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Cleft lip and palate- Improving lives through awareness.

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Abstract:
Background: Cleft surgeries in the developing world serve as not only aesthetic and functional ones but, in some cases, as life saving operations too.
Aim: To evaluate the level of awareness of cleft patients with regards to their defect and relate it to their quality of life taking internationally approved and local factors into consideration.
Settings and Design: Random study 123 patients completed the MOS short form – 36 questionnaire to evaluate the health related quality of life along with a few other questions. The aesthetic, functional and psychological outcomes were assessed on a visual analog scale.
Results: The main cause for clefts was considered to be god’s will. 29% of the patients were not allowed to draw water from the local well and 38% were not allowed to join school before the surgery, while post surgically only 6% had the same problems. The health related quality of life questionnaire demonstrated higher scores in all subsets under the mental health criteria after cleft surgeries.
Conclusion: Where myths and beliefs are still present, the surgery not only improves the facial appearance and function, but also helps the patient to be inculcated back into the society.

Key Words: Cleft Lip and palate, Health related quality of life, Myths and beliefs, Psychological aspects, Short form questionnaire.

Introduction:
StROKE is the leading cause of death and long-term disability in Assessment of quality of life after cancers and other major pathologies has been a topic of vital importance in research of many institutes worldwide. Similar work in the field of cleft surgeries has also been reported in the literature. It gains even more leverage in a place like India where the patients often report late for their primary visit. These people harbour various myths and beliefs about the defect which can have catastrophic repercussions. Monster, devil, a curse of god are the oft heard phrases used by the rural, illiterate people pertaining to the cleft children. The child or sometimes even the family has been shown to be ostracized from the civil society and forced to live an isolated, unsocial life of shame and guilt for no wrong of theirs.

Material and methods:
123 patients with a complete unilateral or bilateral cleft lip and palate were included in the study. Of these, 23 did not turn up for the second visit after 12-18 months of the surgery. None of these individuals had other associated diseases. All
the patients included in the study were in the age bracket of 6 – 14 years. During these visits, according to the stage in which the patient presented themselves, routine cleft surgeries and associated treatment was carried out. The MOS short form – 36 questionnaire was put up to evaluate the health related quality of life along with a few pertinent questions before the surgery and at the time of follow up 12 -18 months later. All the surgeries were carried out by 2 senior surgeons certified by Smile Train in the institute while the questionnaires were conducted by the author himself, along with the help of a translator, whenever required.

The questionnaires were put up at the time of the primary visit and during their follow up, 12 – 18 months later. Patients were requested to assess their esthetic and functional outcomes separately on visual analog scales (VAS). VAS was given preference over Likert scales because the former employs a 100-mm scale with a broad range of distinctive possibilities, whereas the latter uses ratings from 1 to 5 or from 1 to 10. In addition, a few pertinent questions regarding the causation and the local problems faced by the patients were asked. A written consent was obtained from all the patients. The questions and the study were approved by the local ethical committee. Facial appearance was judged by the patient’s degree of satisfaction with the lip, nose, and lower face. Patients rated their functional outcome with regard to biting, chewing, swallowing, and the comprehensibility of their speech for others. Complete dissatisfaction was marked at the left end and complete satisfaction at the right end of the 100-mm scale[1]. Patients’ well-being and health related quality of life (HRQoL) were assessed using the MOS Short-Form 36[2]. The questionnaire takes about 5 to 10 minutes to complete and comprises 36 items in different formats, spanning two to six categories. In all the cases, either a part or the whole questionnaire had to be translated in the language of the patients’ understanding. The questionnaire investigates eight health concepts: physical functioning, role limitations due to physical health problems, bodily pain, general health perceptions, vitality/fatigue, social functioning, role limitations due to emotional problems, and general mental health[3].

**Results:**

Of the total 100 patients who reported for both the visits, 48% were males while 52% were females. 68 % had a unilateral while 32% had a bilateral complete cleft lip and palate. (Figure 1)

The mean value of the patients’ outlook regarding their facial appearance before the surgery on the VAS scale was at 21mm which improved significantly to 79mm after 12- 18 months. Similarly, the functional outcome with regard to biting, chewing, swallowing, and the comprehensibility of their speech for others had a mean value of 16mm at the first visit, while at the end of 12 -18 months it had significantly improved to 72mm on the VAS scale. (Figure 2)

