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CAREGIVERS' EXPERIENCES OF CLEFT LIP AND PALATE SURGICAL CARE IN RURAL NORTHWEST NIGERIA: A QUALITATIVE STUDY OF EXPECTATIONS, SATISFACTION, AND PERCEIVED OUTCOMES

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ABSTRACT

Background: **Cleft lip and palate (CLP) is among the most prevalent congenital anomalies worldwide, yet access to surgical care remains severely limited in sub-Saharan Africa. Caregivers play a pivotal role in treatment-seeking, yet their perspectives on service quality are underexplored in rural Nigerian settings.**

Objective: **This study explored caregivers' expectations, experiences, satisfaction, and perceptions of CLP surgical care in rural northwest Nigeria.**

Methods: **A qualitative study using semi-structured in-depth interviews was conducted with 22 caregivers of CLP patients at four cleft treatment centres in northwest Nigeria (Jan 2017-Dec 2020). Purposive sampling was employed to ensure diversity of experiences across treatment stages. Interviews were conducted in Hausa, transcribed verbatim, translated to English with back-translation verification, and analysed using inductive thematic analysis. COREQ guidelines guided all aspects of study design, conduct, and reporting.**

Results: **Participants (aged 18-60 years) were predominantly mothers (12/22, 54.5%) and housewives (16/22, 72.7%) with non-formal education (17/22, 77.3%). Three major themes emerged: (1) treatment expectations: caregivers hoped for improved appearance, speech, and uncomplicated surgery; (2) positive experiences: widespread appreciation of staff professionalism, empathy, and free treatment; and (3) negative experiences: prolonged waiting times, poor communication about timelines, and concerns about sanitation and ward congestion. Most participants expressed reluctance to criticize services, reflecting cultural norms of gratitude.**

Conclusion: **While caregivers reported high satisfaction with surgical outcomes and staff professionalism, systemic gaps in communication, waiting times, and hospital infrastructure require urgent attention. Patient-centred improvements including clearer communication, expanded surgical capacity, and enhanced hospital infrastructure could enhance service sustainability and accessibility in underserved communities.**

Keywords: Cleft lip and palate; Ccaregivers; Patient satisfaction; Qualitative research; Sub-Saharan Africa; Health services research

INTRODUCTION

Cleft lip and palate (CLP) is among the most prevalent congenital craniofacial anomalies worldwide, with an estimated global incidence of approximately 1 in every 600–700 live births.[1,2] This condition disrupts the normal development of the upper lip and palate during embryogenesis, resulting in functional challenges including feeding difficulties, speech impairment, and hearing problems, alongside psychosocial

consequences such as social stigma and discrimination.[3] Early surgical intervention is considered the cornerstone of comprehensive management and plays a crucial role in improving both functional outcomes and quality of life for affected individuals.[3,4]

Despite significant advances in cleft care globally, access to timely surgical treatment remains a major challenge in many low- and middle-income countries, particularly in sub-Saharan Africa.[3,5] Nigeria, as the most populous country in Africa with over 200 million people, continues to bear a substantial burden of untreated cleft deformities due to limited healthcare infrastructure, financial constraints, cultural beliefs, and delayed presentation for treatment.[1,3,5] Previous studies have documented that many Nigerian patients present for surgical repair well beyond childhood sometimes in adulthood which complicates clinical management and adversely affects long-term functional and aesthetic outcomes.[3,4] Caregivers particularly parents and extended family members play a critical role in facilitating and sustaining treatment for children with CLP.[3-5] Their perceptions, expectations, and experiences with healthcare services can significantly influence health-seeking behaviour, adherence to treatment protocols, and long-term follow-up.[6-9] Positive interactions between caregivers and healthcare providers including effective communication, empathy, and culturally sensitive care have been shown to enhance trust in the healthcare system and encourage continued service utilization.[6,9] Conversely, negative experiences can deter caregivers from seeking timely treatment or completing the full course of multidisciplinary care.

In rural communities where healthcare resources are often scarce, caregiver experiences assume even greater importance in shaping community perceptions of medical services.[5,6,10,11] Word-of-mouth communication among families can strongly influence whether other caregivers seek treatment for children with similar conditions.[5,6,12] Consequently, understanding caregivers' perspectives is essential for improving the quality, accessibility, and sustainability of cleft surgical programmes in underserved regions. This is particularly relevant in northwest Nigeria, where vast rural populations face significant geographical and economic barriers to accessing specialized surgical care.

However, most studies on cleft care in Nigeria and other parts of sub-Saharan Africa have focused primarily on clinical outcomes and surgical techniques, with limited attention given to the experiences and perspectives of caregivers who utilize these services.[1,3,4,12] Quantitative satisfaction surveys, while useful, may fail to capture the depth and nuance of caregivers lived experiences.[13,14] Qualitative research approaches offer an opportunity to explore these lived experiences in greater depth and to identify barriers and facilitators to accessing cleft care that may not emerge from structured questionnaires.[13,14]

Therefore, this study aimed to qualitatively explore caregivers' expectations, experiences, satisfaction, and perceptions of cleft lip and palate surgical care in rural northwest Nigeria. By examining these perspectives, the study seeks to provide actionable insights that may contribute to improving the quality of cleft care and strengthening healthcare delivery in resource-limited settings.

