



UNIVERSITI PUTRA MALAYSIA

***QUALITY OF LIFE OF PEOPLE LIVING WITH SEX DEVELOPMENT
DISORDERS AND SEX RE-ASSIGNMENT IN NIGERIA***

ABDURRAHMAN MUHAMMAD SANI

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By

ABDURRAHMAN MUHAMMAD SANI

**Thesis Submitted to the School of Graduate Studies, Universiti Putra Malaysia,
in Fulfillment of the Requirements of the Degree of Doctor of Philosophy**

July 2018

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DEDICATION

This Thesis is dedicated to:

*The People Living with Disorders of Sex Development and Sex Re-assignment in
Nigeria who participated in this study*



Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfillment of the requirement for degree of Doctor of Philosophy

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July 2018

Chairman : Associate Professor Soh Kim Lam, PhD
Faculty : Medicine and Health Science

Disorders of sex development is a complex medical, social and psychological emergency that required prompt intervention in the treatment of the condition. Sex assignment is considered as an emergency issue and as such should not be delayed, this is due to social and psychological crisis that parents and patients may undergoes as a result of ambiguous genitalia. The quality of life of people with disorders of sex development depends largely on the psychosocial management of the condition. Early diagnosis and proper counselling facilitate appropriate management and produce positive outcome.

In Nigeria, many people living with disorders of sex development faced serious psychological and social traumas such as marginalization, rejection, isolation, feeling of sadness, feeling of uncertainty, and feeling of shame. Although, disorders of sex development has received a considerable level of interest from medical practitioners, researchers and human right groups in the last decade; little is focused on the quality of life of people living with disorders of sex development. In Nigeria, there are few studies conducted in the field of disorders of sex development and most of the studies employed quantitative paradigms. Therefore the need to explore and described the quality of life of people living with disorders of sex development in Nigeria using qualitative paradigm.

The study was guided by quality of life model to understand the quality of life of people living with disorders of sex development and sex re-assignment in Nigeria. The overarching research question of the study is; what are the quality of life of people with disorders of sex development and sex re-assignment in Nigeria? The specific research questions are: what are the physical, psychological, social and

spiritual experiences of as well as the treatment process employed by people living with disorders of sex development and sex re-assignment in Nigeria.

This study employed qualitative approach using phenomenological research design. Non probability purposive sampling technique was used to recruit 13 people living with disorders of sex development and sex re-assignment in Nigeria. The participants had been diagnosed and treated with disorders of sex development and sex re-assignment in Nigeria for at least 6 months. The data were collected primarily through face to face interviews. The data were analysed using the principles of interpretative phenomenological analysis with the aid of NVivo software. Field notes from observation and documents analysis were used to triangulate the data.

Data analysis revealed 15 major themes which answer the overarching research question; what are the quality of life of people with disorders of sex development and sex re-assignment in Nigeria. The major themes are: physical wellbeing and symptoms, infertility, psychological impact of DSD, lower self esteem, feeling about body ambiguity, socialization and social relationship, spiritual wellbeing, spiritual adaptation to DSD and life management. Others are identification of the condition, sex re-assignment, patients' treatment concerns, and nursing experience. The findings indicated that disorder of sex development affect the quality of life of the people physically, psychologically, socially and spiritually.

The findings of this study were in line with the Ferrel's quality of life model. The findings provided information on the quality of life of people with disorders of sex development and sex re-assignment in Nigeria. The study contributed in the field of quality of life of people with disorders of sex development by adding treatment process and nursing experiences to the model. It would help the healthcare professionals in the provision of quality care with the view of improving the quality of life of people with disorders of sex development and sex re-assignment. There is need for research study on the impact of nursing care on the quality of life of people with DSD.

Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia sebagai memenuhi keperluan untuk ijazah Doktor Falsafah

**KUALITI HIDUP DAN PENGALAMAN KEJURURAWATAN INDIVIDU
DENGAN KHUNSA DAN PENUKARAN JANTINA DI NIGERIA**

Oleh

ABDURRAHMAN MUHAMMAD SANI

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Khunsa merupakan perubatan kompleks, kecemasan psikologi dan sosial yang memerlukan intervensi segera dalam merawat keadaan ini. Penukaran jantina adalah kecemasan dan tidak patut ditangguhkan kerana ini akan mengakibatkan krisis sosial dan psikologi yang akan dialami oleh ibu bapa akibat jantina anak yang kabur. Kualiti hidup individu dengan khunsa bergantung kepada pengurusan psikososial. Diagnosis awal dan kaunseling yang berkesan memudahkan pengurusan yang sesuai dan dapat memberi hasil yang positif.

