

Multidisciplinary Management of Adults with Differences in Sex Development (DSD): How is Nigeria Positioned?

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ABSTRACT

Background: The management of adults living with disorders of sex development has not been discussed in literature. In Nigeria, adult presenting with DSD is common with no specific route to ensure comprehensive treatment. **Methods:** In this cross-sectional study, we surveyed 613 plastic surgeons, urologists and gynecologists targeting response from those who managed adults with DSD. **Results:** Of the 29 response we got 26(89.7%) were male while 3(10.3%) were female specialist involved with the treatment of adults DSD. Majority of the specialists 10(34.5%) had more than 15 years' experience as specialist medical doctors. Fifteen (51.8%) of them worked in hospitals located in the North-Central region of the country, 19(65.5%) were plastic surgeons and gynecomastia (31.1%) was the most common patient presenting complaint. Though 19(65.5%) specialists treated the patients alongside other specialists, the teams were not comprehensive and lacked key members. **Conclusion:** The need for a consensus document is important so these group of individuals can enjoy a happy and fulfilled life.

Keywords: Nigeria, Differences of Sex Development, DSD, Multi-Disciplinary Treatment, MDT.

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BACKGROUND

Disorders of sex development (DSD) are a wide range of conditions affecting human sex determination and differentiation.^[1] They are congenital disorders characterized by anomalies in the urogenital tract and reproductive system. In the newborn, ambiguous genitalia are the commonest reason for presenting in hospital^[2] as parents are unable to comfortably assign a gender to the child.^[2] In adolescence, delayed or a typical sexual development and primary amenorrhoea are the usual presenting complaints.^[3,4]

These group of disorders have varying incidence rate, when considered together the global incidence rate may be as high as 1:200-300 live births.^[5] but specific incidence rate in Nigeria is lacking. Persons who receive surgical intervention from birth still face physical and emotional distress on how to conform to societal norms. Adult presentation brings with it a unique set of issues that need to be explored and addressed. A consensus statement on the best possible quality of life in persons with DSD advocates for holistic care centered on a multidisciplinary (MDT) approach.^[4] This has been domesticated in the paediatric age-group^[6] in Nigeria but unfortunately it has not extended to adults presenting with DSD or children as they age out of paediatric care.

This study is specialist-centered that explores the extent to which multidisciplinary approach has implemented in the care of adults presenting with DSD, identifying the gaps in therapy and bring up recommendations to improve overall care of the patients.

METHODS

This was a cross-sectional Google survey-based study using both quantitative and qualitative methods. It was targeted at specialists that most frequently treated adults with DSD in our setting – OBGYN, Plastic Surgeons and Urologist. The survey was repeated on the social platforms of the all the specialists for one month.

Data collected was demography of specialist, location of practice in Nigeria, area of specialization, years as a specialist, patient presenting complaints, surgery offered, degree of multi-disciplinary treatment (MDT) and specialist satisfaction with care.

Data was collected and transferred into an excel sheet where it was analysed for frequencies, means and ranges.

RESULTS

The survey was publicized on the social platforms of the Nigerian Association of Plastic Aesthetics and Reconstructive Surgeon (NAPRAS) with 143 members, Nigerian Association of Urological Surgeons of Nigeria (NAUS) with 250 members, and Society of Obstetricians and Gynaecologist of Nigeria (SOGON) with 220 financial members.

There were 29 respondents (Specialist) to our Google survey, 26 (89.7%) males and 3(10. 3%) females. Fifteen of them practice in North-Central Nigeria, 4(13.8%) each in the North-Western and North-Eastern regions of the Country (Table 1).

Nineteen (65.5%) of the respondents were plastic surgeons, 6(20.8%) were urologist, the others were gynaecologists (Table 2); seventeen (58.6%) of the specialists were more than 10 years post-specialist qualification (table 3). Between the 29 specialists, they had treated 77 adult DSD patients, half of the patients were seen as referrals from non-specialist physicians and family physicians. Other referrals were between specialists like urologist, gynaecologist, general surgeons and paediatric surgeons.

Respondents reported gyneacomastia 9(31.1%) as the most common presenting complaint followed clitoromegaly, vaginal atresia and hypospadias at 4(13.4%) each. Other presenting complaints were infertility, primary amenorrhoea and undescended testis. Five (17.3%) did not specify the most common presenting complaints (Figure 1). Of the 77 patients treated, 61 wanted to maintain their phenotypic gender and the motivation for seeking

treatment included preparation for marriage, improving physical appearance, improving sexual function and self-esteem.

Nineteen (65.5%) of the specialists treated patients in a multi-disciplinary team but though the teams lacked specialists considered as essential like counsellors (for the patients and their spouses), psychologists, geneticists and social workers. Thirteen (44.8%) specialists were satisfied with the treatment they were able to offer patients though most of the patients were lost to follow-up once their primary concerns were treated.

DISCUSSION

The incidence of DSD in Nigeria is not known but it brings up the issues of stigmatisation and discrimination which make adjusting into adult life difficult. This study had only 29 respondents out of a combined 613 specialists on the platforms the survey was administered on. This is <5% of the total number of specialists who responded to the survey. This may indicate on the lack of awareness or expertise in treating DSD patients into adulthood. DSD is a topic explored exhaustively in the paediatric patient but globally specialists in adult DSD care are rare.^[7] Though there were respondents from each geopolitical region in Nigeria, majority were in the North-central part of Nigeria (Figure 1). It is not clear whether this region has more patients willing to present to hospital for care.

Plastic surgeons got the most referrals which may indicate that the adult DSD patient is more concerned with aesthetic rather than functional issues. This also supported by the highest presenting complains of gynaecomastia shown by the survey. Primary amenorrhoea and infertility were less common complaints which may be because of the patients believe it is spiritual.^[8]

The need for sex-change surgeries were few because most of the specialist treated patients that wanted to maintain their phenotypic sex. The patients may feel more comfortable maintaining their assigned sex rather than undergo the rigors involved transiting to their genetic sex.

About half of the respondents were part of a multidisciplinary team that included a minimum of 3 specialists, but they all agreed that the teams were not comprehensive in composition. The ideal multidisciplinary team include at the minimum urology, endocrinology, andrology, psychology, nursing, social workers, geneticists, and medical ethics.^[1] Patient advocacy groups are very important part of the MDT in adult DSD management.

The pillar of adult DSD treatment according to Nowotny et al is building a trusting relationship is the key to optimal care.^[7] The outcome of care for DSD patients can be divided into short term and long-term outcomes.^[9] Short term outcomes are related to physical appearance and functionality of the genitalia,^[4, 10] while long-term outcomes include personal satisfaction, gender satisfaction, quality of life, social adaptation, and sexual function.^[4,10,11]

All the specialists sampled stated that they lost their patients to follow up. This may be because the system does not provide other care that patients consider necessary after their primary symptoms have been treated. It is important to chart an effective plan on how to treat adults with DSD that would take care of them holistically.

CONCLUSION

Though the knowledge of DSD has evolved over the decades, this has primarily been in the care of paediatric patients. Even in this age group, transiting from paediatric to adult care program is not smooth. In Nigeria, where patients are still being diagnosed as adults, a proper framework for adult care is essential to forestall the emotional and cultural difficulties faced by these patients.

Recommendations

1. Development of a nationwide registry which all specialist treating adult DSDs will be encouraged to contribute to.
2. Formation of MDTs registers that patient can access so they reach out to specialist in their local area.

- Confidential registries for patient to enter their personal details and contact patient support advocacy groups.

List of abbreviations

- DSD – Differences in Sex Development
- MDT – Multi-Disciplinary Treatment
- NAPRAS - Nigerian Association of Plastic Aesthetics and Reconstructive Surgeon
- NAUS -Nigerian Association of Urological Surgeons of Nigeria
- SOGON - Society of Obstetricians and Gynecologist of Nigeria.

a. Declarations

Ethical Approval and Consent to Participate
Ethical Approval was received from University of Abuja Teaching Hospital HREC. Consent was obtained from all participants

b. Consent for publication

All authors have given consent to have this publication in the African Journal of Urology

c. Availability of Data and Material

The data used for this manuscript is available on demand as well as all the instruments of research.

d. Competing Interest

All authors declare no competing interest in this research.

e. Funding

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