Conceptual framework

This study was guided by Donabedian's healthcare quality evaluation model[15], which conceptualizes quality as the interplay of three components: structure, process, and outcomes. This framework was selected because it allows systematic examination of how healthcare delivery conditions, provider-patient interactions, and service outcomes interact to influence caregiver engagement with CLP treatment in resource-limited settings. Structural factors including hospital infrastructure, staff availability, service accessibility, and cost of care influence the conditions under which care is delivered. Process factors such as interpersonal interactions, communication quality, waiting times, and clinical procedures shape caregivers' experiences and perceptions during their engagement with services. Outcome factors such as surgical results, satisfaction, and functional improvement determine whether caregivers perceive the treatment as successful and whether they would recommend services to others or return for future care.

In the context of cleft surgical services in rural northwest Nigeria, the framework helps to explain how structural constraints (e.g., limited operating theatre capacity, staff shortages) may affect process factors (e.g., waiting times, communication) and, ultimately, outcomes (e.g., satisfaction, likelihood of referral).

The framework as illustrated in Figure 1 and guided the development of the interview guide, analysis, and interpretation of findings.

MATERIALS AND METHODS:

Study design

This was a qualitative study employing semi-structured in-depth interviews to rigorously explore the lived experiences and perspectives of caregivers of patients with CLP who presented for primary or secondary cleft surgeries at UDUTH and three other cleft treatment centres in the northwestern region from November 2017 to February 2020. The study design

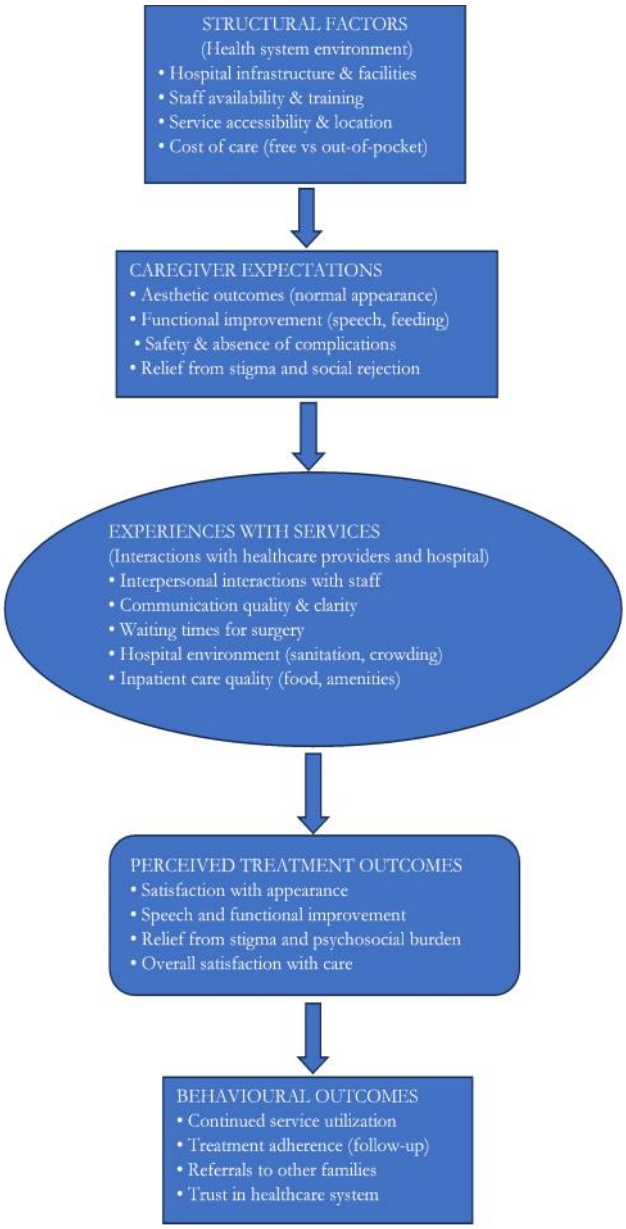


Figure 1: Conceptual framework for assessing cleft lip and palate surgical services in rural northwest Nigeria, adapted from Donabedian's healthcare quality model.[15]

was chosen to capture the richness and nuance of participants' experiences, which may not be adequately reflected in quantitative surveys [16]. Research protocols, procedures, and reporting were tailored to the Consolidated Criteria for Reporting Qualitative Research (COREQ)[17] (Supplementary file 1).

Study setting and population

The study was conducted across a vast rural population exceeding 6 million people in Sokoto and neighbouring states including Kebbi, Zamfara, Niger, Katsina, and the Niger Republic; covering a land mass of more than 25,973 square kilometres. Most inhabitants are predominantly subsistence farmers and cattle herders, as the land is arid with rainfall limited to a few months annually.

