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EMOTIONAL EXPERIENCES AND SOCIAL CHALLENGES OF OROFACIAL CLEFT IN RURAL SUB-SAHARAN AFRICA: A QUALITATIVE INTERPRETIVIST APPROACH

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ABSTRACT

Background: **Orofacial Cleft (OFC) is the predominant congenital facial malformation with an incidence of 1 in 600-700 for every live birth. This unexpected condition often provokes adverse emotional and social reactions from the families and the larger society. OFC optimal management require extensive parental care such as feeding coupled with multiple complex medical, surgical and dental treatment needs which; thus, imposed further strain on the mothers and family carers.**

Sadly, OFC impacts negatively on many families in rural sub-Saharan African communities signaling an urgent imperative to address this as a public health policy emergency. However, there is scant qualitative data regarding this problem in rural northwest Nigeria.

The purpose of this study was to explore the psychosocial lived experiences of family carers of children with OFC in the northwest, Nigeria.

Materials and Method: **Twenty-two participants from four collaborating tertiary specialised hospitals in northwest Nigeria were recruited into the study between 2017 and 2020. Semi-structured in-depth interviews were conducted and inductive thematic analysis of verbatim transcribed textual data was utilized.**

Results: **The participants were largely from rural farming districts; mothers constituted more than three-quarters of the participants (n=15). Three major themes emerged: emotional experiences, social challenges and the support system. The study identified covert discrimination and negative stereotypes of children with OFC were identified.**

Conclusion: **The study findings showed that mothers were emotionally and socially more impacted by OFC.**

Keywords: Qualitative study, Orofacial cleft, Prenatal diagnosis, Psychosocial, Stigma, Sub-Saharan

INTRODUCTION

Worldwide, normal facial appearance is expected and taken for granted in the birth of newborn.[1] Thus, the occurrence of any congenital facial anomaly is sensitive and often provokes myriad of serious social and emotional trauma.[2-4] Orofacial cleft (OFC) encompassing cleft lip, cleft palate and cleft lip/palate is the predominant hereditary craniofacial malformation worldwide.[5] It has a global incidence of 1 in 600-700 for every live birth with prevalence of 1 in 500 (Asian), 1/1000 (Caucasian) and 1 in 2500 (African) respectively.[6,7]

The numerous health/nutritional needs and heavy financial challenges of taken care of children with OFC coupled with multiple treatment appointments imposed enormous emotional and social distress on their carers and families.[7,8] These stressors could result in poor uptake of cleft treatment leading to delay in surgical management in poor vulnerable communities.[8,9,10]

Pre-natal diagnosis detection of OFC has been shown to preempt this adverse emotional burden by early initiation of counselling and treatment planning. Sadly, recent studies from developing countries suggest non-availability of this service with late diagnosis of these anomalies worsening the heavy psychosocial load of those caring for these children.[1-5,10] In resource challenged health systems of sub-Saharan Africa (SSA) scarce manpower, finance and facilities have been geared toward surgical correction of these abnormalities at the detriment of the enormous psychosocial burden of OFC on the mothers and their families.[1,11-15] Therefore, highlighting the intricacies of the emotional and social trauma experienced by mothers and families caring for children with OFC in this region could pave way for more holistic management, judicious use of resources, better treatment outcomes and optimal rehabilitation.

The flexible approach of qualitative method could help to comprehend the diverse day to day psychosocial experiences of persons dealing with OFC.[16,17] Unfortunately, there are scarce qualitative studies in this direction from remote rural northwest Nigeria. Therefore, the purpose of this study was to explore the psychosocial lived experiences of family carers of children with OFC in the northwest of Nigeria.

MATERIALS AND METHODS

The study was performed in the cleft clinics of four collaborating networks of tertiary hospitals with combined bed capacity of over 2000 located in extreme northwest Nigeria comprising of Sokoto, Kebbi, Zamfara and Katsina sharing boundaries with neighboring country of Niger. The area is largely rural with arid climate and agrarian including small scale farming and nomadic cattle rearing.

