



THE INITIATIVE FOR
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**AN EXPLORATORY STUDY ON
KNOWLEDGE PRACTICES OF
HEALTHCARE PROFESSIONALS
AND FAMILIES OF INTERSEX
PERSONS IN NIGERIA.**





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List of Abbreviations

1. **ABUTH** - Abubakar Tafawa Balewa University Teaching Hospital
2. **UATH** - University of Abuja Teaching Hospital
3. **UNTH** - University of Nigeria Teaching Hospital
4. **ESUTH** - Enugu State University Teaching Hospital

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SUM MA RY

Background

The term 'intersex' is a general term adopted for a variety of conditions. Specifically, it has been described as a condition in which people are born with reproductive or sexual anatomy that does not fit the typical definitions of male and female. The Kenyan Statute, Persons Deprived of Liberty Act of 2014, defines 'intersex' as a person certified by a competent medical practitioner to have both male and female reproductive organs. Generally, an intersex person might be born with female-typical external genitalia but have male-typical anatomy internally. Some intersex persons may also have cells with XX and others with XY chromosomes.

In Nigeria, in addition to the societal discrimination against intersex persons and the lack of public knowledge on the subject, managing and taking care of intersex persons is a significant public health challenge. Unnecessary surgeries on intersex persons have received attention from organisations like the World Health Organization and other

international health and human rights bodies. When intersex babies are born with obviously non-conforming or non-binary genitalia, medical practitioners and parents seek to immediately alter these to fit into binaries. This occurs where the surgeries are not needed but are merely to achieve conformity, without regard to changes that occur with puberty. The harmful and unnecessary procedures have been proven to cause intersex persons lifelong, severe, and irreversible physical harm and mental, emotional, and psychological trauma. While clinical variants of intersex have been identified and studied in previous research, there is a lack of information available to healthcare professionals, medical students, and families of intersex persons on the current management of intersex persons. The findings from this study could guide the development of appropriate interventions targeted at health professionals towards the care of intersex persons, and where a knowledge gap is evident, make recommendations to address the identified gaps.

This study, therefore, aims to assess the knowledge, attitude, and practice of health care professionals and students on intersex issues and the experiences of families of intersex persons in Nigeria. The specific objectives are:

1. To determine the knowledge level of health care professionals and students regarding intersex persons in Nigeria.
2. To assess health care professionals' attitudes towards intersex persons in selected states in Nigeria.
3. To identify ongoing practices of health care professionals towards intersex persons in selected states in Nigeria.
4. To gain insights into the experiences of families of intersex persons in Nigeria.

Methods

This research is a descriptive cross-sectional study. We employed a mixed approach to study 415 randomly selected health professionals in six selected states, including the Federal Capital Territory (Abuja), representing the six geopolitical zones of Nigeria. These are Bauchi, Cross River, Enugu, Kaduna, Lagos, Oyo, and the Federal Capital Territory, Abuja. The research centres are in the South-west region: University College Hospital, Ibadan and St. Nicholas Hospital, Lagos; South-east region: University of Nigeria Teaching Hospital, Enugu and Enugu State University Teaching Hospital, Parklane; North-central region: University of Abuja Teaching Hospital and National Hospital Abuja; South-south region: University of Calabar Teaching Hospital; North-east region: Abubakar Tafawa Balewa Teaching Hospital, Bauchi and Bayara General Hospital, Bauchi; and North-west region: St Gerard's Hospital and Barau Dikko Teaching Hospital, Kaduna. These study sites are teaching hospitals and private hospitals with high patronage.

We purposively selected these study sites because our target participants, medical students and health professionals (especially doctors and nurses) involved in the management of intersex patients, are found mainly in these health facilities where they are more likely to encounter these cases.

Also, a total of 250 medical students participated in the survey. Intersex persons and family members with intersex children were targeted for the qualitative interviews.

The research team designed a semi-structured pretested self-administered questionnaire to obtain demographic data and assess health professionals and students' knowledge, attitude, and practices on intersex patients. We also developed an in-depth interview guide to explore the experiences of intersex persons and their families. A total of 40 questions assessed knowledge. A score of 1 was given to a correct response and 0 for an incorrect answer. 50% was taken as the cut-off mark for good knowledge from the respondents. Therefore, a respondent with a total score of 20 and above out of 40 questions bordering on their understanding of intersex issues suggested good knowledge, while less than $50\% \leq 19$ implied poor knowledge.