Four cleft treatment centres served as study sites:

1. Usmanu Danfodiyo University Teaching Hospital, Sokoto a tertiary referral centre with approximately 1000 beds, performing an estimated 80-100 cleft surgeries annually
2. Noma Children Hospital, Sokoto; a specialist paediatric facility with 200 beds, performing 40-60 cleft surgeries annually
3. Sir Yahyah Memorial Hospital, Birnin-Kebbi a secondary referral centre in Kebbi State with 300 beds, performing 20-30 cleft surgeries annually
4. Federal Medical Centre, Gusau, Zamfara State a tertiary centre with 500 beds serving Zamfara and surrounding areas, performing 20-30 cleft surgeries annually

All centres offer free surgical services through a combination of government funding and non-governmental organization support (primarily Smile Train). Multidisciplinary teams at each centre include maxillofacial surgeons, paediatric anaesthetists, ENT specialists, speech therapists, and nursing staff.

Participants and sampling

Potential participants include parents or family caregivers of patients with orofacial clefts were approached when they presented to any of the cleft multidisciplinary clinics. Caregivers were eligible if they were: (1) related to a patient diagnosed with CLP who was amenable for surgical correction; (2) the primary caregiver of a patient with CLP; (3) able to communicate in Hausa or English; and (4) willing to provide written informed consent; (5) permanent Nigerian residents from the time of birth of the patient with CLP. There were no restrictions based on patients' treatment stage (pre-surgery, post-surgery).

The study employed purposive sampling to recruit participants with diverse experiences across treatment stages, ages, and clinical presentations, ensuring rich and varied data.[18] Recruitment continued until thematic saturation was achieved defined as the point at which three consecutive interviews yielded no new codes or themes.[19] This approach aligns with established recommendations for qualitative sample sizes, which typically range from 12 to 30 interviews for in-depth exploration of a phenomenon.[19,20]

Data collection

A semi-structured interview guide was developed based on the conceptual framework, experts' consultations and existing literature on caregiver experiences in cleft care.[6,9,12] The guide covered five domains: (1) sociodemographic characteristics; (2) treatment expectations; (3) experiences with surgical services; (4) perceived treatment outcomes; and (5) suggestions for service improvement. The guide was revised for clarity, cultural appropriateness and flow (Appendix 1).

Semi-structured face-to-face in-depth interviews were conducted by the principal investigator (TAO), a trained clinician with over 15 years of experience in cleft surgery and qualitative research, assisted by two native Hausa-speaking research assistants trained in qualitative interviewing techniques (IS and L-JS).[21] Interviews were conducted during participants' hospital visits or patients' admission in private consultation or waiting rooms based on the participants' availability. This ensured confidentiality, privacy and minimize external interruptions. Most participants were interviewed alone while some preferred being interviewed as a couple or family unit. The joint interview helped participants' recollection and corroboration of crucial details.

Interviews began with collection of baseline sociodemographic data, followed by open-ended questions exploring experiences with surgical cleft services. The interviews transitioned from a structured to a more unstructured format as the interview progressed, allowing participants to freely share their narratives. Interviews lasted 35 to 45 minutes, with clarification sought on unclear areas immediately during the interview.

All interviews were digitally audio-recorded. Recordings were transcribed verbatim in Hausa by trained transcribers, then translated into English by two bilingual co-researchers (SGL and AU). Back-translation was performed by an independent bilingual researcher to ensure accuracy of meaning. Transcripts were de-identified by removing all names and specific location details. The complete de-identified dataset was securely stored on password-protected computers accessible only to the research team. Data collection ceased following attainment of thematic saturation, when no new themes or ideas emerged from three consecutive interviews.[19,20,21]

Data analysis

Data were analysed manually using inductive thematic analysis following the six-phase framework proposed by Braun and Clarke[22]:

1. Familiarization: Multiple readings of transcripts to gain immersion in the data
2. Initial coding: Systematic coding of relevant segments using descriptive codes
3. Theme identification: Grouping codes into potential themes
4. Theme review: Refining themes to ensure coherence and distinctiveness
5. Theme definition: Defining and naming themes with clear descriptions
6. Report writing: Selecting compelling quotes and weaving them into the narrative

Descriptive statistics were used to summarize participants' sociodemographic and clinical data using Microsoft Excel. Coding was performed manually, with regular team discussions to resolve discrepancies. Codes and themes were organized in a hierarchical structure, with major themes and sub-themes clearly delineated.

Rigour

Credibility was established by the use of same moderators, homogenizing the interview process,

repeated clarifications during the interview sessions, and triangulation of data collection and analysis.[23] Trustworthiness and dependability of this study were ensured by generating a proper audit trail with documentation of the study protocol and the preservation of the audio recordings of all the interviews, transcripts, and translations.[24] Dependability was established by comprehensive accounts of the study setting, unambiguous expositions of the research processes, detailed illustrations of the data analysis, findings and discussion, and broad understanding and insights of the participants' perspectives and experiences of cleft surgical services were made available to other researchers.[23,24] This is hoped would enable other researchers in comparable settings to make definite judgement on the transferability of the study findings.[24]

Ethical considerations

Ethical approval for the study was obtained from the University of the Western Cape Higher Degrees Research Ethics Committee (130416-050) and the Usmanu Danfodiyo University Teaching Hospital Health Research and Human Ethics Committee (HREC). The research was conducted in accordance with the guidelines and protocols approved by these bodies, consistent with the 1964 Helsinki Declaration and its subsequent amendments.