This was an exploratory qualitative study based on constructivist phenomenological theory that ensured authentic engagement with the research participants and a real world understanding of their lived experiences. Thus, facilitating deep exploration and gathering of rich data will help to comprehend their emotional and social needs when caring for children with OFC.[17,18]

Twenty-two carers who met the study inclusion criteria consented and were recruited into the study by purposive sampling from the participating cleft centres. They were required to be mothers or relatives providing primary care for children diagnosed with OFC. Furthermore, they must be fluent, and comfortable being interviewed in the native language of "Hausa" or English and possess~~es~~ no major psychiatric disorder that might interfere with their ability to participate in qualitative interview or adhere to the study protocol. This ensured that credible textual data were gathered and pursued to the point of saturation.[19]

All the participants were native speaker of "Hausa" and so face-to-face in-depth interview were conducted in this language by the principal researcher (TAO) in conjunction with two other researchers; IS & SJ (native Hausa speaker and proficient in English) utilizing a semi-structured interview guide developed by TAO.[20] The guiding questions apart from demographics were tailored towards the study objectives and constructed based on literature review on the subjects and previous experiences in OFC management in the region. This included the following:

1. *Have you encountered or heard about this condition before?*
2. *Can you tell us what impact this condition had on your life?*
3. *Can you tell us how people in your society reacted to this condition?*
4. *Are there any other insights you think we should know regarding your experiences with this condition?*

Flexibility was adopted which helped to adapt questions based on the responses of the interviewees; the interviews transited from structured format to a more unstructured format.[19,20] As interesting information arises, follow up open ended questions was used as arsenals to probe participants' answers in-depth as the interview progresses. Clarification on any area that is unclear was easily sought during the interview. Confidentiality and privacy were actualised by conducting the interviews in an ambient secluded consulting office during their visit to the hospital. Displaying personal sentiments that might unwittingly compromise the participants was avoided.[21,22] The interviews were audio-tape recorded with the participants' consent and ranged from 35-45 minutes. Data collection ceased following attainment of data saturation when no new themes or ideas emanated from the interviews.

Descriptive statistics were used to summarize the participants' sociodemographic data using Microsoft excel. Following verbatim transcription, translation to English, and back transcription to Hausa of the recorded data by two members of the research (SGL and UA). Data familiarization via several readings of the English translations, followed by thematic data analysis by inductive process in which relevant themes emerged from categories and patterns were performed by TAO and LU.[23] Every process was scrutinized thoroughly by the rest of the research team to confirm that the conclusions reached closely mirrored the participants' views. Differences at all stages were resolved by intense engagement and dialogue until concordance was arrived at.

Credibility, dependability and confirmability of the study were ensured by clear adherence to key objectives of qualitative research, the approved study protocol, method of data analysis, triangulation, reflexivity, attention to negative cases, fair dealing, and giving voices to wide perspectives. Member checking with the participants to see that their response was accurately captured and the findings reflect their views.[24,25] Trustworthiness was achieved by familiarity with the study setting, member checking content accuracy with the participants during the interviews; reflexivity and joint comparison of the data and results among the researchers.[17,24,25] Moreover, detailed information about the entire study and exposition of the participants' emotional journeys were made available to enable other researchers to make inferences on the transferability of the study findings to their own settings.

Ethical approval for the study was obtained from the University of Western Cape Higher Degrees Research Ethics Committee (130416-050) and Usmanu Danfodiyo University Teaching Hospital (UDUTH) Health Research and Human Ethics Committee (HREC). Involvement in the study was voluntary as verbal explanation was mandatory. A participant information sheet containing critical information regarding the study in both Hausa and English was made available to all participants before the procurement of written informed consent and study commencement.[26] Research protocols, procedures and reporting were tailored to the Consolidated Criteria for Reporting Qualitative Study (COREQ).[27]

RESULTS

The study participants consisted of 22 carers (aged ranged from 18 to 60 years) with more than half of the participants being mothers and housewives (n=16) without any previous family history of orofacial cleft (Table 1). Single interviews were fourteen with four joint interviews of both parents (Table 1).