We analysed the received quantitative data using descriptive statistics

(frequency, proportions, means and standard deviation) and charts to summarise variables. Bivariate analysis was carried out using Chi-square to test for associations between various categorical variables and t-test for associations between continuous variables. We equally set statistical significance at a p-value of <0.05 .

The qualitative data were analysed using a framework thematic analysis approach.

We obtained ethical clearance to conduct this research from the National Health Research and Ethics Committee and the State Ethical committees or ethical boards from the selected states and institutions.

SUMMARY OF FINDINGS

Healthcare professionals

A total of 415 health professionals and 250 medical students participated in this study. The overall mean age of respondents was 36.3 ± 8.74 years. Among the medical doctors recruited for this study, more were either registrars 85(30.5%) or house officers 80(28.7%). In comparison, nursing officers 53(39%) and senior nursing officers 37(27.0%) made up a more significant portion of the nurses' population.

As listed above, 10 healthcare facilities were selected from the country's six geopolitical zones, with 7 Teaching Hospitals and the rest being private or missionary hospitals.

Knowledge of intersex issues

Most health professionals (88.9%) had heard about the term intersex, and the commonest source of information

was the internet (62.2%), followed by medical books (56.9%). A little above half (54.7%) of the health professionals interviewed had sufficient knowledge on intersex, while 45.3% had a poor understanding of the condition. An assessment of attitude towards intersex revealed that a vast majority (90.6%) of the respondents had positive attitudes towards intersex persons.

In this study, a little over a quarter (25.8%) of the health professionals were involved in providing care or managing intersex persons. Of this group, the most repeated management option used was corrective surgery, better known as intersex genital mutilation (56.6%), followed by adopting a multi-disciplinary approach (17.9%) and a combination of corrective surgery and hormonal treatment (7.5%).

Factors associated with poor knowledge of intersex and its management among

health professionals were: being aged ≤ 29 years 64(60.4%), had attained a post-tertiary education 76(69.7%), were Muslims 36 (64.3%), in the nursing profession 102(75%) and were house officers 43(53.8%) $p(<0.05)$.

Based on geopolitical zones, knowledge of intersex was poorest in the northeast zone 31(100%), followed by the southeast region 57(51.8%) and the northcentral zone 56(48.3%). The difference was statistically significant ($p<0.05$). Also, certain healthcare professionals were more likely to have inadequate knowledge of intersex conditions than their counterparts.

A significantly higher proportion of health professionals who had not attended seminars on intersex issues 163(49.8%) or received formal training 158(50.5%) and did not want more information on the condition, were more likely to have inadequate knowledge on intersex issues 50(56.2%) compared to their counterparts ($p<0.05$).

Also, we observed that knowledge of intersex issues was (more) limited or inadequate among health professionals in Abubakar Tafawa Balewa University Teaching Hospital Bauchi 31(100%), University of Nigeria Teaching Hospital Enugu 30(75.0%) and National Hospital Abuja 20(66.7%).

Medical students

The overall mean age of medical students was 24.6 ± 3.43 years, with more respondents 134(53.6%) in the 20-24 age bracket. More of the respondents were males 148(59.2%), in their fifth year of study 151(60.4%) and Christians 191(75.4%). Regarding their training institutions, more respondents were from the University of Nigeria Teaching Hospital 60(24%), followed by University of Abuja Teaching Hospital 44(17.6%), and Abubakar Tafawa Balewa Teaching Hospital 41(16.4%).

More students indicated that they studied intersex conditions in their fourth 103(41.2%) and fifth 117(46.8%) levels of study.

A vast majority of the medical students recruited into the study (84%) had heard of the term intersex, and their most typical source of information was the internet 74%.

This source was followed by medical books (59.6%). In assessing medical students' knowledge of 'intersex' and its variants, about half of those surveyed (50.4%) had adequate knowledge, while 49.6% had insufficient knowledge on the subject.



