



Social Well-being, Social Experience and the Quality of the Life of People Living with Disorders of Sex Development and Sex Re-Assignment

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Abstract

Background: Disorders of Sex Development (DSD) is the congenital abnormality in which the chromosomal, gonadal or anatomical sex genitalia is atypical. In Nigeria, sex assignment is considered as an emergency and as such should not be delayed. This is due to cultural, social and psychological crisis that the patient/parents may undergo as a result of ambiguous genitalia.

Aim: To explore the social well-being, social experiences and social quality of life of the people with DSD in Nigeria. **Methods:** A qualitative study approach using a phenomenological study design was employed in the study to recruit thirteen participants using purposive sampling technique. One-on-one and face to face interviews were used for data collection. Semi-structured interview guide, document analysis and field notes from participant observation were used as the method of data collection and triangulation. The data were transcribed verbatim and analysed using interpretative phenomenological analysis. **Results:** Findings revealed that four themes emerged from the data which includes; socialization and social isolation, intimate relationships, sexuality and relationships with people. Participants experienced social isolation, marital problems, poor sexual experience, the absence of sexual pleasure and stigmatization.

Conclusion: People with DSD had poor social well-being which negatively affects their social quality of life. Findings would inform the multidisciplinary team the need to incorporate social well-being and social experiences of people with DSD in their treatment to promote their quality of life and the need to explore public perception on people living with DSD in Nigeria.

Keywords: *Disorders of sex development, Social experience, Social well-being, Social quality of life*

Introduction

Sex identification is done immediately after birth by the midwife, the mother, the traditional birth attendant, or any close relative that is conducting 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. This may be detected mostly during puberty

or early adulthood (Lisdonk, 2014; Özbey et al., 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 (Hughes et al., 2006; Woodward & Neilson, 2013).

In Nigeria, sex assignment is considered an emergency as such should not be delayed (Mungadi, 2015). This is due to the cultural, social, and psychological crises that the parents may undergo as a result of ambiguous genitalia (Mungadi, 2015). Gender assignment is a difficult and most challenging aspect in the management of DSD due to a number of factors; such as difficulty in diagnosis (Palmer et al., 2012), the potential for intercourse (Özbey et al., 2004), diagnosis-specific psychosexual outcome, the 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 which is considered the most important factor (Mungadi, 2015).

The quality of life of people with DSD depends largely on the availability of psychosocial management of the disorder (Cohen-Kettenis, 2010). 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 DSD in developing countries 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).

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 negative impact on the quality of life of people living with the condition. Other consequences are difficulty in having sexual intercourse (Boyle et al.,

2005; Chadwick et al., 2005; MacKenzie et al., 2009; Sanders et al., 2015).

Meanwhile, in late diagnosis of DSD, there is a marked difference in the attitude of sex of rearing between developing countries and developed countries. In developing countries, a man is considered as the breadwinner and a woman as the housewife and the mother while in developed countries, the case is not the same (Al-Jurayyan, 2010; Özbey et al., 2004; Özbey and Etker, 2013; Rebelo et al., 2008).

In developing countries, many people with DSD 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, 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, social experiences and social quality of life of people with DSD (Lisdonk, 2014). Therefore, there is need to explore the social wellbeing, social experiences and social quality of life of people living with DSD in Nigeria.

Methods

Research Design

The study employed qualitative approach to understand the social experiences of people with DSD in Nigeria. The research utilized transcendental phenomenological study design according to Husserl's philosophy (Creswell, 2013; Merriam and Tisdell, 2016; Speziale et al., 2011). It is the most suitable method for exploring the health experiences of clients in order to make meaning into their lived experiences (Krauss, 2005; Lee and Krauss, 2015). Phenomenology is the most appropriate method for studying the healthcare experiences of people with DSD (Speziale et al., 2011). This study was aimed to make meaning into the essences of the social experiences of people living with DSD (Creswell, 2013). Therefore, this study employed phenomenological study approach

because the main purpose of the study is to explore and describe the social wellbeing, social experiences and social quality of life of people living with DSD in Nigeria.

Research Setting

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 located in Sokoto State and receive 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 every day. Patients with DSD are seen at the Institute of Urology and Nephrology and therefore, this served as the recruitment centre for the study.

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. 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

This study employed face to face interviews using semi-structured interview guide. In addition to interviews, document analysis and field notes from participant observation were used for triangulation. The interview was conducted by the first author. Before the commencement of the interview, few minutes

were allocated for briefing about the study. The interviews were audio-taped and recorded with digital voice recorder. All the participants were asked same set of questions. However, some questions were not asked in the same order because of the flow of the conversation. Probing questions were used in the course of the interview when needed. Field notes were taken during the interviews about the verbal and non-verbal cues.

