

Caregivers' perceptions of cleft deformity and experiences in accessing cleft services at a tertiary public hospital in Sokoto, NorthWest, Nigeria

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Expectations

Caregivers



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Acronyms

ANC:	Antenatal Care
CL±P	Cleft lip and/or palate
LGA:	Local Government Authority
NDHS:	Demographic Health Survey
PHC:	Primary Health Care
SSA:	Sub-Saharan Africa
TBA:	Traditional Birth Attendants
UDUTH:	Usmanu Danfodiyo University Teaching Hospital
WHO:	World Health Organization



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Declaration

I declare that is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have quoted have been indicated and acknowledge by complete references.

Abdurrazaq Taiwo **6th November 2018**

Signature:



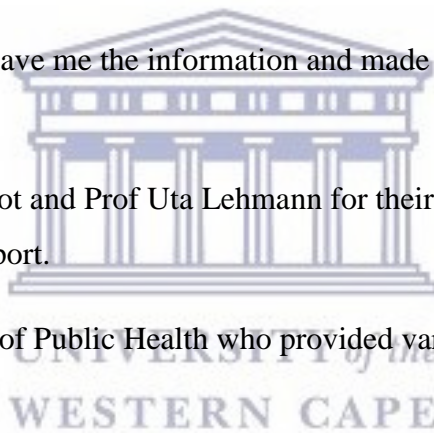
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Dedication

This work is dedicated to God Almighty, the source of all knowledge, for preserving my life and keeping me on the straight path. I also dedicate this work to my loving family especially my dear wife (Zulfah) and the children (Maryam, Jibril, AbdulWarith, Aisha and Khadijah) for tolerating my absence and giving me the needed emotional backing during this project.

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Abstract

Cleft lip and/or palate deformity is the most common facial birth defect with an incidence of 1 in 600 for every live birth worldwide. Despite the availability of specialised cleft care in Nigeria, many cleft patients are not aware that CL±Ps can be repaired and, thus, present late for treatment. As a result, there is a high incidence of unoperated CL±P in the country which has a grim negative health impact on the population. Furthermore, it was noted that the family caregivers including parents and other members of the extended family are crucial in getting early care for these children with CL±P. Therefore, understanding the perception of CL±P, attitude and experience with cleft services would go a long way in reducing the problem of late presentation and under-utilisation of these services.

Therefore, the aim of the study was to explore the care givers' perception and experience in accessing cleft services at Usmanu Danfodiyo University Teaching Hospital, Sokoto, Nigeria.

In this study, we employed an exploratory qualitative methodology that gave deep insights and provided clear understanding of the perceptions by caregivers of children with CL±P on the aetiology of cleft, family reactions and their experience in accessing cleft services at our hospital. Data analysis was done following verbatim transcription using thematic analysis.

Ethics statement: Before commencement of the study, ethical approval was obtained from the Institutional Review Boards of the University of Western Cape and the Usmanu Danfodiyo University Teaching Hospital Health Research and Ethics Committee. Informed consent was sought from each prospective participant and the signed form appropriately documented.

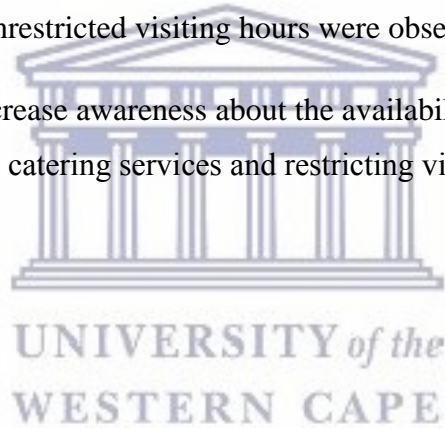
The study participants consisted of 20 caregivers and one adult cleft patient (Key informant). Most of the participants had single interviews (n=14) with four joint interviews of both parents being conducted at the interviewees' own request. About two-thirds of the participants (n=13) were females and their ages ranged from 18 to 60 years. Half of the participants were mothers trailed by five fathers. The respondents were overwhelmingly Muslims (n=18); all were geographically from north-western Nigeria. A leading proportion of the respondents were housewives (n=14) without any previous family history of cleft lip and palate (n=18). Most of the in-depth interviews were conducted before the surgeries (n=15). Six themes were explored

including history of a cleft deformity in the family, beliefs about the aetiology of cleft, reaction to the occurrence of a cleft by the caregivers, extended family and society; and treatment expectations

The study found that there were lack of knowledge and awareness about the causes, risk factors and treatment of CL±P deformity and also identified strong resilience, strong spirit and high hopes for positive treatment outcomes among the caregivers of children with CL±P. The result of the study further exposed significant barriers in accessing cleft surgical treatment particularly in the area of misinformation from primary health care workers and the great distance that is needed to travel in getting to the hospital surgical care.

Furthermore, the present work also indicated that the participants mostly had a good experience with most of the hospital services. However, complaints about the long waiting time for surgery, poor sanitation and food, and unrestricted visiting hours were observed.

The effective use of radio to increase awareness about the availability of free cleft treatment, improving hospital's sanitation, catering services and restricting visiting time were some of the study recommendation.



Chapter One: Introduction

This study explores the question why children with cleft deformities present late at Usmanu Danfodio University Teaching Hospital (UDUTH) in Sokoto, Northern Nigeria, along with beliefs and experiences which may have determined caregivers' health seeking behaviour.

I am a maxillofacial surgeon and a member of the cleft team at the Teaching Hospital, Sokoto, Nigeria. Since my training days I have been wondering how to confront late presentation for cleft treatment and find ways to make parents and family caregivers bring their children early for treatment. I used to ask myself how congruent our cleft service is with the local prevailing culture and beliefs. My interest in this topic lingered after my residency training and when I moved to my current abode. Here am I in a far-flung, isolated territory serving a mainly Hausa-Fulani-speaking population with distinct cultural beliefs and practices; and vastly divergent ways of doing things. Although, no existing official documentation on the prevalence or incidence of cleft lip and palate (CL±P) deformity occurred in this area, we were observing an average of five cases of cleft per week.

With the widespread endemic high poverty rate, low literacy level and sparse utilisation of health services in the area, I realized that to improve cleft awareness/service uptake and deliver appropriate culturally congruent care, I need to critically harness resources to overcome structural barriers and social determinants of health. Examples are inadequate health infrastructures, a chronic shortage of trained workforce and other logistics. Therefore, it was even more crucial to urgently understand the cultural beliefs surrounding CL±Ps in this area and get insight into the expectations and previous experience of cleft treatment in the community. This study helped me to gain deeper insight.

1.1 Background

Cleft lip and/or palate deformity is the most common and noticeable birth defect in the orofacial region, with an incidence of 1 in 600 for every live birth worldwide (Butali et al., 2014; Butali et al., 2017; Olasoji et al., 2002). Cleft lip and palates are a global health problem affecting all races from different geographical origin, with the highest birth prevalence in Asia (1.54-1.60), North America (1.53-1.59), Europe (1.52-1.58), Oceania (1.30-1.36), and 0.96-1.02 in South America

(Fogh-Anderson, 1971; Panamonta et al., 2015; Vanderas, 1987). In some earlier studies from the sub-Saharan Africa (SSA) population, incidences of 1 per 689, 1 per 1055, and 1 per 2,703 live births in the African population were observed (Gupta, 1969; Iregbulem, 1982; Simpkins & Lowe, 1961). However, Panamonta et al. (2015) in an extensive systematic review found a prevalence of 0.54-0.64 per 1000 live births in Africa, which is consistent with an earlier Nigerian genetic-epidemiological study that found a prevalence of 0.5 per 1000 live births (Butali et al., 2014).

Unfortunately, globally persons with CL±P and their families have encountered severe discrimination, stigma and social inequalities. Therefore, it is sad to note that in some developing countries of SSA like Ghana, Nigeria and Zimbabwe infanticide has been noticed (Antwi-Kusi et al., 2015; Mzezewa & Muchemwa, 2010; Nwoku, 1974).

The ideal treatment of cleft anomalies starts at early infancy stretching over childhood and adolescence (Emeka et al., 2017; Morgan, 1992; Oluwasanmi & Adekunle, 1971; Taiwo et al., 2016). Hence, it is highly desirable that babies born with cleft deformities are seen and attended by a specialist cleft surgeon immediately after birth. Previous studies have established that this early evaluation and initiation of counselling and treatment of those living with congenital cleft lip and palate defects have a very positive impact on the general quality of life of the individual and positive psychosocial development (Adeyemo et al., 2009; Iregbulem, 1982; Mzezewa & Muchemwa, 2010).

Early presentation would also facilitate optimal repair of cleft lip which should be done in early infancy and cleft palate repair be done before speech development i.e cleft lip before or at 12 weeks of age and that of cleft palate at nine to twenty-four months of age (Adeyemo et al., 2009; Adesina et al., 2010; Nwoku, 1976). Previous reports of timely surgical closure of the cleft lip suggested that patients benefited from improved cosmetic, psychosocial adjustment and better quality of life (Marcusson et al., 2002; Ross, 1987). Ideal timely closure of cleft palate also fostered improved speech development (Dorf & Curtin, 1982; Haapanen, 1992; Simpkins & Lowe, 1962). In addition, it leads to favourable wound healing/surgical outcome and enhance psychosocial-economic integration of the individual (Adetayo et al., 2012; Adeyemo et al., 2009; Iregbulem, 1982; Mzezewa & Muchemwa, 2010; Olasoji et al., 2002). More advantages include attractive face accomplishment, cognitive development, attenuation of child's parental/family

apprehension, increased acceptance of the child, better mother/child bonding, optimal facial growth and development of immunity to childhood infectious diseases (Adeyemo et al., 2016; Emeka et al., 2017; Olayinka et al., 2014). Other benefits comprised achieving equity, social justice and eradication of marginalisation, stigma and infanticide.

Prenatal diagnosis of cleft lip attributable to advances in obstetrical ultrasound has been effectively exploited in developed countries to achieve early mobilisation and counselling for cleft treatment (Blumenfeld et al., 1999). However, this is yet to gain ground in SSA countries where it was observed that there is wide variation at the age of presentation of children with CL±P for treatment (Agbenorku et al., 2013a, 2013b; Mzezewa & Muchemwa, 2010; Olasoji et al., 1997; Onyango & Noah, 2005). Similarly, this was supported by Conway et al. (2015) in a 10-year review of cleft surgeries in 33 African countries which detected that 36,384 patients had an average age of 9.34 years at surgery.

Findings from South-West Nigeria showed that between 8.6% and 33% of cleft patients presented for treatment after the age of commencement of primary schooling (6 years old) (Abdurrazaq et al., 2013; Adeyemo et al., 2009; Ugboko et al., 1997). Furthermore, numerous reports across Nigeria observed that 2.8-63.6% of patients with cleft were of adolescent or adult age (Adekeye, 1985; Adeola et al., 2003; Adigun & Adeniran, 2004; Datubo-Brown & Kejeh, 1990; Nwoku, 1974; Olasoji et al., 2002; Orkar et al., 2002). In a recent study, Oladele et al. (2012) found that 24.1% of their cleft patients were between ages 13 and 76 years. Therefore, there does not seem to have been any improvement in the age of presentation over time, as the above recent African studies from 2012 till date have reported late presentation as an ongoing challenge. The reasons for delays in treatment are multi-faceted. They include lack of awareness of treatment availability, poor health infrastructure, the paucity of specialised health service care, logistics and cultural factors (Adeyemo et al., 2009; Antwi-Kusi et al., 2015; Aziz et al., 2009; Kesande et al., 2014; Schwarz & Khadka, 2004). Cost of treatments, which can at times stretch over many years (Emeka et al., 2017; Taiwo et al., 2016), can also place an enormous socioeconomic burden on not only the affected person(s) but the entire family/community (Adetayo et al., 2012; Conway et al., 2015). The shame, stigma, discrimination and ostracization create additional barriers, which might make people hesitant to seek care (Adeyemo et al., 2016). Subsequently, these unoperated clefts results in tremendous backload posing a considerable

burden on the African continent's over-stretched health system (Adetayo et al., 2012; Adeyemo et al., 2016; Olasoji et al., 2009).

The treatment of cleft deformities in large parts of Nigeria mirrors the situation in other SSA countries as described above. Particularly, with the vast difficult terrain and largely dispersed population predominantly inhabiting rural areas comprised of assorted ethnicities, religion, and cultures with different peculiar perceptions of CL±P causality and management (Oginni et al., 2010; Olasoji et al., 2007; Owotade et al., 2014). This is compounded by poor antenatal attendance and a high prevalence of home births by traditional birth attendants in Nigeria and Sokoto in particular (Bukar & Jauro, 2013; NHDS, 2013).

For all the above reasons, a landmark meeting convened in 2006 by the Centers for Disease Control and Prevention declared CL±P as a key public health priority (Yazdy et al., 2007). A lack of relevant literature on this topic from Sokoto and other states in the north-western region makes it imperative to look at the unique understandings of the caregivers about their treatment experience. Future planning and improvement of the quality of cleft care could be eased and long-term compliance with multiple surgeries required to correct these anomalies heightened (Mandrano et al., 2017; Taiwo et al., 2016).

1.2 Study setting/context of the study

1.2.1 The hospital

This study was conducted at UDUTH, Sokoto, located in the most geographically extreme and arid part of the north-western zone of Nigeria. Sokoto State covers an area of 25,973 km² with an estimated population of 5.4 million in 2017 (Health policy plus, 2017) and a population density of 170 per km². The inhabitants are mainly Hausa and Fulani ethnic groups. Other major and minor ethnic groups also reside in the state. The main economic activities in the area are farming, trading and cattle rearing, and Islam is the predominant religion. The state has one of the lowest literacy level and highest maternal and child mortality in Nigeria. There are 23 local government areas (LGA), in Sokoto state. There are two tertiary hospitals within Sokoto metropolis.

