medical needs of patients (Cowley, 1995; IIIich, 1976; Sidel & Sidel, 1982). Health care is supposed to be motivated by a concern for people, not profit.

Lastly, under the social conflict analysis, medicine is seen as politics. Though science affirms to be politically neutral, scientific medicine frequently takes sides on significant socialissues (Schaefer, 2005). The history of medicine has shown that racial and sexual discrimination have been supported by so-called scientific opinion (Leavitt, 1984). Even today, according to conflict theory, scientific medicine explains illness in terms of bacteria and viruses, ignoring the damaging effects of social inequality. However, the impact of culture, family, friends, and the medical profession means that health and illness are not only biological occurrences but also sociological occurrences (Schaefer, 2005). The social conflict analysis provides another view of the relationships among health, medicine, and society. According to this paradigm, social inequality is the reason some people have better health than others.

Problems Associated With Cleft Lips and Palate Deformities

Clefts are gaps in developing lips and palates. They can range from small cuts to large openings in the area of the mouth and lips. Cleft lips are associated with problems during prenatal development when the two sides of the face fail to meet and join correctly. The causes range from genetic factors to exposure to drugs or toxins during pregnancy. The cleft expresses itself in varied ways, such as a little notch in the lips or an imperfection, where the barrier between the mouth and the nose is missing. It can occur on one side of the face, both sides, or in the middle. In some cases, the bone of the palate may be cleft, yet the overlying tissue in the mouth remains intact. Clefts have feeding problems, speech development problems, dental problems, and concomitant problems such as ear infections. The deformity lasts until it is corrected. According to the researchers who conducted this study, surgery is usually the main treatment.

Methodology

The sociological study of patients with cleft lips and palate deformities in Nigeria was conducted in Sokoto, the capital of Sokoto State in the northern part of Nigeria with patients attending the Noma Centre and Children's Hospital. The study also was conducted at the Centre for Oral Health and Cranio-Facial Repairs (COHACR), in Benin City, southern Nigeria. The study was conducted using questionnaires, interview schedules, and case studies. The researchers made use of questionnaires whose questions, wording, and sequence were identical for every respondent.

The questionnaires had five major sections. Section 1 dealt with the personal information/demographics of the respondents. Section 2 addressed the respondents' awareness/definition of the condition as well as the cost/burden of the condition on them. Section 3 was on the respondents' interaction with health workers, nongovernmental organizations (NGOs), or herbal or spiritual home prior to meeting one of the dental surgeons. Section 4 was on interviews and case studies. Section 5 dealt with the challenges faced by the patients.

The respondents were cleft lip patients attending the Noma Children's Hospital in Sokoto, northern Nigeria. An explanation of the objectives of the study was stated in detail to the patients and the guardians of the patients under the age of 18. The objectives of the study were explained in Pidgin English and Hausa, the indigenous language of most of the patients. The patients who agreed to be interviewed and answer the questionnaire first gave their consent to participate in the study. The questionnaire was written in English. Individuals and/or families with a literate person answered the questions directly on the questionnaire. Those who were not literate in English were asked the questions in Pidgin English or Hausa. The answers thus obtained were used to fill out the questionnaire. At the end of the interview, the responses were read and translated back into Pidgin English or Hausa for the respondent to confirm everything that had been written.

Unstructured oral interviews with questions similar to those in the questionnaires were also conducted by the dental surgeons with patients and the parents of very young patients. Issues raised by the respondents in the course of the interviews were analyzed. Case study as a research method also was used in this research. Social scientists make wide use of this qualitative research method to examine contemporary, real-life situations. A total of 32 valid questionnaires were obtained for the study. Oral interviews were conducted randomly with 18 patients who consented to the interview. In addition, 2 case studies from the COHACR were reviewed.

The COHACR, which is in Benin City, Nigeria, has a mission to promote oral health care and correct cranio-facial anomalies in Nigeria through systematic research, documentation, training, enlightenment, and information dissemination. According to the president of the COHACR, who also was the primary researcher of this study, the Nigerian public is not informed enough about the need to take adequate care of dentition. Patients usually report to the dental clinic only when pain in the mouth becomes unbearable. Worse still, patients with cleft lipand palate deformities are subject to experiences categorized as "spoiled identity" and are discriminated against by society.