Knowledge of intersex issues

This study revealed that a significantly higher proportion of medical students who were aged ≤ 19 years 5(100%), in their fourth year of study 13(92.9%), and were Muslims 46(82.1%) were more likely to have insufficient knowledge of intersex compared to their counterparts. Also, based on health facilities, more medical students from Abubakar Tafawa Balewa University Teaching Hospital, Bauchi 41(100%), the University College Hospital Ibadan 22(71.0%), and Barrau Dikko Teaching Hospital Kaduna 7(50%) had limited knowledge on intersex conditions, compared with medical

students from other centres ($p < 0.05$). Additionally, medical students who admitted that they were not introduced to the term 'intersex' and its variants (86.7%), unaware of 'intersex' 65%, did not want an inclusive curriculum on intersex and its management 86(65.2%), felt it was unnecessary for doctors to have adequate information on Intersex 79(66.9%), and did not think the formal curriculum prepared them to adequately manage intersex (55.1%), were more likely to have limited information on intersex compared to their counterparts.

Findings from in-depth qualitative interviews with intersex persons and family members

In this study, we set out to interview families with intersex persons (including young children). However, we were only able to find willing intersex persons who are adults and not families with younger children still accessing care in various hospitals, despite the interventions of their primary healthcare providers. This is mainly a result of the stigma and discrimination associated with non-conforming genitalia prevalent in Nigeria.

The qualitative interviews revealed that some respondents understood intersex as a condition in which a person is born with reproductive sexual anatomy that doesn't seem to fit the typical recognition of being identified as male or female. Interviewees described their sources of information on the conditions as being very limited. Most interviewees reported that they depended on the healthcare professionals, their personal experiences and the internet for information on intersex issues. Interviewees also expressed dissatisfaction with the level of knowledge of health professionals on the condition. They reported that many health professionals who were relied on to provide information lacked in-depth knowledge about intersex and

its variants, showed a lack of empathy and tended to use them for experiments (without their consent).

The experience shared by most respondents was that they grew up with an assigned gender at birth but started manifesting features of a different sex during puberty. Case studies described the discovery period of their condition as challenging and embarrassing. For instance, they felt awkward and confused because their genitals did not fit into the binary male-female anatomies. Many respondents admitted living in denial, becoming more reserved, were depressed, and one case study reported contemplating suicide. Their experiences with healthcare professionals contributed to these experiences.

The majority were not satisfied with the care received from the health care providers, which was characterised by the lack of privacy and discriminatory treatment. Case studies also disclosed that doctors consultants arbitrarily used them to make examples for their students or made a public show of their bodies. One respondent added that doctors usually assign genders based on what was easier for them to carry out during surgery, without consulting the patients, which they felt was wrong. The interviews further highlighted that most interviewees, based on their experience with the health system, perceived that

most doctors in Nigeria needed to undergo training on intersex issues and the best ways to manage patients using a patient-centred approach. Some suggestions made by the interviewees include the following: health professionals should delay surgeries done on intersex persons until they are mature and old enough to decide; these surgeries should not be forced on children; healthcare professionals should also undergo more training to better manage their intersex persons in Nigeria, and the training of doctors should commence early whilst in medical school.

Respondents also made significant recommendations for the provision of non-discriminatory treatment by health professionals.

On the part of the parents, our case studies urged parents of intersex children to prioritise early education of the child and themselves, provision of adequate care, love and support.

Conclusions

Although a little over half (54.7% vs 50.4%) of the study population had good knowledge of intersex in this study (slightly higher among health professionals compared to the medical students), their attitude towards the condition was good (90.6%).

The findings from our in-depth interviews confirmed this low knowledge level where respondents stressed the need for doctors to undergo more training to manage their conditions better. In-depth training sessions will reduce the risks of intersex genital mutilation and arbitrary sex assignment. As we found in this study, assigning sex early through corrective surgeries was the commonest practice (56.5%) among health care professionals in the selected facilities.

Factors associated with inadequate knowledge among health care professionals were younger age, did not attend seminars or had any formal trainings on intersex, being a nurse, or from the north-east zone. Barriers identified among medical students were being in the fourth level of study, younger age (<19 years), and not having learnt about intersex issues in medical school.

The knowledge gap identified among medical students and health professionals must be filled. To address these, health institutions need to organise more seminars, provide resource materials to staff and students, regularly train and retrain students and professionals on the best patient-centred approaches to caring for intersex persons.

Results for Healthcare Professionals

415 healthcare professionals participated in the present study out of the proposed 450 number, giving a response rate of 92.2%.