Data Analysis

Qualitative data analysis consists of data transcription, data organization, data reduction and data presentation (Creswell, 2013). All aspects of data including field notes, diaries and recordings were analysed 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 and 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 of DSD. The transcript was then uploaded in the NVivo software for initial coding and tentative themes generation. All the new ideas that came up were checked in the rest of the interviews. The interviews were supported by the field notes from participant observations. Memos and notes were written while reading the transcripts in order to documents any thoughts as they emerge.

Ethical Approval

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 and information sheet were discussed with the participants prior to the interview. Anonymity and confidentiality were ensured. Pseudonyms

were used which represent names of the days in Hausa such as Jummai (Friday), Laid (Sunday) etc.

Findings

Background Information

All the participants were diagnosed with DSD and had sex re-assignment surgery. They were Muslims, Nigerian nationals, and belonging 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 informal education. Five participants were reared as male while eight as female. 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.

Four themes described the social wellbeing, social experiences and social quality of life 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 due to the effect of the condition and fear of rejection which affect their socialization processes. Some participants had normal socialization while others experienced social isolation.

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 reported that, this condition does not affect them socially, because it is not associated with pain or any physical symptoms that hindered their socialization process. Jummai narrated:

This condition doesn't affect me physically or socially, because 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 similar experience; she was socializing normally because her condition is private and has no physical symptoms. Most people don't know her condition or the nature of the surgery she had. She stated:

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).

Female participants 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 were having inadequate vagina. On the other hand, male participants were having normal socialization despite the obvious physical symptoms; like female breast. They concealed their breast and socialized normally. Tanko and Bala shared their socialization experience. Tanko, a businessman was concealing his breast in order to socialize normally. He shared:

This condition does not stop me from my normal socialization, I'm having good relationship with people and I'm visiting people like friends and families. I am socially normal, the way I'm tying

my breast help me to conceal it from them. I am a businessman, I have to interact with people, go to market and the rest (Tanko).

Most people were not aware of the participants' condition which gives them more chance to socialize normally when they concealed their breast. Bala described; "I don't believe this condition affects my socialization, I am socializing well with my peers and none of them is aware of my condition. I am hiding my breast from the people. I always visit people and places as normally as possible".

Disorders of sex development did not affect the socialization process of people with the condition, because it is a condition that was not physically visible to the public. On the other hand, other participants experience social isolation due to the impact of the condition on their social wellbeing. They were isolating themselves because of fear of stigmatization and rejection. The breast and menstruation were the main reason why they were isolating themselves. 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 is an embarrassment for me to wear small shirt or play half naked. 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 breast. He was feeling breast as embarrassment in his life. But 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 the female breast and menstruation. This affects their socialization and social life. Despite concealing their breast they were not comfortable to socialize with people resulting in social isolation and avoidance of school and games.

Apart from normal socialization, the participants were encouraged and motivated to further their education by their health teams. The analysis of the data shows that, there is 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 Prof to further her education. She had completed NCE course in English/Hausa education at Federal College of Education Technical (FCET) 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 Prof to further her education, 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).

Similarly, Ladi, a diploma holder in Health Information Management and student midwife at the time of the data collection; was motivated by her health team 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 was encouraged consistently whenever she went to the hospital for follow ups. She elaborated:

She always emphasized on me to continue my studies and study 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 taken the advice of her doctor and further her study to become a midwife in addition to her diploma in Health Information Management. Moreover, Abu was determined to get his bachelor 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 encourage me to continued my normal

life and he emphasize me to continued my studies as such I have taken his advice and did continued my studies. I have Bachelor degree in Biological Sciences now.

Intimate Relationships

Analysis of the interviews revealed that ten participants reported good intimate relationships with their spouse while, three participants reported marital problems.

Participants cited reasons for their good intimated relationships with their spouse as loves and care, good relationships, and patience and sympathy. Women were loves by their husbands and they were taking care of them despites their condition. Ladi was loved by her husband more than her co-wife because he was showing her loves, care and concern. 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 understand and he is paying more attention to her than me (Ladi).