Discrimination includes babies being abandoned or left to die without any attempt being made to obtain medical relief for them. Older patients and even the parents of young children with cleft lip and palate deformities sometimes spiral into a depression that compounds their social and financial problems. Treatment often is justified by the potential enhancement of social and psychological well-being through improvements in appearance. Therefore, one objective of the COHACR is to ensure that the public is well informed and aware that individuals with cleft lip and palate deformities can be rehabilitated.

Routine interviews conducted by the COHACR on patients in Benin City, Nigeria, identified the patients' experiences as the following:

1. Stigmatization from family members and the general public.
2. False accusation of witchcraft against the mothers, who were held responsible for their infants' cleft defects.
3. Lack of finances to take care of the numerous medical problems associated with cleft defects.
4. Parental ignorance that these deformities can be corrected.

Case Studies

Case Study 1: 17-Year-Old Girl With Cleft Lip and Alveolus Deformity From Birth

The patient lost her parents shortly after birth. Things became so difficult for the family that her elder sister had to enter into an early marriage in order to cope with caring for the younger ones. Despite her sister's marriage, the child could not go to school because of stigmatization. Her sister brought this young girl to the COHACR clinic, where the dental surgeon met her for the first time.

Case Study 2: Baby Girl With Bilateral Cleft

The family had five sons before the arrival of the sixth child, a girl. Unfortunately, the child had bilateral cleft lip and palate and was polydactyl (i.e., having more than five digits on the hands and feet). The child, who had not been fed since birth, was brought to the clinic 3 days after birth. The child had breast milk for the first time after having been brought to clinic, but she was too weak to swallow. She was becoming asphyxiated and had to be admitted to the children's emergency ward at the university teaching hospital in Benin City. Comments from the maternal grandmother revealed that the baby deliberately had not been fed because of the deformity. The child was taken home and was never brought back. She was most probably left to die. These case studies, which were among many others collected in the course of this study, revealed ignorance and poverty on the part of parent, in-laws, and Nigerian society at large toward cleft lip and palate deformities.

Data Analysis

The analysis of the data basically followed the same five major sections as the questionnaire: (a) information/demographics of the respondents; (b) respondents' awareness/definition of the condition as well as the cost/burden of the condition on them; (c) analysis of the respondents' interaction with health workers, NGOs, or herbal or spiritual home prior to meeting one of the dental surgeons; (d) reevaluation of the interviews and case studies; and (e) the challenges faced by the patients and recommendation for best practices. The sample at the dental clinic comprised 32 individuals: 26 males (81.2% of the respondents) and 6 females (18.8% of the respondents; see Figure 1).

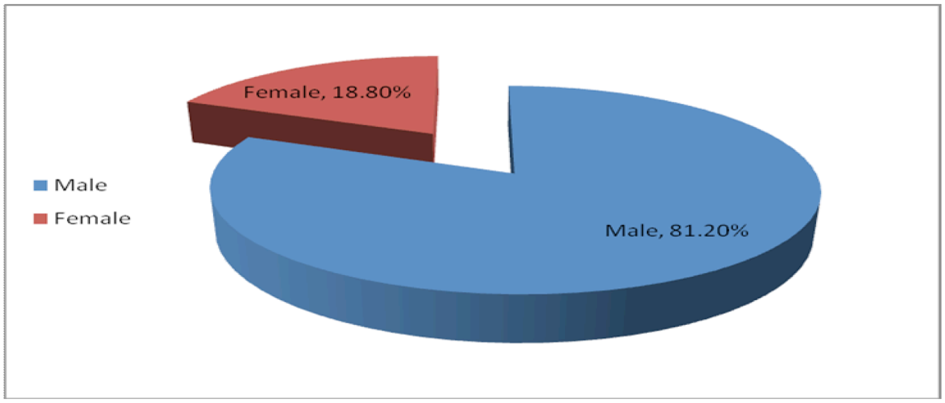

Figure 1: *Sex of the Respondents*

The age structure of the respondents indicated that 16 (50%) were between the ages of 10 and 15; 20 (62.5%) of them were between the ages of 10 and 20. Children and youth constituted the majority of cleft palate deformities in the hospital (see Figure 2).