Di Nigeria, individu yang mengalami masalah kekeliruan jantina berhadapan dengan trauma psikologi dan sosial akibat daripada faktor sosio-budaya seperti bias kecenderungan jantina lelaki, kepercayaan agama dan tradisi, serta tekanan daripada datuk dan nenek mengenai peranan jantina. Isu sosial yang lain juga merangkumi stigma, pengasingan dan hubungkait keadaan itu dengan sihir atau individu ini dianggap sebagai penyihir.

Kajian ini bertujuan untuk meneroka kualiti hidup dan pengalaman kejururawatan individu-individu dengan khunsa dan penukaran jantina di Nigeria. Kajian ini berpandukan model kualiti hidup bagi memahami kualiti hidup individu yang hidup dengan khunsa dan penukaran jantina di Nigeria. Persoalan untuk kajian ini adalah; apakah kualiti hidup dan pengalaman kejururawatan individu dengan khunsa dan penukaran jantina di Nigeria?

Kajian ini menggunakan pendekatan kualitatif dengan reka bentuk penyelidikan fenomenologi. Tiga belas (13) individu dengan khunsa dan penukaran jantina telah dipilih dengan menggunakan teknik pensampelan tanpa probabiliti biasa. Responden yang dipilih telah didiagnosa dan dirawat selama sekurang-kurangnya 6 bulan. Data dikumpul melalui Teknik temu bual, pemerhatian, dan ulasan dokumen. Data dianalisis menggunakan prinsip analisis fenomenologi tafsiran dengan menggunakan perisian NVivo. Transkrip dari temu bual informan bukan kunci, nota lapangan dan analisa dokumen digunakan untuk tranguulasi data.

Analisis data mendedahkan 18 tema utama yang menjawab soalan penyelidikan; apakah kualiti hidup dan pengalaman kejururawatan orang-orang yang mempunyai khunsa dan penukaran jantina di Nigeria di Nigeria. Tema-tema utama adalah: gejala dan kesejahteraan fizikal, ketidaksuburan, gangguan rehat dan tidur, gejala dan kesejahteraan psikologi, perasaan jantina dan alat kelamin yang keliru, kesejahteraan sosial, mencari rawatan tradisional, kesejahteraan rohani dan pengurusan hidup, mengenalpasti masalah, penukaran jantina, proses rawatan, dan pengalaman kejururawatan. Dapatan menunjukkan bahawa masalah kekeliruan jantina menjejaskan kualiti hidup individu secara fizikal, psikologi, sosial dan rohani

Dapatan kajian ini selari dengan Model Kualiti Hidup Ferrel. Hasil dapatan ini memberikan maklumat tentang kualiti hidup dan pengalaman kejururawatan individu-individu yang mengalami khunsa dan penukaran jantina di Nigeria serta telah menyumbang kepada bidang kualiti hidup individu masalah kekeliruan jantina terutama dari aspek rawatan dan pengalaman kejururawatan. Ini akan membantu pengamal kesihatan dalam menyediakan penjagaan berkualiti dengan meningkatkan kualiti hidup individu yang mengalami masalah kekeliruan jantina dan penukaran jantina. Kajian penyelidikan mengenai kesan penjagaan kejururawatan terhadap kualiti hidup orang dengan khunsa perlu diteruskan.

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I certify that a Thesis Examination Committee has met on 23 July 2018 to conduct the final examination of Abdurrahman Muhammad Sani on his thesis entitled "Quality of Life of People Living with Sex Development Disorders and Sex Re-Assignment in Nigeria" in accordance with the Universities and University Colleges Act 1971 and the Constitution of the Universiti Putra Malaysia [P.U.(A) 106] 15 March 1998. The Committee recommends that the student be awarded the Doctor of Philosophy.

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LIST OF ABBREVIATIONS

DSD	Disorder of sex development
CAH	Congenital Adrenal Hyperplasia
AIS	Androgen Insensitivity Syndrome
QOL	Quality of Life
UDUTH	Usmanu Danfodiyo University Teaching Hospital



CHAPTER 1

BACKGROUND OF THE STUDY

1.1 Introduction

Sex identification is usually done immediately after birth by midwife, mother, traditional birth attendance or any close relative that is conducting delivery; using external genitalia as a reference point. There are some cases when the external genitalia may appear normal for the sex but genetically the sex is different from what is in the external genitalia. This may be detected mostly during puberty or early adulthood (Lisdonk, 2014; Özbey, Darendeliler, Kayserili, Korkmazlar, & Salman, 2004). On the other hand, there are some instances in which the external genitalia may be looking so ambiguous which may lead to difficulty in sex identification. These are known as disorders of sex development (DSD) which is defined as the congenital abnormality of the sex development in which the chromosomal, gonadal or anatomical sex genitalia is atypical (Hughes, Houk, Ahmed, & Lee, 2006a; Woodward & Neilson, 2013). Disorders of sex development or intersex condition was defined by Lisdonk (2014), as *“an umbrella term used to describe various congenital conditions in which the development of sex differs from what medical professionals generally understand to be ‘male or ‘female’. The differences may be chromosomal, gonadal or anatomical”* (P. 26).