UDUTH is the apex academic training and research institution in the region affiliated to the regional university of the same name. It is an 850-bed hospital which takes care of patients from

Sokoto, Kebbi, Zamfara, Katsina and Niger state, as well as the neighbouring country of Niger. The hospital is located within the capital metropolis in Wamakko LGA of Sokoto state. The hospital maintains 3 comprehensive Primary Health centres in Kware and Ringim Sambo both within the state and Argungun in Kebbi state. It provides broad range of services that encompasses primary, secondary and tertiary healthcare, which caters for vulnerable population with diverse health conditions including birth defects. Owing to the target population's low socio-economic status the hospital offers free cleft services funded by an international NGO (Smile train). Previously, foreign doctors used to come to the state for bi-annual two weeks free medical mission hosted at the hospital. Owing to the huge turnout, only a limited number eventually received treatment during that period.

However, for the last 10 years a resident/indigenous multidisciplinary cleft team consisting of Plastic, Maxillofacial surgeons, dentists, nurse, anaesthetists, community health extension workers (mobilize patient from the community) and other health professionals have been providing all year free surgical cleft services. Over 100 new children with CL±P are registered and treated annually by the team at the hospital.

1.2.2 Health system/health statistics in Sokoto

The Sokoto state health system consists of UDUTH (Federal government hospital) that principally provides tertiary care that covers all fields of medicine, dentistry and surgery. In addition to the above reference hospital serving the population, there are 18 district (General) hospitals spread across 23 local government areas and a specialist Hospital in metropolis funded by the state that provide secondary health-care. However, they have limited number of doctors, nurses and specialist compared to UDUTH. These are supplemented by primary health-care centres (PHC) in all 247 wards and by health outpost/dispensaries in the villages which are largely staffed by community health officers who are funded by the local government but supported by state and federal governments (Akeju et al., 2016). These officers have two to four years (junior and senior cadres) formal training in tertiary health institutions following completion of 12 years formal schooling (secondary). They are essentially equipped for preventive health care such as health promotion, health education activities, community mobilisation/outreach, family planning, immunisation, counselling, environmental sanitation/hygiene, maternal/child health, screening for communicable diseases and

health/nutritional talks. Others also include mosquito nets distribution, first-aid treatment, basic malaria treatment, dispensing of over-the-counter drugs, collecting statistics, maintaining records and providing health-care referrals (Akeju et al., 2016). However, they do not have surgical training or cleft expertise, and so families with children that have CL±P have to make the long journey to the capital to access care.

At this junction, it is pertinent to bear in mind that health-care services at all level are fee for service based, although, less than 10% of the population of Nigeria mostly government workers have limited health coverage by the national health insurance scheme (Akeju et al., 2016).

The northwest region and Sokoto state have of one of the highest maternal and child mortality rate in Nigeria (Maternal and infant mortality rates are 106 and 185 per 1000 live births respectively), which is ten-fold that of southern Nigeria, mostly stemming from infectious diseases, which has been blamed on high household poverty and extremely poor maternal literacy rates (Morankiyo & Fagbamigbe, 2017; UNICEF, 2017). In addition, the 2013 Nigeria demographic and health Survey (NDHS) revealed that 47% of rural women in Nigeria did not received antenatal care (ANC) compared to 11% of urban women. The survey also showed that two in five women in North-West (NW) Nigeria received antenatal care from a skilled provider compared to nine in ten from the southern zones. Also, 95% of births in Sokoto state are attended by traditional birth attendants (TBA) which is higher than the 86% and 20% recorded in other states in North-West and South-West Nigeria (NHDS, 2013). Delayed health-seeking behaviour was prevalent in various rural districts in Africa owing to the limited access to health services generally; thus, most women are compelled to deliver at home with the assistance of the TBA in their community (Bukar & Jauro, 2013; Eades et al., 1993; Itina, 1997; Mutambirwa, 1985). It needs to be noted that TBA in SSA countries like Ghana and Nigeria predominantly have not undergone any structured training, are not integrated into the westernised health-care system and, therefore, have no formal guidance on how to refer patients with cleft lip and palate to tertiary centres for comprehensive surgical and dental care (Akpala, 1994; Bukar & Jauro, 2013; Itina, 1997; Mathew et al., 1995).

1.3 The problem statement

Despite the availability of specialised cleft care in our region, many cleft patients are not aware that CL±Ps can be repaired and, thus, present late for treatment (Abdurrazaq et al., 2013; Adetayo et al., 2012; Adeyemo et al., 2009; Nwoku, 1972; Orkar et al., 2002). As a result, there is a high incidence of unoperated clefts in Nigeria which has a grim negative health impact on the population.

Furthermore, it was noted that the family caregivers including parents and other members of the extended family are crucial in the care of the child with a cleft (Håkonsen, 2012). Therefore, understanding the perception of clefts, attitude and experience with cleft services would go a long way in reducing the problem of late presentation and under-utilisation of these services (Abdurrazaq et al., 2013; Marcusson, 2001; Naram et al., 2013).

1.4 Aim and objectives

The aim of the study was to explore caregivers' perceptions of cleft deformity and experience in accessing cleft services at Usmanu Danfodiyo University Teaching Hospital, Sokoto, Nigeria.

The study objectives included exploring

1. Caregivers' beliefs about the cause of CL±P;
2. Their experience of family and communities' reactions to CL±P deformities;
3. Their experience of receiving treatment at the hospital; and
4. Their expectations of the treatment process of CL±P and the outcomes of surgical intervention.

Chapter Two: Literature Review

2.1 Introduction

The intent of this literature review is to an overview of the scientific background, cultural beliefs and social reactions to cleft lip and palate CL±P anomalies. The literature on parents' and other family caregivers' reaction to cleft occurrence, their treatment expectations and the variety of experience with current cleft services worldwide is also explored. This was accomplished by taking a look at research conducted in developed and developing countries including Nigeria. In addition, in this review we also attempt to develop a clear understanding of pertinent issues that influence the caregivers in deciding to use cleft services.

2.2 Epidemiology of cleft lip and/or palate

The exact incidence of cleft lip and palate is difficult to determine because of marked geographical and ethnic variations (Adeola et al., 2003; Sitversen et al., 2008; Vanderas, 1987). Other reasons for variations are substantial under-reporting, conflicting methods of data collection, lack of uniform reliable birth registry and induced abortion following prenatal diagnosis (Olasoji et al., 2007). In addition, lack of diagnosis and treatment in remote areas, as well as infanticide are key issues (Blumenfeld *et al.*, 1999; Datubo-Brown and Kejeh, 1990; Morgan, 1992). However, it is estimated that 1 in every 600 live births is born with CL±P (World Health Organization (WHO), 2002).

Evidence from epidemiological studies suggests that globally, infants with these deformities are at increased risk of mortality in their first year of life. This scenario is even more pronounced in low-resource settings of Africa where fragile health systems are battling with other serious health emergencies (Mossey, 2003; WHO, 2002, 2005). In 2004 of the 1.16 million infant deaths recorded in Africa congenital anomalies were the fourth (6%) leading cause (WHO, 2005). Nigeria ranks as number one in Africa for newborn and maternal deaths with, over a quarter of a million babies dying per year (WHO, 2005). Butali et al. (2017) blamed rising mortality among infants with birth defects on the persistent infrastructural deficit, dearth of skilled workforce and cultural beliefs.

In developed countries, virtually all deliveries happen in hospitals, with highly skilled personnel in attendance, thus, cases of cleft deformities are most often diagnosed at birth. In contrast, in developing countries most deliveries are either happening at home or done by untrained traditional birth attendants. According to the 2013 Nigeria Demographic Health Survey (NDHS), only 22% of all deliveries were taken in the medical facilities. Although, no data exist currently assessing TBA' knowledge about CL±P, however, previous findings suggest that they lack formal training in obstetrics or neonatal health (Ross, 2007). Hence; there might be failure to detect the anomaly and promptly refer for correction.

2.3 Aetiology, diagnosis and problems associated with cleft lip and/or palate

The aetiology of CL±P is not clear. The interplay between genetics and environmental risk factors appear to affect the fusion of the lip and palate, and clefts develop when environmental factors trigger the genetically susceptible phenotype (Butali et al., 2011, 2014, 2017).

Evidence suggests that teratogens such as exposure to tobacco smoke, alcohol, vitamin deficiencies, viral infections, and certain medications such as anticonvulsants during embryogenesis markedly increase the risk of clefting (Abdurrazaq et al., 2013; Park-Wyllie et al., 2000; Romitti et al., 2007).

A positive family history has been reported in 20% of patients with cleft in different populations, suggesting an important role for genetics (Crainci et al., 2003; Fogh-Andersen, 1971). Therefore, a detailed family history is required to assess risks fully and genetic counselling is an indispensable preventive tool (Abdurrazaq et al., 2013; Crainci et al., 2003).

2.4 Timing of repair of cleft lip and palate

Among the problems/challenges associated with cleft lip and palate deformities which have been reported (Adeyemo et al., 2009) are feeding and airway problems, speech and language delays, ear infections/hearing loss, dental anomalies, psychosocial problems and reduced quality of life (Edward, 2003).

For this reason, cleft lip surgery should ideally be done as early as ten weeks adhering to the proven 'rule of 10' (10 weeks of age, 10-pound body weight and 10 g of haemoglobin) to determine when an otherwise healthy baby is suited for the elective surgery (Edward, 2003;

Olasoji et al., 1997; Orkar et al., 2002). However, this could be postponed if there is a co-existing medical condition that could jeopardize the surgery of the child (Edward, 2003). The timing of hard and soft palate surgery is preferably before speech development, i.e. six and 24 months. This appeared to be a compromise between the need for normal facial growth and the goal of normal speech (Dorf & Curtin, 1982; Nwoku, 1974; Olasoji et al., 2002).

2.5 Knowledge and beliefs about cleft lip and palate

Worldwide, different traditions, cultural beliefs and myths on cleft deformities exist (Oginni et al., 2010; Olasoji et al., 2007). These beliefs predate modern scientific explanation and treatment evolution of CL±P and are not limited to specific geographical areas (Mandrano et al., 2017) child is regarded as belonging to the entire community, and the care of children is a communal affair; entrusted not only to the parents but other members of the extended family (Adeyemo et al., 2016; Loh & Ascoli, 2011; Ross, 2007). Therefore, the cultural beliefs and perceptions of these family caregivers on the aetiology of cleft and their expectations and attitudes towards treatment are crucial influences on the eventual management and utilisation of these services (Loh & Ascoli, 2011; Mandrano et al., 2017; Nelson & Kirk, 2013; Oginni et al., 2010; Olasoji et al., 2007; Ross, 2007).

Supernatural explanations are the most prevalent cultural beliefs surrounding CL±Ps (Nelson et al., 2012; Olasoji et al., 2007; Ross, 2007; Venkatesan, 2015). Many adherents of principal religions give various spiritual labels to CL±Ps. Ross (2007) also observed that the belief that an evil spirit or jinn was very prevalent among the South African Hindu and Muslim community. In a recent survey in Ghana, 35% of mothers with CL±P children who were interviewed associated the cause of the condition to superstitions (Antwi-Kusi et al., 2015). Other mothers see cleft as God's will, fate or divine punishment (karma) which must be accepted (Håkonsen, 2012; Oginni et al., 2010). Another study conducted by Weatherley-White et al. (2005) in rural India observed that 84% of parents of CL±P patients attributed the cause of the cleft to God sent or divine predestination (Butali et al., 2014; Butali & Mossey, 2009; Mandrano et al., 2017; Naram et al., 2010; Ross, 2007; Weatherley-White et al., 2005). Some communities have been found to be more tolerant of these deformities than other religious groups as they do not view cleft as a handicap but an act of God (Loh & Ascoli, 2011; Oginni et al, 2008; Olasoji et al, 2007).

Many also blamed bad luck, curse, retribution or karma for past evil deeds, mocking a cleft person and pregnant woman going out during solar eclipse (Oginni et al., 2010; Olasoji et al., 2007). In an Indian study, 10% of their participants linked the deformity to sins committed in past life of patients (Weatherley-White et al., 2005).

Furthermore, in some cultures certain foods eaten during pregnancy such as beef snout, rabbit meat in addition to excessive drinking by the expectant father and worms within the abdomen of the expectant mother have also been blamed for cleft abnormality (Alnujaim et al., 2017; Daack-Hirsch & Gamboa, 2010; Mandrano et al., 2017; Olasoji et al., 2007).

Antwi-Kusi and co-workers (2015) demonstrated that public enlightenment campaigns by the public health sector can reduce these beliefs among their Ghanaian subjects.

Any apathy or ineffectiveness in engaging these beliefs by the public health community could impede the development of a client-oriented culturally compliant cleft service (Mendoza et al., 2001; Taiwo et al., 2016). Recent findings demonstrated that understanding populations' culture and religious beliefs could facilitate the development of appropriate cleft interventions (Antwi-Kusi et al., 2015; Louw et al., 2006).

2.6 Societal reactions and its consequence

Facial appearance is important in the way society perceived individuals (Yunusa & Obembe, 2013). An attractive face attracts a lot of windfall for the owner. Likewise, any deviation from what the society perceives as normal heralds multifaceted consequences, which often are not pleasant for the persons involved (Venkatesan, 2015).

The biomedical outlook sees CL±P as a purely anatomical deviation from normal, restricted to the face (Adeyemo et al., 2016; Adeyemo, James & Butali, 2017; Adigun & Adeniran, 2004; Agbenorku, 2013; Orkar et al., 2002). The impairment is also viewed as owing to the element of structural disfigurement (Adeyemo et al., 2016; Naram et al., 2013; Venkatesan, 2015).

Furthermore, it qualifies as a social and physical handicap because of the attendant societal stigma from the structural incapacitation of speech, breathing, aesthetics, mastication and other things (Venkatesan, 2015). The earlier three constructs can be improved by surgery and other medical remedies. However, resolving the lifelong social handicap of CL±P is more challenging

(Adeyemo & Butali, 2017; Oladega et al., 2016; Venkatesan, 2015). Negative and faulty societal reflections of these individuals with CL±P have resulted in flawed stereotypes as they conclude that their ‘ugliness’ translates to ‘evil’. These transcultural faulty impressions and judgements triggers a vicious cycle of more damaging scenarios of personal/social stigma, prejudices, hopelessness, pessimism, ostracization, socio-economical disempowerment, poverty, violence, depression and possibly suicidal tendencies (Oladega et al., 2016; Venkatesan, 2015).