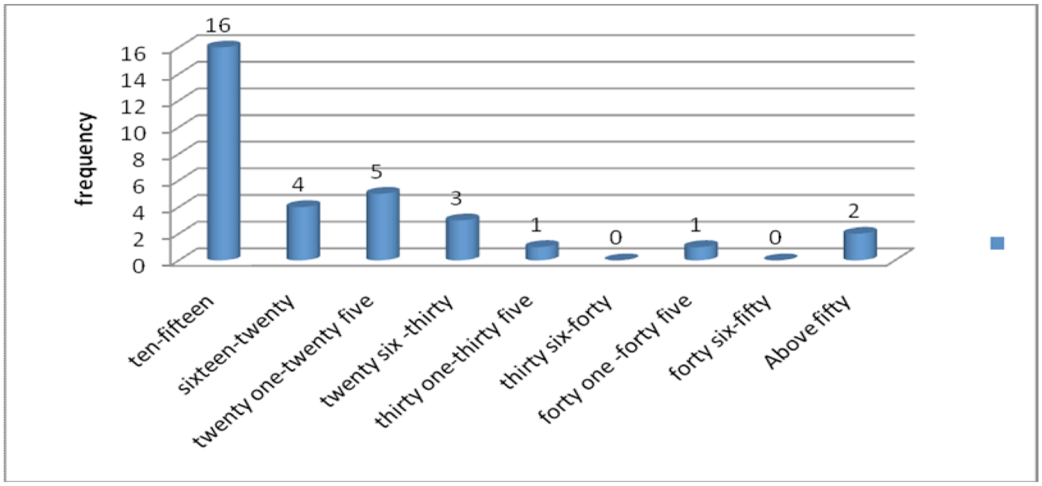

Figure 2: *Ages of the Respondents*

The questionnaires were mainly administered in Sokoto, the seat of the Caliphate in Nigeria, so it was expected that most of the patients would be of the Muslim faith. This was the case, with 31 (97%) of the respondents indicating that they belonged to the Muslim faith (see Figure 3).

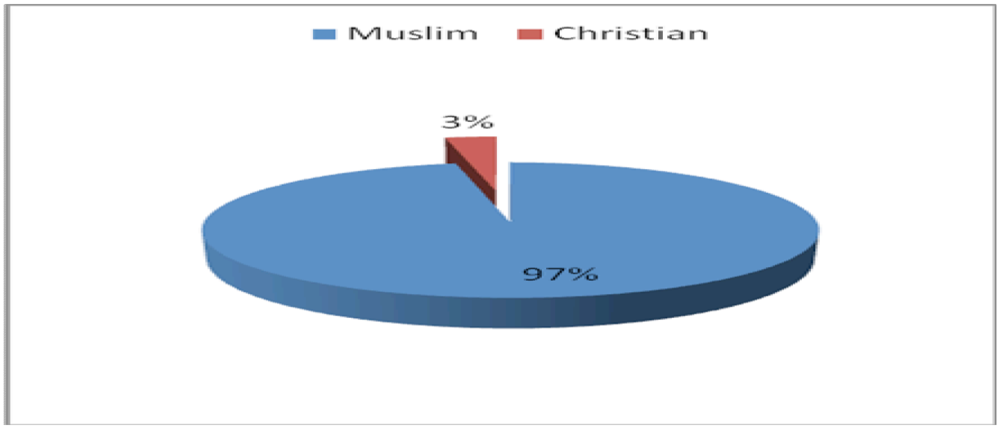

Figure 3: *Religion of the Respondents*

Because the questionnaires were administered in northern Nigeria, it was not surprising that the dominant group of Hausa-Fulani comprised the majority of the respondents. The respondents came mainly from the northern Nigerian states of Adamawa, Gombe, Jigawa Kaduna Kano Katsina, Kebbi, Niger, Sokoto, Taraba, and Zamfara. One respondent came from the nearby Republic of Niger, and another respondent came from the western Nigerian Yoruba ethnic group. He had settled in Jigawa state with his parents (see Figure 4).

