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Social Repercussions of Labial-Alveolar-Palatal Clefts in African

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Abstract

Original Research Article

Labial-alveolar-palatal clefts (LAPC) remain a wide spread congenital malformation throughout the world, the psychological impact of its diagnosis notification whether it is antenatal or postnatal period, could lead to emotional upheaval and vulnerability in parents. The objective of this work was to describe the impact of labial-alveolar-palatal clefts on the social behaviors of parents of children suffered from this malformation in our context. This was a descriptive cross-sectional study conducted in Mali from March 2020 to February 2021 and involved mothers of children with labial-alveolar-palatal clefts who agreed to participate in the study. The sample consisted of 60 cases, The mean age of the patients was 7 years and 8 months with a standard deviation of 5.85, The male sex accounted for 68% of cases with a sex ratio of 2.15, The unilateral labial-alveolar cleft was the most met with 55% of cases. Obstetrical ultrasound made the diagnosis in two mothers, The announcement of the malformation was made with tact and respect in 52 cases, The majority of the parents (58 cases) decided to look after their child. Fourteen mothers reported a negative impact on their household activities, In 39.4 per cent of the cases, the respondents stated that they felt responsible for the occurrence of the malformation and did not wish to have a child afterwards for fear of reliving this experience. This study made possible to highlight particular experiences and parenthood during the birth of a flap-bearing child.

Keywords: Social repercussion, labial-alveolar-palatal clefts, mother, African setting.

INTRODUCTION

The labial-alveolar-palatal clefts (LAPC), formerly known under the term of "harelip" remain a congenital malformation widespread around the world [1, 2]. In popular language, this unsightly name brings to light the "dehumanization" of the concerned child. The psychological impact of the LAPC diagnosis notification whether is prenatal or postnatal, causes emotional upheaval and vulnerability in parents. They are thus plunged into a reality which they did not expect which could even lead to a family tragedy [1]. In the African environment, the LAPC is generally perceived by the population as a divine punishment, a fate or a mark of the devil, or rather as a spell from enemies. All these harmful visions of the disease engender in the parents of sick children a state of resignation, especially when it affects the child of a young unmarried woman.

The objective of this work was to describe the impact on social behaviors of parents of children suffered from of LAPC.

MATERIALS AND METHODS

This was a multicenter descriptive cross-sectional study; it took place in three referral hospitals where patients were admitted and treated for LAPC in Mali, over a twelve-month period from March 2020 to February 2021. All mothers were included in this study who having given birth to a child with LAPC; even if the patient was treated or not, consent and agreement of mothers were mandatory to take part voluntarily in. The variables studied were: concerning the child (age, sex, type of cleft, family history), concerning the mother (notion of consanguineous marriage, place of birth, announcement of the diagnosis, mother's reaction to birth, parent-child-neighborhood interactions).

The data were collected using face to face interviews and written on a survey sheet or by phone call recorded on a Dictaphone then entered and analyzed using the SPSS 22.0 software. The identity of the interviewers was preserved and the free and informed verbal consent of each respondent was obtained.

RESULTS

1- Epidemiology

The majority of patients with LAPC were aged ≤ 5 years, with a value of 66.7%. The mean age was 7 years and 8 months with a standard deviation of 5.85. The extreme ages were 6 months and 25 years. The male sex represented 68% of cases with a sex ratio of 2.15. The unilateral labial-alveolar-nasal cleft was the most common in 55% of cases. The family history of LAPC was found in 6 cases (10% of cases). Among the documented family history, 4 cases were on the paternal side and 2 cases on the maternal side. The notion of consanguinity was found in 65% of cases. Childbirth took place in a health facility in 70% of cases.

2- Social Repercussions

- **Announcement of the diagnosis:**

The obstetric ultrasound diagnosed the LAPC in 2 mothers while for 58 mothers, the diagnosis of the malformation was made at birth. The announcement was made with tact and respect and reassurance from health workers 86.7% of the time. For 13.3% of mothers, announcing the diagnosis was difficult and often in the following terms: "My mother threw the child to me, blaming me".

- **Mothers' experiences of meeting their child following the birth:**

The mothers' first contact with their babies was difficult in all cases. At the sight of the baby, the majority of mothers felt: stupor (21 cases), fear (13 cases), pity (6 cases), idea of abandonment (5 cases). The fathers' reaction to the sight of the baby was mostly pity, indifference and fear. One mother described her husband's discomfort: "My husband passed out at the sight of the baby." The majority of parents (58 cases) decided to keep the child and justified this as: "being the will of God" or "it is my destiny." Two mothers decided to claim the termination of pregnancy if the diagnosis was made before the birth and mentioned that they were not yet married.