Therefore, the emotional trauma of dealing with the birth of a child with a facial anomaly like CL±P is quite severe, even in ‘enlightened’ circles where access to treatment and support is reachable. Reactions and attitudes of various cultures, communities and family to cleft children vary from indifference, avoidance, support, and blame to hostility (Adeyemo et al., 2016; Naram et al., 2013).

Several studies have demonstrated mixed responses from mothers, family, friends and society to those mothers and children born with CL±P. Some react out of fear that the cleft child might bring bad luck to the family, perhaps because of the mother’s infidelity or violating an important religious precept of the family (Antwi-Kusi et al., 2015; Kesande et al., 2014). The birth of a new baby is usually a joyous occasion. Owing to the high societal premium placed on motherhood and children, family members, especially mothers, exploit this occasion to highlight this achievement and showcase their new arrival to the world. Occurrence of a visible cleft deformity jeopardizes this dream with mothers often fearing embarrassment and scorn from friends and the larger society if they present such children during this naming ceremony (Adeyemo et al., 2016; Antwi-Kusi et al., 2015). They cry privately, try to screen the child from the public glare and postpone this event until an appropriate solution is found. In some cases, out of despair and desperation infanticide has been reported as a last resort (Adeyemo et al, 2016; Butali et al., 2017).

Importantly, the immediate families, relatives and friends play a critical role in the optimum management and well-being of mothers and children with CL±P (Adeyemo et al., 2016; Oshodi & Adeyemo, 2015; Venkatesan, 2015). In many African societies, the extended family members command great influence and perform a strategic role in the functioning of the family and society (Adeyemo et al., 2016; Loh & Ascoli, 2011). They are the gatekeeper to information across generations and intra-generation, hence, in the way individuals and communities view

disabilities and their ultimate rehabilitation of children with disabilities (Adeyemo et al., 2016; Black et al., 2009).

2.7 Sources of information about cleft lip and/or palate

In several African countries, caregivers of children with cleft find getting accurate and timely information about the nature of CL±P, how to feed these babies, where to obtain proper treatment and other germane information challenging (Adeyemo et al., 2009; Antwi-Kusi et al., 2015; Kesande et al., 2013; Mandrano et al., 2017; Owotade et al., 2014). In previous studies, it was disclosed that many CL±P caregivers derived their source of information about cleft mostly from family members (Antwi-Kusi et al., 2015; Kesande et al., 2013). Owotade et al. (2010) in a survey to check the level of awareness about cleft among pregnant women attending ANC at three tertiary facilities across Nigeria, observed that 76.3% of 200 antenatal care attendees examined got their information about cleft from family members and casual encounters with members of the community.

In Ghana, a hospital-based cross-sectional study among 80 mothers of children with CL±P revealed that 33.7% of the subjects admitted their ignorance on surgery as treatment for this condition (Antwi-Kusi et al., 2015). Kesande et al. (2013) showed a slightly higher figure of 35.5% among 20 Ugandan mothers of CL±P children studied.

2.8 Treatment expectation by families

For families, especially from rural populations, it is common to consult traditional healers first before using conventional Western medicine, while others may concurrently use the two options (Naram et al., 2014; Oginni et al., 2010; Ross, 2007). Findings from Nigeria indicate low treatment seeking behaviour for cleft deformities among rural dwellers (Adeyemo et al., 2009; Nwoku, 1974; Orkar et al., 2002). For example, Olasoji et al. (2007) interviewed 36 mothers of CL±P children drawn from Yoruba and Hausa/Fulani, two major ethnic groups from southern and northern parts of Nigeria, respectively. They discovered that two-thirds of the southern group had been referred by the traditional healers, and all those from the northern group had used various animal and plant products to treat the cleft before presenting for treatment.

When families find their way to western hospitals they expect to receive cleft services that respect their culture and are responsive to their various needs such as information, accessibility and cost-effectiveness (Adeyemo et al., 2009; Agbenorku et al., 2013; Antwi-Kusi et al., 2015; Mandrano et al., 2017; Taiwo et al., 2016).

Lots of studies from outside Africa also indicate that parents and caregivers have lofty expectations about cleft services besides the surgical outcome (Hamlet & Harcourt, 2014; Mendoza et al., 2001; Nelson & Kirk, 2013). Many displayed high social expectations and were hopeful that the treatment offered at the hospital would restore their babies to normalcy and help them to integrate into society (Antwi-Kusi et al., 2015; Mandrano et al., 2017; Naram et al., 2013). They also cherish the comfort, therapy and companionship of other CL±P caregivers and cleft staff (Antwi-Kusi et al., 2015). Besides the surgeon's technical competency and quality of care, the caregivers placed a great premium on interpersonal skills that include empathy, ability to communicate, friendliness, politeness, sensitivity, and warmth (Mendoza et al., 2001; Nelson & Kirk, 2013). Nelson and Kirk (2013) and Mandrano et al. (2017) observed that they are comfortable with cleft services that have a high rate of staff retention, familiarity and provide continuous care. This was supported by an earlier study by Mendoza and colleagues (2001) in Bangladesh who showed that those who attended cleft outreach were more dissatisfied than those who visited fixed services because of high turnover of healthcare providers, domination by strangers (mostly expatriates) and intermittent/short duration of care provided.

Nevertheless, some expressed concern that little information about the actual surgeries are provided, compounded by poor service coordination (Nelson & Kirk, 2013).

Earlier findings from developed and developing countries in Africa and other continents showed that most cleft caregivers, including parents, hold a positive impression about cleft-care delivery (Nelson & Kirk, 2013; Noor & Musa, 2007; Semb et al., 2005; Taiwo et al., 2016). Most of these studies have dwelt on clinical and treatment outcomes such as aesthetics, quality of life and speech (Emeka et al., 2017; Semb et al., 2005; Taiwo et al., 2016). However, Nelson and Kirk (2013) postulated that apart from the attending health personnel's medical knowledge and technical capability, soft (interpersonal) skills such as empathy, emotional intelligence, friendliness, sensitivity and effective communication are other less researched areas valued by caregivers in cleft services. Other reports demonstrated that building rapport by listening and

gauging patients/caregiver perspectives, giving opportunities for enquiries/feedback, addressing socio-psychological needs of the caregivers and open access to information are relevant to patient satisfaction and achieving caregivers centred care (Cassell et al., 2013; Nelson & Kirk, 2013; Stewart et al., 2003; Taiwo et al., 2016).

Nelson and Kirk (2013) observed that the development of caregiver centred cleft services leads to trust and greater acceptance of the surgical risks involved in the treatment of these cleft children. In addition, warmth, caring attitude, caregivers centred information delivery helps mothers and fathers to effectively deal with their emotional turbulence, adjust and comply with the lengthy treatment demands required for the correction of the anomaly.

Correction of CL±P anomalies required continuous care spanning close to two or more decades in the life of the patients, family and other caregivers (Akinmoladun et al., 2007; Cassell et al., 2012). Nelson and Kirk (2013) noted that appropriate engagement through regular reassurance and display of genuine empathy has been demonstrated, together with the cultivation of the cordial relationship between managing team and the family is essential to attain the desired objective. This, in the long run, improves the public and caregivers perception of cleft-care practitioners as acting in their best interest, thus, pivot to reducing the public resistance to the utilisation of these cleft services.

A United Kingdom qualitative study of in-depth interviews of 27 parents of children with OFC identified several areas of unmet cleft service needs (Nelson & Kirk, 2013). These included ways and depth of delivering information especially the surgeries involved; and better service coordination among the multidisciplinary cleft team management.

2.9 Reasons for late presentation for CL±P treatment

2.9.1 Lack of information

The lack of information has already been mentioned as the key reason why parents and caregivers bring children born with CL±P to hospital late or not at all (Onyango & Noah, 2005; Adeyemo et al., 2009; Agbenorku et al., 2013; Oginni et al., 2010; Oladega et al., 2016; Owotade et al., 2014).

2.9.2 Financial constraints

A prospective case series of 43 patients/parents from Lagos Nigeria revealed that 13.3% of subjects attributed their late presentation for treatment to a lack of finances (Adeyemo et al., 2009). Adesina et al. (2010) in a case series from North-eastern Nigeria spanning two years, interviewed parents and relations of 72 CL±P patients and discovered that a lack of finances was the most important (49%) cause of presenting late for cleft treatment.

2.9.3 Lack of proximity to health services

A study from Nepal disclosed that 29% of their subject presented late for cleft treatment as a result of a lack of proximity to a proper health care facility (Schwarz & Khadka, 2004).

Similarly, two studies from northern and southern Nigeria revealed that 8% and 18% of subjects attributed their late presentation for treatment to the far distance of the cleft centre (Adesina et al., 2010; Adeyemo et al., 2009).

2.10 Gap in the literature

Most of the studies on CL±P perceptions' and management are descriptive and quantitative. However, qualitative studies are well positioned in helping to unravel the various complexities surrounding cleft deformity and suggest ways to improve cleft services. Unfortunately, there are few qualitative studies dedicated to children with craniofacial congenital abnormalities especially in developing countries of SSA (Orkar et al., 2002; Taiwo et al., 2016). Most of the studies have focussed on CL±P causation, with no emphasis on service delivery. Even these reports principally checked the perspective of the mothers and sometimes that of the fathers of these children. However, in many African settings including those of Nigeria, members of the extended family are frequently the main caregivers of these children. Therefore, their views and perceptions on these topics might even be more important than those of the biological parents (Naram et al., 2013; Ross, 2007).

Currently, only one qualitative study from United Kingdom critically scrutinized the cleft service from the children with cleft parents' perspectives (Nelson & Kirk, 2013).

Therefore, the purpose of this study was to explore caregivers' perceptions of cleft deformity and experience in accessing cleft services at Usmanu Danfodiyo University Teaching Hospital, Sokoto, Nigeria.

Chapter Three: Methodology

3.1 Introduction

In the previous chapter, a critical review of the scientific and common religion-sociocultural perceptions about the aetiology of CL±P was given. Exploring caregivers' perceptions of the aetiology, societal responses to CL±P, and their experiences with CL±P services at Usmanu Danfodiyo University Teaching Hospital Sokoto, Nigeria formed the aim of the study. The following will be a comprehensive narrative of the methodology utilised to accomplish this aim.

3.2 Study design

This exploratory, descriptive study that employed a qualitative research approach enabled the researchers to comprehend and construe caregivers' constructs of the CL±P phenomenon and their interactions with the hospital cleft services.

Cleft lip and/or palate is a complex phenomenon with broad social consequences and clinical dimensions (Adeyemo et al., 2016; Orkar et al., 2002; Venkatesan, 2015). Black et al. (2009) stress that sensitive public health phenomenon with multiple dimensions like CL±P can best be tackled by a flexible qualitative method that is well suited to the African oral tradition which rewards the participants' opinion. Therefore, its conversational interview style permits the participants to proficiently elaborate on their statements and the researcher to systematically engage and clarify relevant details concerning cleft care which a rigid quantitative approach might not easily offer. In contrast, a quantitative methodology that is research driven, relying on various assumptions would struggle to untangle how these participants make sense of these phenomena (Abdurrazaq et al., 2013; Black et al., 2009; Oginni et al., 2010; Robson, 2011).

Qualitative design in this study was used to obtain rich descriptive textual data predicated on the participants' own words that helped to explore and examine the research topics painstakingly. Moreover, this approach also unravelled the phenomenon in its real-life context through the eyes of individuals that have actually lived these experiences and

thereby, gained holistic insights into the actual functioning of the cleft service (Mack et al., 2005; Mays & Pope, 2000; Robson, 2011).

In addition, the narrative style of qualitative research reports would have helped to easily and widely disseminate key findings of this study to influential stakeholders within and outside the health sector, especially caregivers, health workers, non-governmental organisations, politicians, policy makers, traditional rulers, religious leaders, journalists and most importantly the overwhelming lay people in the region (Smit, 2003).

3.3 Study setting

The setting of this study was at the specialist cleft centre of UDUTH a federal tertiary facility located in the ancient city of Sokoto, NorthWest Nigeria. The hospital serves a considerably remote rural population of over six million spanning states like Sokoto, Kebbi, Zamfara, Niger, Katsina; and the neighbouring country Niger Republic with land mass spanning more than 25,973 square kilometres. Most of the inhabitants are subsistence farmers and nomadic pastoralists with a very low level of western-style education uptake and poor socio-economic status. Availability of modern infrastructures like clean drinkable water, modern transportation including quality health care in many remote is virtually non-existence. Hence, many in the region accessed not only specialised tertiary care at UDUTH but also primary and secondary healthcare services. These services are fee-based with only government and some private sector employees that enjoy the existing health insurance that has limited coverage.

A multidisciplinary team consisting of plastic maxillofacial surgeons, dentists, nurses, anaesthetists and other health professionals mostly provide surgical and dental care to CL±P patients. Over 100 new cleft babies are registered and treated annually. The free surgical cleft care also includes feeding and boarding for the patients and their accompanying relatives and caregivers' right through the duration of their treatment and recovery. Mothers, fathers and other members of the extended family constituted the principal caregivers of cleft children in our setting (Abdurrazaq et al., 2013).

3.4 Study population and inclusion criteria

The study sample was drawn from caregivers of patients with CL±P who presented for primary or secondary cleft surgeries at UDUTH from November 2017 to February 2018.

Caregivers had to be related to a patient diagnosed with CL±P who was amenable for surgical correction and actively contribute to the care of the cleft patient to qualify for this study. They had to be willing to seek treatment at UDUTH and be permanent Nigerian residents from the time of birth of the cleft patient. They also had to consent to participate in the study voluntarily.

Persons who did not strictly comply with these criteria were excluded from the study. Eligible persons met these conditions and included parents and family members of different ages and occupations as reflected in Table 1. All eligible participants were approached and invited to participate in the study.