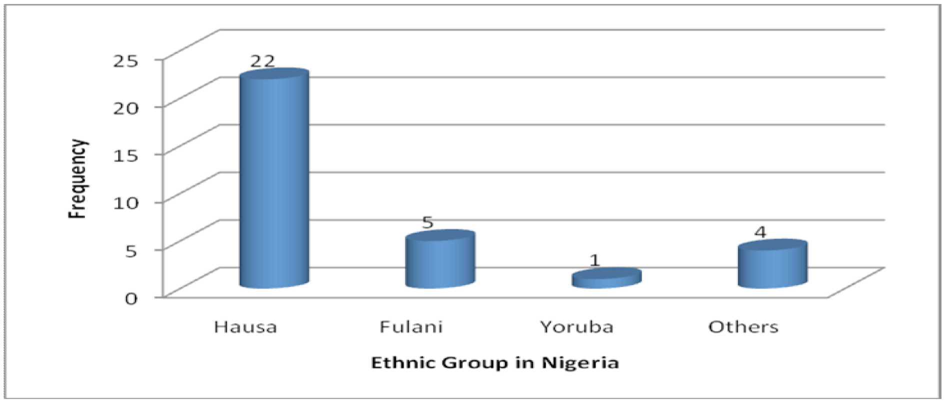

Figure 4: *Ethnic Groupings of the Respondents*

Based on the distribution of the respondents by years of schooling, 7 (21.9%) of the respondents had a basic primary school education, 5 (15.6%) had a secondary school education, and 3 (9.4%) attended Arabic school. None of the patients had a tertiary education, and the majority (17, 53.1%) had no formal education.

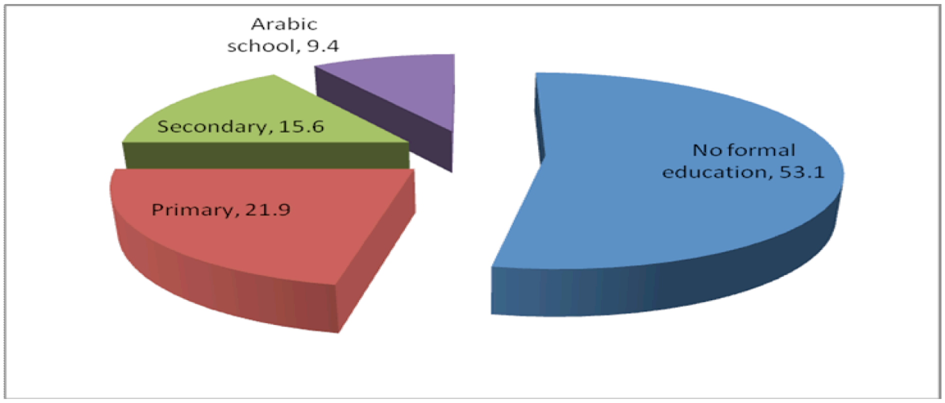

Figure 5: *Education Status of the Respondents*

Because 20 (62.5%) of the respondents were between the ages of 10 and 20, their occupations ranged from students (11, 34.4%) to unskilled jobs, with 3 (9.4%) involved in animal rearing and 9 (28.1%) in farming. Two (6.3 %) of the patients were traders of petty wares, 1 (3.1%) was a tailor, and 1 (3.1%) was a barber. The remaining 3 (9.4%) respondents worked at a combination of odds jobs (see Table 1).

Table 1: *Occupations of Respondents*

Occupation	Frequency	Percentage
Student	11	34.4
Animal rearing	3	9.4
Farmer	9	28.1
Housewife	2	6.3
Barber	1	3.1
Tailor	1	3.1
Trader	2	6.3
Other	3	9.4
Total	**32**	**100.0**

Demographic figures derived from the survey indicate that 17 (53.1%) of the respondents come from polygamous families and 15 (46.9%) from monogamous families. However, all of the respondents had large family sizes. Twenty (62.5%) of the respondents' fathers were from families of between 6 and 20 in number.

Fifty percent (16) of the respondents' fathers had no formal education, 8 (25%) had ended their education at the primary level, 4 (12.5%) had a secondary school education, 2 (6.3%) had gone to Arabic school, and 1 (3.1%) had a tertiary education. Farming is the highest form of occupation of patients' fathers, with 43.8% involved in it. Other forms of occupation indicative of the respondents' families' low socioeconomic class in Nigerian society included animal rearing, blacksmithing, bricklaying, mechanic, trading, unskilled labor, and trading. Occupations indicative of the middle class included 3 (9.4%) participants who were civil servants and 2 (6.3%) who were involved in business ventures (see Table 2).