Theme 1: Emotional experience of Orofacial Cleft

Sub-Theme 1: Pre-natal experience of Orofacial Cleft

The data of the study showed that although many of the carers had no prenatal detection or education about OFC and were experiencing OFC for the first time at the birth of their children, it may have impacted their psychosocial reactions. However, some of the participants recollected seeing individuals with OFC in their communities in retrospect not knowing its significance. Comments such as the quotes below dominated:

*I have never seen this thing before…before this time I don't know what to do about his condition (***Participant 1***)*

…one of my neighbour (woman) when I was young I saw with this kind of problem (**Participant 11**)

*…I have heard and even seen somebody with the condition in our place…my husband side (*Participant 12)

I have seen similar condition in one person…..(**Participant 16**)

Moreover, the study suggests that there is still a yawning gap to be filled not just in the public enlightenment campaign on OFC but also regarding the training of frontline healthcare providers and traditional birth attendants as some lacked the capacity to give adequate parental counselling at the time of birth of these children with OFC. Thereby, prolonging the agony of these families and placing the child at risk of not getting proper care. For instance;

*…traditional birth attendant was the first to notice…..she does not know anything about it at all…we went to a senior hospital staff …several times I can't even remember the number of times and each time he will say let him grow a bit longer….****(Participant 21)***

Sub-Theme 2: Post-natal emotional experiences of OFC

The participants volunteered varying emotional experiences following the birth of their children with OFC.

Acceptance

The data from the research suggests that many mothers were unperturbed and quite remarkably accepted the condition by taken solace in their faith despite the unwelcomed public attention. This research data demonstrated that the remarkable positive adjustment to this troubling scenario might be a reflection of the ascription of the phenomenon to the divine. As illustrated in the following:

People are coming to see her condition, and I don't hide her from them, since this is how Allah gave her to me... (Participant 3)

I was not sad when I had her I have 5 previous children that were okay... It didn't disturb me in fact I am going around with my baby like that... ***(Participant 17)***
They said look at her leg I said no problem it is God that gave me... I thank God... ***(Participant 20)***

Despair, grief and resignation

However, some openly expressed their worries and helplessness at the situation, perhaps a cry for help. For examples:
To say the truth, I felt bad… ***(*****Participant 5*****)***
I was disturbed a little bit… *(***Participant 15***)*
…before this time I don't know what to do about his condition… ***(Participant 19****)*

Anxiety, concerns and self-withdrawal

A few of the study participants expressed severe anxiety and dreaded their children being marginalise, being made laughing stock in the society or their future marriage prospects. This led to mothers being over protective of these children, keeping them at home and preventing them from attending school; thus, restricting their interaction with other children and the larger public. This could in the medium and long-term impact negatively on the mental health adjustments and socio-economic aptitudes of these children. For examples:
…people avoiding to marry her. ***(Participant 10****)*
I couldn't put her in school since people around use to laugh at her because they couldn't hear the way she is talking. This makes her cry when they imitate her... *(***Participant 17***)*
All the children are going to school I leave her because of this condition...her speech is not like the rest at times if she talks, they can't understand what she says. They would ask her what she said, and she would say can't you hear me. If at times she talks they would laugh at her... ***(Participant 20)***

Table 1: Socio-demographics characteristics of carers

Participants characteristics	N (%)
Relationship of carers to cleft patient	
Mother	12 (54.6)
Father	5 (22.7)
Extended Family	5 (22.7)
Age group of carers of cleft children	18-60years
Type of cleft of carers' children	
Cleft lip only	2 (9.1)
Cleft lip and palate	17 (68.3)
Cleft palate only	3 (13.6)
Age Groups (Years)	
<21	3 (13.6)
21-40	15 (68.2)
>40	4 (18.2)
Ethnicity	
Hausa /Fulani	20 (90.1)
Non-Hausa	2 (9.1)
Religion	
Christianity	2 (9.1)
Islam	20 (90.9)
Occupation	
House wife	16 (72.8)
Farmer	3 (13.6)
Others	3 (13.6)
State of domicile	
Sokoto	14 (63.6)
Others	8 (36.4)
Education	
Non-formal	17 (77.3)
Formal	5 (22.7)
History of cleft in the family	
Present	2 (9.1)
Absent	20 (90.9)

The above quotes illustrate the mental and emotional strain that some carers experienced at seeing their child excluded. The last quote is interesting as it shows a grandmother's determination to ensure her granddaughter's ability to marry and to seek treatment at this point. Unfortunately, she did not provide more detail.