Despites the differences in the vagina and the breast due to her condition; her husband loved her. 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 whom they love each other; “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, expressed a good intimate relationship with his girlfriend whom doesn’t know 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 that his girlfriend love him because she don’t know his condition and she considered him as a complete man. Moreover, other participants reported good intimate relationships with their spouse because they don’t 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 vagina and the type of vaginal construction surgery underwent by participants. Delu related her normal intimate relationship to the lack of awareness of her condition and the treatment by her spouse. She explained:

I have 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 knows that I had surgery but don’t know the reason for the surgery. It is something secrete in my life. This condition didn’t affect my intimate relationship. I have normal intimacy (Delu).

The secrecy attached to DSD made the participants to feel that their condition is personal and don’t need to be known by people including their spouses. This was to prevent stigmatization, rejection and marital problems. Laraba was single and think that 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”. Because of the fear of separation and divorce, participants concealed DSD information to their spouses or give insufficient information.

Some participants cited character of their spouse as the reason for maintaining good intimate relationship in the midst of DSD condition. Jummai had good intimate relationship with her husband because of his good character. 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 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 care. She described him as very kind and caring husband despite the lack of satisfactory intercourse. Ado’s good relationship with his wife made her to be always with him and cannot live her life without him. 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 want 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).

Ado was having good relationship with his wife and she cannot live without him. Although she divorced him three years ago, but 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 good intimate relationships due to the patience and sympathy of their spouses. Despite the lack of vagina, most 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. The condition did not affect her relationship because of the husband's sympathy, patience and care. She elaborated:

I had good intimate relationship with my husband; he was 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 was very patient 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, which is necessary for heterosexual intercourse. Her husband was not disturbed and worried about it, but keeps on 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 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 preferred divorce. Similarly, Ado was divorced by his wife due to infertility but they later re-united after a while. 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 about his infertility related to his condition but was later reunited with his wife. Lami and Tanko were divorce because of absence of vagina and

small penis respectively. The absence of vagina was the reason why Lami was maltreated and divorced by her husband. She discovered her problem after her marriage due to the inability to perform penetrative intercourse. This 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 were considered as the right equipment for heterosexual intercourse. After treatment Lami was praying to get a good husband that will take care of her. People with DSD were motivated to seek for the treatment because of the need for heterosexual intercourse and avoid divorce and separation due to the effect 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 share their sexual experiences. Four participants had normal sexual intercourse with their partners. 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 other women. She had to undergo 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 experienced difficulty in penetration but since then we have been having normal sexual relationships (Ladi).

Both of them were experiencing sexual pleasure and satisfaction with normal penetrative intercourse.

Moreover, male participants were having normal sexual intercourse despite the small penis, and common perineal opening. Tanko was having normal sexual intercourse with his wife and both of them were satisfied sexually. 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 small penis and the sperm was released through the common perineal opening. Similarly, Abu and Ado had normal sexual intercourse with sexual satisfaction of themselves and their spouses. 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 absence of or small vagina. Lack of penetrative intercourse was the main symptoms identified by some of the participants with DSD. Four female participants did not experience penetrative sex due to the absence of vagina. Jummai described her experience on the first day of

her marriage as embarrassment. She was not happy and cried about it. 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 were having small vagina which cannot accommodate penis. Talatu with 4cm vaginal depth 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 is 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 the 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 because is his marital right. 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 vagina neither satisfied themselves sexually nor satisfied their partners.

Relationship with People

People with DSD have cordial relationship with their families, friends and significant others. All the participants in the study reported cordial relationships with family members, friends and significant others. Majority of the 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 good relationship with people and they were showing their concerns over her infertility. They advise her to seek treatment about her infertility because most of them were not aware of her condition. Asabe 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 the significant others. Abu experienced good relationships with his families and friends. He received support from his families and friends to get treatment for his condition. He had cordial relationship with the general public, because they don't know his condition. Abu 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".

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."

Discussion

Healthcare professionals motivated the participants to further education in order to be self-reliance despite the effect of DSD on their lives such as infertility. When the participants are well educated they can get white collar jobs, which will help them to be out of the depression of infertility and have fruitful future. The findings of this study was similar to other findings in which DSD diagnosis motivated some people to work hard academically in the school and in their places of work with the aim of having fruitful future (Chadwick et al., 2005; Ernst et al., 2016). On the other hand, other studies reported that DSD compromised students' educational carrier leading to school dropout and examinations failures (Chadwick et al., 2005). Although studies had found that DSD had negative effect on the academic performance of the patients, because of lack of focus and concentration on school activities following DSD diagnosis. 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 need to motivate and encourage people with DSD to pursue their educational carriers despite DSD condition. 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 affecting their performance (MacKenzie et al., 2009).