Table 2: *Occupations of Respondents' Fathers*

Occupation	Frequency	Percentage
Farmer	14	43.8
Civil servant	3	9.4
Animal rearing	1	3.1
Business	2	6.3
Trader	5	15.6
Motor mechanic	1	3.1
Laborer	2	6.3
Bricklayer	1	3.1
Blacksmith	1	3.1
Other	2	6.3
Total	**32**	**100.0**

Twenty-three (71.1%) of the respondents' mothers had no formal education, 3 (9.4%) had a primary education, 3 (9.4%) had a secondary education, and 3 (9.4%) had attended Arabic classes. None of the mothers had a tertiary education (see Table 3).

Table 3: *Occupations of Respondents' Mothers*

Occupation	Frequency	Percentage
Housewife	3	9.4
Trader	17	53.1
Tailor	3	9.4
Farmer	3	9.4
Retired	1	3.1
Other	3	9.4
Deceased	2	6.3
Total	**32**	**100**

Trading was the highest form of occupation among the respondents' mothers, with 17 (53.1%) of the respondents involved in it. Other occupations included full-time housewives, tailoring, farming, and retirees from government work. Three (9.4%) could not describe the specific jobs that their mothers were involved in. In some cases, the mothers were involved in farming and trading, as the seasons demanded. Two (6.3%) of the mothers were deceased.

Ten (31.3 %) of the respondents were married, and 22 (68.8%) were single. The unmarried patients should be viewed in light of the fact that 20 (62.5%) of the respondents were between the ages of 10 and 20. Out of the 10 (31.3%) married patients, 7 (21.9%) of the spouses had no formal education; 1 (3.1%) had a primary education, and 1 (3.1%) had a secondary education. Seven (21.9%) of these spouses were involved in petty trading. One (3.1%) was a farmer, and another (3.1%) was a tailor. Considering the ages of the patients, 17 (53.1%) came to the clinic unaccompanied, and the remaining 15 (46.9%) were accompanied by parents, siblings, other relatives, or friends.

Awareness/Definition of Condition and Cost/Debt/Burden of the Condition

Description of Condition

Only 4 (12.5%) of the cleft palate patients described their condition as a cut in the lip or that they were born like that, while the remaining 28 (88.9%) patients could not offer any adequate description of their condition. Furthermore, the majority of the patients (28, 88.9%) claimed that not only were they born like that but also that it was the will of God for them to be born with the deformity (see Figures 6–9). The cause of their conditions also was explained as God's will. Ninety-Eight percent (31) of the respondents interviewed at the COHACR clinic in Benin City attributed it to witchcraft on the part of mothers of babies with cleft, which corroborated the results from a previous study in southern Nigeria (Umweni & Okeigbemen, 2009).