Disorders of sex development can be categorized into three major forms which include; under-virilized genetic male (46,XY), over-virilized genetic female (46,XX) and sex chromosome (variable) DSD (Rothkopf & John, 2014; Woodward & Neilson, 2013).

According to Jost (1973), normal sex development comprises of four steps that occur during sexual development and differentiation. These steps are establishment of chromosomal sex at fertilization, formation of undifferentiated gonads, gonadal differentiation into testes or ovaries, and finally development of the internal and external genitalia (Jost, 1973; Massanyi, DiCarlo, Migeon, & Gearhart, 2013). Failure of any of these phases may lead to disorders of sex development which may result into defect of sex development.

The sex chromosomes (XY and XX) play an important role in normal sex development. The development of sexual organs starts at about 6th week of gestation, following the migration of primordial germ cells from yolk sac to the genital ridge in the mesoderm (Lisdonk, 2014; Woodward & Neilson, 2013). At about 7th week, there will be formation of bipotential gonads which in the presence of Y chromosomes the testes will develop and the Sertoli cells produce anti-Müllerian hormone (AMH) which is responsible for inhibition of Müllerian duct/structures that consist of upper part of the vagina, cervix, uterus and fallopian tubes (Lisdonk, 2014;

Woodward & Neilson, 2013). While the Leydig cells in the testes will produce testosterone that is responsible for the formation of Wolffian duct/structures which lead to the formation of male internal genitalia (Seminal vesicles, vas deference, and epididymis). Then the testosterone is converted to dihydrotestosterone (DHT) which is responsible for the development of male external genitalia and descent of the testis. This occurs in about 9th to 14th weeks of gestation (Lisdonk, 2014; Woodward & Neilson, 2013). Testosterone is responsible for the formation and growth of penis and scrotum and any situation leading to the absence of testosterone production, or the testosterone is produced but cannot function effectively for some reason, the male external genitalia may generally develop into vagina (Lisdonk, 2014).

The absence of Y chromosome, AMH and testosterone will result into the formation of ovaries and the Mullerian structures. This will lead to the formation of female internal genitalia while the Wolffian ducts will regress. Also in the absence of dihydrotestosterone, female external genitalia is formed (Lisdonk, 2014; Woodward & Neilson, 2013).

Worldwide there is no exact or standard estimation of the epidemiology of disorders of sex development; because it is relatively an unknown condition (Lisdonk, 2014). Therefore, strong variation exists in the data from one article to the other and from one country to another. According to some studies about 1.7% of the world population are suffering from disorders of sex development/intersex (Lisdonk, 2014; Woodward & Neilson, 2013). Accordingly, there are no clear estimate rates of the incidence of ambiguous genitalia immediately after birth, but there are some proportions of the patients that present a major challenge regarding male or female gender/sex assignment issues. This was estimated to be approximately 1 in 4,500–5,500 (Lee et al., 2016). According to Woodward and Neilson (2013), the incidence rate of disorders of sex development is 1-2/10,000 live births. In Netherland, there were about 800,000 cases of disorders of sex development/intersex in 2014 (Lisdonk, 2014).

Analysis of 6.5 million new-borns worldwide found that the incidence of congenital adrenal hyperplasia is 1 in 15,000 live births (Hutcheson, 2016). Frequency was highest in neonates of European, Jewish, Hispanic, Slavic, or Italian descent (Hutcheson, 2016). In the United State, the prevalence differs like in most countries, and with congenital adrenal hyperplasia occurring as the highest and followed by mixed gonadal dysgenesis (Hutcheson, 2016). There is lack of data on the incidence of intersex/disorders of sex development in Africa. This is due to paucity of information and research in this area (Lisdonk, 2014; MacKenzie, Huntington, & Gilmour, 2009; Rebelo, Szabo, & Pitcher, 2008).