Informed consent

Written informed consent was obtained from all participants prior to commencing interviews. Participant information sheets containing critical information regarding the study in both Hausa and English were made available (Appendix 2). All study activities, benefits and risks of voluntary participation, and withdrawal procedures were clearly explained. Ample opportunity for questions was provided, with satisfactory clarifications given.

Interviews were strictly confidential and conducted in seclusion. Participants were informed of their rights with no wrong or right answers and freedom to respond only to comfortable questions. Recordings and all data were secured under lock and key, with access limited to research team members. To protect participants' identity, specific details (names and places mentioned) were deliberately erased. No harm or injury to participants was recorded.

RESULTS

Twenty-two caregivers participated in the study (age range: 18–60 years). The majority were mothers (12/22, 54.5%) and housewives (16/22, 72.7%), with non-formal education (17/22, 77.3%). Most participants were from rural districts (18/22, 81.8%) and of Hausa ethnicity (20/22, 90.9%). Two families had a history of cleft (2/22, 9.1%). Participants' sociodemographic characteristics are summarized in Table 1, and clinical biodata of caregivers and patients are presented in Table 2.

Table 1: Socio-demographics characteristics of participants

Participants' relationship to patient	N
Mother	12
Father	5
Extended family members	5
Age range of caregivers	18-60years
Age Groups (Years)	
<21	3
21-30	6
31-40	9
>40	4
Tribe	
Hausa	20
Non-Hausa	2
Religion	
Christianity	2
Islam	20
Occupation	
House wife	16
Government employed	2
Self-employed	4
State of domicile	
Sokoto	14
Kebbi	5
Katsina	1
Outside states	2
Level of education	
Non-formal	17
Formal	5
History of cleft in the family	
Present	2
Absent	20
Type of interviews	
Single	14
Joint	4
Timing of interview	
Before Surgery	15
After Surgery	7

Theme 1: Treatment expectations

Caregivers articulated multiple expectations regarding the outcomes of cleft surgery, reflecting their strong desires that surgery would restore their children to a state of normality and alleviate the burden of living with a visible facial difference.

Sub-theme 1.1: Aesthetic Expectations

The most frequently expressed expectation was improvement in facial appearance. Many caregivers hoped that surgery would make their children look like other children, thereby reducing the visible

Table 2: Caregivers' and patients' clinical cCharacteristics

Participant ID	Caregiver	Patient Age/Sex	Type of Cleft	Residence
P01	Father, 29y	11y/M	Unilateral left incomplete CL	Rural
P02	Mother, 22y	1y1m/F	Unilateral right complete CL	Rural
P03	Mother, 38y	18y/F	Unilateral right complete CL	Rural
P04	Step-aunt, 25y	5d/F	Syndromic unilateral right complete CLP	Rural
P05	Mother, 29y	5m/F	Bilateral CL	Urban
P06	Father, 35y	8m/M	Unilateral right complete CL	Rural
P07	Mother, 29y	8m/M	Unilateral right complete CL	Rural
P08	Father, 35y	5y/F	Bilateral complete CL	Rural
P09	Grandmother, 53y	5y/F	Bilateral complete CL	Rural
P10	Grandmother, 40y	13y/F	Unilateral right incomplete CL	Rural
P11	Father, 41y	3y/M; 4m	Unilateral right incomplete CL; Bilateral incomplete CL	Rural
P12	Mother, 20y	3y/M; 4m	Unilateral right incomplete CL; Bilateral incomplete CL	Rural
P13	Grandmother, 60y	4y/F	Bilateral complete CL	Rural
P14	Uncle, 29y	1y5m/M	Unilateral CL	Urban
P15	Mother, 20y	1y5m/M	Unilateral CL	Rural
P16	Mother, 35y	2y2m/M	Unilateral right complete CL	Rural
P17	Mother, 40y	6y/F	Isolated cleft palate	Rural
P18	Uncle, 55y	50y/M	Isolated cleft palate	Rural
P19	Mother, 18y	2y/M	Unilateral left incomplete CL	Rural
P20	Mother, 35y	4y/F	Unilateral CLP	Urban
P21	Mother, 30y	1y/M	Unilateral left incomplete CP	Urban
P21	Self, 50y	50y/M	Left complete CL	Rural

CL: Cleft Lip; CLP: Cleft Lip and Palate; y: years; m: months; d: days, P-Participant, M-Male, F-Female, CL-Cleft lip, CLP-Cleft lip and palate

difference that attracted unwanted attention and social stigma.