Socio-demographic profile of Health professionals in Nigeria

The overall mean age of health professionals recruited into the study from the six senatorial districts of Nigeria was 36.3 ± 8.74 years, with more respondents 169 (40.7%) in the 30-39 age bracket, followed by respondents 106 (25.5%) who were at least 25 years. A higher proportion of healthcare professionals interviewed were Christians, 359 (86.5%) of the medical profession 279 (67.2%) and had attained a tertiary education 306 (73.7%).

Among the doctors recruited into the present study, more were either registrars 85 (30.5%) or house officers 80 (28.7%). Nursing officers 53 (39%) and senior nursing officers 37 (27.0%) made up larger portions of the nurse population. A total of ten health care facilities were selected from the country's six geopolitical zones, with 8 being teaching hospitals and the rest being private and missionary hospitals. More of the respondents 71 (17.1%) came from the University of Calabar Teaching Hospital, Enugu State University 70 (16.9%), and St Nicholas Hospital 52 (12.5%) (**Table 1**).

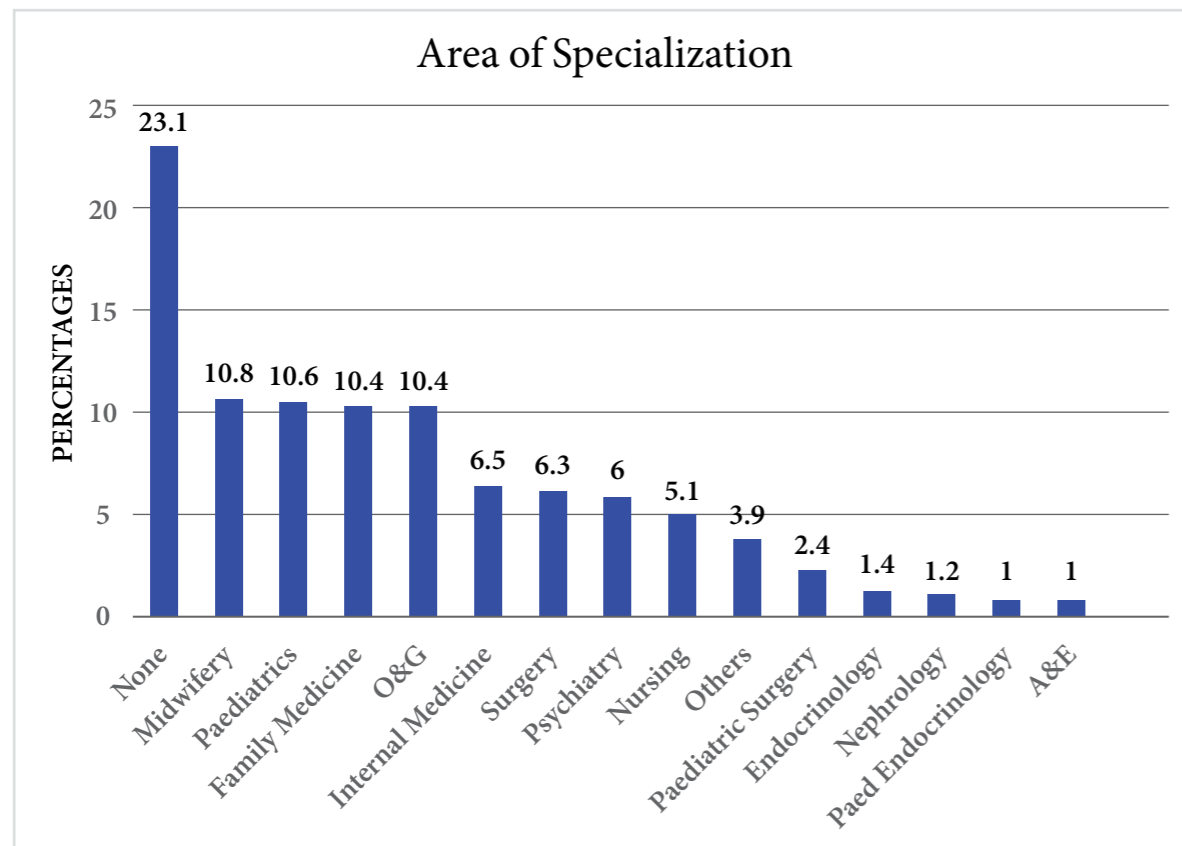
Variable	Frequency	Percentage
Age (years)		
≤ 29	106	25.5
30-39	169	40.7
40-49	96	23.7
≥ 50	44	10.6
Mean age ± SD	36.3 ±8.74	
Highest level of education		
Tertiary	306	73.7
Post- tertiary	109	26.3
	136	32.8
Religion		
Christianity	359	86.5
Islam	56	13.5
Profession		
Medical	279	67.2
Nursing	136	32.8
Designation for Doctors (N=279)		
House officers	80	28.7
Medical officer	19	6.8
Registrar	85	30.5
Senior registrar	54	19.4
Consultant	41	14.6
Designation of Nurses (N=136)		
Nursing officer	53	39.0
Senior Nursing Officer	37	27.0
Principal Nursing officer	19	14.0
Assistant Chief Nursing officer	2	1.9
Chief Nursing officer	21	15.2
Director	4	2.9