3.5. Sampling procedure and sample size

Patton (2002) advanced that sampling in qualitative research seeks to select subjects who can deliver rich information for in-depth appraisal. Liamputtong & Ezzy (2005) further advocated that the study participants should be able to bring data that will facilitate a broad and dense understanding of every aspect of the topic under investigation. Therefore, a purposive sample (non-probability sampling technique) of 20 cleft caregivers who were eligible and capable of assisting in unravelling the research problem was chosen for the study. This limit was the maximum imposed by the mini-thesis and achievable within the narrow available time frame while recognising the exploratory nature of the study.

Although not statistically representative of the study population, this sampling preference made the inclusion of diverse participants with some fundamental characteristics possible. Examples were being parents or family members, having different ages, and rural or urban residency as reflected in Table 1 which helped shed light on the study objectives (Daack-Hirsch & Gambosa, 2010).

The unintended recruitment of an adult with into the study, whose uncle was one of the participants, was expected to contribute to data source triangulation and completeness of the data

gathered. He would possibly be able to give a direct comprehensive account of his experience of the phenomenon and fill the gaps omitted by the uncle.

3.6 Data collection

3.6.1 Data instrumentation

Verbal in-depth face-to-face interviews were vital for data collection in this study. This tool has been shown to afford participants ample opportunity to volunteered sensitive information they might not be prepared to divulge in the presence of others (Robson, 2011). The interviews were audio recorded digitally to permit the researcher's unhindered attention to what the participants' had to say and facilitate verbatim transcription of the data collected. 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. The interview sessions lasted between 30 to 45 minutes.

The design of the semi-structured interview instrument was predicated on the research aim and objectives, an extensive review of the CL±P literature, expert consultations with two Nigerian cleft researchers and previous experience of the researcher with the study population and CL±P research. The interview guide consisted of closed and open-ended questions with a few probes that guided the process (see Appendix 2). A wide range of items addressing the research topic was included to enhanced reliability and content validity of the interview schedule. Topics that were included covered participants beliefs about cleft, and their expectations and experience of treatment in the hospital. The questions were categorised into four parts. 1.) Individuals' information such as name, age, gender, marital status, occupation, ethnic group, address, religion and name of cleft children. 2.) Information about cleft: Family caregiver's personal belief about the cause of CL±P as well as current cultural beliefs on the pathogenesis of CL±Ps and the community's reaction to the cleft child was explored. 3.) Knowledge and expectations of cleft treatment with their experience in accessing the hospital cleft programme. 4.) Ways to increase awareness about the causes and management of CL±Ps and recommendations to improve the cleft services were sought.

In-depth interviews were suitable for this study as they offered the opportunity to ask sensitive questions adapted to the individual confidentially. Thus, it fostered trust and confidence between

both parties and helped accustomed the participants to the nuances of the qualitative interview. Truthful responses to questions on their perceptions of the aetiology of cleft, treatment expectations and vivid experience in using the cleft services were facilitated (Macks et al., 2005).

3.6.2 Preparations for interviews

Ground work involved getting the hospital management approval and the key staff cooperation following a series of discussions regarding the purpose of the study. The management responded affirmative, and the staffs were very enthusiastic. Both sides regarded the study as an opportunity to obtain feedback from their clients that would guide them on ways to engage the community and improve on service delivery. The staff of the cleft programme eagerly offered their cooperation. Hausa is the most widely spoken language in the research location and the regular dialect of all the participants. However, the researcher is not a fluent speaker of the language. Hence, data collection was assisted by three unpaid native speakers of Hausa who were also quite versed in English.

Before the collection of data, briefings and sensitisation of these three local translators on the aim of the research, the qualitative approach of data collection, interview guides and research ethics were held successfully. Deliberation of issues that might arise during data collection were addressed. The team reviewed the English and Hausa versions of the interview guides for clarity and accuracy, which was complemented by a mock qualitative in-depth interview.

Participants were recruited via the hospital specialised CL±P clinic with the assistance of their staff. Prospective participants were approached in person by the research team. Comprehensive explanation of the study aim and its ramifications preceded their invitation to participate in a face-to-face in-depth interview. The subject of non-financial compensation for taking part in the study was emphasised during this process. The researcher arranged an agreed time and place for the interview when a participant expressed an interest in participation. Participants were given the preference to be interviewed together or separately. None who were approached had previously taken part in any study, and many of them were surprised and enthusiastic at being invited to participate. Then again, some were shy and unsure how to respond to such a request until their fears were allayed by the staff of the cleft programme. Essentially, none of them declined our request to participate in the study.

3.6.3 Conduction of interviews

Informed consent was obtained from each participant before the start of the interview (attached in Appendix 1). All the interviews were preceded by research team observance of appropriate local address, personal introductions, salutations and local cultural norms. Moreover, the participants were given full details about the study including the aim and objectives. Without pressurising them, the importance of their contribution, anonymity and confidentiality of the data collected were stressed, and their queries were answered appropriately.

The face-to-face interviews were conducted in English and Hausa. The researcher conducted all the interviews guided by using the English and Hausa interview guides developed for this study. During these interviews, non-prewritten questions were translated from English into Hausa and their responses concurrently translated back into English by the translators. The participants were encouraged to speak their mind without intrusions and probing questions were cautiously asked to clarify certain matters without disturbing the flow of these interviews. Moreover, to avoid the distraction of the participants and ensure maximum concentration, field notes were sparsely taken by the researcher during these sessions. The privacy, trust, cordiality, interview style and rapport established between the researchers and the participants during these interviews provided the enabling environment for the participants' frank expression and detailed responses to the relevant enquiries (Arkey, 1996; Kvale, 1997; Robson, 2011).

The interviews were conducted in privacy at the agreed time and locations within the hospital premises. These premises were convenient, as many participants and the patients stayed there throughout the treatment duration after having travelled from remote rural areas over challenging terrain (average distance travelled 205km). Sometimes at the scheduled appointment, the caregiver would be absent only to be told that they had gone out on an errand or needed to attend to some urgent matters in their village. Therefore, the interview had to be postponed. Some caregivers were only available just before the surgery, and these interviews had to be conducted in the theatre's waiting room. There, we faced the challenge of being interrupted by the theatre staff calling the patient to proceed to the operating room.

During the interviews, only the CL±P children, their caregiver(s) and authorised members of the research team were present, although only the caregivers were interviewed. Since the hospital did not have enough nurses or ward attendants to care for these children, they passively sat in on

the interviews. In three cases, interviews were carried out twice as these participants were only available before and after the surgery. Most of the interviews went well, however, some of the female participants were reluctant to volunteer information regarding the family or community's reactions to cleft deformities or their experience with the hospital services. They had to be persuaded and reassured before commenting.

The interviews lasted approximately 30 to 45 minutes. All interviews were digitally audio-recorded and conscious efforts were made to accurately transcribe them into written transcripts taking cognisance of voice tone, verbal and non-verbal expressions of the participants, thus, ensuring the study's credibility. There was also the challenge of translating different dialects spoken by the rural participants into English and translating certain English words into the local Hausa version spoken by some participants. A few of the participants found it difficult to relate study questions such as the family and society's reactions to cleft deformities and their current experience in the hospital to the treatment of their children. Others were afraid that what they said would be displaying ingratitude if they criticised the hospital services.

3.7 Data analysis

The data analysis was a continuous process initiated during the process of data collection which guaranteed that emerging themes could easily be followed and verified (May & Pope, 2000; Miles & Huberman, 1994). Preliminary data analysis and data collection happened concurrently with the researcher asking probing questions following participants statements during interviews. These assisted focus refinement of questions and further pursuance of emerging themes in subsequent interviews (Legard, 2003; Robson, 2011). Continuous analysis occurred even after the immediate conclusion of each interview, the research team met to cross-check the interview recordings, discuss and identify themes in data for further exploration and to clarify concerns from any interviewees before the final exit of the study setting.

On completing data collection, the recorded in-depth interviews were transcribed verbatim with the insertion of non-verbal expression into these transcripts to facilitate coding by multiple researchers (Mack et al., 2005; Miles & Huberman, 1994; Robson, 2011). Two separate independent bilingual translators who were experienced colleagues from other hospital Departments assisted in completing these. Descriptive analysis of the socio-demographic data of

the study participants was also done using Statistics Package for Social Sciences (SPSS) for Windows Version 20 (IBM Corp., Armonk, NY, USA).

Finally, the researcher and the supervisor performed manual data analysis and interpretation to obtain the study findings. Thereby, achieving researcher triangulation which critically contributed to the study result's credibility (Green & Thorogood, 2004; Robson, 2011).

Thematic coding analysis as prescribed by Miles and Huberman (1994) and Green & Thorogood (2010) were followed throughout this process. The researchers familiarised and immersed themselves with the data through repetitively listening to the audio recordings and comparing the transcripts multiple times until clear recurring words or ideas emerged (Daack-Hirsch & Gambosa, 2010). These repeated words and ideas (God's will, belief, perception, attitudes, culture, food, parents, caregivers, spiritual, appearance, talk, diagnosis, stigma, awareness, access, difficulties, surgery, money, expectations, distance, ignorance, treatment seeking, cleft services) were organised and categorised into initial meaningful codes (May & Pope, 2000; Robson, 2011). Then, these initial codes (aetiology, information about cleft, caregiver perceptions, barriers to care, cultural, attitudes, emotional reactions, family reaction, parent reaction, societal reaction, family support, difficulties, late presentation, facial appearance, speech, constraints, financial implication, experience, recommendation) were refined and related codes with their variances were grouped into candidate themes based on deep reflections of the various participants' responses to the research questions (Patton, 1990).

Subsequently, in collaboration with the supervisor for correct data interpretation, six themes in line with key areas of investigation were agreed on as a sequel of proper checks and fine-tuning (Green & Thorogood, 2010; Robson, 2011). Ultimately, these final themes were summarised in narrative form using examples from each code identified from the data as spoken by the participant (Daack-Hirsch & Gambosa, 2010).

3.8 Rigour

Creswell & Miller (2000) postulated that the worth or merit of any research undertaking is determined by its validity or credibility and reliability or trustworthiness following careful scrutiny. Unfortunately, there is no unanimously accepted criterion for this assessment of the quality or rigour of a qualitative study (Creswell & Miller, 2000; Lincoln & Guba, 1985;

Malterud, 2001; Mays & Pope, 1996, 2000). Therefore, the following strategies were used to establish credibility and trustworthiness in the study and its findings (Malterud, 2001; May & Pope, 1996, 2000).

A proper audit path was followed as the study was conducted in compliance with the approved research and ethics committee (REC) protocol and all the interviews were digitally recorded. All research decisions, activities, roles of research assistants, the staff of the hospital and peer debriefing by colleagues in the hospital were highlighted.

The authority of the researcher was well stated as the researcher possessed theoretical and practical knowledge about CL±P research and had undergone practical training in conducting in-depth interviews at the School of Public Health. However, the researcher was reflexive during the study and strived to examine the impact of his quantitative research background, previous research on cleft deformities, and his job as a clinician in the hospital on data collection and analysis.

There was prolonged engagement and varied experience with the study setting, as the researcher is well familiar with the area having lived and worked there for the last seven years.

Furthermore, data source triangulation was attained by interviewing a broad spectrum of caregivers and an adult cleft individual as informant facilitating the comprehensiveness or completeness of the data gathered. Also, the use of two researchers to carry out the data analysis helped to reflect the multiple dimensions of the data.

Member/participant checks also took place during the study by seeking clarifications during the interviews and verifying after data collection whether the translations accurately captured their responses or conversations (Malterud, 2001; Robson, 2011).

The data wererevisited repeatedly to verify that the conclusions echoed the data, not the researcher's voice. Researcher bias was reduced by corroboration and conformability of the data with the themes generated. The supervisor checked the researcher's coding against the data with areas of agreement and divergence discussed before the adoption of the categorisation of themes and interpretations.

The study adhere to the key objective of qualitative research by not seeking to produce results that are statistically generalisable to the broader population. However, through detailed descriptions of the study setting, explicit expositions of the research processes, precise illustrations of the data analysis, findings and discussion, broad understanding and insights of the participants' perspectives and experience of cleft beliefs, expectations and experience of cleft services . This would enable other researchers to make definite judgement on the transferability of the study findings to CL±P caregivers in similar settings (Robson, 2011).

3.9 Study limitations

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

Also, the sample size was another limitation of this study as the research was not pursued until saturation was reached in keeping with the rigorous standard of qualitative tradition owing to the stringent constraint of mini-thesis protocol.

The staff of the cleft programme 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.

Owing to the time constraints in which the study was conducted, it was not possible to do a longitudinal study on the child's treatment course to see if the perception of causality of CL±P and experience with the treatment received remain constant (Arkey, 1996).

3.10 Ethical considerations

A proposal to conduct the study was submitted and approval obtained from the University of Western Cape higher degrees Research Ethics Committee (APPROVAL REC NUMBER-130416-050) and UDUTH Health Research and Human Ethics Committee (HREC). Participation in the study was voluntary, and the research was conducted based on the guidelines and protocol approved by the above bodies. Following this procedure assured that the autonomy of the participants was protected, and their identity and data collected always kept confidential.

In compliance with the information sheets and informed consent form (Appendix 1&2), the study purpose and processes were explained in detail as participants they were approached and given opportunities to ask questions. Their autonomy, confidentiality and anonymity were respected and assured. All participants were requested in advance to give informed consent once they accepted to be part of the study (attached in Appendix 1).

The researcher is a surgeon at the hospital cleft programme and aware of the power differential that exists between health care providers and their clients (patients and family caregivers). He took steps to ensure that the participants know that the study was voluntary and that their refusal to consent or withdraw from the study had no negative impact on the quality or scope of their care.

Recruitment was facilitated by members of the hospital cleft care programme to guard against the participants being influenced by the researchers, thus, reducing intimidation or bias. The participants were not coerced or offered any financial inducements to partake in the study.

The research design possesses no experimental or quasi-experimental parts, hence, carried no direct health risks to the participants. The study held potential benefits and harm to the study participants. The opportunity to tell their story and be heard hopefully brought the participants psychological relief and the researchers sought to maximise this potential benefit by listening attentively. Additionally, sensitivity to the emotions of the interviewees was upheld. They alluded that their rights of no wrong or right answers and the freedom to respond only to questions with which they were comfortable.