However, some interviewees were quite clear that stigmatization was not something that they experienced or that concerned them:
Ah, the truth is there is none, I personally do not hear of it, even if there is any since I'm not always at home... *(***Participant 5***)*
As for me, since my childhood I'm the type that mingles a lot with my peers, but they never showed me any discrimination, and up to today... ***(Participant 22)***

Family separation

The study data demonstrated that there were instances of the OFC occurrence causing schism among married couple and tragically resulting in divorce with abandonment of the children involved as exemplified with this quote;
Her father divorced her mother and since then she has not come back to see her since years ago... ***(Participant 10)***

Theme 2: Social challenges of OFC

The findings of the study observed that OFC could inadvertently trigger stigma, hurtful labelling and bullying of these children within and outside the family circle as reflected in these quotes;
…even inside our house there are those that don't want to eat with her. ***(Participant 10)***
…they even went to the extent of calling him the one with "mouth cut" and he will be crying. ***(Participant 12)***
…people are trooping in some simply for gossips…some are avoiding her…she used to go out with other children only that sometimes they beat her... ***(Participant 13)***
"...They are only saying he is one of those creatures…" ***(Participant 15)***

…they said to my friend………. she has a problem in her brain…. up to the extent they nicknamed her ~~us~~ "YiYi" and also usually laugh at her.. ***(Participant 17)***

Theme 3: Support System for OFC

The study findings also revealed that most of the mothers enjoyed good relationship and obtained critical support, information and networks from their relatives, in-laws and associates. These helped to accessed surgical care, allayed negative emotions about OFC and resolved spousal conflicts. In fact, one of the participants stated that her husband was miserable but was later enlightened about the condition by other family members as reflected below;

*All our relatives (accepted) and said it is nothing... they said cases like this are seen often. …he was not happy but later when they told him it can be repaired, he then changes his mind (***Participant 5***)*

A younger brother of mine was here. He brought someone he called me on the phone because he had a discussion with a staff member here and explained to him that he has a niece with this condition. (**Participant 8)**

*We are now like brothers…..We use to go and come with him (****Participant 19****)*

*….the teacher doesn't allow it, the other children will attempt to but the teacher after realis~~z~~ing ,it won't allow it….even the teacher do understand him except for a few words that not easy, so the teacher has to bear with him…they don't even care about the problem, they will come and look for him so that they can go and eat together…(****Participant 21****)*

DISCUSSION

The study revealed non-existent of prenatal diagnosis as many of the participants were given the diagnosis of OFC long after the birth of their children. This is in concordance with earlier reports across several low-middle income countries (LMIC) but contrary to findings from developed countries of western Europe, America and Asia.[1,2,29-32] Numerous studies revealed that it is highly desirable that OFC detection, diagnosis and counselling are preferably done in the antenatal period or immediately after birth.[30,31] These studies established that positive impact on the psychosocial wellbeing of the families especially mothers such as diminution of parental apprehension, increased acceptance of the child, better mother/child bonding, facilitate early presentation for surgical correction and compliance with long-term treatment plan.[1,30,31,32]

The present study showed certain negative social and emotional reactions experienced by mothers and families of children with OFC which might make coping with the malformation more stressful and challenging. This mirrors many reports globally that demonstrated wide spectrum of emotions by mothers of children born with OFC.[1,2,32-37] The dominant emotions displayed have been anxiety and fear of discrimination that the OFC child might bring embarrassment and scorn from neighbours, acquittances and the larger society.[1,2,13,15,34,35,37] In fact, many of the mothers of females with OFC in this study were afraid of the future prospect of their girls getting married as marriage is highly revered in the African traditional context as shown by previous studies.[2,13,15,36,37] Others, kept these children away from attending conventional or Islamic schools with the hope of checkmating negative representations, bullying and stigmatization of these children. Some previous findings revealed that this screening by mothers of their children from the public glare though considered to be protective could inevitably delay~~ed~~ the psychological adjustment, potentiate poor social integration and defective coping mechanism.[32,37]

The current study observed that the participants had good relationship and received appreciable support from their extended families which is in tandem with a published report from Senegal and in conflict with others from the region.[3,36] Earlier studies showed that support from family members and friends is crucial in boosting the coping mechanism, better adjustment, combat outside discrimination, lower psychological stress, improve quality of life and mitigate social isolation of the mothers and their children.[36,37]

In summary, the results of this study disclosed that mothers were more negatively impacted emotionally and socially by OFC as facilities such as 3D ultrasonography for early prenatal detection of OFC were lacking.