Variable	Frequency	Percentage
Health care Facility		
University of Calabar Teaching Hospital (UCTH)	71	17.1
University of Nigeria Teaching Hospital (UNTH)	40	9.6
Enugu State University of Technology Teaching Hospital Parklane (ESUTH)	70	16.9
St Nicholas Hospital Lagos	52	12.5
University College Hospital Ibadan	36	8.7
St Gerard's Catholic Hospital Kaduna	17	4.1
National Hospital Abuja	30	7.2
Abubakar Tafawa Balewa University Teaching Hospital Bauchi	31	7.5
Barau Dikko Teaching Hospital Kaduna	34	8.2
University of Abuja teaching Hospital	34	8.2

Area of Specialisation by respondents

All major specialities that play a significant role in the management of intersex persons were represented in our study. More of the respondents are not yet specialising (house officers, medical officers, newly employed nurses) (23.1%), midwives (10.8%), paediatrics (10.6%), family medicine practitioners and obstetricians and gynaecologists (10.4%). (Figure 1)

Figure 1: Area of Specialisation of respondents



None- No speciality area yet - mainly House officers, medical officers and newly recruited nurses

Awareness of the intersex condition among healthcare professionals

A vast majority of the health professionals surveyed 369(88.9%), had heard of the term 'intersex.' Their major sources of information were the internet (62.2%), medical books (56.9%) and medical journals (36.4%). The least source of information reported by the respondents were lectures (3.3%). (Figures 2 and 3)