No incident of any emotional upset was recorded throughout the data collection process. The participants were earlier told that if they became unduly upset while telling their story, the opportunity to stop the interview with the option (but not expectation) of resuming later was available. Also, the availability of counselling by trained hospital psychiatrists after the interview was mentioned. Participants were reminded of their right to withdraw from taking part at any stage of the study without jeopardising their children receiving optimal treatment and follow-up care in the hospital.

Interviews were strictly confidential and conducted in seclusion with recordings and other data adequately secured under lock and key. Only the researcher and the supervisor had access to these data, and the interview transcripts were shared between them. Names of persons and places mentioned in the course of the interviews were erased and replaced with aliases.

On completion of this study and after the publication of the full report, no personal identification of the participants was retained. Pseudonyms were used for participants in this study and subsequent publications. However, permission will be sought from affected participants should there be unavoidable exigencies to use any easily traceable information. The data will also be kept for the maximum number of years as required by the University REC before destruction.

that the study would help to develop and plan a cultural congruent health education programme in tandem with local customs and beliefs about CL±P and consequently, impact on the health of the region and the country at large. Results will be shared with the hospital management as well as the regional Department of Health officials responsible for the craniofacial anomalies community awareness programme.

Chapter Four: Findings

4.1 Introduction

The findings of this study including the socio-demographics of the family cleft caregivers (Table 1) are presented in this chapter. These findings are presented and organised according to the themes that emerged based on the objectives of the study and the data analysis done.

The analysis showed great overlap and consistency among participants' experiences and responses to questions with little divergence. Most of the themes emerged from the participants' answers to the questions during the face-to-face in-depth interviews.

Generally, it was found that there were common elements of caregivers' beliefs about cleft aetiologies, expectations, perceptions and experience of cleft services. Six themes were explored with caregivers and one adult cleft patient:

- (1) Beliefs about the aetiology of cleft;
- (2) Reaction to the occurrence of a cleft by the caregivers, extended family and society;
- (3) Source of information about the surgical treatment;
- (4) Treatment expectations;
- (5) Experience with the cleft service of the hospital; and.
- (6) Recommendations on how to increase awareness and improve services were volunteered.

4.2 Socio-demographic characteristics of the cleft patients' family caregivers

The study participants consisted of 20 caregivers and one adult cleft patient (Key informant). Most of the participants had single interviews (n=14) with four joint interviews of both parents being conducted at the interviewees' own request. About two-thirds of the participants (n=13) were females and their ages ranged from 18 to 60 years. Half of the participants were mothers trailed by five fathers. The respondents were overwhelmingly Muslims (n=18); all were geographically from north-western Nigeria. A leading proportion of the respondents were

housewives (n=14) without any previous family history of orofacial cleft (n=18) (Table 1). Most of the interviews were conducted before the surgeries (n=15).

Table 1. Socio-demographics characteristics of participants

Participants characteristics	N
Caregivers	20
Key informant (Patient)	1
Relationship of caregiver to cleft patient (n=20)	
Mother	10
Father	5
Grandmother	2
Paternal Uncle	2
Step Aunt	1
Type of interview	
Single	12
Joint	4
Gender	
Male	7
Female	13
Age Groups (Years)	
<21	3
21-30	6
31-40	7
>40	4
Tribe	
Hausa /Fulani	18
Non-Hausa	2



Religion	
Christianity	2
Islam	18
Occupation	
House wife	14
Teacher	1
Health related employee	1
Farmer	3
Artisan	1
State of domicile	
Sokoto	12
Kebbi	5
Katsina	1
Plateau	2
Level of education	
Illiterate	17
Literate	3
History of cleft in the family	
Present	2
Absent	18
Type of cleft of caregivers' children	
Cleft lip only	2
Cleft lip and palate	16
Cleft palate only	2
Age group of caregivers' cleft children	5 days -50years
Timing of interviews	



Before	15
Before and After	5

Theme 1: Common beliefs about the aetiology of clefts

We asked caregivers whether they had encountered cleft lips and palates before their own children were born with the condition as well as what they and their communities more generally believed to be the cause of cleft deformities.

Sub-theme 1.1: Previous encounters with cleft

Most carers reported that they had never come across cleft until the birth of their child.

Comments such as the quotes below dominated:

...only my son has it. (29-year-old farmer from rural district, father of 11-year-old boy with cleft lip)

...In Lagos I have not any... (35-year-old housewife from rural district, mother with 2-year-old cleft-lip boy)

Several, when we were students during our hospital postings... (29-year-old community health officer from rural district, paternal uncle of 1 year 5-month-old boy with cleft lip)

This was supported by the finding that not many of the caregivers had a previous family history of CL±P (Table 1).

However, a few of the participants had encountered cleft before. For example:

...I have seen it in our two town children. (22-year-old house wife from rural district, mother of 1-year-old girl with cleft lip)

Even my own sister had a similar case then... (30-year-old Step Aunt from rural district of 5-days-old baby girl with median cleft)

The truth is that I have been seeing it with others... (35-year-old farmer from rural district, father with 5-year-old girl with cleft lip)

Sub-theme 1.2: Caregivers' beliefs about the causation of cleft lip and/or palate.

Most of the caregivers we interviewed, regardless of age, declared ignorance about the cleft aetiology, stating quite openly, for example:

...I don't know anything that causes this problem... (40-year-old house wife from rural district, mother of 6-year-old girl with cleft palate)

I don't know the cause, since I gave birth to her like that. (20-year-old housewife from rural district, mother of 1 year 5-month-old boy with cleft lip)

The truth is I don't know what causes it... (35-year-old farmer from rural district, father of 5-year-old girl with bilateral cleft lip and palate)

I am not thinking that it is anything that caused it... (30-year-old unemployed woman from rural district, Step Aunt a 5-day old baby girl with median cleft)

True to God, I do not know anything about this or whatever caused it... (38-year-old housewife from rural district, mother of 18-year-old girl with cleft lip)

Furthermore, most participants went on to spiritually link it to divine will and predestination in resonance with the strong religious and cultural convictions among the respondents (Table 1). For example:

I just believe that is how Allah created her... (22-year-old housewife from rural district, mother of 1-year-old girl with cleft lip)

In fact, I think it is just that Allah made it happen, I never thought of any other thing. (18-year-old housewife from rural district, mother of 2-year-old boy with cleft lip).

...I do not know the cause of this, except that it is God's will...it is only God has decreed that he is going to be born like that, therefore he has to be born... (55-year-old farmer from rural district, uncle of 50-year-old man with cleft lip)

The truth is that...I think it is God's will. (60-year-old housewife from rural district, grandmother of 4-year-old girl with bilateral cleft lip)

However, three participants including a community health officer involved in cleft mobilization in one of the local districts in Sokoto state and two mothers; one with previous surgical repair for her daughter in this hospital and the other who delivered in one of the hospitals in the metropolis blamed herbal medicines, prescription drugs and over-the-counter medications used during pregnancy. These assertions might be as a result of the health training exposure or information obtained from former contacts with health professionals. For example:

...and I also discussed causes of this issue which include herbal medications, unprescribed drugs for headache, abdominal discomfort as self-medication which is very common in that area. (29-year-old health care worker from rural district, uncle to 1-year 5-month-old boy with cleft lip)

They are saying that it is probably from the drugs I took while pregnant, because I was admitted at Specialist Hospital when the pregnancy was four months. That I had malaria and I reacted to some of the drugs like Amoxil and Avomie. (29-year-old housewife from rural district, mother of 5-months-old girl with bilateral cleft lip)

Sometimes I used to ask people what doctor said cause this cleft they would say it is medicine...I suspect it is that medicine I used from the chemist during pregnancy caused this... (35-year-old housewife from urban district, mother of 4-year-old girl with bilateral cleft lip and palate)

Sub-theme 1.3: Society's belief on the causation of CL±P

Society's understanding and dominant explanation of any disease influence the individual and collective decision of members in their choice of solution and coping with the fall out of the disease. Therefore, the health/well-being of the cleft patient and the caregivers dealing with the plethora of negative psychological impact of this phenomenon are predicated on the society knowledge and understanding of the causation of CL±P. In turn, this affects the awareness about availability, timing and advantages of early repair of cleft which ultimately reduce both the caregivers and society psychosocial burden and help to produce a well-adjusted aesthetically pleasing person to the society.

We asked carers what beliefs about causes of cleft deformities were held in their communities. Unsurprisingly we found that these largely mirrored of the participants' belief. However, some carers had encountered superstition and belief in spirits:

...Hausa people sometimes do say it is jinn (spirit)... (35-year-old Mechanic from urban district, father of 8-month-old boy with cleft lip)

...They are only saying he is one of those creatures... (20-year-old housewife from rural district, mother of 1-year 5-month-old boy with cleft lip)

...It was only the people that were saying it was from jinn that caused it that I should take her to traditional doctors... (40-year-old housewife from rural district, mother of 6-year-old cleft-palate girl)

These beliefs may also reflect a lack of health education (and thus one could argue a demonstration of the underperformance of the Nigeria's health system) as the overstretched hospital community cleft outreach programme clearly does not reach remote communities.

Theme 2: Reactions to the cleft lip and/or palate

The participants displayed conflicting emotions in response to the occurrence of orofacial cleft as observed in this study.

Sub-theme 2.1. Common reactions to CL±P

The study results revealed that the birth of child with cleft with aesthetic or speech impairment elicited myriads of emotional reactions depending on the participants' close relation to the affected child and religious orientation (Table 1).

The data from the research suggests that many mothers among the female caregivers were unperturbed and quite remarkably accepted the condition adjusting accordingly. For example:

I was not sad when I had her I have 5 previous children that were okay... (40-year-old housewife from rural district, mother of 6-year-old cleft-palate girl)

It didn't disturb me in fact I am going around with my baby like that... (40-year-old housewife from rural district, mother of 6-year-old girl with cleft palate)

People are coming to see her condition, and I don't hide her from them, since this is how Allah gave her to me... (22-year-old housewife from rural district, mother of 1-year-old girl with cleft lip)

They said look at her leg I said no problem it is God that gave me... I thank God... (35-year-old housewife from urban district, mother of 4-year-old girl with bilateral cleft lip and palate)

However, some were worried and expressed their helplessness at the situation, again highlighting the lack of reach of the hospital outreach programme. For example:

To say the truth, I felt bad... (29-year-old housewife from urban district, mother of 8-months-old girl with cleft lip)

I was disturbed a little bit... (20-year-old housewife from rural district, mother of 1-year-old boy with cleft lip)

...before this time I don't know what to do about his condition... (18-year-old housewife from rural district, mother of 2-year-old boy with cleft lip)

A few of the study participants expressed severe anxiety and dreaded the prospect of being marginalised or being made a laughing stock in the society. For example:

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... (40-year-old housewife from rural district, mother of 6-year-old cleft palate girl)

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... (35-year-old housewife from urban district, mother of 4-year-old girl with bilateral cleft lip and palate)

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...(60-year-old housewife from rural district, grandmother with 4-year-old girl with cleft)

...they said to my friend don't take your child she has problem in her brain. (40-year-old housewife from rural district, mother of 6-year-old cleft palate girl)

...So, I said let me bring her too, before she reaches that stage of people avoiding to marry her. (40-year-old housewife from rural district, grandmother of 13-year-old girl with cleft lip)

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 why she had not brought the child at an earlier stage.

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 personal do not hear of it, even if there is any since I'm not always at home... (35-year-old farmer from urban district, father of 5-year-old girl with cleft lip)

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...(50-year-old man with cleft lip)

In addition, our findings also revealed that numerous participants received appreciable support from their extended family members which helped to allay anxiety, worry and other negative emotions about their social image, child's integration in the society and future. For example:

All our relatives (accepted) and said it is nothing... they said cases like this are seen often. (29-year-old housewife from rural district, mother of 5-months-old girl with bilateral cleft lip)

Although, one of the participant stated that her husband was unhappy with another respondent pointing at the breakdown of her son's marriage.

...he was not happy but later when they told him it can be repaired he then changes his mind. (29-year-old housewife from rural district, mother of 5-months-old girl with bilateral cleft lip)

Her father divorced her mother and since then she has not come back to see her since 12 years ago... (40-year-old housewife from urban district, grandmother of 13-year-old girl with cleft lip)



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Sub-theme 2.2: Reasons for delays in seeking treatment

Lack of information

The data demonstrated that many participants brought their children late for diagnosis and surgical correction (Table 1). The study results exposed a range of reasons for this.