"…I wish this place can be closed (repaired) *to look like any other person...."*

(P01, 29-year-old farmer from rural district, father of an 11-year-old boy with a cleft lip)

" *I have been hearing that some children after they have repaired them you will not even know they had it before…."*

(P02, 22-year-old housewife, mother of a 1-year-old girl with cleft lip)

Sub-theme 1.2: Functional Expectations

Speech improvement was a prominent expectation, particularly among caregivers of older children or those with cleft palate involvement. Caregivers expressed hope that surgery would resolve feeding difficulties in infants and enable clear speech in older children, facilitating social integration and educational attainment.

".....I would be happy if her speech is okay."

(P05, 35-year-old housewife, mother of a 4-year-old girl with bilateral cleft lip)

"….she had operation she can go to school and mix with others without any trouble."

(P08, 35-year-old farmer from rural district, father of a 5-year-old girl with a bilateral cleft lip)

Sub-theme 1.3: Successful and Safe Surgery Expectations

The desire for successful surgery with concerns about surgical safety particularly regarding general anaesthesia were evident in participants' narratives. Many caregivers expressed anxieties about the potential risks of surgery, reflecting widespread community fears that patients might not survive the procedure.

"*……by doing this operation…..without any complication"*

(P18, 55-year-old farmer, uncle of a 50-year-old man with cleft lip)

"*…They will only be congratulating us for a successful surgery.*

(P10, 40-year-old housewife from rural district, grandmother of a 13-year-old girl with a cleft lip)

Theme 2: Positive experiences with surgical services

Caregivers reported overwhelmingly positive experiences with healthcare providers, characterized by warmth, empathy, professionalism, and the provision of free treatment.

Sub-theme 2.1: Appreciation of Staff Professionalism and Hospitality

Caregivers expressed gratitude for how they were warmly received at the hospital, the friendliness and empathy displayed by staff particularly towards their children and the unhurried, thorough medical examinations provided.

"In fact, they are all trying their best, especially the first day that I came when the doctors collected her from me and checked her properly, I was impressed with that."
(P05, 29-year-old housewife, mother of a 5-month-old girl with bilateral cleft lip)
"...no rejection. Everybody is welcoming us... no harassment..."
(P06, 35-year-old mechanic, father of an 8-month-old boy with cleft lip)

Sub-theme 2.2: Appreciation of Free Treatment
The provision of free surgical services, medications, inpatient care, and dressings was highly valued and frequently mentioned as a source of relief for families who would otherwise be unable to afford treatment.
"... in terms of providing free medications and everything is free..."
(P02, 22-year-old housewife, mother of a 1-year-old girl with cleft lip)
"If we had to pay for this, we would never have been able to afford it...."
(P13, 60-year-old grandmother of a 4-year-old girl with bilateral cleft lip)

Sub-theme 2.3: Satisfaction with Surgical Outcomes
Caregivers expressed profound satisfaction with surgical results, particularly regarding improvements in facial appearance and speech. Many described feelings of relief, joy, and gratitude.
"We are happy with the surgery."
(P10, 40-year-old housewife, grandmother of a 13-year-old girl with cleft lip)
"Since I have seen that mine was operated....and I am pleased..."
(P19, 18-year-old housewife, mother of a 2-year-old boy with cleft lip)

Sub-theme 2.4: Reluctance to Criticize Despite Challenges
Despite experiencing difficulties, many caregivers were reluctant to voice negative judgments about the services received, often expressing gratitude and emphasizing positive aspects.
"People should be glad about what is being done for them in this hospital."
(P03, 38-year-old housewife, mother of an 18-year-old girl with cleft lip)
"…*there were no*[t] *any difficulties*…"
(P08, 35-year-old farmer from rural district, father of a 5-year-old girl with bilateral cleft lip)
This reluctance appeared to stem from cultural norms emphasizing respect for healthcare providers and gratitude for services provided free of charge.

Theme 3: Negative experiences and challenges
Despite overall positive experiences, caregivers identified several challenges that affected their hospital experience.
Sub-theme 3.1: Ambiguous Surgery Timelines and Communication Gaps
Caregivers expressed frustration about prolonged waiting times for surgery, lack of clear information about treatment timelines, and poor coordination between appointments. Complaints about uncertainty when subsequent procedures (e.g., palate repair) would be performed were rife.
"...make the timing for surgery very short."
(P14, 29-year-old community health worker from a rural district, uncle to a 1-year 5-month-old boy with cleft lip)

"….this waiting is long..".
(P17, 40-year-old housewife from rural district, mother of a 6-year-old cleft-palate girl)
"... For us, the only way you can help us is by doing this operation…discharge us when due so that we can go and continue our work.
(P21, 55-year-old farmer from rural district, uncle of a 50-year-old man with a cleft lip*)*

Sub-theme 3.2: Suboptimal Inpatient Food and Ward Congestion
Dissatisfaction with the quality of food provided to patients and caregivers, as well as overcrowding in wards, were frequently mentioned concerns.
"Truthfully...they are not eating the food; it does not have taste..."
(P05, 35-year-old housewife from urban district, mother of a 4-year-old girl with bilateral CLP)
"Visiting should be reviewed so that we can decongest the ward."
(P14, 29-year-old community health worker, uncle of a 1-year-5-month-old boy with cleft lip)