Figure 2: Awareness of the term 'intersex' by respondents

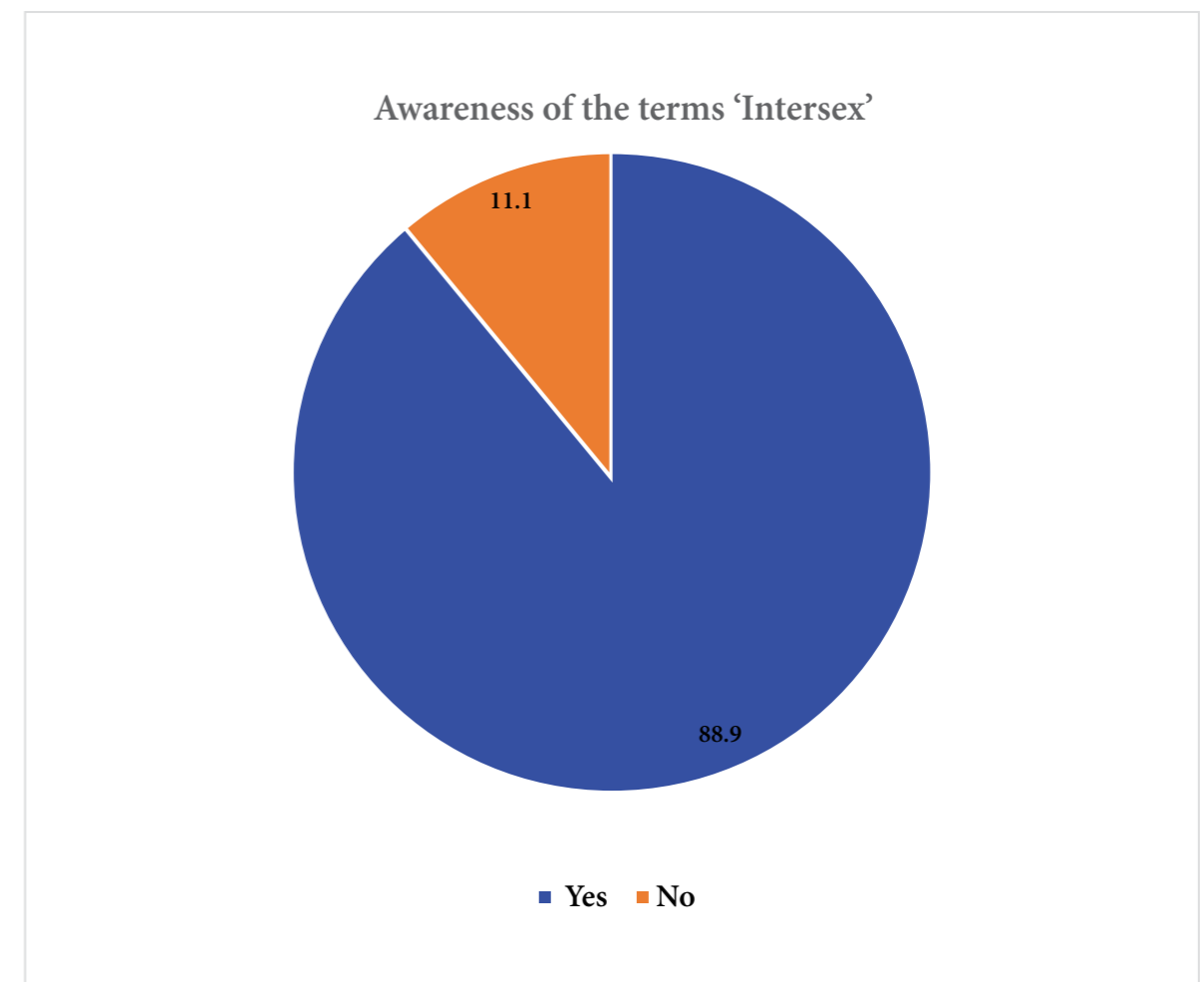
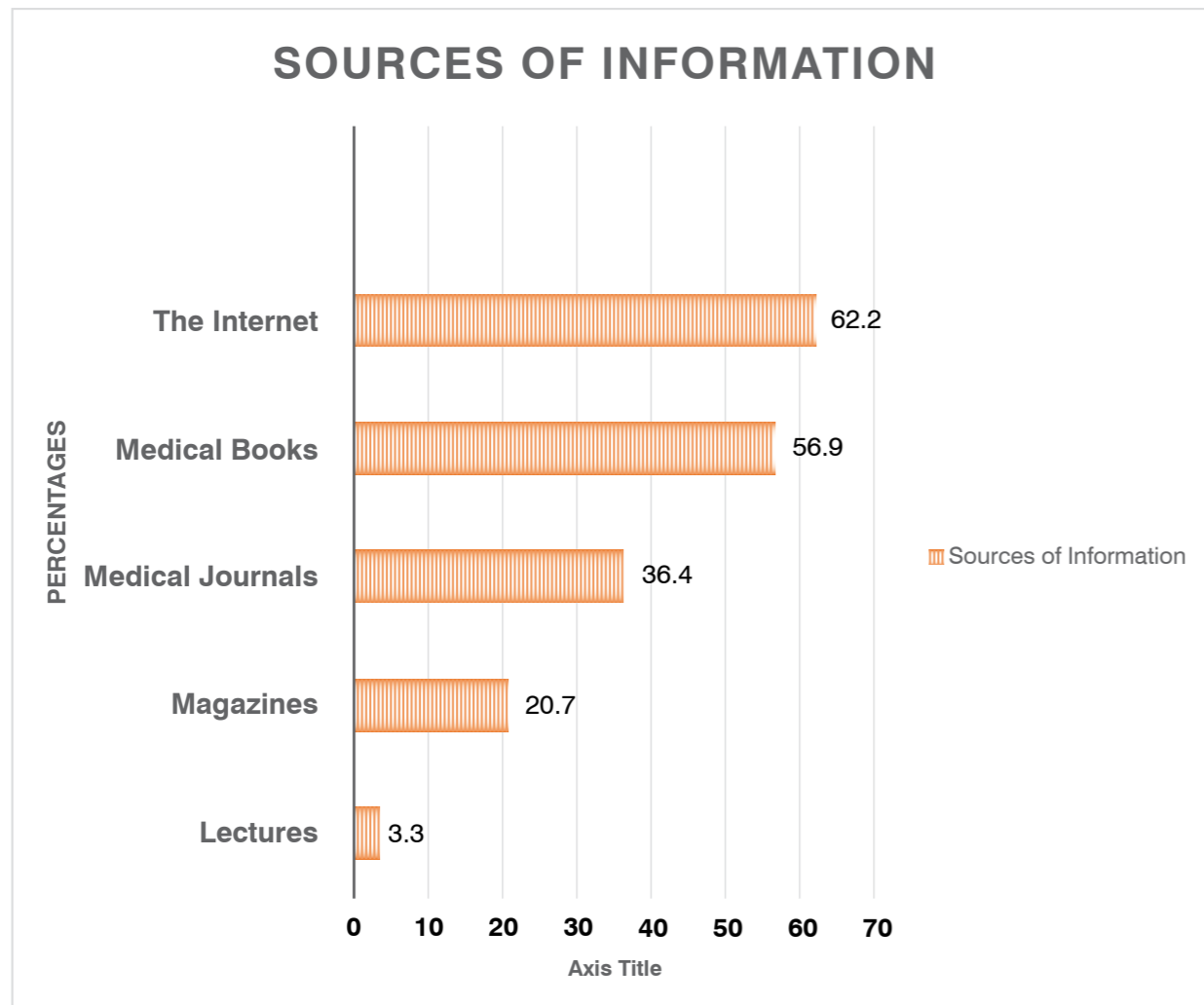