Patients with intersex/disorders of sex development can present with the condition at birth or at puberty and early adulthood stage (Al-Jurayyan, 2010; El-Sherbiny, 2013; Woodward & Neilson, 2013). At birth the presentation include overt genital ambiguity like cloacal exstrophy, enlarged clitoris, posterior labial fusion, inguinal

or labial mass associated with female genitalia. While, those associated with male genitalia include bilateral impalpable testes, hypospadias with undescended testes and bifid scrotum (Al-Jurayyan, 2010; El-Sherbiny, 2013; Woodward & Neilson, 2013). Other forms of late presentation at puberty or early adulthood include unrecognized genital ambiguity, female inguinal hernia, delayed or incomplete puberty, primary amenorrhoea, virilisation in female, absence of breast development in female at puberty or early adulthood, breast development in male, and gross and occasional haematuria in male (El-Sherbiny, 2013; Mungadi, 2015; Woodward & Neilson, 2013). Others include complaints from husband about inadequate vaginal passage and refusal of marriage from males (Mungadi, 2015).

Disorders of sex development can be diagnosed through laboratory investigation like karyotyping of X and Y chromosomes, blood and urine biochemistry, radiologic investigation such as ultrasonography, Magnetic Resonance Imaging (MRI) or Computed Tomography (CT) scan and retrograde genitogram in order to assess the Mullerian structures and the kidneys (El-Sherbiny, 2013; Woodward & Neilson, 2013). Others are preoperative endoscopy, laparoscopy and gonadal biopsy (El-Sherbiny, 2013; Woodward & Neilson, 2013).

The management of intersex/disorders of sex development is considered as a complex medical, social and psychological emergency that required prompt intervention (Al-Jurayyan, 2011; Mungadi, 2015). Therefore, management of intersex/disorders of sex development serve as a challenging problem, not only because of the chronicity of the problem and associated consequences, but due to the complexity of sex assignment/re-assignment and its impact psychologically (Al-Jurayyan, 2010). In Nigeria, sex assignment is considered as an emergency issue and as such should not be delayed. This is due to cultural, social and psychological crisis that the parents may undergoes as a result of ambiguous genitalia (Mungadi, 2015).

After evaluation of the danger and successful benefit of the assigned gender by multidisciplinary team, surgical and medical management are carried out in order to correct the anomalies (Massanyi et al., 2013). The surgical management are more preferable and most successful when carried out during infancy especially less than 24 months of birth (Al-Jurayyan, 2010, 2011; El-Sherbiny, 2013; Lee, 2011; Palmer et al., 2012). The surgical management include feminizing genitoplasty and masculinizing genital surgery (El-Sherbiny, 2013; Woodward & Neilson, 2013).

Moreover, following surgical intervention in patients with disorders of sex development, medical treatment is also necessary in form of hormonal replacement therapy due to hypogonadism which is common in individual with gonadal dysgenesis (Woodward & Neilson, 2013). Testosterone is administered in males while oestrogen supplementation with or without progestin in females (Woodward & Neilson, 2013).

Gender assignment is a difficult and most challenging aspect in the management of disorders of sex development due to a number of factors such as difficulty in diagnosis (Palmer et al., 2012), potential for intercourse (Özbey et al., 2004), diagnosis-specific psychosexual outcome, potential for fertility, surgical treatment options available, the possibility for gonadal hormone replacement therapy at puberty (Palmer et al., 2012). Others are psychosocial well-being, overall gender appropriate appearance, cultural factors and the patient's views which is considered the most important factor (Mungadi, 2015). Gender assignment involves judgmental decision of the multidisciplinary team that involves endocrinology, urology, nursing, psychology, social worker, gynaecology, bioethics and parents of the child or patient (El-Sherbiny, 2013; Lee et al., 2016).

Nursing service is very vital in ensuring the good psychosexual outcome of people with disorders of sex development from diagnoses to the management of the condition. Therefore, nurses should communicate the outcome to parents/patient when discussing options for gender assignment (Palmer et al., 2012). Nursing information is a key strategy to ensuring psychological adjustment and coping among people living with disorders of sex development (Cohen-Kettenis, 2010). Early planning, and recurrent, gradual education and counselling services provided by nurses has been recommended (Cohen-Kettenis, 2010; Hughes et al., 2006a). Because timely and well informed children with disorders of sex development have good opportunity to develop effective coping skills, positive self-image, deal with infertility and other psychosexual problems (Cohen-Kettenis, 2010). Therefore, nursing services is effective in promoting good quality of life of people living with disorders of sex development and sex re-assignment (Rothkopf & John, 2014). What does it mean for a person to live with disorders of sex development and sex re-assignment in Nigeria where sociocultural factors plays an important role in the health and illness behaviour among people? What are the nursing experiences and the processes for the management of people with disorders of sex development and sex re-assignment in Nigeria?