Sub-theme 3.3: Poor Sanitation and Hygiene
Concerns about hospital hygiene particularly regarding toilets and general ward cleanliness were raised by several caregivers.
"Antiseptic should be used in cleaning the ward... awareness creation... for example... spitting of saliva or coughing on the ground... use their leg to rub it on the ground... visiting should be reviewed... decongest ward."
(P14, 20-year-old community health worker, uncle of a 1-year-5-month-old boy with cleft lip)
"Even the toilet like me I have a small baby I don't use to go there since they stopped washing the place. That place is very dirty. If you enter only the smell alone..."

(P05, 35-year-old housewife from urban district, mother of a 4-year-old girl with bilateral CLP)

DISCUSSION

Majority of the participants were mothers and employed in the home in this study which possibly reflects the gendered structure of the burden of caregiving responsibilities in this Nigerian population context. Thus, they might be disproportionately burden and affected with loss of economic opportunities and social interactions during the care of their wards in the hospitals. The present study suggests some form of financial compensations in terms of stipends or family support.

The strong expectations for improved appearance and speech among caregivers align with findings from similar studies in low- and middle-income countries.[25-27] These expectations reflect the significant psychosocial burden associated with visible facial differences in communities where stigma and social rejection are common.[28,29] Caregivers' hopes for normalcy that their children would "look like other children" underscore the profound impact of cleft deformities on family and community dynamics.

The expectation of surgical safety is noteworthy, as it reflects widespread community anxieties about surgery and general anaesthesia. Previous studies in Nigeria have documented similar fears, often leading to delayed presentation or refusal of surgery.[3,24,25] The fact that these caregivers chose to proceed despite their fears suggests that trust in the surgical team, fostered through positive interactions and clear communication, may have mitigated these anxieties. This highlights the importance of pre-operative counselling in addressing fears and building trust.[6,9]

The overwhelming appreciation for staff professionalism, empathy, and free treatment is consistent with studies from other resource-limited settings.[6,9,12,30] Positive interpersonal interactions characterized by warmth, respect, and unhurried care were clearly valued by caregivers and appear to have been instrumental in building trust in the healthcare system. This is particularly significant in rural communities where scepticism toward medical interventions may be prevalent due to cultural beliefs, historical marginalization, or previous negative experiences.[31,32]

The provision of free treatment emerged as a critical enabler of access. In many Nigerian public hospitals, patients are required to bear substantial out-of-pocket expenses for surgical care, which can act as a major barrier, particularly for low-income families.[3,5,24,25] The availability of free cleft services through NGO partnerships has likely expanded access and contributed to the positive experiences reported. These finding echoes broader literature on the importance of financial protection in improving healthcare utilization in low-resource settings.[33,34]

The high satisfaction with surgical outcomes "my tears have been wiped away" indicates that clinical results meet or exceed caregivers' expectations. Positive surgical outcomes can significantly reduce anxiety, reinforce confidence in the healthcare system, and encourage future treatment-seeking and referrals.[6,9,12,28] In a context where word-of-mouth is a primary channel for health information, satisfied caregivers are likely to become advocates for cleft services, potentially improving community awareness and early presentation.

A notable finding was caregivers' reluctance to express strong criticism despite encountering challenges. This phenomenon has been observed in other studies in resource-limited settings[12,25] and may reflect cultural norms emphasizing gratitude and respect toward authority figures, particularly when services are provided free of charge. Caregivers may perceive negative feedback as inappropriate, ungrateful, or even risky potentially jeopardizing future access to services.[35] This reluctance has important implications for service evaluation and quality improvement. If caregivers are unwilling to voice concerns, healthcare providers may remain unaware of service gaps that affect patient experience. This highlights the need for anonymous feedback mechanisms and culturally sensitive approaches to gathering patient perspectives that minimize perceived risk and power imbalance.[36,37]

The identified challenges prolonged waiting times, poor communication, overcrowding, and sanitation issues reflect broader structural deficits in Nigeria's healthcare system. In Donabedian's framework, these are structural factors that directly affect process quality and, ultimately, outcomes.[15] Waiting times and communication gaps were among the most significant concerns. Prolonged delays of estimated several months reported in the present research are consistent with findings from other Nigerian studies[3,4,24,25] and reflect limited surgical capacity, operating theatre availability, and anaesthesia staffing constraints.[38] Effective communication about timelines is essential for managing caregiver expectations and reducing anxiety[39]; the current findings suggest this is a key area for improvement.

Hospital infrastructure and sanitation were major concerns observed in this current study highlighting the broader challenges facing healthcare institutions in

resource-constrained settings. Overcrowding and poor sanitation not only affect comfort but also pose infection risks and may deter future utilization.[40-42] Addressing these issues requires investment in hospital infrastructure, infection control protocols, and ward management systems.