Ignorance on the various types of cleft and lack of proper knowledge on timing, how and where to obtain treatment were prevalent among the participants, especially those residing in rural districts with limited access to modern health care resources. Some of the participants who commented on this tried to exclude themselves from this position as evident in the following expressions:

For people that [who] live in the village they do not know that it can be repaired and is even free... (35-year-old mechanic from urban district, father of 8-month-old boy with cleft lip)

The truth is that we were waiting for him to grow bigger and more so I have never heard of this program in this hospital despite the fact that I have been coming to this town for more than 20 years.(41-year-old school teacher from rural district, father of 3-year-old boy with cleft lip)

...they do not know it can be repaired...they said to my friend she is “juyaya”(Mad) that is why they don't bring her to the hospital.(40-year-old housewife from rural district, mother of 6-year-old cleft palate girl)

...their reason is that they have nobody to advise them and they think it is too late... (29-year-old community health worker from rural district, uncle to 1-year 5-month-boy with cleft lip)

Importantly, some participants reported that they were advised by some health care workers that the surgery can only be done until the child is older; hence, they kept on waiting for the right time. This also reflects misinformation and lack of relevant knowledge among frontline healthcare providers, emphasising an urgent need to educate this group of health professionals on cleft deformities and the timing of cleft surgery. For example:

...the person I told you we went to is a senior hospital staff and he told us that until the child has grown up nothing can be done...I went to him several times I can't even remember the number of times and each time he will say let him grow a bit longer....the staff said no we should allow him

to grow a bit more before taking him to the hospital is better... (40-year-old farmer from rural district, father of 6-year-old boy with cleft lip)

Lack of finances

Furthermore, the issue of finance was also implicated in the study as the reason for late presentation by some of the caregivers. For example:

...we had no money for treatment until when the agent (volunteer community mobilizer) that send me to this place gave me assurance that all I need to do is get transport money. (41-year-old school teacher from rural district, father of 3-year-old boy with cleft lip)

We are farmers and do not have money for treatment we are just trying to survive... (38-year-old housewife from rural district, mother of 18-year-old girl with cleft lip)

The research also showed that the study participants covered large distances from their homes to access surgical care at the hospital (Table1). Out-of-pocket expenses like transportation and upkeep of the child, caregivers and other family members that would accompany the child to the hospital from their remote homesteads might have been underestimated by the cleft service provider and hospital management as a strong barrier to accessing care in the hospital. Coupled with the timing of the surgery clashing with crucial work as several participants were farmers or cattle herders, they could not afford the cost of prolonged hospital stay and hiring workers to help on their farms or look after their herds particularly in the short planting and harvesting seasons. Sometimes this hospitalisation could drag longer than two to three weeks as a result of the large volume of patients, lack of theatre space, incessant power outage as the hospital relied on a generator because of the unreliable public power supply; the surgeons are on official assignments like annual leave or the theatre staff declaring an industrial action. For example:

I said I will not go to anywhere again (I will remain in the hospital until all treatment are concluded)...if they finish the surgery I will go back to Warri. (35-year-old housewife from urban district, mother of 4-year-old girl with cleft lip and palate)

We advised the parent to come to the hospital when they are capable (have enough money for treatment)... (40-year-old housewife from rural district, grandmother of 13-year-old girl with cleft lip)

...until when the agent (volunteer community mobilizer) that sends me to this place gave me assurance that all I needed to do is get transport money... (41-year-old school teacher from rural district, father of 3-year-old boy with cleft lip)

We are farmers and do not have money for treatment we are just trying to survive... (38-year-old housewife from rural district, mother of 18-year-old girl with cleft lip)

...what we spend on transport from our district to shuni and then shuni to Sokoto is not more than #10000 (~\$3) the truth is that we have abandon our farming work because it has already started before we came here...(55-year-old farmer from rural district, uncle of 50-year-old man with cleft lip)

The study also revealed that the participants covered a tremendous large distance from their homes to access surgical cleft treatment at the hospital. They cited having to risk using commercial motorcycles as their villages' roads were in deplorable condition, and how hazardous and expensive this mode of transport was to them and their family. These structural barriers highlight the caregivers hurdles they have to overcome to utilise the hospital cleft service and suggests the need to bring this programme closer to this deprived and neglected communities.

In addition, the cultural norm of obtaining permission from the father of the child was also observed as a possible factor in the present study. The mothers expressed difficulty in getting this from some fathers in a situation where they are difficult to reach because of the nature of their work that does not permit them to stay in a location for long.

However, one participant divulged that two decades ago they tried unsuccessfully to access cleft treatment in the hospital when foreign surgeons on a medical mission were there to provide these services. These missions used to last for two weeks and about three times a year with the constant change of personnel.

He was once here in this hospital about 20 years ago, by then it was Europeans that[who] usually came in large numbers, he was even on admission for 20 days, he was even prepared for surgery, and then they said he was not the one to be operated upon. So, he went back home, so I said to him that he should exercise patience. He said he has accepted his fate from God. Not

until two days ago, on Wednesday, when somebody met us to inform us to come to this hospital on Thursday, i.e. the following day... (55-year-old farmer from rural district, uncle of 50-year-old man with cleft lip)

Theme 3. Source of information about the surgical treatment

The study finding demonstrated that the caregivers' sources of information were by word of mouth, contact with previously treated patients, radio, family members, religious scholars and close friends. Most of the participants came from traditional communities where importance is placed on regular communal interaction and ceremonies, as each individual is considered to be a member of the society. Hence, people rely on the information of those patients from their community who have been treated. Also, religious scholars, who are integral members of the local communities, are highly revered for their vast knowledge, piety, leadership and accessibility. Moreover, radio is the most popular and reliable source of information in this region, as it is very portable, cheap and easy to operate. Therefore, it can be found in the most remote parts of the region. For example:

We heard it on radio, but I have already told you how I came to know about this hospital because I asked, and they told me it was done in Sokoto. (40-year-old housewife from rural district, grandmother of 13-year-old girl with cleft lip)

I have seen two children in my village with cleft that [who] were brought here for treatment. It was after seeing their repair that gave me courage to bring my child here... (22-year-old housewife from rural district, mother of 1-year-old cleft-lip girl)

A younger brother of mine was here, he brought someone, and he called me on phone because he had [a] discussion with a staff [member] here and explained to him that he had a nephew with this condition. So, I was told to bring her on Monday, but I was not called on Monday until Tuesday, so I brought her on Tuesday... (35-year-old farmer from rural district, father of 5-year-old girl with bilateral cleft lip)

The data highlighted that many of the caregivers were given the wrong information about the cleft surgeries before their presentation for treatment. This suggests the need to urgently address these concerns by making available simplified public-friendly information covering every aspect of the services. For example:

Some people told me that part of my skin will be used to correct the defect... (29-year-old housewife from rural district, mother of 5-month-old girl with a bilateral cleft)

I thought if they do the surgery(cleft-lip repair) only once everything would be fine, but they told me there is still inside (cleft-palate repair)...(35-year-old housewife from urban district, mother of a 4-year-old girl with bilateral cleft lip and palate)

Theme 4: Treatment expectations

The study showed that the caregivers had great hopes in the cleft treatment with strong desires that the surgeries would reverse to normality the looks and speech of their wards. They displayed tremendous endurance making personal and collective sacrifices while awaiting surgeries.

The data also displayed that many participants, since they had come to the hospital, had great hopes for the surgical repair and eventual social integration of their children. Although, they knew little about the surgery duration, how long they would have to wait, and how many other surgeries would be needed to correct their child's malformation. The study exposed the need of the cleft team to fully inform caregivers and address their emotional concerns by the provision of free psychological services. Also, to create more awareness about the realistic outcomes of the treatments and communicate effectively regarding the surgery through more community involvement.

In the present study, the caregivers' high hopes for a successful treatment outcome were underlined. They had multiple expectations including aesthetics, speech, social acceptance and general improvement. Some caregivers were hopeful that their children's speech would be corrected, and they would not continue to be an object of ridicule by their peers which would boost their confidence in personal interactions, facilitate their making friends, ensure their children participate in public activities and guaranteed seamless integration into the society. They also desired that it would help them to get both formal western and Islamic qualitative education. Here are some of the caregivers' comments:

Hawwh, I wish this place can be closed (repaired) to look like any other person I would be very happy... (29-year-old farmer from rural district, father of an 11-year-old boy with a cleft lip)

...They will only be congratulating us for a successful surgery. (40-year-old housewife from rural district, grandmother of a 13-year-old girl 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... (22-year-old housewife from rural district, mother of a 1-year-old girl with a cleft lip)

I know by God's grace everything would be fine...I would be happy if her speech is okay. (35-year-old housewife from rural district, mother of a 4-year-old girl with a bilateral cleft lip and palate)

My child is 18 years old, she has finished primary very long time ago...when I bring her to this place I want it to be repaired after then I will get her to start secondary school.(38-year-old housewife from rural district, mother of 18-year-old girl with a cleft lip)

If for instance, she had operation she can go to school and mix with others without any trouble. (35-year-old farmer from rural district, father of a 5-year-old girl with a bilateral cleft lip)

One of the caregivers was hopeful that there might not be any complication of surgery as many of the locals has fears that there are high chances that one would not make back alive after surgery especially under general anaesthesia.

For us the only way you can help us is by doing this operation and if it heals God willing without any complication. (55-year-old farmer from rural district/50-year-old nephew cleft patient)

The study showed that the caregivers were not sufficiently informed about what to expect during their stay in the hospital. Because of the complexity of procedures, there were often substantial delays in surgery and thus prolonged hospital stays. Because the hospital is severely understaffed, attending caregivers are also expected to assist with a range of non-medical duties at the hospital. These may include cooking and cleaning, taking blood samples to the laboratory, and retrieving laboratory results among other things (Abdurrazaq et al., 2013). These rules of staying and helping in the hospitals and the resulting potential of loss of time, productivity and huge unforeseen expenses were not brought to their awareness. Instead, they expected to go home immediately after surgery. For example:

...I expect that when she gets well we can go back home. (22-year-old housewife from rural district, mother of a 1-year-old girl with cleft lip)

The hospital should improve...make the timing for surgery very short. (20-year-old community health worker from a rural district, uncle to a 1-year 5-month-old boy with cleft lip)

...mmm the wards you know at times people they are plenty some will be neat some will be dirty if you tell them to be neat or if they mess up the place you tell them to sweep it they will 'ah' this one is worrying people may be you come so you mind your business...I will sweep the place before the woman come I will sweep the place. The other Hajiya (Lady) too use to sweep the place...because if they come they will not say that it is only one person they will say it's all of us.(35-year-old housewife from urban district, mother of a 4-year-old girl with cleft lip and palate)

These data also highlighted that many of the caregivers possessed sparse information about the cleft surgeries before their presentation for treatment. Therefore, the need to urgently address these concerns is again suggested by making simplified public-friendly information available that covers every aspect of the services. For example:

Some people told me that part of my skin will be used to correct the defect... (29-year-old housewife from rural district, mother of a 5-month-old girl with a bilateral cleft)

I thought if they do the surgery (cleft lip repair) only once everything would be fine, but they told me there is still inside (cleft palate repair).(35-year-old housewife from urban district, mother of a 4-year-old girl with bilateral cleft lip and palate)

Theme 5: Experience of care givers with treatment

The data demonstrated that most caregivers had warm recollections of their encounters with the hospital's cleft services. They commended the clinical staff work ethics, expertise and inter-personal relationship. Also, they were pleased with the free medications/treatment and surgical outcomes. However, there were some expressions of discontentment on the long waiting time for surgeries, limited communication about the timing of treatment for those who required multiple surgeries, lack of cleanliness/poor sanitation, low quality of in-patient food, and indiscriminate visiting times.

Sub-theme 5.1: Pre-operative experience of care givers

The study data revealed that the caregivers were not at ease in articulating negative judgment regarding their pre-operative hospital experience, as they probably saw the doctors as God sent to bail them out of their predicaments and were shy to appear ungrateful. The difficulties encountered were considered as part of the price of getting surgical care for their children. The rigours of travelling multiple times from their home to the hospital to see many specialists involved in cleft management, performing various investigations prescribed and eventually getting clearance for surgery, they presumed were necessary experience before their dreams were actualised. An example:

People should be glad about what is being done for them in this hospital. (38-year-old housewife from rural district, mother of an 18-year-old girl with a cleft lip)

Moreover, there were widespread expressions of appreciation by a cross-section of the caregivers on how they were warmly received at the hospital at their first visit, the friendliness and empathy displayed by the staff and specifically to their children. Also, the valuable time invested and the unhurried thorough medical examinations given to their children before arriving at a diagnosis. These findings suggested that they perceived the doctors and other cleft staff of the hospital to be competent, have good interpersonal skills, and caring, trustworthy and empathic to their needs. They also displayed immense confidence in the expertise of the team, as they were not disappointed by the professionalism witnessed at hand. For example:

In-fact they are all try[ing] 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. (29-year-old housewife from rural district, mother of a 5-month-old girl with a bilateral cleft lip)

...no rejection. Everybody is welcoming us no harassment... (35-year-old mechanic from urban district, father of an 8-month-old boy with a cleft lip)

‘...there were no[t] any difficulties... (35-year-old farmer from rural district, father of a 5-year-old girl with a cleft lip)

...the outpatient department to the laboratory, they are all hospitable especially one guard man is exceptional...they talk to us politely...we did not pay for any services. (20-year-old community health worker from rural district, uncle of a 1-year 5-month-old boy with a cleft lip)

Nevertheless, few of the study participants did express concern about the unexpected delay in surgery, paucity of detailed information about the surgeries, long interval between the repairs of the lip and the palate and poor coordination of appointments, which had caused protracted hospitalisation, loss of productivity, financial inconvenience, absence from work and their loved ones. For example:

I was very eager to do the surgery they told me one part would be taken care of first, before closing the inside. Then she fell sick and it is like this waiting is long... (40-year-old housewife from rural district, mother of a 6-year-old cleft-palate girl)

The hospital should improve on surgical expertise and also make the timing for surgery very short. (20-year-old community health worker from rural district, uncle to a 1-year 5-month-old boy with a cleft lip)

One mother expressed her dislike of the quality of the food served and the need to add more seasoning. The poor state of sanitation in living areas of the hospital such as the bad odour from the unhygienic toilets and the irregularly cleaning of wards was also observed. The uncontrolled access of people to the wards at all times of the day, which compromised their privacy was also frowned upon. For example:

Truthfully it is only the food...they are not putting enough ingredients like Maggi (seasoning) and oil... at times they are not eating the food it does not have [a] taste...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...the ward people are plenty; some would be neat some would be dirty...you come I come mind your [own] business [do not intervene in fellow carers' issues]. (35-year-old housewife from urban district, mother of a 4-year-old girl with bilateral cleft lip and palate)

...visiting should be reviewed so that we can decongest the ward. (20-year-old community health worker from rural district, uncle to a 1-year 5-month old boy with a cleft lip)

Sub-theme 5.2: Post-operative experience of care givers in the hospital

The data revealed that the small cohorts of five participants who were interviewed after surgery shared general positive views about their post-operative experience. They were especially pleased that their children's surgeries turned out successfully, which they could see in their children appearance and speech. Many people, globally, have a great fear of surgery under general anaesthesia, worrying that one would not make it back alive. Hence, they would only consent to it out of necessity. In addition, while surgery is ongoing, there is a lot of anxiety with many praying while pacing up and down the theatre vicinity. They are eager for any news from the theatre staff and were quite invigorated to learn that there was no casualty or occurrence of any adverse outcome. Many of the interviewees having lived with their children's OFC and some with the stigma for a long time felt overjoyed and at ease on seeing the dramatic transformation in the look and manner of speaking of their children. They were exhilarated that the right decision was made in bringing their children for treatment and would be returning home to reuniting with their communities and resume their social life/daily source of income. Hence, they profusely shower prayers and gratitude to the surgical team for lifting this heavy burden. For example:

We thank God that on the day of surgery we did not experience bad things we appreciate everything... (29-year-old farmer from rural district, father of an 11-year-old boy with a cleft lip)

...we are happy with the surgery... May Allah reward you all. (40-year-old housewife from a rural district, grandmother of a 13-year-old girl with a cleft lip)

By Allah we are happy, we thank Allah, we praise the Prophet (Peace be upon Him) and may Allah reward you abundantly...indeed thank you. (60-year-old housewife from rural district, grandmother of a 4-year-old girl with a cleft lip)

...since I have seen that mine was operated, I have seen with my own eyes and I am pleased...now my tears have been wiped away... (18-year-old housewife from a rural district, mother of a 2-year-old boy with a cleft lip)

The norm in many public hospitals across SSA including Nigeria is for patients' relatives and carers to purchase and provide the necessary consumables for surgeries and drugs which are not

limited to antibiotics and analgesics from their pockets in addition to paying the surgical fee. This could be quite expensive and often strenuous as they have to move from the inpatient pharmacy to the outside chemist for those they could not find in the hospital. For a stranger who is unfamiliar with the city, this can also be stressful which make them fall prey to fake drugs peddlers, street urchins and confidence tricksters. Therefore, they displayed immense appreciation with the provision of free drugs, consumables, inpatient care, regular dressings, and other miscellaneous gratuities.