The study recommend the incorporation of necessary psychosocial supports for cares especially mothers and their families so as to empower them to adequately cope and adjust to the anomaly. In addition, provision of facilities; optimal investments in prenatal detection and counselling; regular training of traditional birth assistants and frontline health workers on diagnosis and treatment of OFC should be instituted.

Study Limitations

The participants were not selected through a probability random sampling technique and were largely from one region of the country. Thus, generalisability to the entire part of Nigeria might not be feasible. Moreover, this was hospital-based study as carers without any engagement with the hospitals' cleft programme were not included in the study population since it was beyond the study scope. They were recruited exclusively from cleft centres in remote north-western Nigeria which might not fully reflect the views of those carers who were not intimate with the hospitals' cleft services or those using other cleft centres in the country. The probability exists that there are many carers of cleft patients outside the study population who do not seek services for one reason or another. Hence, the study only allows conclusions to be drawn from this study population.

The staff of the cleft program helped in the recruitment of the participants and their influence on the participants' study performance might not be easily accounted for.

Assumptions were made that the participants would respond truthfully and that the interview guide was valid and reliable in eliciting correct answers to the research questions.

List of abbreviations
OFC-Orofacial clefts
SSA-Sub-Saharan Africa
COREQ-Consolidated Criteria for rReporting Qualitative Study

Declarations
Clinical trial number
Not applicable as this was a qualitative study
Ethics declarations

Ethics approval
Ethical Approval for the study was obtained from the University of Western Cape higher degrees Research Ethics Committee (130416-050) and Usmanu Danfodiyo University Teaching Hospital (UDUTH) Health Research and Human Ethics Committee (HREC). The research was conducted based on the guidelines and protocol approved by these bodies in accordance with 1964 Helsinki declaration and its amendments.

Consent to participate in the study
Involvement in the study was voluntary as a participant information sheet containing critical information regarding the study in both Hausa and English was made available to all participants before the procurement of signed written informed consent and study commencement. All the study activities, benefits/ risks of voluntary participation, and withdrawal from the study were clearly explained to the family carers/ guardians in English and/or Hausa. And ample opportunities for questions about the study were given with satisfactory clarifications given to the potential participants.

Interviews were strictly confidential and conducted in seclusion. The opportunity for the participants to tell their story and be heard hopefully brought psychological relief and the researchers sought to maximise this potential benefit by listening attentively. Additionally, sensitivity to the emotions of the interviewees was upheld. Alluded to their rights to no wrong or right answers and the freedom to respond only to questions with which they were comfortable. The recordings and all the data were adequately secured under lock and key limiting access only to the research team members. To protect participants' identitiesy, specific details about them were deliberately erased such as names of persons and places mentioned in the course of the interviews. Research protocols, procedures and reporting were tailored to the consolidated criteria for reporting qualitative study (COREQ).

Consent for publication
Not applicable

Availability of data and materials
The datasets used and/or analysed during the current study cannot publicly be made available as required consent to publish data were not given. However, the corresponding author on reasonable request can make deidentified data available.

Competing interest
The authors declare that they have no competing interests.

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Author contributions
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Footnotes

The data of this study was partly used for dissertation for master in public health (MPH), university of western cape (UWC), South Africa and parts were presented at the 107th FDI World Dental Congress, September 5–7, 2019, San Francisco, California, USA; 14th Annual international cleft congress (Cleft 2022) July 11–15, 2022, in EICC, Scotland, United Kingdom and 98th International Association of Dental Research (IADR) Annual meeting, March 18-21, 2020, Washington, DC USA.

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