Figure 3: Sources of information on intersex for respondents

**Knowledge of possible causes of intersex and level of exposure**

A higher proportion of health professionals interviewed reported that intersex and its variants are part of the curriculum in their medical school 223(53.7%). Many also did not attend seminars on intersex 327(78.8%) or receive any form of training on managing intersex persons 313(75.4%). In assessing knowledge of health professionals on the possible causes of the intersex variation, more respondents reported that intersex and its variants could result from a chromosomal defect, 311(74.9%) could be considered hereditary 156(37.6%) and were familiar with intersex and its variants 222(53.5%). This finding is presented in **Table 2**.

Table 2: Respondents Knowledge of Intersex

Variable	Frequency	Percentage
Intersex and its variant are part of the curriculum in medical school		
Yes	223	53.7
No	192	46.3
Attended seminars on intersex		
No	327	78.8
Yes	88	21.2
Received formal training on managing intersex cases		
No	313	75.4
Yes	102	24.6
I am familiar with intersex and its variants		
No	222	53.5
Yes	193	46.5
Intersex and its variant are considered hereditary		
Yes	156	37.6
No	128	30.8
Don't know	43	10.4
Maybe	88	21.2
Intersex and its variant could result from chromosomal defect		
Yes	311	74.9
No	23	5.5
Don't know	43	10.4
Maybe	38	9.2

Knowledge of Risk factors for intersex

In assessing health professionals' knowledge regarding risk factors for intersex, more respondents indicated that a family history of genetic abnormalities 195(47%), mothers exposed to tobacco and alcohol 142(34.2%), harmful chemicals 199(48%) and harmful drugs 199(48%) during her period of pregnancy were risk factors for intersex. However, 167(40.2%) respondents were unsure if the intersex condition connects with the consumption of certain foods during pregnancy. **Table 3**

Table 3: Respondents Knowledge on possible 'risk' factors for the intersex variation

Variable	Frequency	Percentage
Family History of genetic abnormalities		
Yes	195	47.0
No	42	10.1
Maybe	76	18.3
Don't know	102	24.6
Mother exposed to alcohol and tobacco during pregnancy		
Yes	142	34.2
No	62	14.9
Maybe	88	21.2
Don't know	123	29.6
Mother being exposed to harmful drugs during pregnancy		
Yes	199	48.0
No	32	7.7
Maybe	72	17.4
Don't know	112	26.9
Mother being exposed to harmful chemicals during pregnancy		
Yes	199	48.0
No	34	8.1
Maybe	70	16.9
Don't know	112	27.0
Consumption of certain foods during Pregnancy		
Yes	63	15.3
No	101	24.3
Maybe	84	20.2
Don't know	167	40.2

Knowledge of methods of diagnosing intersex persons

This finding revealed that a higher proportion of health professionals, 209(50.4%), indicated that the condition could be diagnosed during pregnancy. In the determination of the biological sex of the child, more respondents reported that this could be through physical examination 234(56.5%), ultrasound scan 287(69.1%), karyotyping 232(55.9%), hormonal assessment 178(42.9%), and using a combination of tests 211(50.9%).