We are grateful for all that was done to us, because a lot has been done to us, in terms of providing free medications and everything is free, may Allah reward you abundantly. (22-year-old housewife from a rural district, mother of a 1-year-old girl with a cleft lip)

Theme 6: Caregivers' recommendation to improve cleft services

In the present study, several suggestions were made by the participants to widen and improve the quality of cleft services in the hospital. The study data highlighted that information was crucial to the mothers and other caregivers to know the causes of the cleft, seek proper diagnosis and care of the cleft deformity. Information about cleft was totally inadequate, as in several rural and urban centres the nurses, community health officers and the attending doctors failed to furnish them with this much-needed support. Even after delivery, there was no cogent explanation given to the mothers and their family on the diagnosis of clefts, health implications and the modalities of treatment. Therefore, some of the participants stressed the importance of providing timely information about cleft during this early period, especially targeting women of reproductive age. Four of the participants, for example, suggested:

...educate our villagers more than anybody with this type of condition should come to the hospital and treatment is free...educate people about...the likely cause and how to prevent it most especially women. (35-year-old mechanic from urban district, father of an 8-month-oldboy with a cleft lip)

...people should be educated about those causes so that they can avoid them... (41-year-old school teacher from rural district, father of a 3-year-old boy with a cleft lip)

Eh-eh-eh, okay you know there is [an] advertisement that can be done, it depends on villagers, you know if he didn't hear the news, it will be difficult for him to know what is going on, you see.

But when he hears the advertisement it is possible for him to follow how he can get to that place, so that he can come and benefit from that. (18-year-old housewife from rural district, mother of a 2-year-old boy with a cleft lip)

My advice is that you people should continue your public enlightenment so that people will respond when they listen to it. (40-year-old housewife from rural district, mother of a 6-year-old girl with cleft lip and palate)

Furthermore, the study participants emphasised the need to utilise radio more effectively as a means to popularly disseminate information about cleft to the public especially those in rural communities where radio is more patronised than other forms of communication. For example, three of the caregivers stated that

...since this programme is now on [the] ground it will be very good if you advertise on radio that anybody with this condition should come for treatment... (41-year-old school teacher from rural district, father of a 3-year-old boy with a cleft lip)

...people in the village don't use to have television or telephone but virtually all of them have radio set...continue public awareness on radio... (29-year-old farmer from rural district, father of an 11-year-old boy with a cleft lip)

...there are certain villagers that neither use cell phone nor radio but when they hear from those that listen to radio they will get the message... (18-year-old housewife from rural district, mother of a 2-year-old boy with a cleft lip)

The study results also showed that stakeholders outside health sectors such as Islamic scholars who are highly revered in the communities should be deliberately targeted, enlightened and provided with relevant information/brochure on cleft management. Furthermore, it also suggests the need to involve others like local teachers, traditional birth attendants and students to be co-opted in spreading timely information to caregivers and society about the cause of cleft and how to easily get treatment (Table 1). For example, one mother said:

Our Malaams (Islamic scholars) are well respected since people accept that it is from God if they also tell people since God brought it He has also brought the solution through surgery...many people don't know about this place and the correction of this problem if radio

broadcast can be maintained and use to tell people I believed our people with this problem will come. (40-year-old housewife from rural district, mother of a 6-year-old cleft-palate girl)

They also advised on the speedy treatment dispensation to minimise their stay in the hospital, dislocation from home, disruption in the child's education and loss of income. For example, some of the caregivers, mostly males and farmers, said:

There should be ways to improve, shorten the length of the processes so as to reduce stress... (28-year-old farmer from rural district, father of an 11-year-old boy with a cleft lip)

...so, I will be coming and going every time every time every time...I want them to finish their work first. (35-year-old housewife from rural district, mother of a 4-year-old girl with cleft lip and palate)

... 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. (55-year-old farmer from rural district, uncle of a 50-year-old man with a cleft lip)

...I have planted but you know even after planting you have to plough...now in our area, the millets have grown. (40-year-old farmer from rural district, father of a 6-year-old boy with a cleft lip)

Additionally, the findings of the current study also demonstrated that some participants advised that the hospital should improve its general hygiene, environmental sanitation, visiting timing and inpatient food. For example:

...toilet maintenance should be improved...they should be cleaning it regularly. (20-year-old housewife from rural district, mother of a 1-year 5-month-old boy with a cleft lip)

Antiseptic should be use[d] in cleaning the ward...awareness creation...for example...spitting of saliva or [a] cough on the ground...use their leg to rub it on the ground...visiting should be reviewed...decongest ward. (20-year-old community health worker from rural district, uncle of a 1-year 5-month-old boy with a cleft lip)

...They are cooking nice, but they are not cooking enough...the food doesn't have taste. (35-year-old housewife from urban district, mother of a 4-year-old girl with cleft lip and palate)

Chapter Five: Discussion

Introduction

In this chapter, the analysis and interpretation of the results of this study relating to the literature and research done elsewhere are presented. The key issues that emerged based on what was learned from engagements with caregivers and the underlying rationale for this study are highlighted. These were to understand better why children with CL±P deformities present late at our hospital, although a free service is available.

5.1 Knowledge and attitudes towards CL±P

In the study, we showed that the attitudes towards CL±P that caregivers displayed were fundamentally shaped by their deep Islamic faith in contrast to other findings from various part of Africa that observed beliefs in myths and spirits (Antwi-Kusi et al., 2015; Adeyemo et al., 2017; Oladega et al., 2017). While some did express worry and sadness, the predominant sentiment was one of acceptance and a belief that this was Allah's will.

The current work also underlines that there is little or no information available in communities about CL±P deformities perhaps in part, because of limited access to health services. Another reason highlighted in the literature is that health service providers do not necessarily provide the correct information, possibly as a limitation of their formal training and exposure to cleft anomalies. This observation supports previous findings by Adeyemo et al. (2009), Agbenorku et al. (2013) and many other studies that late presentation for treatment persists in low-income and low-middle-income countries in SSA.

Encouragingly, the research also demonstrates that once the correct information about surgical cleft services at the hospital was made available, there was great eagerness to present their charges for treatment among the study participants. Therefore, this positive attitude towards cleft treatment displayed by the caregivers can be exploited by the cleft awareness team. This could be achieved through the early empowerment of the caregivers providing them with adequate information and expanding the theatre facilities. Also, engaging more peri-operative personnel

and cleft surgeons to reduce the workload and avoid client disappointment when they do respond to this social marketing campaign will be advantageous.

5.2 Barriers to treatment seeking

However, even when the study revealed that barriers to treatment of cleft were substantial, the hospital seemed to be underestimating the financial and time costs needed to be borne by families of CL±P patients, although the treatment is free. Although earlier studies have considered the cost of surgery, drugs/consumable and hospitalisation in isolation, there is a paucity of specific information on the effects of expenses such as transport, feeding and loss of productivity as barriers in accessing cleft services in developing countries (Adeyemo et al., 2009; Agbenorku et al., 2013; Nelson et al., 2012; Cassell et al., 2012, 2013). Cassell and colleagues (2013) discovered that caregivers with CL±P children considered long travel distance, transportation means/cost and time as serious impediments in the accessibility of cleft services. Agbenorku and other workers (2013) stated that these barriers could be removed by decentralising cleft care through improving the knowledge of primary health care providers about CL±Ps and posting cleft specialists to these peripheral clinics.

In this study, other health system barriers were also exposed which include:

5.2.1 Absence of traditional birth attendants' connection to the formal health system

The finding of the research showed that TBA, who had no link with the formal health system, attended most births, and thus may have neither the knowledge nor the intention to refer babies born with CL±P deformities as soon as possible. Information is essential to the mothers and other carers of cleft during this trying early period to aid diagnosis and give treatment direction. Therefore, because of the deep trust enjoyed by the TBA in their various communities, a direct formal contact with the cleft team would have helped the children with CL±P. Benefits from early surgical intervention decrease the burden of cleft on the region's fragile health system. Therefore, it becomes imperative to team up with the TBA and accord them a prominent role in the cleft management and mobilisation efforts. Regular structured training should be given to them on how to recognise CL±Ps and the importance of quick referral to the cleft specialists or centres.

5.2.2 Primary healthcare providers' insufficient knowledge about CL±P

Health care providers in decentralised facilities do not have the necessary knowledge to advise and refer patients accurately. Previous research in the SSA countries held the low cadre of health care workers with little or no training in CL±P manning these centres and the dearth of cleft specialists to visit the vast terrain and population of the region responsible.

The finding in this study, thus, suggests that there is an urgent need to provide regular cleft education on the early referrals of cleft babies for surgical corrections for different health cadres at the numerous peripheral clinics spread throughout the region. Irreversible consequences of cleft treatment delay like speech impairment and mortality recorded should be drawn to their attention.

5.2.3 Lack of sufficient information from the hospital

In addition, the study revealed that the hospital does not supply sufficient communication to carers. Seemingly this concerns all aspects of treatment such as length of stay, what to expect, need for support and others. Nelson & Kirk (2013) observed that delivering quality cleft care is demanding and would require the provision of clear, detailed, specific explanations of the surgical treatment sequence, duration, associated risks and possible postoperative complication; the need for multiple surgeries if necessary, feeding and further rehabilitation needs like speech therapy. Addressing these issues would assist the caregivers to handle the emotional, physical and financial dimensions of their children treatment journey. These highlighted the need for the cleft team to communicate effectively and address this vital segment of the cleft service, thereby, reducing the emotional anxiety of the caregivers and fostering more realistic outcomes of the treatments.

The processes and structures in the hospital are not necessarily set up to reduce barriers.

5.3 Hospital experience

Nonetheless, like other studies (Taiwo et al., 2016; Nelson & Kirk, 2013) the result of the current one revealed that most carers are very positive about having chosen surgical treatment for their children. An explanation for this could be explained the rapport and trust developed by the carers as a result of the staff's high work ethic, surgical expertise, good inter-personal relationship compounded by the hospital's free cleft treatment. While some of the past Nigerian and

Ethiopian studies demonstrated that caregivers were more concerned about surgical expertise (Håkonsen, 2011; Orkar et al., 2002; Taiwo et al., 2016), reports from western countries like UK showed that carers placed greater premium on family-centred care, information delivery and service coordination (Cassell et al., 2012; Nelson & Kirk, 2013).

Notably, the suggestions made by the caregivers centred on better communication of treatment options, improving hospital processes and providing a better environment to reduce the length of hospital stay and create a more pleasant hospital experience.



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Chapter Six: Conclusions and Recommendations

6.1 Conclusions

First, this study showed a lack of knowledge and awareness about the causes, risk factors and treatment of CL±P deformity. Second, the findings of the study identified strong resilience and indicated a tremendous overall acceptance of children with CL±P among the respondents.

Third, the study exposed significant barriers in accessing cleft surgical treatment particularly in the area of misinformation from primary health care workers and the great distance that is needed to travel in getting to the hospital surgical care.

Fourth, the research data observed the strong spirit and high hopes of the participants for positive treatment outcomes which bolstered their resolve in the course of getting surgical care.

Furthermore, the present work also indicated that the participants mostly had a good experience with the staff and most of the hospital services. They particularly appreciated the amiability, friendliness and professionalism on display. However, they complained about the long waiting time for surgery, poor sanitation and food, and unrestricted visiting hours.

6.2 Caregivers' recommendations

1. Caregivers strongly urged that the radio should be more effectively utilised to increase awareness among the rural population about the availability of free cleft treatment at the centre. The location of the hospital and its provision of free lodging and food supplies during admission should also be well publicised.
2. Caregivers also recommended that the hospital's sanitation be improved.
3. They also recommended that catering services be improved, and more palatable dishes be served to the inpatients.
4. They further proposed that the hospital's visiting time should be strictly regulated.

6.3 Research recommendations

Drawing on the above conclusions, we would like to put forward the following recommendations to bridge the gap in cleft awareness, fulfil the unmet needs of the users of the hospital cleft service and expand the hospital cleft outreach to the neglected clientele of the populous rural communities of the region:

1. The mass media should be effectively employed to convey information about cleft environmental and genetic background to the broader population in the region. Radio is suggested as the most viable medium because of the fact it is easily accessible, affordable, reachable, handy, portable and possessed by highly mobile pastoralists, farmers and the vast majority in many of the far-flung rural districts.
2. Effective multi-sectoral collaboration particularly with influential community figures like Islamic scholars and traditional rulers (Sultan, Emirs, district heads, Dogari) to help to increase awareness, sensitisation and wider dissemination of cleft information in the region.
3. The establishment of counselling services in the hospital and society for the promotion of CL±P treatment to support carers, families and children afflicted and provide psychological, social and material support.
4. Establishment of a free referral transport reimbursement scheme for the patients and their caregivers between the primary centres and hospital, and their homes.
5. Provision of annual continuous medical education, sensitisation and training of primary health care professionals, social workers and nurses for capacity development and increase their understanding of cleft lip and palate management.
6. Formal recognition and incorporation of the TBA into cleft mobilisation campaign and management. Regular structured training should be given to them on how to recognise CL±Ps and the importance of quick referral to the cleft specialists or centres.
7. Incorporation of cleft management into the curriculum of the hospital's training schools for community health officers, nursing and midwifery.
8. Reduction of the long waiting times through expansion of the theatre facilities and engagement of more cleft surgeons and specialists in the hospital.