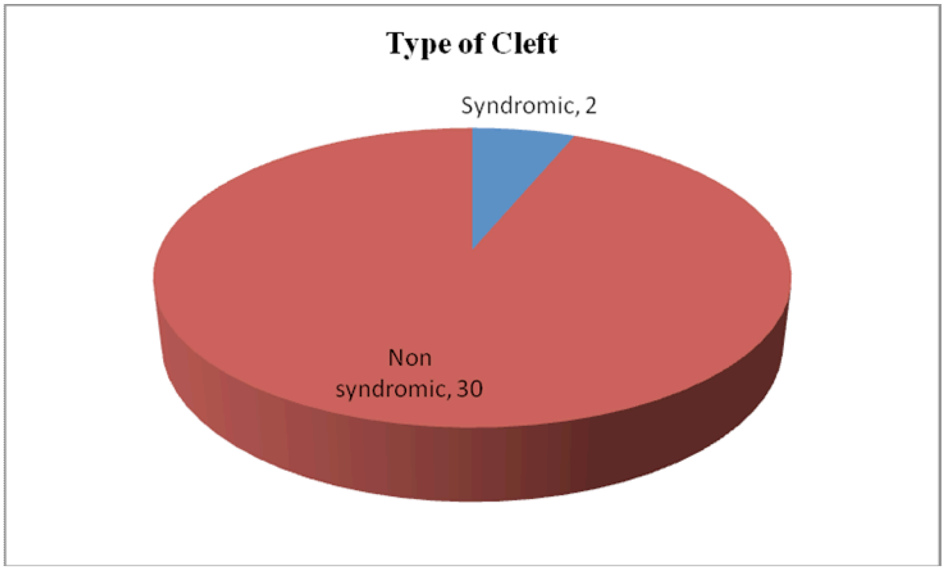

Figure 6: *Type of Cleft*

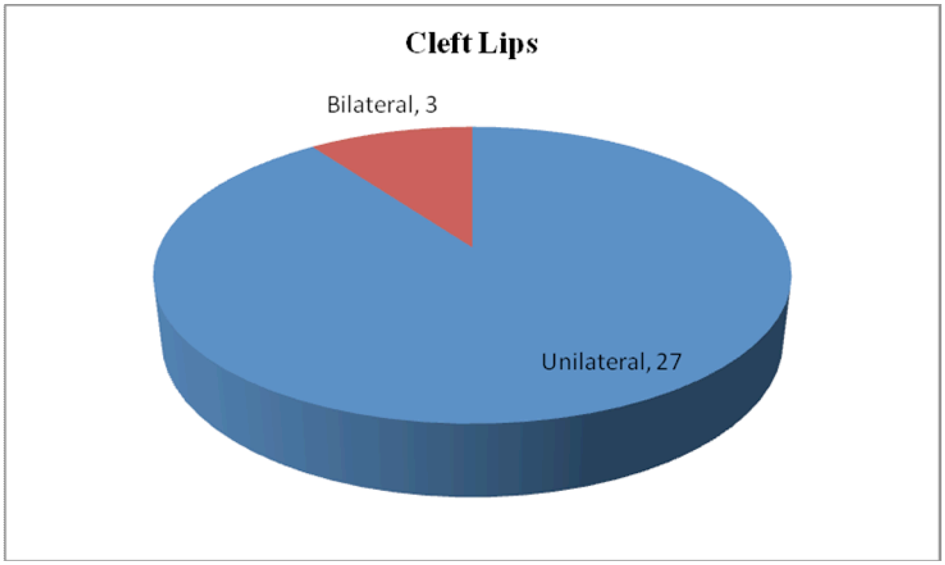

Figure 7: *Cleft Side*

Figure 8: *Left Unilateral Cleft Lip and Alveolus in a 35-Year-Old Man*

Figure 9: *Right Unilateral Cleft Lip and Alveolus in a 24-Year-Old Woman*

How Condition Affected Aspects of Respondents' Lives

When the respondents were asked to indicate the most important impact of the condition, 30 (94%) claimed that the condition has affected their social life. The other areas of life mentioned included marriage, psychological well-being, performance in class, and education. Some recurrent comments made in this regards by patients are quoted in the following text.

The comments made by the respondents can be summarized that the condition affected them in two ways: educationally by the school-age children and in relationships with the opposite sex by the older respondents.

Fourteen (45%) of the patients claimed that their fellow classmates and, in one case, a teacher laughed at them; as such, they were discouraged from attending school. A teacher refused a pupil entry into the class, 8 (25%) of the respondents had speech problems, and some claimed that because they could not talk properly, they could not attend school. Others did not start school early because of the condition, or their parents decided against sending them to school because of the condition. A little girl who was sent to school was reported to be playing truancy because of her defect. She was withdrawn from school.

Social Relationships

Twenty-one (66%) of the respondents claimed that relationships with same-sex friends were affected by their condition. They were frequently teased and laughed at because of their condition. The remaining 11 (34%) respondents claimed that their relationships with their companions were not affected by their defects. Relationships with the opposite sex were more affected. Twenty-six (80%) of the respondents answered that the condition affected them seriously. The ways in which the condition affected their relationships were described as follows:

> *"That they laughed at him before he spoke to the ladies." "They do not love him, because of the condition."*

For the respondents who were married or of marriageable age, the condition also had affected them. Following are statements made by the respondents that explained how it has affected their married life and ability to get married:

> *"I could not get married because of the problem."*
>
> *"Could not marry more wives as he would have desired." "Not married because people were laughing at her." "Had a sudden divorce without cogent reason."*
>
> *"I only got married last year because I did not believe that any girl will agree to marry me, only last year, I saw a woman who said she loved me."*

A 25-year-old male respondent commented:

> *I could not speak because of the cleft; I could not also attend school. When it was time to get married, women laughed at me and said they did not want to deliver a baby with a cleft defect after they married me. (February 8, 2005)*

Generally, the condition affected them in terms of ability to socialize. They had some of the following to say in terms of how it affects them:

> *"It discourages me from socializing." "Self-discouragement."*

> *"Shy in the company of other."*
>
> *"I am not able to attend ceremonies and functions because of the problem." "I got discouraged with life especially when friends laughed at me."*
>
> *"I am socially affected."*

Familial relationships with siblings, parents, and extended family members were described by the majority of respondents as satisfactory; however 4 (12.5%) of the respondents claimed they were at times teased and laughed at because of their condition.

Religious Beliefs

The respondents' religious outlook and place of worship were not negatively affected by the condition. Advanced and unrepaired defects have been common in the north, as exemplified by Sokoto State, because of the acceptance of the condition as God's will. Only 1 (3.1%) respondent claimed he was affected by the shame that he felt. The respondents from the south of Nigeria, using Edo State as a case study, were mainly of the Christian faith. They attributed the condition to spiritual attacks and witchcraft. They subsequently sought help from various churches, whose members prayed for them to receive healing for their condition. As to whether any of them had been constrained to do anything because of the condition, 30 (94.1%) of the respondents claimed that the condition had forced them to engage in begging at one point in life.

Cost of Burden

Although some of the respondents claimed that the condition was not a financial burden because they had accepted their fate, the parents of 1 respondent tried to obtain treatment at the Maiduguri teaching hospital, but the bill was too high, so they had to forego the treatment.

Another respondent complained about the cost of treatment as too high. He had feeding difficulties, and he was already spending his money on artificial feeding. Another respondent also claimed that he had spent money on a failed operation and that looking for medical help also cost him money.

The condition also forced 8 respondents to do what they claimed they would not have had to do if they had not had the defect: begging. The majority of respondents at one time or another were involved in begging for alms. They made the following statements:

> *"Begging when he was a small boy." "Begging in marketplaces." "Begging for food."*
>
> *"Had to stop begging when the Bungundu Local Government of Zamfara State sponsored me to the Noma clinic for treatment."*

Analysis of Help Prior to Meeting the Dental Surgeon

The only Christian respondent in Northern Nigeria got help and support from the pastor of the church. Twenty (62.5%) of the other respondents got help and needed support from their relatives. Such help were explained in terms of cash, information from relatives on how to solve their defects, and neighbours who provided transportation to the Noma clinic. However, some patients claimed that help came only from the Noma clinic.

Two (6.3%) respondents had sought help for their condition. A patient attempted twice to solve the cleft palate before attending the Noma clinic, and the other patient was introduced to health workers by someone who previously had had a cleft palate and had surgery to repair it. Most patients had encountered others with similar conditions. Places where they met other cleft patients were at the clinic, in the marketplace, on the street, in villages, and in their neighbourhood. One respondent had a brother with the same condition.

Challenges Faced by Patients and Recommendation for Best Practices

At the clinics in northern and southern Nigeria, the respondents got to know about surgery and ways to repair the defects. They attributed the delay in the rectification of their condition to ignorance, financial inability, and the lack of proper information on the treatment protocol of the defects. With surgical repairs, the majority of the patients had high hopes for the

future. Education was a priority for the youth because they wanted to go back to school, start or continue their education, or get a form of training. Some older respondents in the north talked about marrying more wives, furthering in their education, or making plans to expand their trades or businesses. The majority of the patients responded to question on what advice to give others in similar conditions as the following: "*Tell them/direct them to the centre for treatment*."

Conclusion

From the analyses, the researchers made several findings about patients with cleft lips and palate deformities in Nigerian society. The findings revealed the predominance of the defect among the lowest income group in society. Because of the financial constraints involved in medical treatment, the defects were not attended to earlier in life. Stigmatization and discrimination as the result of ignorance are prevalent. In northern Nigeria, 31 (98%) of the respondents who were interviewed are of the Muslim faith, and they saw the defect as the will of God. In southern Nigeria, witchcraft was basically seen as the cause of the defect. The need for public awareness should be emphasized to ease early apprehension about the defect and to promote early treatment to enable those affected by it to live healthy and productive lives.

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