Moreover, the participants in this study had good socialization process which is related to the good coping strategies adopted by the participants. They related their good socialization to the absence of pain or physical disability that will impaired their socialization process. This is similar to the findings of Kanhere et al. (2015) who reported that DSD did not interfere with the socialization and social relationships of people with the condition.

Participants in this study had good intimate relationships with their partners because of love, care, good relationships, patience and sympathy despites the DSD condition either treated or untreated. This is in contrast with the findings of previous studies where people with DSD experience difficulty in engaging and maintaining intimate relationships because of 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 due to the fact that, 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 2 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 include hugging, kissing, romance, sexual intercourse and feeling of love (Sanders et al., 2015). Overall, this finding showed that participants had good sexual relationships following genital surgery which indicated good sexual quality of life of people with DSD. This finding is contrary to the findings of some previous studies which indicated that people with DSD had difficult sexual experience due to small vagina, small penis and undescended testes (Boyle et al., 2005; Guntram, 2013; MacKenzie et al., 2009; Sanders et al., 2015). The difficult sexual experience by people with DSD may be related to the physical or psychological barriers because of the fear of rejection by the partner if found them looking different 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, decrease sexual desire, dyspareunia and decrease sexual arousal (Kanhere et al., 2015; Kohler et al., 2012; Schönbucher et al., 2010). This study is also 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 family members, friends and colleagues. This is in congruent with other findings where DSD did not interfered with the participants social relationships with the other people (Audí, 2014; Garrett and Kirkman, 2009; Kanhere et al., 2015; MacKenzie et al., 2009; McKillop, 2013).

Conclusion

Some of the people living with DSD experience normal social wellbeing and experiences, while some were negatively affected by the condition and sex re-assignment. The people with DSD experienced normal socialization, good intimate relationships and cordial

relationships with families, friends and significant others. The negative social impact of DSD includes social isolation, marital separation and divorce, poor sexual experience, absence of sexual pleasure and stigmatization. These affect the social quality of life of people with DSD and sex re-assignment in Nigeria.

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

References

- Al-Jurayyan, N. (2011). Ambiguous genitalia: Two decades of experience. *Annals of Saudi Medicine*, 31, 284–8. <http://dx.doi.org/10.4103/0256-4947.81544>
- Al-Jurayyan, N. (2010). Ambiguous Genitalia, Two Decades of Experience: Clinical Management and Sex Assignment. *Journal of Taibah University Medical Sciences*, 5, 13–20. [https://doi.org/10.1016/S1658-3612\(10\)70119-0](https://doi.org/10.1016/S1658-3612(10)70119-0)
- Audí, L. (2014). Past Experiences of Adults with Disorders of Sex Development, in: Hiort, O., Ahmed, S.F. (Eds.), *Endocrine Development*. S. KARGER AG, Basel, pp. 138–148.
- Boyle, M.E., Smith, S., and Liao, L.-M. (2005). Adult Genital Surgery for Intersex: A Solution to What Problem? *J Health Psychol* 10, 573–584. <https://doi.org/10.1177/1359105305053431>
- Chadwick, P.M., Liao, L.-M., and Boyle, M.E. (2005). Size Matters: Experiences of Atypical Genital and Sexual Development in Males. *Journal of Health Psychol*, 10, 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, 325–334. <https://doi.org/10.1016/j.beem.2009.11.005>
- Creswell, J.W. (2013). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. 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. and 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., and Dessens, A.B. (2015). Body Image and Sexuality in Indonesian Adults with a Disorder of Sex Development (DSD). *The Journal of Sex Research*, 52, 15–29. <https://doi.org/10.1080/00224499.2013.816260>
- Ernst, M.E., Sandberg, D.E., Keegan, C., Quint, E.H., Lossie, A.C., and Yashar, B.M. (2016). The Lived Experience of MRKH: Sharing Health Information with Peers. *Journal of Pediatric and Adolescent Gynecology*, 29, 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., and Richter-Appelt, H. (2014). Sexual Life and Sexual Wellness in Individuals with Complete Androgen Insensitivity Syndrome (CAIS) and Mayer-Rokitansky-Küster-Hauser Syndrome (MRKHS). *Journal Sex*

- Medicine*, 11, 729–742.
<https://doi.org/10.1111/jsm.12321>
- Garrett, C.C. and 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, 428–446.
<https://doi.org/10.1080/07399330902785380>
- Guest, G., Bunce, A., and Johnson, L. (2006). How Many Interviews Are Enough? An Experiment with Data Saturation and Variability. *Field Methods*, 18, 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., and 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., and Lee, P.A. (2015). Psychosexual development and quality of life outcomes in females with congenital adrenal hyperplasia. *International Journal of Pediatric Endocrinology*, 2015, 21.
<https://doi.org/10.1186/s13633-015-0017-z>
- Kohler, B., Kleinemeier, E., Lux, A., Hiort, O., Gruters, A. and 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, 339–341.
<https://doi.org/10.1097/OGX.0b013e318259bef1>
- Krauss, S.E. (2005). Research Paradigms and Meaning Making: A Primer. *The Qualitative Report*, 10, 758–770.
- Kwak, K., Knoll, J., Otten, B., De Gier, R., Kortmann, B., and Feitz, W. (2010). The Role of the Nurse Practitioner in the Disorder of Sex Development Study. *Journal of Pediatric Urology*, Abstracts of the ESPU XXI Annual Congress, Antalya, Turkey, 28 April - 1 May 2010 6, Supplement 1, S104.
<https://doi.org/10.1016/j.jpuro.2010.02.201>
- Lee, K., and 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, 1–6.
- Liao, L.M., Green, H., Creighton, S., Crouch, N. and Conway, G., (2010). Service users’ experiences of obtaining and giving information about disorders of sex development. *BJOG: An International Journal of Obstetrics & Gynaecology*, 117, 193–199.
<https://doi.org/10.1111/j.1471-0528.2009.02385.x>
- 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*, The Hague.
- MacKenzie, D., Huntington, A. and Gilmour, J.A., (2009). The experiences of people with an intersex condition: a journey from silence to voice. *Journal of Clinical Nursing*, 18, 1775–1783.
<https://doi.org/10.1111/j.1365-2702.2008.02710.x>
- Malouf, M.A., Inman, A.G., Carr, A.G., Franco, J. and 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, 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 (DClinPsy)*. The University of Glasgow.
- Merriam, S.B., and 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, Sokoto, Nigeria.
- Özbey, H., Darendeliler, F., Kayserili, H., Korkmazlar, Ü. and Salman, T. (2004). Gender assignment in female congenital adrenal hyperplasia: a difficult experience. *BJU International* 94, 388–391.
<https://doi.org/10.1111/j.1464-410X.2004.04967.x>
- Özbey, H., and Etker, S. (2013). Disorders of sexual development in a cultural context. *Arab Journal of Urology*, 11, 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., ... and Kropp, B.P. (2012). A model of delivering multi-disciplinary care to people with 46 XY DSD. *Journal of Pediatric Urology*, 8, 7–16.
<https://doi.org/10.1016/j.jpuro.2011.08.013>
- Patterson, C.J., Crawford, R., and Jahoda, A. (2014). Exploring the psychological impact of Mayer–Rokitansky–Küster–Hauser syndrome on young women: An interpretative phenomenological analysis. *J Health Psychol*, 1359105314551077.
<https://doi.org/10.1177/1359105314551077>
- Rebelo, E., Szabo, C.P., and Pitcher, G. (2008). Gender assignment surgery on children with disorders of sex development: a case report and discussion from South Africa. *J Child Health Care*, 12, 49–59.
<https://doi.org/10.1177/1367493507085618>
- Rothkopf, A.C., and John, R.M. (2014). Understanding Disorders of Sexual Development. *Journal of Pediatric Nursing*, 29, e23–e34.
<https://doi.org/10.1016/j.pedn.2014.04.002>
- Sanders, C., Carter, B. and 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, 1904–1913.
<https://doi.org/10.1111/jan.12661>
- Schönbucher, V., Schweizer, K., and 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, 193–215.
<https://doi.org/10.1080/00926231003719574>
- Smith, J.A., (2015). *Qualitative Psychology: A Practical Guide to Research Methods*. SAGE.
- Smith, J.A., and Osborn, M., (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *Br J Pain*, 9, 41–42.
<https://doi.org/10.1177/2049463714541642>
- Speziale, H.S., Streubert, H.J., and Carpenter, D.R. (2011). *Qualitative Research in Nursing: Advancing the Humanistic Imperative*, Fifth. ed. Lippincott Williams & Wilkins, Philadelphia.

Woodward, M., and Neilson, A., 2013.
Disorders of sex development.
Surgery (Oxford), *Paediatric Surgery*
II, 31, 646–651.
<https://doi.org/10.1016/j.mpsur.2013.10.005>