9. The urgent need to set up a quality control and maintenance Unit that will promote quality assurance policy, measure patient satisfaction regularly and improve sanitation and catering services.
10. Development of a quality assurance policy aimed at improving service quality and patient satisfaction should be considered, and this policy document should be well circulated in the hospital.
11. The hospital staff should be commended for being courteous, dedicated, selfless and displaying high exemplary professional competence. They should be encouraged by given regular monetary and non-monetary incentives.
12. The employment of sufficient workforce in vital areas such as social work, cleaning, sanitation, porter, catering and security to ensure holistic quality health care delivery in the hospital.
13. Advocacy visits to policymakers in the ministry of health, social welfare, women and children and legislatures across all tiers of government and major stakeholders in the communities to see cleft care as a fundamental human right, promoting equity, social justice/equality and an essential part of primary health care delivery.
14. The urgent necessity to bring cleft care closer to the general population by posting cleft specialists to district hospitals to provide optimal surgical care.
15. Therefore, it is pertinent that to build on the findings of the recommendations of this study, additional health systems research is needed to remove all obstacles in accessing qualitative cleft health services and reduce the burden of CL±P in the region.
16. Owing to the limited sample size and restriction to single hospital, the results of this study might not be generalisable to the whole of Nigeria. Therefore, it is also advocated that comparable studies should be encouraged across other regional cleft centres in Nigeria.

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Appendices

Appendix 1: Information Sheet

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INFORMATION SHEET

Project Title Caregivers' perceptions of cleft deformity and experience in accessing cleft services at a tertiary public hospital in Sokoto, Northwest, Nigeria

What is this study about?

This is a research project being conducted by Abdurrazaq Taiwo of school of Public at the University of the Western Cape. We are inviting you to participate in this research project because you have a child or children with congenital cleft lip and palate and you are currently attending the cleft services of Usmanu Danfodiyo University Teaching Hospital (UDUTH), Sokoto, Nigeria. The purpose of this research project is to explore the perceptions of cleft deformity and experience in accessing cleft service at UDUTH.

What will I be asked to do if I agree to participate?

You will be asked to give information about your age, gender and residential address. In addition, you will be asked to report on your views about causes of cleft, family reaction to cleft, expectations about treatment, perceptions and experience of barriers accessing cleft services in this hospital. These questions would mostly be open and would require that you should be as candid as you can in giving answers. It is your prerogative not to answer any question you considered personal or sensitive. Some questions might be unexpected and could refer to the past, please try to recollect as best as you can in answering. In this interview, there are no wrong or right answer, your perspective is the most pertinent. If any question cause you distress, we can stop to continue when you are ready or move on to other areas. This interview will be recorded and take approximately 60 minutes to complete in the counselling room.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, your name will not be included in the transcribed data and data analyses; and will contain no information that may identify you. Through the use of identification key, the researcher will be able to link your recorded interview to you and only the researcher will have access to the identification key

To ensure your confidentiality, Data collected will be kept in a passworded computer and other saving devices. In addition all related recordings and saving device shall be kept in locked filing cabinets. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

If we write a report or article about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator and hospital learn more about the barriers to accessing cleft services in the hospital, thus, helping to make these services better and easier to access by others in the future, and also reduce cases of late presentation.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you

decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify

What if I have questions?

This research is being conducted by *Abdurrazaq Taiwo, School of Public Health* at the University of the Western Cape. If you have any questions about the research study itself, please contact School of Public Health, University of the Western Cape, Private Bag X17, Bellville 7535, South Africa or +234-8078061517, email: 3515746@uwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Helen Schneider

School of Public Health

Head of Department

University of the Western Cape

Private Bag X17

Bellville 7535

e-mail: soph-comm@uwc.ac.za

Prof José Frantz

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17



Appendix 2: JAMI'AR WESTERN CAPE

TAKARDAR BAYANI

Aikin kammala karatu: Abinda mai kula da marar lafiya ya hango akan yaran da ake haihuwa da tsaguwar lebe, dasashi da hanci da kuma kwarewa wurin binciken rashin lafiya a babbar asibitin koyarwa ta usmanu danfodio sakkwato arewa maso yamma Najeriya.

Me wannan darasin ya kunsu?

Wannan wani bincike ne da Abdulrazaq Taiwo na jami'ar Western Cape yayi. Muna gayyatar ku da ku shigo cikin wannan binciken saboda kuna da yaro ko yaran da aka haifa da matsalar tsagewar lebe da dasashi tun daga haihuwa kuma kuna zuwa asibitin koyarwa ta usmanu dan fodio wurin neman magani. Dalilin wannan binciken shine don a binciko yadda aka dauki wannan matsalar tsagewar lebe da dasashi da ake haihuwar yara das hi a asibitin UDUTH.

Me za'a tambaye ni idan na shiga wannan binciken?

Za'a tambayeka shekaru, jinsi, adiresi. Za'a tambayeka abin da kake ganin ke kawo wannan matsalar da yadda iyalan gidan da aka haifi irin wannan yaron ke daukar matsalar da kuma abinda kake tsammani daga asibiti. Wadannan tambayoyin duk zasu zama bude ne kuma ana son ka bada amsa yadda ya kamata. Wasu tambayoyin nab a zata ne, wasu kuma na abinda ya faru da dadewa. Wannan tambayoyin ba'a damu da abinda ke dai dai ko kuskure ba, kawai dai gaskiya ake so. Wannan tambayoyin za'a dauke su ayi recording na tsawon minti sittin a dakin ganawa da marar lafiya.

Shigata cikin wannan aikin zai zama abin sirri?

Masu binciken sun dau hakkin kare sanen sirrinka da abinda ka fada, domin tabbatar da haka baza'a sa sunanka cikin rubutun ba ko kuma wani abu da zaisa a gane kai ne. Duk da cewa amfani da sunanka zai taimaki mai bincike don ya hada abubuwan day a samu daga gareka amma shi kadai ne zai san ko kai waye.

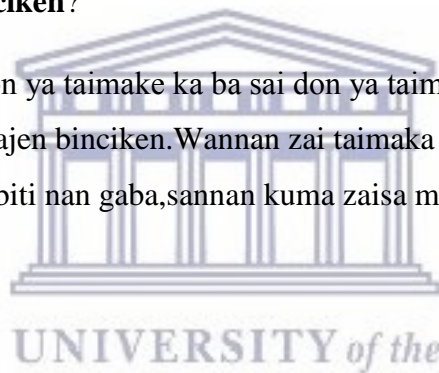
Dangane da ka'idar shari'a da kwarewar aiki,zamu bayyana ma hukuma ko ma'aikata,mashar'anta idan muka ci karo da cin zarafin yara gareka ko ga waninka.A wannan wurin zamu gaya muku cewa dole mu bayyanawa masu hakkin sanin wannan matsalar.

Menene hatsarin wannan binciken?

Dukkan wata hulda ta mutane akan ka ko wasu yana dauke da hadari.Duk da haka zamu rage wadannan hatsarukka kuma zamu taimaka maka duk inda kaji bakaji dai dai ba cikin wannan aiki.

Menene amfanin wannan binciken?

Wannan binciken ba'ayi don ya taimake ka ba sai don ya taimaki mai bincike da kuma asibiti don sanin hanyoyin bi wajen binciken.Wannan zai taimaka wajen saukakama masu wannan matsalar da zasu zo asibiti nan gaba,sannan kuma zaisa masu matsalar suzo asibiti da sauri ba tare da matsala ba.



Zan iya zama cikin wannan aikin bincike kuma zan iya fita daga ciki ko wanne lokaci?.

Shigarka cikin wannan aikin gaba daya taimako ne na ganin dama.Ka na iya kaki yinshi gaba daya,idan ka yanke shawarar shiga wannan binciken,kana iya bari duk sanda ka ga dama.Idan ka yanke shawarar barin wannan taimakon ba za'a hukunta ka ba kuma bazai sa ka rasa wani abu da ka cancanci samu ba.

To idan ina da tambaya fa?

Wannan binciken Abdulrazaq Taiwo na makarantar kula da lafiyar al'umma na jami'ar Western Cape yayi shi.Idan kana da wata tambaya akan wannan binciken sai ta tambayi makarantar kula da lafiyar al'umma ta jami'ar Western Cape,a wannan adireshi;

Private Bag 17,Bellville 7535

South Africa. Ko 002348078061517

Email: 3515746@uwc.ac.za

Idan kana da wata tambaya a matsayinka na mai hannu a cikin wannan binciken ko kuma wata matsala dangane da wannan aikin sai ka tuntubi:

Prof Uta Lehmann

School of Public Health

Head of Department

University of the Western Cape

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Prof José Frantz

Dean of the Faculty of Community and Health Sciences

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Appendix 3: Informed Consent Form

If you agree to participate in this study, the things we require from you are:

1. sign this consent form
2. answer questions in the interview

Your participation in this study is voluntary. You have the right to refuse to participate or answer any questions that you feel uncomfortable with. If you change your mind about participating during the course of the interview, you have the right to withdraw at any time. The decision to withdraw will not affect any future medical care you should require at this centre.

Declaration of the respondent

The study has been described to me in language that I understand. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or in any way affect the future medical care of myself or my child.

Signature of respondent..... Signature of investigator

Date Date.....

Appendix 4: Takardar Yarjejeniya

Idan ka yarda ka shiga wannan aiki, abubuwan da muke so gareka sune;

1. Sa hannun wannan takarda
2. Amsa tambayoyin bincike

Shigar ka cikin wannan aiki taimako ne.kana da dammar amsa tambayoyin, idan kuma baka so sai ka fadi.Idan ka canja ra'ayinka cikin wannan aiki kana da damar fita. Fitar ka bazai zama matsala gare ka ba anan gaba wurin neman wani abu cikin asibiti.

Amincewar Wanda Ake Tambaya

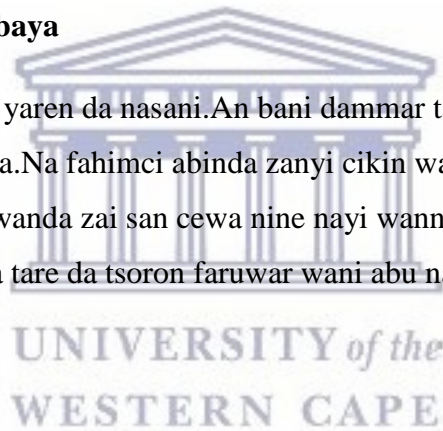
Karatun anyi min bayani nai da yaren da nasani.An bani dammar tambaya, kuma duk abinda na tambaya an bani amsa ta fahimta.Na fahimci abinda zanyi cikin wannan binciken kuma na amince da haka.Na fahimci ba wanda zai san cewa nine nayi wannan aiki.Na fahimci cewa ina iya fita duk sanda naga dama ba tare da tsoron faruwar wani abu nan gaba ba.

Sa hannun wanda ake tambaya_____

Rana_____

Sa hannun mai bincike_____

Rana_____



Appendix 5: Interview Guide

Before starting I would ensure that the tape recorder is working and there are spare batteries.

I would also ensure that the environment is conducive for the interview. To start the conversation, I would introduce myself, purpose of the study, benefits, risk, and confidentiality; and ask the participant to consent for the interview.

Questions

1. Please can you introduce yourself?

Probes:

Where do you come from?

Can you tell us your family background?

Is there anything more you will like us to know about you?



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3. Have you encountered or heard about cleft lip and palate before?

In your opinion what is responsible for this?

4. Can you tell us the beliefs about this condition in your culture or how does your culture explain this occurrence?

Can you tell us in your opinion what can be done to help someone in this condition?

5. Can you tell us about your expectations of coming to this hospital?

6. Can you share with us your experiences accessing cleft services in this hospital?

Can you tell us about what impact this treatment has on your life?

Are there any other insights you think we should know regarding cleft services in this hospital?

7. Would you recommend our services to others with this condition?

Do you think that there are other things that can be done to make your experience in this hospital more positive?

Thank you for sharing your insights with us.



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Appendix 6: Tsarin Tambayoyi

Kafin in fara, zan tabbatar da rediyo tana da batir, in tabbatar da inda za'ayi wannan tambayoyin bazan samu matsalar komai ba. Idan zan fara zan bayyana ko ni wanene, dalilin bincike, amfanin shi, matsalolin da zasu iya tasowa da kuma sirrin da ke ciki kuma in samu amincewar wand azan tambaya.

Tambayoyi

1. Don Allah kai waye?

Daga ina kake?

Dan wane asali ne kai?

Akwai abinda kake so mu sani game da kai?

2. Ka taba ganin mai irin matsalar tsagewar lebe ko dasashi a baya?

A ganinka me yakawo wannan matsalar?

3. Zaka iya fada mana abinda kuka dauki wannan matsalar a al'adance?

Zaka iya fada mana abinda ya kamata ayi don taimakon mai irin wannan matsalar?

4. Zaka iya gaya mana abinda kake tunanin samu a wannan asibiti ga mai wannan matsalar?

5. Zaka iya fada mana fadi tashin da kayi a cikin wannan asibitin da marar lafiya

Zaka iya fada mana amfanin wannan aikin da aka yi ma yaron a rayuwarka?

6. Zaka iya yiwa masu irin wannan matsalar jagora anan asibitin?

Kana ganin akwai abinda ya kamata asibitin nan tayi don samun sauki ga masu irin wannan matsalar?

Mungode da wannan dama taka da ka bamu.





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