- **Parents, child and family interactions**

The parents of 58 patients (96.7%) were in a relationship. A case of separation was observed, a mother confided: "My husband abandoned me and remarried because I was the only culprit according to him". In 46 families, the birth of a baby with LAPC had no impact on the life of a couple. Fourteen mothers, on the other hand, reported a negative impact in their household. The majority of mothers (51 cases) raised the importance of remarks from the family in broadest sense. Many mothers (52 cases) benefited from family assistance to overcome the hardship. In 39.4% of cases, the respondents claimed to have the feeling of having responsibility for the occurrence of the malformation and had wished not to have a child afterwards for fear of reliving the same experience.

DISCUSSION

1- Epidemiology

LAPCs are a widespread malformation across the world [2-6]. The mean age in the present study was 7 years and 8 months. This observation is noticed in most developing countries where the management of LAPC is very often the prerogative of humanitarian missions. Such missions arrive to support a majority of family by delivering adequate specialized care; and the consultation delay is mainly due to difficult access to care [3, 4, 5, 6]. On the other hand, in the Western series, treatment is carried out before the age of 6 months thanks to the systematic search for malformations in the fetus during prenatal surveillance, but also thanks to the easy access of the population to a specialized structure [2, 7]. The observed male predominance has also been reported in the literature [2, 5, 6]. However, some authors have observed above all a female predominance [3, 8, 9]. The family history of LAPC has also been reported by some authors [2, 6, 10].

2- Social Repercussions

Once the LAPC diagnosis was known, parents, and especially mothers, experienced varying levels of what can be termed "post-traumatic stress" and "depression" [11]. The decision of voluntary termination of pregnancy has decreased over the past 20 years due to early management of LAPC [12]. Following the announcement of malformation to parents, various reactions were recorded during this study such as "fear, indifference, dismay" and among others: "feelings of incapacity and pity". When a cleft diagnosis was made at birth, parents felt more fearful and more concerned about their child's health or the care to be provided". When a baby is born with malformation, it awkwardly affects family circle and even society in African environment. In African culture, the family designates a wider circle of members much larger than what the word means in its American-European usage. It is not uncommon for the father, hurt by his narcissism for this "deformed" child and throws the responsibility on the mother and saves his honor by invoking a fault committed by his wife [13]. A mother raised some abandonment remarks from both her family and family's in-law following the birth of her child with LAPC. It is difficult to control the behavior and unpredictable remarks of family or loved ones when a new born baby has birth defect.

In Mandingo society, the voluntary or involuntary violation of prohibition affects the *tere* of a human (the *tere* is an innate force of the personality composed on the one hand by parents force, on the other hand by ancestor force and it is affected by the violation of prohibition). In this society, the eye is the first to be affected because it is the first "witness" to this transgression [14].

The African family is united in order to be able to open up to the community, without being too dependent on it. Family solidarity is so strong that we cannot abandon and let our loved one's suffering; independently to the degree of generation of kinship may be. What affects one family member, affects the whole group. In a difficult situation, the solidarity of the African family makes possible to protect everyone, including in sickness, impotence, old age; it doesn't only offer assistance and a certain security, but also material. Social solidarity is thus only a projection of family solidarity [15]. In these series, family assistance has been widely seen in overcoming the hardship. African society may have a tendency to exclude or dismiss any "abnormal", deformed, frightening or different new born, it can often trigger in mothers, a feeling of shame; some of them even feel compelled to leave the family home, to prevent this negative feeling from spreading to the family and even beyond the group. Thus, from the conception of the baby, the mother must fix her thoughts and actions on the good and the beautiful. She should avoid all negative ideas, as well as the sight of objects, animals, or abnormal beings; when respecting these pieces of advice, her baby won't exhibit at birth any of these characteristics [16]. For Harper and Richman [17], children with visible physical disabilities (facial dysmorphia, impaired physical mobility, obesity or amputation of limbs) often experience a hostile, rejecting and ambiguous social environment. Poverty and begging are more frequent and more quickly occur in these patients than in the general population [18].

CONCLUSION

The birth of a child with LAPC is a tough spot for parents. This study made possible to highlight particular experiences and parenthood during the birth of a child with LAPC.

LAPC management requires both surgical care and psychological support to families; it could be extended to friends and relatives in order to avoid the heavy weight of the stigmatization experienced by mothers of children with this malformation.

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