1.2 Background of the Study

The quality of life of people with disorders of sex development/intersex depends largely on the good nursing and psychosocial management of the disorder (Cohen-Kettenis, 2010). Although, early diagnosis of the condition and a clear counselling provided by nurses is expected to facilitate appropriate management and produce positive outcome of the condition (Lisdonk, 2014; Özbey et al., 2004; Rebelo et al., 2008). But, socio-cultural factors such as bias concerning the male gender preference in the community associated with economic activities, religious and traditional beliefs, and pressures from grandparents influence gender assignment (Al-Jurayyan, 2010, 2011; Mungadi, 2015; Özbey et al., 2004; Rebelo et al., 2008). Moreover, other social issues associated with disorders of sex development/intersex in Nigeria are stigma, isolation and linking the condition to witchcraft or the person is considered as a witch (Lisdonk, 2014; Özbey et al., 2004; Rebelo et al., 2008). One of the key role of nurses is the provision of counselling services both to the patient

and the family which help in dealing with the social issues associated with disorders of sex development (Kwak et al., 2010; Rothkopf & John, 2014). Family counselling is very effective in the management of disorders of sex development, this is because it helps to deal with social environment and ensure effective family coping (Cohen-Kettenis, 2010). Nurses have the role of providing family and patient education in the management of disorders of sex development and sex re-assignment (Rothkopf & John, 2014).

People with disorders of sex development/intersex have a range of experiences; physically, psychologically, and socially. The physical experiences include physical appearance, amenorrhoea, small stature, small penis, and infertility (Alderson, Madill, & Balen, 2004; Boyle, Smith, & Liao, 2005; Chadwick, Liao, & Boyle, 2005; Guntram, 2013b; Guth, Witchel, Witchel, & Lee, 2006; Malouf, Inman, Carr, Franco, & Brooks, 2010; Sanders, Carter, & Lwin, 2015a). Moreover, the psychological experiences faced by people living with disorders of sex development include depression, anxiety, fear, low self-esteem, suicidal thought and ideation, and psychological distress (Alderson et al., 2004; Chadwick et al., 2005; Ernst et al., 2016; Guth et al., 2006; MacKenzie et al., 2009; Patterson, Crawford, & Jahoda, 2014).

There are numerous social experiences resulting from living with disorders of sex development/intersex. These include feeling of shame, secrecy surrounding the condition, and failure to initiate and maintain intimate relationships (Boyle et al., 2005; MacKenzie et al., 2009; Malouf et al., 2010; Patterson et al., 2014). These have negative impact on the quality of life of people living with disorders of sex development/intersex. Other consequences are difficulty in having sexual intercourse (Boyle et al., 2005; Chadwick et al., 2005; MacKenzie et al., 2009; Sanders et al., 2015a).

Nurses and other health care professionals have a role of promoting good quality of life of people with disorders of sex development. The main aim of the management of disorders of sex development is to promote good quality of life of the patient as much as possible (Lee et al., 2016). Coping strategies plays a vital role in managing the lifelong physical, psychological and social effects of disorders of sex development/intersex especially in the area of diagnosis, treatment and sex re-assignment (Alderson et al., 2004; Chadwick et al., 2005; MacKenzie et al., 2009). Therefore, effective coping is associated with good quality of life outcome, while ineffective coping is associated with poor quality of life outcome in people living with disorders of sex development/intersex (Malouf et al., 2010).

1.3 Statement of the Problem

Disorders of sex development is a lifelong condition that is associated with differences in bodily structures due to absence or malformation of reproductive organs which have serious effect on the life experiences and quality of life of the individuals physically, psychologically, socially, and sexually (Sanders et al., 2015a). Disorders of sex development are complex interactions between biological, psychological, social, and cultural factors making it necessary for the multidisciplinary team to decide on individualized patient basis and the characteristics of the individual patient, family and the social background are taken into consideration in order for the individual to derive maximum benefit (Wiesemann, 2010). In a situation whereby the condition affects the external genitalia, the condition is easily identified at birth and reported to the hospital for necessary action (Lisdonk, 2014). On the other hand, if the condition affects the internal sex organs, this is mostly discovered during puberty or early adulthood or sometimes when a woman is unable to conceive or become pregnant (Lisdonk, 2014). The medical consequences of disorders of sex development varies greatly depending on the type and severity (Lisdonk, 2014) and many of them have an impact on fertility which is a serious concern especially among people of the developing world where fertility is considered as an ultimate gift (Lisdonk, 2014; Özbey et al., 2004; Rebelo et al., 2008). Meanwhile, there is a marked difference between the attitude of sex of rearing in late diagnosis of disorders of sex development in developing countries and the developed countries. In Nigeria, a man is considered as the breadwinner and woman as the housewife and the mother (Al-Jurayyan, 2010; Özbey et al., 2004; Özbey & Etker, 2013; Rebelo et al., 2008).

Moreover, in Nigeria, many people living with disorders of sex development faced serious psychological and social traumas such as marginalization, rejection, isolation, feeling of sadness, feeling of uncertainty, and feeling of shame (Liao et al., 2010; Lisdonk, 2014; MacKenzie et al., 2009; Rebelo et al., 2008). Although, disorders of sex development/intersex has received a considerable level of interest from medical practitioners, researchers and human right groups in the last decade; however, majority of attention has focused on the area of sex re-assignment, medical and surgical management of the condition with less emphasis on the quality of life (Liao et al., 2010; Lisdonk, 2014; MacKenzie et al., 2009). Most of the studies conducted in the field of DSD pays little attention to the physical, social, and psychological wellbeing of the patients with this condition (Lisdonk, 2014; MacKenzie et al., 2009). Also, there is little solid, research-based knowledge on the impact of disorders of sex development on the physical, psychological and social situation of those affected with the condition (Lisdonk, 2014).

In Nigeria, the management of disorders of sex development is characterized by delay in presentation until adolescent or adulthood when the patient had developed body ambiguity and psychological problems (Ekenze et al., 2015; Mungadi, Ahmad, Yunusa, Agwu, & Ismail, 2010; Mungadi, 2015). In adequate diagnostic facilities, the need for sex reassignment, lack of trained personnels, and poor follow up were

the challenges affecting the management of disorders of sex development in Nigeria and this subsequently affect the quality of life of people living with disorders of sex development (Achigbu, Odinaka, & Achigbu, 2016; Ekenze, Adiri, Igwilo, & Onumaegbu, 2014; Ekenze et al., 2015). People living with DSD in Nigeria experienced psychological morbidity, gender dysphoria, rejection and social embarrassment which negatively affect their quality of life leading poor quality of life among people with DSD (Achigbu et al., 2016; Ekenze et al., 2015; Mungadi, 2015). Socio-economic and sociocultural factors such as poverty, male gender supremacy, consanguinity and poor healthcare resources affect the quality of life of people with DSD in Nigeria (Achigbu et al., 2016; Ajiboye, Omokanye, Olatinwo, & Biliaminu, 2017; Ekenze et al., 2014; Sowande & Adejuyigbe, 2009). People with DSD in Nigeria experienced poor quality (Ajiboye et al., 2017). Studies conducted in Nigeria were focussed on the medical and surgical management of disorders of sex development despite several suggestion on the need to study the quality of life of people with DSD (Achigbu et al., 2016; Ajiboye et al., 2017; Ekenze et al., 2014, 2015; Mungadi et al., 2010; Sowande & Adejuyigbe, 2009). To the best of my knowledge this is the first study that explored the quality of life of disorders of sex development and sex reassignment in Nigeria.

To assist people with disorders of sex development/intersex, nurses and other healthcare professionals are required not to only have the scientific knowledge but, also to have a greater understanding of the phenomena and sensitivity to the experiences of people living with disorders of sex development/intersex. Nurses and other health care providers shared information with patients and parents about disorders of sex development and sex reassignment (Sanders & Carter, 2015). This information is expected to reduce the social and psychological crises face by people with DSD, but the type and the impact of this information need to be recognized (Sanders & Carter, 2015; Sanders et al., 2015a). The aim of nursing care in the management of patient with DSD is to promote best quality of life (Lee et al., 2016). Therefore, the need to explore, describe and understand the quality of life of people with disorders of sex development and sex reassignment in Nigeria.

Moreover, there is mixed experiences in the processes that patients and parents of children with DSD undergoes in the hospital from diagnosis to treatment and follow ups (Alderson et al., 2004; Guntram, 2013c; Guth et al., 2006; Patterson et al., 2014).. These affects patient and parents compliance to treatment and follow ups visit which is one of the essential component in the management of DSD as a lifelong condition (Sanders & Carter, 2015; Sanders et al., 2015a). studies has not been conducted on the treatment processes involved in the management of people with DSD and sex re-assignment. Therefore, the need to explore and describe the treatment processes undergo by people living with disorders of sex development in Nigeria.

There are few studies on the quality of life of people with DSD and sex re-assignment in Nigeria. Most of these studies were conducted using quantitative paradigm which cannot adequately describe the quality of life and experiences of people living with DSD and sex re-assignment (Julka et al., 2006; Kanhere et al., 2015; Schönbucher, Schweizer, & Richter-Appelt, 2010). Therefore, this study explores, describes and understands the quality of life and experiences of people living with disorders of sex development and sex re-assignment in Nigeria.

Moreover, the few qualitative research in the field of disorders of sex development/intersex which seek to explore the quality of life and experiences of people living with intersex in order to make meaning out of the patients' condition were conducted in developed countries where patients were diagnosed early with modern facilities and well trained health personnel unlike Nigeria where there are poor resource settings (Lisdonk, 2014; MacKenzie et al., 2009). Most of these studies were conducted in United Kingdom (Liao et al., 2010), United State (Ernst et al., 2016; Malouf et al., 2010), Netherland (Lisdonk, 2014) and New Zealand (MacKenzie et al., 2009) among others. The experiences of people living with DSD in developed countries differ from those in the developing countries (Achigbu et al., 2016; Ediati, Faradz, et al., 2015; Ediati, Maharani, & Utari, 2016). Therefore, this study explores and describes the quality of life of people living with disorders of sex development and sex re-assignment in Nigeria.

Meanwhile, the few studies published in the area of disorders of sex development/intersex, did not utilize theory or model as a theoretical framework to guide their studies and in order to determine its validity and applicability in this field. Therefore, this study employed quality of life model as a theoretical framework to explore, understand and describe the quality of life of people living with disorders of sex development and sex re-assignment.

In recent years, several calls are being made on the use of qualitative research in the field of health sciences and disorders of sex development in particular (Lundberg, Roen, Hirschberg, & Frisé, 2015). Qualitative research serves as a vehicle for addressing issues that cannot be addressed by quantitative research survey or experimental studies (Lundberg et al., 2015), including an in depth exploration of lived experiences of people and more importantly when there is small sample size or the sample is too small for analysis (Liao, Baker, Boyle, Woodhouse, & Creighton, 2014; Lundberg et al., 2015). Phenomenological approach is the most appropriate method for the study of quality of life of people living with disorders of sex development and sex re-assignment, which required the researchers to study the in-depth life experiences of people in a given phenomenon holistically and it is the suitable method for studying important nursing phenomena (Speziale, Streubert, & Carpenter, 2011). Transcendental phenomenology was used to explore and understand the quality of life of people with disorders of sex development. It is the most suitable method for exploring the quality of life of people with disorders of sex development in order to make meaning into their life experiences (Krauss, 2005; Lee

& Krauss, 2015). Therefore, there is need to conduct qualitative study in order to explore the quality of life of people living with disorders of sex development/intersex and sex re-assignment in Nigeria.

Usmanu Danfodiyo University Teaching Hospital (UDUTH) Sokoto is the major referral hospital of people living with disorders of sex development in northern Nigeria. It receives patients from the 19 northern states. Therefore, patients with disorders of sex development and sex re-assignment were recruited from UDUTH Sokoto in order to explore, understand and describe the quality of life of people living with disorders of sex development and sex re-assignment in Nigeria.

1.4 Purpose of the Study

The main purpose of this study is to explore, describe and understand the quality of life of people living with disorders of sex development and sex re-assignment in Nigeria. Transcendental phenomenological study design was employed as the methodology of this research in order to study the life experiences of people living with DSD and sex re-assignment in Usmanu Danfodiyo University Teaching Hospital Sokoto, Nigeria. This is because it is concern with the experiences of group of individuals in order to describe the essence of the experiences of people living with DSD and sex re-assignment.

1.5 Research Objectives

1. To describe the physical experiences of people living with disorders of sex development and sex re-assignment.
2. To describe the psychological experiences of people living with disorders of sex development and sex re-assignment.
3. To describe the social experiences of people living with disorders of sex development and sex re-assignment.
4. To describe the spiritual experiences and coping strategies employed by people living with disorders of sex development and sex re-assignment.
5. To describe the treatment process undergoes by people with disorders of sex development and sex re-assignment in Nigeria.

1.6 General Research Question

The general research question of this study is; what are the quality of life of people living with disorders of sex development and sex re-assignment in Nigeria?

1.7 Specific Research Questions

1. What are the physical experiences of people living with disorders of sex development and sex re-assignment?
2. What are the psychological experiences of people living with disorders of sex development and sex re-assignment?
3. What are the social experiences of people living with disorders of sex development and sex re-assignment?
4. What are the spiritual experiences and coping strategies employed by people living with disorders of sex development and sex re-assignment?
5. What are the treatment processes undergone by people with disorders of sex development and sex re-assignment in Nigeria?

1.8 Significance of the Study

Findings of this study has provided empirical evidence to nurses, other health professionals and the general public on the treatment processes, nursing experiences, and quality of life of people with disorders of sex development, in order to utilize the findings toward improving the quality of life of the affected individuals. This study has provided a voice for the people living with DSD and sex re-assignment in order for the policy makers to utilize the findings of the study to develop policies that will assist people living with disorders of sex development/intersex in getting early treatment of their condition and quality of life improvement. The study provided information on the nursing care experiences of people living with disorders of sex development in UDUTH with the view of improving nursing care of patients with disorders of sex development. Findings of this study may serve as a guide in the provision and improvement of the training need of nurses and other healthcare practitioners involved in the management of disorders of sex development. The study will serve as a guide for developing the training module that will improve the quality of care provided to the people living with the disorder. The study highlighted the processes involved the management of disorders of sex development with the view of improving the process and reducing bureaucratic bottle neck in order to encourage compliance with treatment and reduce long waiting time.

The study add to the existing body of nursing knowledge in the area of disorders of sex development by contributing and filling the gap in the physical, psychological, social, spiritual and nursing experiences of people living with disorders of sex development/intersex. People in Nigeria have unique health experiences, which are affected by socio-cultural factors that affect their health and illness behaviours. This

study described the way people living with DSD are seeking traditional treatment in order for the healthcare professionals to guide patients to avoid harmful traditional practice associated with DSD. The study provided information on the coping strategies employed by people living with disorders of sex development, in order for the nurses to utilize the positive ones when counselling patients with disorders of sex development/intersex, as well as prevent patients from using maladaptive coping behaviours.

Moreover, the study provided empirical evidence on the validity and applicability of quality of life model in the study of quality of life of people living with disorders of sex development/intersex.

1.9 Scope and Limitation of the Study

This study covered the nursing experiences as well as the physical, psychological, spiritual and social aspect of quality of life of people living with disorders of sex development/intersex. Patients with all forms of disorders of sex development or intersex conditions such as congenital adrenal hyperplasia, androgen insensitivity syndrome, Mayer-Rokitansky-Kuster-Hauser syndrome were included in the study. Patients with disorders of sex development receiving treatment in Usmanu Danfodiyo University Teaching Hospital Sokoto participated in the study. The study employed phenomenological study design which limited patient recruitment to Usmanu Danfodiyo University Teaching Hospital Sokoto, Nigeria only.

The study was limited by lack of patients' visibility because the condition is associated with secrecy and feeling of shame. Difficulty in the recruitment of the participants serve as the limitation of the study because of the sensitivity of the condition as indicated in the previous studies (MacKenzie et al., 2009; Patterson et al., 2014). But this was overcome by engaging the clinician to assist in the participants' recruitment. Although Northern Nigeria has more than two hundred different ethnic groups and languages; Hausa and English are the dominant and official languages respectively; therefore, the study was limited by language barrier as the interview was conducted in English and Hausa language, thus, they are the languages the researcher can speak. The study faces practical limitation of time; as the study is a PhD research thesis that was expected to be complete in six semesters due to sponsorship and employment issues.

1.10 Definition of Terms

Coping : This is the conscious efforts to reduce stress and distress such as life adjustment of people with disorders of sex development/intersex. The psychological mechanism to live successfully with a distress condition is known as coping strategies (Stanton et al., 2000).

Disorders of sex development : This is a congenital condition in which the development of gonadal, chromosomal or anatomical sex is different from what medical professionals believed to be male or female. In this study, it includes all forms of condition associated with ambiguous genitalia (Lee et al., 2016; Lisdonk, 2014).

Experiences : This is a practical contact with or observation of events or facts which leaves an impression, knowledge and feelings that makes up someone life or character (Carr, Gibson, & Robinson, 2001). For example the concerns or situations that are undergoes on daily basis by people living with disorders of sex development/intersex

Nursing : This encompasses the autonomous and collaborative care of individuals of all ages, families, groups, and communities, sick or well and in all settings for the promotion of health, prevention of diseases, and the care of the ill, disabled and dying people. In this study, nursing refers to as the care of the people with disorders of sex development/intersex for health promotion, illness prevention, health restoration, and rehabilitation (International Council of Nurses, 2007).

Quality of Life : This is the general wellbeing of individuals, families, group or society that involves positive and negative features of life and observes life satisfaction such as physical health, family, education, employment, finance, religious belief and environment (Barbara, 2013).

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