The findings of this study have several implications for cleft surgical programmes in rural Nigeria and similar settings:

1. Strengthen Communication Systems: Clear, regular communication about treatment timelines should be prioritized. This includes providing caregivers with realistic expectations about waiting times, explaining delays when they occur, and coordinating appointments to minimize unnecessary travel. Simple interventions such as appointment tracking systems, patient information leaflets, and designated staff for caregiver communication could significantly improve the experience.
2. Expand Surgical Capacity: To reduce waiting times, surgical capacity must be expanded. This may include: increasing operating theatre availability, training additional surgeons and anaesthetists, establishing more cleft centres in underserved regions, and optimizing scheduling to maximize efficiency. Task-shifting and collaboration with international partners may also be considered.
3. Improve Hospital Infrastructure and Environment: Investment in hospital infrastructure including ward decongestion, sanitation, and food services is essential. Simple interventions, such as regulating visiting hours, improving cleaning protocols, and enhancing meal quality, could significantly improve caregiver comfort and satisfaction.
4. Incorporate Caregiver Feedback Mechanisms: Patient-centred care requires active engagement with caregiver perspectives. Anonymous feedback mechanisms such as suggestion boxes, exit interviews, and post-discharge surveys could help identify service gaps without placing caregivers in a position of perceived risk or ingratitude.[36,37]
5. Community Engagement and Health Promotion: Community awareness programmes should address misconceptions about cleft aetiology, promote early presentation, and demystify surgery and anaesthesia. Satisfied caregivers can serve as powerful advocates; involving them in health promotion activities may enhance community trust and referral networks.

This study has several strengths. The use of qualitative methods allowed for in-depth exploration of caregivers lived experiences, capturing nuances that quantitative surveys might miss. The multi-site design across four centres in three states enhances the transferability of findings. Rigorous attention to COREQ guidelines, member checking, back-translation, and team-based analysis strengthens the credibility and trustworthiness of the data. The inclusion of both positive and negative experiences ensures a balanced perspective.

Limitations

Several limitations should be acknowledged. First, participants were selected from a single region of Nigeria, which may not reflect the full diversity of experiences across the country or sub-Saharan Africa. Second, caregivers outside the hospitals' cleft programmes were not included, potentially excluding those who may have had more negative experiences or faced insurmountable barriers to access. Third, staff members of the cleft programme facilitated recruitment, which may have influenced participants' willingness to share negative experiences (though confidentiality was emphasized). Fourth, the principal investigator's clinical background may have influenced interpretation, though this was mitigated through team-based analysis, peer debriefing, and member checking. Finally, the study did not include longitudinal follow-up to assess how satisfaction and experiences evolve over time.

Future research should address the limitations of this study by: (1) conducting multi-regional studies across Nigeria to explore regional variations; (2) including caregivers who did not access services to understand barriers to care; (3) using longitudinal designs to track caregiver satisfaction over the treatment trajectory; (4) incorporating quantitative measures to complement qualitative findings; and (5) exploring the perspectives of healthcare providers to understand their challenges and enablers in delivering cleft services.

CONCLUSION

This study provides important insights into caregivers' experiences with cleft lip and palate surgical services in rural northwest Nigeria. This study findings revealed a nuanced picture while caregivers reported high satisfaction with surgical outcomes and strong appreciation for staff professionalism and free treatment, significant challenges persist in communication, waiting times, and hospital infrastructure. These positive findings largely reflect strong process quality particularly interpersonal interactions while the challenges highlight structural deficits requiring investment and system strengthening. Addressing these gaps will be essential for improving the quality and sustainability of cleft surgical services in rural settings.

Declarations
Clinical Trial Number
Not applicable (qualitative study).

Ethics approval
Ethical approval for the study was obtained from the University of the Western Cape Higher Degrees Research Ethics Committee (Approval No: 130416-050) and Usmanu Danfodiyo University Teaching Hospital Health Research and Human Ethics Committee (HREC). The research was conducted in accordance with the guidelines and protocols approved by these bodies, consistent with the 1964 Helsinki Declaration and its subsequent amendments.

Consent to participate
Involvement in the study was voluntary. Participant information sheets containing critical information regarding the study in both Hausa and English were made available to all participants before procurement of signed written informed consent. All study activities, benefits and risks of voluntary participation, and withdrawal from the study were clearly explained to family caregivers/guardians in English and/or Hausa. Ample opportunities for questions were given, with satisfactory clarifications provided.

Interviews were strictly confidential and conducted in seclusion. Participants were informed of their rights no wrong or right answers and freedom to respond only to comfortable questions. Recordings and all data were securely stored under lock and key, with access limited to research team members. To protect participants' identity, specific details (names and places mentioned) were deliberately erased.

Consent for publication
Not applicable (no individual person's data in identifiable form is presented).

Availability of data and materials
The datasets generated and/or analysed during the current study cannot be publicly made available, as the consent obtained from participants did not include permission for public data sharing. However, de-identified data can be made available by the corresponding author upon reasonable request.