The main cause for clefts was considered to be god’s will by 72% of the patients.12% blames sins of previous life while 6% thought that it was due to hereditary factors or problems during
pregnancy. The rest 10% did not have any opinion regarding the matter. (Figure 3)

Figure 3. Causes of clefts

Of the 100 patients who were interviewed, 38 of them lamented that they were not allowed to attend school because of the deformity. Further 29 said that they were not allowed to draw water from the local well by the village elders. After 12-18 months it was noted that only 6% were still not allowed to attend school and draw water from the local well. (Figure 4)

Figure 4. Common social problems affecting quality of life

The health related quality of life questionnaire demonstrated higher scores in all the subsets under the mental health criteria after cleft surgeries. Vitality, social functioning and emotional role showed higher scores post surgically. (Figure 5)

Discussion:
In this study it was observed that the problems faced by the cleft patients and their parents in a developing or third world country are very different than those seen in their western counterparts. This may be attributed to the lack of knowledge and the various beliefs which are present in the rural societies of these countries. In Nigeria, some groups considered the origin of cleft deformities mostly an act of God; whereas, the others displayed a greater variety of cultural beliefs such as witchcraft, evil spirit or devil, the mother, and occasionally the child[4]. In rural Indian studies regarding causation, the vast majority (84%) ascribed the cleft to “God’s will” and 10% to sins committed in past lives. Only 2% parents acknowledged the influence of genetics.[5] In this study also, 72% considered this defect to be due to god’s will while 12% blamed sins of previous life. Only 6% believed it to be due to hereditary factors or problems due to pregnancy while the rest of the patients (10%) did not have any opinion regarding the matter. This clearly demonstrated the low level of knowledge regarding clefts and their causes. Knowledge of these issues is important for the more complete care of children in an unfamiliar cultural environment[6].

Anxiety and depression have been reported to be twice as prevalent in adults with clefts compared with normal controls[7]. Dissatisfaction with facial appearance has been found to be a predictor of depression among subjects with clefts and controls[8]. According to Kapp, girls may be more affected by the stigma of a repaired cleft because of the importance given to physical attractiveness in the society[9].
The social stigma which comes along with the cleft patient causes severe psychological trauma and lowered self esteem[10] not only to the patient but also to the family, often leading to complete isolation from the society[11]. Noar suggested that children and young adults with clefts have fewer friends than non cleft controls[3] and sometimes stay in complete isolation with their peers. Dropping out of school,[12] no aspiration for further studies, higher rate of unemployment and significantly reduced income, non marriage ability are some of the other socially relevant problems reported regularly in literature[13]. Children, adolescents and adults have reported that their self-confidence has been significantly affected by having a cleft[3]. Children with cleft also tend to have higher levels of hostility, negative selfworth, a negative outlook and greater dependence compared with the general population[14]. In this study also, the major changes seen in the HrQoL questionnaire were in the mental health subset and functional disability. The general health and other criteria were within normal limits even before the surgery was carried out vis-a-vis 12-18 months post surgically.

The two most common problems which led to increased hardships for the patients and their families were the refusal of the community to allow them admissions in schools and barring the women to draw water from the local well. In many villages, the local well acts as the only source of water and is also the main socializing point for womenfolk. Admissions to schools were not granted by the village elders due to the prevalent myths and beliefs in the society. These aspects completely shut the patients and their families from leading a normal and fruitful life. Social isolation, speech and language difficulties, specific and global learning difficulties and poor self-image were identified as problem areas in a review by Lockhart[15].

The mindset, which says that the defect is caused due to supernatural powers or is the result of the wrath of gods has to be changed through educational schemes in the remotest places of this huge country. The ability of some children with clefts to do better than others, as reported in some western literature, may be explained by the concept of resilience, which necessitates the fact that if these children are functionally and psychologically treated, only then can they expect to be at par with their contemporaries.[16] Patients with realistic expectations in regard to further treatment should be treated by specialists, whereas those with unrealistic expectations should be referred to a clinical psychologist[17]. The data from various other third world countries regarding this appalling behaviour should be assimilated and a concerted effort should be initiated. If reports of this nature are submitted to the respective governments and the charitable organizations, then only a plan can be worked out to save these children and their families. Various educational modalities such as audiovisual aids, presentations and volunteers should be utilized in the rural areas of developing countries so that cleft surgeons enhance the quality of life of the patient as well as the patients’ families.

References:

Conflict of interest: - Authors had not declared any conflict of interest.

Source of funding: - None

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Article citation: