
7-7-2021

Social Wellbeing and Quality of Life of People Living with Disorders of Sex Development and Sex Re-Assignment in Nigeria: A Qualitative Phenomenological Study

Abdurrahman Muhammad Sani
Usmanu Danfodiyo University, Sokoto, abdulsani19@gmail.com

Ismaila Arzika Mungadi
Usmanu Danfodiyo University, imungadi@yahoo.com

Ismi Arif Ismail
Universiti Putra Malaysia

Mohd Mursyid Arshad
Universiti Putra Malaysia

Kim Lam Soh
Universiti Putra Malaysia

Follow this and additional works at: <https://nsuworks.nova.edu/tqr>

 Part of the [Nursing Commons](#), [Quantitative, Qualitative, Comparative, and Historical Methodologies Commons](#), and the [Social Psychology Commons](#)

Recommended APA Citation

Sani, A. M., Mungadi, I. A., Ismail, I. A., Arshad, M. M., & Soh, K. L. (2021). Social Wellbeing and Quality of Life of People Living with Disorders of Sex Development and Sex Re-Assignment in Nigeria: A Qualitative Phenomenological Study. *The Qualitative Report*, 26(7), 2189-2205. <https://doi.org/10.46743/2160-3715/2021.3699>

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.

A promotional banner for the Qualitative Research Graduate Certificate at Nova Southeastern University. The banner is split into two sections. The left section has a dark blue background with the text 'Qualitative Research Graduate Certificate' in white, 'Indulge in Culture' in a smaller white font, 'Exclusively Online • 18 Credits' in white, and the NSU logo (a sunburst over 'NSU' and 'NOVA SOUTHEASTERN UNIVERSITY') in white. A white button with 'LEARN MORE' in black text is at the bottom. The right section shows a group of seven diverse people sitting on a stone ledge in front of a building with 'NOVA SOUTHEASTERN' visible on the wall.

Qualitative Research Graduate Certificate
Indulge in Culture
Exclusively Online • 18 Credits
LEARN MORE

NOVA SOUTHEASTERN UNIVERSITY

NOVA SOUTHEASTERN

Social Wellbeing and Quality of Life of People Living with Disorders of Sex Development and Sex Re-Assignment in Nigeria: A Qualitative Phenomenological Study

Abstract

Disorders of sex development is a complex interaction between biological, psychological, social, and cultural factors, making it necessary for the multidisciplinary team to decide on the individualized patient basis. The characteristics of the individual patient, family and the social background are taken into consideration in order to derive maximum benefit. In developing countries, 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. Therefore, this study explores the social wellbeing and quality of life of people with disorders of sex development in Nigeria. We used qualitative phenomenological approach to explore the social wellbeing and quality of people with disorders of sex development in Nigeria. We recruited thirteen participants using purposive sampling technique from Usmanu Danfodiyo Teaching Hospital Sokoto, Nigeria. We conducted data collection exercise using face to face interviews, transcribed, and analysed using interpretative phenomenological analysis technique with the aid of NVivo software. Four themes emerged from the data that describe the social wellbeing and quality of life of people with disorders of sex development in Nigeria. These themes are socialization and social isolation, intimate relationships, sexuality, and relationships with people. Participants experienced social isolation, marital problems, poor sexual experience, absence of sexual pleasure and stigmatization. People with disorders of sex development had poor social wellbeing which negatively affects their quality of life. Findings would inform the multidisciplinary team the need to incorporate social wellbeing of people with disorders of sex development in their treatment and the need to explore public perception on people living with disorders of sex development in Nigeria.

Keywords

social experience, social wellbeing, quality of life, Nigeria, disorders of sex development, phenomenology, qualitative research

Creative Commons License



This work is licensed under a [Creative Commons Attribution-Noncommercial-Share Alike 4.0 International License](https://creativecommons.org/licenses/by-nc-sa/4.0/).

Social Wellbeing and Quality of Life of People Living with Disorders of Sex Development and Sex Re-Assignment in Nigeria: A Qualitative Phenomenological Study

Abdurrahman Muhammad Sani and Ismaila Arzika Mungadi
Usmanu Danfodiyo University, Nigeria

Ismi Arif Ismail, Mohd Mursyid Arshad, and Kim Lam Soh
Universiti Putra Malaysia, Selangor State, Malaysia

Disorders of sex development is a complex interaction between biological, psychological, social, and cultural factors, making it necessary for the multidisciplinary team to decide on the individualized patient basis. The characteristics of the individual patient, family and the social background are taken into consideration in order to derive maximum benefit. In developing countries, 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. Therefore, this study explores the social wellbeing and quality of life of people with disorders of sex development in Nigeria. We used qualitative phenomenological approach to explore the social wellbeing and quality of people with disorders of sex development in Nigeria. We recruited thirteen participants using purposive sampling technique from Usmanu Danfodiyo Teaching Hospital Sokoto, Nigeria. We conducted data collection exercise using face to face interviews, transcribed, and analysed using interpretative phenomenological analysis technique with the aid of NVivo software. Four themes emerged from the data that describe the social wellbeing and quality of life of people with disorders of sex development in Nigeria. These themes are socialization and social isolation, intimate relationships, sexuality, and relationships with people. Participants experienced social isolation, marital problems, poor sexual experience, absence of sexual pleasure and stigmatization. People with disorders of sex development had poor social wellbeing which negatively affects their quality of life. Findings would inform the multidisciplinary team the need to incorporate social wellbeing of people with disorders of sex development in their treatment and the need to explore public perception on people living with disorders of sex development in Nigeria.

Keywords: social experience, social wellbeing, quality of life, Nigeria, disorders of sex development, phenomenology, qualitative research

Introduction

Sex identification is done immediately after birth by a midwife, mother, traditional birth attendant, or any close relative conducting the delivery, using external genitalia as a reference point. There are some instances when the external genitalia may appear normal for the sex, but genetically the sex is different from the external genitalia. (Lisdonk, 2014; Özbey et al., 2004). On the other hand, there are some instances in which the external genitalia may look

ambiguous, which may lead to difficulty in sex identification. These instances 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 et al., 2006; Woodward & Neilson, 2013).

In Nigeria, sex assignment is considered as an emergency as such should not be delayed. This urgency to assign a gender is due to cultural, social, and psychological crisis the parents may undergo as a result of ambiguous genitalia (Mungadi, 2015). Gender assignment is a difficult and challenging aspect in the management of DSD 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, and 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 (Mungadi, 2015).

The quality of life of people with DSD depends largely on the availability of psychosocial management of the disorder (Cohen-Kettenis, 2010). However, socio-cultural factors such as bias concerning male gender preference, 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 DSD in developing countries are stigma, isolation, and linking the condition to witchcraft (Lisdonk, 2014; Özbey et al., 2004; Rebelo et al., 2008). One of the key roles of nurses; is the provision of counselling services which deals with the social issues associated with DSD (Kwak et al., 2010; Rothkopf & John, 2014). Family counselling is very effective in the management of DSD because it deals with the social stressors and promotes effective family coping (Cohen-Kettenis, 2010).

There are numerous social experiences resulting from living with DSD. These include feeling of shame, secrecy surrounding the condition, and failure to maintain intimate relationships (Boyle et al., 2005; MacKenzie et al., 2009; Malouf et al., 2010; Patterson et al., 2014). These have a negative impact on the quality of life of people living with the condition. (Chadwick et al., 2005; Sanders et al., 2015).

Meanwhile, there is a marked difference between the attitude of sex of rearing in late diagnosis of DSD in developing countries and developed countries. In developing countries, a man is considered as the breadwinner and a woman as a housewife and mother (Al-Jurayyan, 2010; Özbey et al., 2004; Özbey & Etker, 2013; Rebelo et al., 2008). Although DSD has received a considerable level of interest from medical practitioners, researchers, and human right groups in the last decade; little has been done to understand the social wellbeing of people with DSD. What is the social wellbeing and social quality of life of people living with disorders of sex development in Nigeria? Therefore, the need to explore the social wellbeing and quality of life of people living with DSD in Nigeria.

The study is part of a larger research on quality of life of people with DSD. The research team consisted of nurses, qualitative researchers, and a reconstructive surgeon who have interest and expertise in the management and research on DSD. All the team members are neither suffering from DSD nor have children or close relations with DSD.

Methods

Research Design and Setting

The study employed a qualitative approach to understand the social experiences of people with DSD in Nigeria. The research utilized transcendental phenomenological study design (Merriam & Tisdell, 2016; Speziale et al., 2011). Phenomenology is the most

appropriate method for studying the healthcare experiences of people with DSD (Lee & Krauss, 2015; Speziale et al., 2011). We aimed to make meaning into the essence of the social experiences and quality of life of people living with DSD (Creswell, 2013; Krauss, 2005). Therefore, phenomenological study approach was employed in order to explore the social wellbeing and quality of life of people with DSD in Nigeria.

The study was conducted in Usmanu Danfodiyo University Teaching Hospital (UDUTH) Sokoto, Sokoto State, Nigeria. It is one of the major referral hospitals for patients with DSD in Nigeria. The institution is in Sokoto State and receives patients from 19 northern states of the country. The hospital has three (3) centres: Regional Centre for Neurosurgery, Institute of Urology and Nephrology, and Institute of Child Health. The hospital has about 80 wards and units and a capacity of about 2000 bed spaces with about 500 patients on admission daily. Patients with DSD are seen at the Tetfund Centre of Excellence in Urology and Nephrology, and, therefore, this served as the recruitment centre for the study.

Participants and Sample

Adults with DSD who can speak English or Hausa Language were recruited in the study. Patients who were in stable psychological condition at the time of data collection and on follow up visits to Usmanu Danfodiyo University Teaching Hospital Sokoto were also recruited. Purposive sampling technique was used to select 13 participants for the study. This is the stage at which the data was saturated (Guest et al., 2006). At this point, there were no new themes that emerged from the data and the data were repeating. In qualitative research, the sample size is determined when the saturation is reached; a point when no more new information is coming to the data (Speziale et al., 2011).

Data Collection

The data was collected through face-to-face interviews using the semi-structured interview guide. The guide includes the following questions: how the condition affects your social life, tell me how this condition affected your intimate relationship, please share with me your sexual experience, how did you manage your life after the diagnosis of this condition, and how do people relate to you after your diagnosis. Further probing questions were followed for deepening and rooting in the phenomena and for clarity.

In addition to interviews, document analysis and field notes from participant observation were used for triangulation which constitutes the data in our study. Before the conduction of each interview, we verified the hospital record file (document) of each participant in order to gain insight into his/her conditions. Then after the interviews, we analysed the documents for supplemental information (Smith, 2015; Smith & Osborn, 2015). Field notes were used during data analysis of interviews for triangulation and supplementation of data (Creswell, 2013; Merriam & Tisdell, 2016). Therefore, it's important for the researcher(s) to combine different method of data collection for validation of the primary method, triangulation, or eliciting additional information to answer research questions (Creswell, 2013; Merriam & Tisdell, 2016). The interviews were conducted by the first author. Before the commencement of the interview, few minutes were allocated for a briefing about the study. The interviews were audio-taped and recorded with a digital voice recorder. Field notes were taken during the interviews about the verbal and non-verbal cues.

Ethical approval was obtained from Research Management Centre, Universiti Putra Malaysia and Human Research, and Ethics Committee of Usmanu Danfodiyo University Teaching Hospital Sokoto. Informed consent was obtained from the participants. Pseudonyms were used to ensure anonymity and confidentiality.

Data Analysis

We analysed the data using the principles of interpretative phenomenological analysis (IPA). The IPA was the appropriate method for data analysis in this study because it deals with emotional and significant life-changing experiences and has been proven to be appropriate for exploring the experiences of people with DSD (Smith, 2015; Smith & Osborn, 2015).

The data analysis started with the completion of the first interview which was transcribed immediately. The transcript was read and re-read in order to understand the meaning of the participants' social experiences. The transcript was then uploaded to the NVivo software for initial coding and tentative themes generation. The interviews were supported by data from field notes and memos.

The trustworthiness of this study was ensured using the following methods: triangulation (for the purpose of validation in this study, different sources of data were compared and cross-checked that includes initial interviews, follow up interviews, field notes from participant observation, and document analysis), reflexivity (to enhance the credibility of the study, we explained our position and interest because researchers are the main instrument of data collection and analysis), audit trail, member checks (the researchers sent a copy of the transcripts and preliminary findings to the participants via emails and asked them to validate their statement and whether what was recorded and transcribed were the same with what they mean and if they agree with the researcher's interpretations or not. They were given opportunity to make any changes, addition, or deletion from the interview transcript), adequate engagement in data collection (in this case, the researchers spent sufficient time of about six months in data collection that involves persistent observation and numerous interviews until no new information surfaced), peer examination was done in all stages of the study and other experts in the field of DSD were consulted in the design, collection, and analysis of data in this study, rich thick description (to achieve transferability, we presented a rich, thick, and details description of the context of the study. Furthermore, we made an exhaustive narrative of findings with sufficient evidence from personal interviews; observation field notes and document analysis, which are presented in the form of quotations where necessary) and maximum variation (For this purpose, we selected the sample of our participants with different types of DSD condition such as MRKH, CAH, Turner's syndrome. We took consideration of other factors like age, duration of diagnosis, and sex of rearing in order to account for maximum variation). Data collection and analysis was done by the first author.

Findings

Background Information

All the participants were diagnosed with DSD and had sex re-assignment surgery. They were Muslims, Nigerian nationals, and belonged to Hausa and Fulani ethnic groups. Nine of the participants had formal education ranging from Senior Secondary School Certificate (SSCE) to master's degree. Meanwhile, the remaining four participants had Islamic education. Five participants were reared as males while eight as females. The participants' age varied, with the youngest being 18 years and the oldest 45 years. Three participants were diagnosed with androgen insensitivity syndrome (AIS), six with congenital adrenal hyperplasia (CAH), two had ovotesticular DSD (true hermaphrodite), and one each with Mayer-Rokitansky-Küster-Hauser Syndrome (MRKH) and Turner's syndrome, respectively.

Social wellbeing refers to one's commitment to maintaining relationships with the people around and their experiences with DSD. Four themes described the social wellbeing of

people with DSD. These are socialization and social isolation, intimate relationships, sexuality, and relationships with people.

Socialization and Social Isolation

People with DSD had diverse social experiences because of the condition and fear of rejection which affects their socialization processes. Female participants had normal socialization while male participants experience social association.

The female participants were motivated to engage in their normal socialization because the condition is neither associated with pain nor physical symptoms that will restrict them from socializing. Jummai and Lami had normal socialization because DSD is not associated with pain or physical symptoms that hindered their socialization process. Jummai narrated:

This condition doesn't affect me physically or socially, because it is not something painful or is not something that can stop you from your normal social activities. It is something secret in the private part (genitalia). I am socially normal; I am visiting friends and relatives as normally as possible. I don't have any social problem. (Jummai)

Jummai described her condition as something secret that did not stop her from socializing. She engaged in her normal social activities without any social problem. Lami shared a similar experience:

This condition doesn't affect me socially. Most people don't know my condition as such I am socializing well with people and places. Even the surgery I had nobody knows the type and nature of the surgery, all those that call to greet me; I didn't tell them what was wrong with me, and you see nobody will discuss what was wrong with me. This is a private sickness; so-so people were not aware of it (laugh). It is not something you will see physically. (Lami)

Women were having good socialization because their condition was personal and private, and most people don't know their condition or the nature of their treatment. This helps them to overcome the fear of rejection or stigmatization in the community, because most of the women with DSD in this study had an inadequate vagina.

On the other hand, male participants experience social isolation due to the impact of DSD on their social wellbeing and quality of life. This is because of fear of stigmatization and rejection as a result of ambiguous presentation like female breast and menstruation. Abu was isolating himself from public places and stopped going to school for three months. He explained:

This condition really affected me socially. Initially before the surgery, especially when I was having the bleeding, I put myself in the room and avoiding going outside the house. I was thinking people will see my breast and make mockery out of me. I stop going to school for about three months, but later on, I got out of the situation, by tying my breast and continue my normal activities and schooling. I love games like football but as a result of this condition I stopped all games because it is an embarrassment for me to wear small shirt or play half nicked. Definitely, people will see my breast, and I will be a subject of public discussion. After surgery, I continued my normal life, but I have stopped all games in my life. It affected my social life so much. (Abu)

DSD had affected Abu's social life leading to social isolation. It has affected his education and games due to fear of stigmatization because of the female breasts. He felt his breasts were an embarrassment. However, the surgery restored his normal socialization, except games. Similarly, Idi was isolating himself from public places because of fear of embarrassment. He echoed:

It affected my social life initially before the surgery, it restricted me from going to some places, and I was confined to the house. I was thinking going outside is an embarrassment to my life. I was thinking people will see my breast despite I was keeping them tight with the chest. It makes me to avoid people and places. But after the surgery, I continued my normal social life. Just that I have to adjust myself so much. (Idi)

Male participants experienced social isolation due to the fear of stigmatization, public embarrassment, and rejection because of their female breasts and menstruation. These physical changes affect their socialization and social life. Despite concealing their breasts, they were not comfortable to socialize with people resulting in social isolation and avoidance of school and games. Ado was feeling uncomfortable and stigmatized with the breast. He echoed, "I always feel highly uncomfortable and feels like people are looking at my chest and breast." He felt people looked at his chest; as such, he isolated himself from public places. The participant's body ambiguity was more stigmatizing than the ambiguous genitalia. Tanko shared, "The breast alone in a man is a stigma; I cannot be in the public everybody will be looking at you as something different. I was very disturbed with my breast than my private part ..." (Tanko).

Additionally, the participants were encouraged and motivated to further their education by their healthcare professionals. The analysis of the data shows there is an indirect relationship between education and DSD because the health professionals were motivating and encouraging the participants to further their education to higher institution. Asabe was motivated by Professor Mamu to further her education. She had completed NCE course in English/Hausa education at Federal College of Education Technical Gusau. She shared her experience:

Then Prof himself encourages and motivates me to further my study, he said it is important to me, but I will not understand till later in life. Sincerely he is the one that motivate me most to further my study, but since my husband disagree, I can't do anything about it. (Asabe)

Following encouragement and motivation by Professor Mamu, Asabe developed interest to further her education which was initially objected by her husband, but later agreed and secured admission for her. She further stated:

Just as a surprised that day, we are together with my husband and tell me to go to FCET tomorrow you have lectures, and I said which lectures; he said he has secured admission for me and have registered me for the programme and paid my registration fees. (Asabe)

Asabe was motivated and encouraged by her doctor to further her education, which she did and studied NCE English/Hausa from FCET Gusau. Similarly, Ladi, a diploma holder in Health Information Management and student midwife at the time of the data collection, was motivated by her doctors to further her study in the medical field. She had her surgery after her junior secondary school but was encouraged and advised to further her study by her doctor. She explained:

After my JLC I had the surgery and my doctor advice and encourage me to further my study and ask me to read health-related courses so that I can help others the way I was helped. That is how my doctor really helps me to further my education. (Ladi)

Ladi was encouraged consistently whenever she went to the hospital for follow-ups. She elaborated, “She always emphasized on me to continue my studies and read health-related courses after my secondary school so that I should help others like the way she helped me” (Ladi). Ladi was determined to help others by taking the advice of her doctor and furthering her studies to become a midwife, in addition to her diploma in Health Information Management. Moreover, Abu was determined to get his bachelor’s degree in Biological Sciences, because of the doctor’s continuous encouragement following his failure to continue his school due to social isolation. Abu narrated:

But after the surgery, my doctor encourages me to continue my normal life and he emphasizes me to continue my studies, as such I have taken his advice and did continued my studies. I have a bachelor degree in Biological Sciences now.

Intimate Relationships

Analysis of the interviews revealed that most of the participants reported good intimate relationships with their spouse while three participants reported marital problems. Two men who were divorced by their wives got remarried to other wives, while one woman was yet to get married at the time of data collection.

Participants cited the reasons for their good, intimate relationships with their spouses as love and care, good relationships, patience, and sympathy. Despite their condition, women were loved and cared for by their husbands. Ladi was loved by her husband more than her co-wife. She narrated:

No! No!! It does not affect my intimate relationship with my husband or spouse before my marriage; he is a man that is too concern and shy. I know he loves me more than he loves the other woman. But later when he discovers how my body is and there are differences in our body in terms of breast and vaginal orifice, but the other woman is normal but now that he understands, and he is paying more attention to her than me. (Ladi)

The bodily difference discovered by her husband does not affect their intimate relationships. Laraba was single at the time of data collection but had good intimate relationships with her boyfriend: “I have a boyfriend, and we are living a normal life with good relationship. I love him so much; he loves me too.”

Moreover, the male participants had similar intimate relationships with their female counterparts. Tanko, who was divorced by his first wife, had good intimate relationships with his second wife whom he described as respectful. He stated, “She is respecting me, and we have formed a happy family despite this condition. I so much love my wife.” Despite his condition, Tanko had a happy family with his wife. Similarly, Bala was single at the time of the interview and expressed a good intimate relationship with his girlfriend who is not aware of his condition. He expressed:

This condition does not affect my relationship with my girlfriend, she loves me so much and she doesn't know my condition. She is seeing me as a complete man. I believe she loves me so much, and she had never told me that I look like a woman. It is my personal secret, and I don't tell anybody because it is personal. (Bala)

Bala believes his girlfriend loves him because she is not aware of his condition, and she considers him as a complete man. Moreover, other participants reported good intimate relationships with their spouses, because their spouses do not know their condition. The fear of separation was reported by the participants as the reason for hiding their condition from their spouses and partners. Laraba echoed, "Men can run away if they know you have a problem in your vagina because the essence of marriage is to have sex." Women were hiding their condition from their spouses because of fear of separation and divorced, especially the absence of the vagina and the type of vaginal construction surgery. Delu related her normal intimate relationship to the lack of awareness of her condition and the treatment by her spouse. She explained:

I have a normal intimate relationship with my boyfriends and fiancé. Most people don't know my condition. They are not aware that I had the problem. Some people know that I had surgery but don't know the reason for the surgery. It is something secret in my life. This condition didn't affect my intimate relationship. I have normal intimacy. (Delu)

The secrecy attached to DSD made the participants feel that their condition is personal and no need to inform their spouses. The aim of secrecy is to prevent stigmatization, rejection, and marital problems. Laraba thinks there is no need to inform her spouse about her condition in order to promote good intimacy. She revealed, "No! No! He don't know I had that problem but now I am normal. Nobody knows my condition. I think there is no need for him to know that because I am normal now." Fear of separation and divorce were the reasons for the concealment of DSD information to their spouses or give insufficient information.

Some participants cited good relationship with their spouse as the reason for maintaining a good intimate relationship amid their DSD condition. Jummai had a good intimate relationship with her husband because of their good relationship. She clarified:

I think this condition doesn't affect my intimate relationships. He was aware of my condition before our marriage but doesn't have the detailed information, but he was told that I have some problem in my private part which is vaginal blockage called *Gurya* in the Hausa language, but I was treated. Even though my husband didn't have satisfactory sexual intercourse with me, but he still loves me and sympathising with me about such condition. He believes everything is from God and he continues to reassured me. He was very kind and sympathetic to me. I thank God for having a very caring husband. (Jummai)

The intimate relationship was maintained due to the inadequate information given to the spouse and their relationships of love and caring. She described him as very kind and caring husband despite the lack of satisfactory intercourse. Ado was having a good relationship with his wife. He stated:

But now, I know she cannot live a good life without me as her spouse. There was a time that we travelled to Zuru, and she said that she wants to visit her

relatives in Niger state, and I gave her permission to spend 2 weeks with them, but she spent only 2 days and come back. She told me that she can't live her life without me close to her because of our intimacy now. I know we have good relationship now. (Ado)

Because of his good relationship with his wife, she indicated she could not live without him. Although she divorced him three years ago, they later re-united. Good relationship, love, care, patience, and sympathy are the factors promoting good intimate relationships among people with DSD.

Moreover, some participants related their intimate relationships to the patience and sympathy of their spouses. Despite the lack of vagina, many husbands tolerated their wives patiently with love and sympathy. Tani, who was a widow at the time of data collection was tolerated by her husband for about 20 years without vagina until his death. DSD did not affect her intimate relationship because of her husband's sympathy, patience, and care. She elaborated:

I had good intimate relationship with my husband; he is relating well with me. This condition did not change his relationship with me. Nobody ever heard anything between me and my husband. He had never shown me his anger over me. He is very patience with me. He has never shown me that he was disturbed about the lack of adequate vagina. He was very patience and empathetic. Nobody knows what was between us. I used to be good to my husband. He has never shown me his worriedness about the lack of vaginal capacity. (Tani)

The good intimate relationship was related to the sympathy and patience of the husband in tolerating his wife despite the lack of vagina necessary for heterosexual intercourse. Her husband was not disturbed and worried about it but kept reassuring her and sympathizing with her.

Meanwhile, some participants were divorced because of their condition. Data analysis shows that three men and one woman were divorced because of factors related to their condition such as infertility and absence of the vagina. Three male participants were divorced by their wives due to infertility related to the effect of DSD. Abu who got married to another wife after his first wife divorced him because of infertility shared his experience:

You know initially people don't know your condition. After my first marriage, I explained to my wife everything, and she agreed to stay with me despite my infertility. After sometimes she said she cannot cope with my infertility as such I have to divorce her. So, because of this condition, I was divorced by my wife. It was a big tragedy. (Abu)

Abu described divorced as a big tragedy in his life due to his condition following the full disclosure of his condition. The wife cannot cope with infertility and prepared divorce. Similarly, Ado was divorced by his wife due to infertility, but they later re-united after some time. He explained:

After my marriage for about 2 years, my wife became so worried about the infertility. One day she visited her parents and told them that we have problem of infertility, and the problem is from me and her parents instead for divorce. ... Later, we were settled by some of her delegates who insisted that is only God that gives children to whom he wants. (Ado)

Ado was divorced by his wife due to his infertility but was later reunited with his wife. Lami and Tanko were divorced because of absence of vagina and small penis, respectively. The absence of vagina was the reason Lami was maltreated and divorced by her husband. She discovered her problem after her marriage due to the inability to perform penetrative intercourse. The discovery made her husband to change his relationship with her leading to ill-treatment and divorce. She stated:

Ehh! I think this condition is the reason why my husband divorced me. He treated me badly before the divorce. He didn't understand that I was not the cause of my problem, and I don't know how I was, I don't know how other women are. I don't know that I have small vagina it could have been corrected earlier before my wedding. But I thank God everything is over; now, I am praying to God to give me good husband that will take good care of me. We were having normal relationship before the marriage and immediately after the marriage but when he discovered that I have such problem, he then started treating me badly and so on. (Lami)

Vagina and penis are considered the right equipment for heterosexual intercourse. After treatment, Lami was praying to get a good husband who would take care of her. People with DSD were motivated to seek the treatment because of the need for heterosexual intercourse and avoid divorce and separation because of DSD.

Sexuality

Sexuality is the ability of one to perform heterosexual intercourse and to satisfy oneself and the sexual partner. People with DSD have small penis and absence of vagina. This leads to difficulty in performing heterosexual intercourse and/or achieving sexual satisfaction. Participants in this study shared their sexual experiences. Two female participants who had surgery before their marriage reported normal sexual intercourse. Asabe and Ladi had a penetrative intercourse after their marriage because they had surgery before their marriage at 18 and 17 years, respectively. Asabe shared her experience:

That is how we started sexual relationship after marriage. My husband was having sexual satisfaction, but I don't get sexual satisfaction. After he married the second wife, that was the time he understood that there is a difference between me and the other wife. But we continued having intercourse despite the differences. Because of his complaints about the differences that was what made me to seek for another surgery so that I will be normal like the other wife. After the surgery now he was more satisfied than before because the whole penis can enter, and the place is very smooth now. I am okay now and having normal sexual intercourse. (Asabe)

Asabe had vaginal reconstructive surgery when she was about to get married. She had penetrative sexual intercourse though without sexual pleasure. She was the first wife of her husband who realized she was sexually different from the other woman. She had to undergo a second surgery in order to satisfy her husband sexually. Unlike Asabe, Ladi, who had vaginal reconstruction surgery, was having sexual satisfaction and she is satisfying her husband. She narrated:

If we are having sexual intercourse, I am having sexual pleasure; likewise, he is having sexual pleasure. I am having sexual satisfaction, also he is having sexual satisfaction. There is no problem with sexual intercourse; nobody complains about our sexual relationships. There was no time my husband complains lack of penetrative intercourse. When I first met my husband, we experience difficulty in penetration but since then we have been having normal sexual relationships. (Ladi)

Both Ladi and her husband were experiencing sexual pleasure and satisfaction with normal penetrative intercourse.

Moreover, male participants were having normal sexual intercourse despite a small penis and common perineal opening. Tanko was having normal sexual intercourse with his wife and both were sexually satisfied. He expressed:

We have normal sexual relationship with my wife. I am satisfying her, and she is satisfying me sexually. We are having sex at normal interval. The small penis and the release of sperm in the abnormal way did not stop us from achieving sexual satisfaction. My wife has never complaint about the lack of sexual satisfaction. (Tanko)

Tanko was having sexual pleasure and was satisfying his wife before the surgery, although he had a small penis, and the sperm was released through the common perineal opening.

Moreover, a field note from one participant observation shows Tanko has a small penis and common perineal opening where he urinates and ejaculates. Similarly, Abu and Ado had normal sexual intercourse with sexual satisfaction. They were on testosterone hormonal therapy before their marriage which increased the size of their penis. Abu narrated his story:

I don't have problem sexually. I told you I was having small penis initially but after the surgery and when I started taking injection my penis increases in size drastically. I am having sexual desire and I am having sexual satisfaction. (Abu)

Normal sexual satisfaction was associated with erection and ejaculation among male participants. Ado explained, "I have a normal sexual relationship with my wife. I am having erection but ejaculating seminal fluid, not sperm."

Meanwhile, some female participants were not able to have penetrative intercourse due to the absence of or small vagina. Lack of penetrative intercourse was often the major symptoms identified by some participants with DSD. Four female participants did not experience penetrative sex due to small or absence of vagina. Jummai described her experience on the first day of her marriage as an embarrassment. She was not happy and cried. She described:

The first day of my marriage was the most embarrassing moment of my life. My husband wanted to have sex with me, but he tried all he could, he cannot penetrate. He has to do it on my external genitalia to release sperm over my labia. He tries all possible ways to enter into me as a woman but couldn't enter. I wasn't happy at all. I cried a lot for having realized that I wasn't a complete woman. It was a very sad moment of my life. The size of my vagina was very little less than the size of the little finger. I think even the little finger cannot enter. (Jummai)

Jummai described the size of her vagina as less than her little finger which cannot accommodate penis. Talatu and Tani had a small vagina. Talatu explained, “there is no road he can enter inside the main vagina just do the sex by the door of the vagina, because of that I’m not enjoying the sex and he has not been satisfied sexually. He is complaining that there is no enough opening. He said is just like 4cm depth.”

Because of inadequate vagina, sexual partners improvised with the external genitalia to have sex and release sperm. Women allowed their spouse to have sex in the external genitalia due to difficulty in the normal heterosexual intercourse. Tani agreed with her husband to have sex with her despite the absence of vagina. She echoed:

He is not happy with lack of penetrative intercourse because it is a sexual pleasure, but he is not having it. I can’t satisfy him; I am worried for him. I agreed with him to have sex even though there is inadequate vaginal passage, this is his marital right, but I know he will not be satisfied sexually. I allowed him to have sex even if I don’t like it, is his right. (Tani)

The women with small vaginas neither satisfied themselves sexually nor satisfied their partners.

Relationship with People

People with DSD have a cordial relationship with their families, friends and significant others. All the participants in this study reported cordial relationships with family members, friends, and significant others. The majority of people were not aware of the participants’ condition except the close relatives and friends of the participants. Family and friends were supportive and sympathetic toward the participants. Asabe had a good relationship with people, and they were showing their concerns over her infertility. They advised her to seek treatment for her infertility because most of them were not aware of her condition. She stated:

People relate to me well and show sympathy with me, especially with my infertility. They always advise me to seek medical attention about my condition so as to conceive pregnancy and give birth. Others are saying the family planning I am using is enough for now. Everybody is saying her own version because they don’t know my condition. (Asabe)

Asabe was supported by her family, friends, and significant others. Abu had good relationships and received support from his families to get treatment for his condition. He had a cordial relationship with the general public because they don’t know his condition. He shared:

I have good relationships with my family and friends. My families did everything possible to help me out of this problem. My family were sympathizing and very supportive towards everything. They really show me care and love. To the general public we have cordial relationship because most people don’t know my condition. I thank everybody for their support. (Abu)

People were showing their support and sympathy to the participants with DSD. Some of them were advised to seek treatment for infertility. Talatu described the support and sympathy she enjoyed from the public. She stated:

My relationship with people is very cordial, everyone is sympathizing with me. They are normal. Families and friends give us advice to seek treatment. They really sympathise with me. They are showing their concerns. I thank God Almighty. I have a lot of friends, but they are giving me good care and concerns.
(Talatu)

Discussion

The social wellbeing and quality of life of people with DSD were affected by this condition. Women had normal socialization while men experience social isolation. The good socialization process is related to the good coping strategies adopted by women with DSD. They relate their socialization to the absence of pain or physical disability that will impair their socialization process, which is like the findings of Kanhere et al. (2015). The authors reported DSD did not interfere with the socialization and social relationships of people with the condition.

The participants were motivated to further their education in order to be self-reliance despite the effect of DSD on their lives such as infertility. Well educated participants can get white collar jobs, which will help them to be out of the depression of infertility and have fruitful future. This finding is similar to other findings in which DSD diagnosis motivated some people to work hard academically in the school and in their places of work for fruitful future (Chadwick et al., 2005; Ernst et al., 2016). On the other hand, other studies reported DSD compromised students' educational carrier leading to school dropout and examinations failures (Chadwick et al., 2005). Although studies had found that DSD had a negative effect on the academic performance of the patients, because of lack of focus and concentration on school activities. People with DSD were paying more attention to thinking of their problem and condition at the expense of their educational activities (Ernst et al., 2016; Malouf et al., 2010). Therefore, there is a need to motivate and encourage people with DSD to pursue their educational carriers. According to McKillop (2013), DSD does not have any effect on academic performance. But people with DSD reported bullying in the school which make them avoid school activities and invariably affect their performance (MacKenzie et al., 2009).

Despite DSD condition, the participants experience a good intimate relationship with their partners because of love, care, good relationships, patience, and sympathy. This is in contrast with the findings of previous studies where people with DSD had trouble managing intimate relationships. Previous findings may be due to the fear of rejection, despair, inability to perform sexual intercourse, and negative reactions from partners about their ambiguous bodily appearance and genitalia (Boyle et al., 2005; Chadwick et al., 2005; MacKenzie et al., 2009; Malouf et al., 2010; Patterson et al., 2014). Also, majority of the people with DSD had never engaged in serious or intimate relationships or had sexual partner (Schönbucher et al., 2010). However, Chadwick et al. (2005) reported that after treatment, men with DSD were able to remove their psychological barrier and engaged in intimate relationships. The possible explanation for this finding may be because, most of the spouses of the participants were not aware of their condition or they were given incomplete information.

Four participants had normal sexual intercourse; two women who had genital surgery before their sexual experience and two men who had sex before their surgery. While four women reported lack of penetrative intercourse as the first symptoms of their condition but had normal sexual intercourse after the surgery. The sexual experience includes hugging, kissing, romance, sexual intercourse, and feeling of love (Sanders et al., 2015). Overall, this finding showed participants had good sexual relationships following genital surgery which indicated a good sexual quality of life. This finding is contrary to other findings which indicated people with DSD had difficult sexual experience due to small vagina or small penis (Boyle et al., 2005;

Guntram, 2013; MacKenzie et al., 2009; Sanders et al., 2015). The difficult sexual experience may be related to the physical or psychological barriers; such as fear of rejection and its associated consequences (Cohen-Kettenis, 2010; de Neve–Enthoven et al., 2016; Kanhere et al., 2015). Other studies reported people with DSD had poor sexual quality of life, sexual dissatisfaction, decreased sexual desire, dyspareunia, and decreased sexual arousal (Kanhere et al., 2015; Kohler et al., 2012; Schönbucher et al., 2010). Meanwhile, this current study is in line with other studies which indicated that people with DSD had good sexual quality of life and were satisfied with their sexual life (Chadwick et al., 2005; Ediati et al., 2015; Fliegner et al., 2014; Kanhere et al., 2015).

Participants in this study had good social relationships with their family members, friends, and colleagues. Therefore, DSD did not interfere with the participant's social relationships with the other people (Audí, 2014; Garrett & Kirkman, 2009; Kanhere et al., 2015; MacKenzie et al., 2009; McKillop, 2013).

Limitations of the Study

The study consists of 13 participants which were recruited from northern Nigeria, although more participants could have been interviewed, but the number are representatives of the people living with DSD and sex re-assignment in Nigeria. Moreover, another limitation of this study is the use of semi-structured in-depth qualitative interviews as the primary source of data. Therefore, the participants' experiences and opinions may be biased by their situations, the way they observe and experience the events. Notwithstanding these limitations, the rich thick descriptions used in this study would be helpful for the patients, family members, health professionals and researchers of DSD to make a deep and meaningful understanding. The study was limited by lack of participants' visibility because the condition is associated with secrecy and feeling of shame. Difficulty in the recruitment of the participants was overcome by engaging a clinician to assist in participants' recruitment.

Conclusion

Social wellbeing and quality of life were affected by DSD both positively and negatively. They experience normal socialization, good intimate relationships and cordial relationships. The negative social impact of DSD includes social isolation, marital separation and divorce, poor sexual experience, absence of sexual pleasure, and stigmatization. These affected the social quality of life of people with DSD in Nigeria. Therefore, it can be concluded that DSD affects the social quality of life of people living with the condition in Nigeria, because of poor social wellbeing and delayed presentation to the hospital.

This study will increase the knowledge and understanding of the multidisciplinary team on the social experiences of the people with DSD in order to incorporate the social aspect of the patients in the DSD treatment protocol. It would help the DSD team to manage the social concern of patients with DSD such as social isolation and stigmatization. There is need to improve the social quality of life of people with DSD. There is a need for further study on the public perception of adults living with DSD and sex re-assignment in Nigeria.

Furthermore, this study significantly contributed to the body of knowledge on the social wellbeing and quality of life of people living with DSD. It provided insights and strengthen social construct of health-related quality of life model by Ferrels et al. (1995), also highlighted the social relationship of WHO quality of life model (WHOQOL Group, 1995). The study also contributed socialization in the social domain of quality-of-life model and was inconsistent with the model. Moreover, the current study strengthens and highlights on social isolation, sexuality, intimate relationships and relationships with people as it affects the quality of life of

people with DSD. The policy makers can utilize the findings of this study to make policies that will improve the social wellbeing and quality of life of people living with DSD.

References

- Al-Jurayyan, N. (2010). Ambiguous genitalia, two decades of experience: Clinical management and sex assignment. *Journal of Taibah University Medical Sciences*, 5(1), 13–20. [https://doi.org/10.1016/S1658-3612\(10\)70119-0](https://doi.org/10.1016/S1658-3612(10)70119-0)
- Al-Jurayyan, N. (2011). Ambiguous genitalia: Two decades of experience. *Annals of Saudi Medicine*, 31(3), 284–288. <http://dx.doi.org/10.4103/0256-4947.81544>
- Audí, L. (2014). Past experiences of adults with disorders of sex development. In O. Hiort & S. F. Ahmed (Eds.), *Endocrine development* (Vol. 27, pp. 138–148). S. Karger AG. <http://www.karger.com?doi=10.1159/000363639>
- Boyle, M. E., Smith, S., & Liao, L.-M. (2005). Adult genital surgery for intersex: A solution to what problem? *Journal of Health Psychology*, 10(4), 573–584. <https://doi.org/10.1177/1359105305053431>
- Chadwick, P. M., Liao, L.-M., & Boyle, M. E. (2005). Size matters: Experiences of atypical genital and sexual development in males. *Journal of Health Psychology*, 10(4), 529–543. <https://doi.org/10.1177/1359105305053420>
- Cohen-Kettenis, P. T. (2010). Psychosocial and psychosexual aspects of disorders of sex development. *Best Practice & Research Clinical Endocrinology & Metabolism*, 24(2), 325–334. <https://doi.org/10.1016/j.beem.2009.11.005>
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). SAGE Publications.
- de Neve–Enthoven, N. G. M., Callens, N., van Kuyk, M., van Kuppenveld, J. H., Drop, S. L. S., Cohen–Kettenis, P. T., & Dessens, A. B. (2016). Psychosocial well-being in Dutch adults with disorders of sex development. *Journal of Psychosomatic Research*, 83, 57–64. <https://doi.org/10.1016/j.jpsychores.2016.03.005>
- Ediati, A., Juniarto, A. Z., Birnie, E., Drop, S. L. S., Faradz, S. M. H., & Dessens, A. B. (2015). Body image and sexuality in Indonesian adults with a disorder of sex development (DSD). *The Journal of Sex Research*, 52(1), 15–29. <https://doi.org/10.1080/00224499.2013.816260>
- Ernst, M. E., Sandberg, D. E., Keegan, C., Quint, E. H., Lossie, A. C., & Yashar, B. M. (2016). The lived experience of MRKH: Sharing health information with peers. *Journal of Pediatric and Adolescent Gynecology*, 29(2), 154–158. <https://doi.org/10.1016/j.jpag.2015.09.009>
- Fliegner, M., Krupp, K., Brunner, F., Rall, K., Brucker, S. Y., Briken, P., & Richter-Appelt, H. (2014). Sexual life and sexual wellness in individuals with complete Androgen Insensitivity Syndrome (CAIS) and Mayer-Rokitansky-Küster-Hauser Syndrome (MRKHS). *The Journal of Sexual Medicine*, 11(3), 729–742. <https://doi.org/10.1111/jsm.12321>
- Garrett, C. C., & Kirkman, M. (2009). Being an XY female: An analysis of accounts from the website of the Androgen Insensitivity Syndrome support group. *Health Care for Women International*, 30(5), 428–446. <https://doi.org/10.1080/07399330902785380>
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59–82. <https://doi.org/10.1177/1525822X05279903>
- Guntram, L. (2013). “Differently normal” and “normally different”: Negotiations of female embodiment in women’s accounts of ‘atypical’ sex development. *Social Science & Medicine*, 98, 232–238. <https://doi.org/10.1016/j.socscimed.2013.09.018>

- Hughes, I. A., Houk, C., Ahmed, S. F., & Lee, P. A. (2006). Consensus statement on management of intersex disorders. *Archives of Disease in Childhood*, *91*, 554–563.
- Kanhere, M., Fuqua, J., Rink, R., Houk, C., Mauger, D., & Lee, P. A. (2015). Psychosexual development and quality of life outcomes in females with congenital adrenal hyperplasia. *International Journal of Pediatric Endocrinology*, *2015*(21), 1–9. <https://doi.org/10.1186/s13633-015-0017-z>
- Kohler, B., Kleinemeier, E., Lux, A., Hiort, O., Gruters, A., & Thyen, U. (2012). Satisfaction with genital surgery and sexual life of adults with XY disorders of sex development: Results from the German clinical evaluation study. *Obstetrical & Gynecological Survey*, *67*(6), 339–341. <https://doi.org/10.1097/OGX.0b013e318259bef1>
- Krauss, S. E. (2005). Research paradigms and meaning making: A primer. *The Qualitative Report*, *10*(4), 758–770. <https://doi.org/10.46743/2160-3715/2005.1831>
- Kwak, K., Knoll, J., Otten, B., De Gier, R., Kortmann, B., & Feitz, W. (2010). The role of the nurse practitioner in the disorder of sex development study. *Journal of Pediatric Urology*, *6*(Supplement 1), S104. <https://doi.org/10.1016/j.jpuro.2010.02.201>
- Lee, K., & Krauss, S. E. (2015). Why use qualitative research methods to understand the meaning of clients' experiences in healthcare research? *International Journal of Public Health and Clinical Sciences*, *2*(4), 1–6.
- Lisdonk, J. van. (2014). *Living with intersex/DSD: An exploratory study of the social situation of persons with intersex/DSD*. Netherlands Institute for Social Research/SCP.
- MacKenzie, D., Huntington, A., & Gilmour, J. A. (2009). The experiences of people with an intersex condition: A journey from silence to voice. *Journal of Clinical Nursing*, *18*(12), 1775–1783. <https://doi.org/10.1111/j.1365-2702.2008.02710.x>
- Malouf, M. A., Inman, A. G., Carr, A. G., Franco, J., & Brooks, L. M. (2010). Health-related quality of life, mental health and psychotherapeutic considerations for women diagnosed with a disorder of sexual development: Congenital adrenal hyperplasia. *International Journal of Pediatric Endocrinology*, *2010*(1), 253465. <https://doi.org/10.1155/2010/253465>
- McKillop, K. A. (2013). *An exploration of the psychosocial consequences of delayed puberty in children who attend the Royal Hospital for Sick Children Endocrine Clinic: A qualitative study and clinical research portfolio* [Doctoral thesis, University of Glasgow]. Enlighten.
- Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation*. John Wiley & Sons.
- Mungadi, I. A. (2015). *Intersexuality, gender and sex reassignment: A fascination in urologic reconstruction*. Graphic Concept Academy.
- Özbey, H., Darendeliler, F., Kayserili, H., Korkmazlar, Ü., & Salman, T. (2004). Gender assignment in female congenital adrenal hyperplasia: A difficult experience. *BJU International*, *94*(3), 388–391. <https://doi.org/10.1111/j.1464-410X.2004.04967.x>
- Özbey, H., & Etker, S. (2013). Disorders of sexual development in a cultural context. *Arab Journal of Urology*, *11*(1), 33–39. <https://doi.org/10.1016/j.aju.2012.12.003>
- Palmer, B. W., Wisniewski, A. B., Schaeffer, T. L., Mallappa, A., Tryggestad, J. B., Krishnan, S., Chalmers, L. J., Copeland, K., Chernausek, S. D., Reiner, W. G., & Kropp, B. P. (2012). A model of delivering multi-disciplinary care to people with 46 XY DSD. *Journal of Pediatric Urology*, *8*(1), 7–16. <https://doi.org/10.1016/j.jpuro.2011.08.013>
- Patterson, C. J., Crawford, R., & Jahoda, A. (2014). Exploring the psychological impact of Mayer–Rokitansky–Küster–Hauser syndrome on young women: An interpretative phenomenological analysis. *Journal of Health Psychology*, *21*(7), 1228–1240. <https://doi.org/10.1177/1359105314551077>
- Rebelo, E., Szabo, C. P., & Pitcher, G. (2008). Gender assignment surgery on children with

- disorders of sex development: A case report and discussion from South Africa. *Journal of Child Health Care*, 12(1), 49–59. <https://doi.org/10.1177/1367493507085618>
- Rothkopf, A. C., & John, R. M. (2014). Understanding disorders of sexual development. *Journal of Pediatric Nursing*, 29(5), e23–e34. <https://doi.org/10.1016/j.pedn.2014.04.002>
- Sanders, C., Carter, B., & Lwin, R. (2015). Young women with a disorder of sex development: Learning to share information with health professionals, friends and intimate partners about bodily differences and infertility. *Journal of Advanced Nursing*, 71(8), 1904–1913. <https://doi.org/10.1111/jan.12661>
- Schönbucher, V., Schweizer, K., & Richter-Appelt, H. (2010). Sexual quality of life of individuals with disorders of sex development and a 46, XY karyotype: A review of international research. *Journal of Sex & Marital Therapy*, 36(3), 193–215. <https://doi.org/10.1080/00926231003719574>
- Smith, J. A. (2015). *Qualitative psychology: A practical guide to research methods*. SAGE.
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, 9(1), 41–42. <https://doi.org/10.1177/2049463714541642>
- Speziale, H. S., Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed.). Lippincott Williams & Wilkins.
- Woodward, M., & Neilson, A. (2013). Disorders of sex development. *Surgery (Oxford)*, 31(12), 646–651. <https://doi.org/10.1016/j.mpsur.2013.10.005>

Author Note

Abdurrahman Muhammad Sani is a Lecturer in the Department of Nursing Sciences at Usmanu Danfodiyo University Sokoto in Nigeria. Please direct correspondence to abdulsani19@gmail.com.

Ismi Arif Ismail and Mohd Mursyid Arshad are in the Department of Professional Development and Continuing Education at Universiti Putra Malaysia I Serdang, Selongor State, Malaysia.

Ismaila Arzika Mungadi is a Professor of Surgery and the Director of the Tetfund Centre of Excellence in Urology and Nephrology at Usmanu Danfodiyo University Sokoto in Nigeria. Please direct correspondence to imungadi@yahoo.com.

Kim Lam Soh (Corresponding author) is an Associate Professor and the Head of Department in the Department of Nursing and Rehabilitation at Universiti Putra Malaysia, 43300 Serdang, Selongor State, Malaysia. Email: sklam@upm.edu.my, Phone Number: +603 89472429, Fax: +603 89472759.

Copyright 2021: Abdurrahman Muhammad Sani, Ismaila Arzika Mungadi, Ismi Arif Ismail, Mohd Mursyid Arshad, Kim Lam Soh, and Nova Southeastern University.

Article Citation

Sani, A. M., Mungadi, I. A., Ismail, I. A., Arshad, M. M., & Soh, K. L. (2021). Social wellbeing and quality of life of people living with disorders of sex development and sex re-assignment in Nigeria: A qualitative phenomenological study. *The Qualitative Report*, 26(7), 2189–2205. <https://doi.org/10.46743/2160-3715/2021.3699>