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

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Authors' contributions
TAO conceived and designed the study. TAO, SGL and AU performed data analysis. TAO, IS, SGL, AU, ROB, AAI, AAB, MB, OME, LSJ, AOI, IOB, AMF, YLA, FSA, AK, GNU, and OLA contributed to data collection. TAO drafted the first manuscript, which was critically reviewed and revised by all authors. All authors read and approved the final manuscript. TAO made the decision to submit the manuscript for publication and vouches for the accuracy and completeness of the data and for the fidelity of the study to the protocol.

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Footnotes
The data of this study were partly used for a dissertation for a Master of Public Health (MPH) at the University of the Western Cape, South Africa. Parts were presented at: the 107th FDI World Dental Congress, September 5–7, 2019, San Francisco, California, USA; the 14th Annual International Cleft Congress (Cleft 2022), July 11–15, 2022, Edinburgh, Scotland, United Kingdom; and the 98th International Association of Dental Research (IADR) Annual Meeting, March 18–21, 2020, Washington, DC, USA.

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APPENDIX 1: INTERVIEW GUIDE

ENGLISH VERSION

Interviewer's Introduction:

"Good morning/afternoon. Thank you for agreeing to speak with me today. My name is [Name], and I am part of a research team from [Institution] conducting a study to understand the experiences, beliefs, and perceptions of caregivers regarding orofacial clefts in this region. Your participation is voluntary, and you can choose not to answer any question or end the interview at any time. Your responses will be kept confidential, and your child's treatment will not be affected by anything you share. This interview will take approximately 30-45 minutes. Do you have any questions before we begin? May I have your permission to record this interview?"

SECTION A: SOCIODEMOGRAPHIC INFORMATION

Collect before the main interview begins

1. What is your age?
2. What is your relationship to the child with orofacial cleft?
3. What is your highest level of education completed?
4. What is your occupation?
5. What is your religion?
6. What is your ethnic group/tribe?
7. Where do you currently reside (village/town)?
8. What is the age of the child with orofacial cleft?
9. What type of cleft does the child have (if known)?

SECTION B-D

1. What were your expectations when you first brought your child for treatment?
2. What did you hope would be achieved through the surgery?
3. Did you have any fears or concerns about the surgery? Please tell me about them.
4. Before the surgery, what did you think would happen to your child?
5. How were you received at the hospital on your first visit?
6. How would you describe your interactions with the doctors, nurses, and other hospital staff?
7. What was the communication like regarding the treatment process? Did you understand what was going to happen?
8. Were there any challenges or difficulties you faced during the treatment? Please describe.
9. How long did you have to wait for the surgery? How did that waiting feel?
10. Can you describe your experience during the hospital stay?
11. How many times did you have to come to the hospital before the surgery?
12. Are you satisfied with the outcome of the surgery? Why or why not?
13. What changes have you noticed in your child since the surgery?
14. Would you recommend this service to other families with children who have cleft lip/palate? Why or why not?
15. What aspects of the service would you like to see improved?
16. Is there anything else you would like to tell us about your experience?

HAUSA VERSION

Sunnunku, sunnana waye

1. Mece ce dangantakar ku da majiyyaci (yaro)?
2. Shekarun ku nawa?
3. Wane aiki kuke yi?
4. Wane matakin ilimi kuka kai?
5. Wace kabila da addini kuke bi?
6. Ina kuke zama yanzu (kauye/garin)?
7. Ko akwai tarihin rabewar lebe ko jakar baki a cikin dangin ku?
8. Menene tsammaninku lokacin da kuka fara kawo yaronku don magani?
9. Me kuke fatan za a samu ta hanyar tiyata?
10. Ko kuna da wani tsoro ko damuwa game da tiyatar? Don Allah ku fada min.
11. Kafin tiyatar, me kuke tunanin zai faru da yaronku?

12. Yaya aka yi muku maraba a asibiti a ziyararku ta farko?
13. Yaya za ku kwatanta hulWarku da likitoci, ma'aikatan jinya, da sauran ma'aikatan asibiti?
14. Yaya sadarwa ta kasance game da tsarin magani? Shin kun fahimci abin da zai faru?
15. Ko akwai wasu ™alubale ko matsaloli da kuka fuskanta yayin magani? Don Allah ku bayyana.
16. Yaya tsawon lokacin da kuka jira tiyatar? Yaya wannan jiran ya ji?
17. Za ku iya kwatanta kwarewarku a lokacin zaman asibiti (masauki, abinci, tsafta, da sauransu)?
18. Sau nawa kuka zo asibiti kafin tiyatar?
19. Shin kun gamsu da sakamakon tiyatar? Me yasa?
20. Wane canje-canje kuka gani a cikin yaronku tun bayan tiyatar?
21. Za ku iya ba da shawarar wannan sabis ga sauran iyalai da ke da yara masu rabewar lebe/jakar baki? Me yasa?
22. Wadanne bangarorin sabis din kuke son a inganta?
23. Akwai wani abin da kuke so ku gaya mana game da kwarewarku?