Table 4: Knowledge of methods of investigating (diagnosing) intersex persons

Variable	Frequency	Percentage
Intersex can be diagnosed during Pregnancy		
Yes	209	50.4
No	44	10.6
Maybe	93	22.4
Don't know	69	16.6
The Biological sex of a child can be determined by		
Physical examination		
Yes	234	56.5
No	46	11.1
Maybe	45	10.8
Don't know	90	21.7
Ultrasound scan		
Yes	287	69.1
No	16	3.9
Maybe	46	11.1
Don't know	66	15.9

Variable	Frequency	Percentage
Karyotyping		
Yes	232	55.9
No	13	3.1
Maybe	40	9.6
Don't know	130	31.4
Hormonal		
Yes	178	42.9
No	34	8.2
Maybe	59	14.2
Don't know	144	34.7
Combination of tests		
Yes	211	50.9
No	10	2.4
Maybe	35	8.4
Don't know	159	38.3

Respondents' knowledge of intersex clinical manifestations and specialists involved in managing intersex persons

Our findings in this respect revealed that more of the respondents were unsure of whether to classify intersex persons as male 158(38.1%), female 167(41.3%) or neither male nor female 178(43.3%). However, a little above half 228(54.9%) reported intersex persons as male and female. Also, a higher proportion of respondents agreed that some of the clinical features of intersex persons include small penis 309(74.5%), excessive body hair 195 (47%), undescended testis 251(60.5%) and large clitoris 271(65.3%). However, a good number of the surveyed healthcare professionals, 166(40%), were unsure about the webbed neck being a clinical feature of intersex and its variants.

Respondents also identified the following specialists to be involved in caring for intersex persons: Paediatricians 210(50.6%), Endocrinologists 221(53.3), Urologists 200(48.2%), Psychiatrists 204(49.2%), Paediatric surgeons 206(49.6%). 262(63.1%) respondents also agreed that a multi-disciplinary approach with various specialists should be adopted in caring for intersex patients.

Respondents' knowledge of intersex clinical manifestations and specialists involved in managing intersex persons

	Yes (%)	No (%)	Maybe (%)	Don't Know (%)
An Intersex person can be classified as				
Male	131(31.6)	74(17.8)	52(12.5)	158(38.1)
Female	124(29.9)	74(17.8)	50(12.0)	167(40.3)
Both male and female	228(54.9)	54(13.0)	45(10.8)	88(21.3)
Neither male nor female	121(29.2)	73(17.6)	41(9.9)	178(43.3)
An Intersex person can present with				
Small Penis	309(74.5)	8(1.9)	40(9.6)	58(14.0)
Excessive body hair	195(47.0)	27(6.5)	62(14.9)	131(31.6)
Undescended testis	251(60.5)	14(3.4)	55(13.3)	95(22.9)
Large clitoris	271(65.3)	12(2.9)	45(10.8)	87(21.0)
Webbed neck	142(34.2)	58(14.0)	49(11.8)	166(40.0)
Specialists involved in the management of intersex				
Paediatricians	210(50.6)	34(8.2)	47(11.3)	124(29.9)
Endocrinologists	221(53.3)	22(5.3)	37(8.9)	135(32.5)
Urologists	200(48.2)	24(5.8)	46(11.1)	145(34.9)
Psychiatrists	204(49.2)	23(5.5)	42(10.1)	146(35.2)
Paediatric surgeons	206(49.6)	20(4.8)	38(9.2)	151(36.4)
Multi-disciplinary	262(63.1)	108(26.0)	16(3.9)	29(7.0)

Respondents' knowledge of medical management of intersex persons

Respondents shared their thoughts on some general knowledge of intersex as well as management of intersex persons. More health professionals were not sure if intersex persons can get pregnant 129(31.1%) if there is a cure for the intersex condition 123(29.6%) and if it is regarded as a/the third sex 164(39.5%). Also, more than half of the respondents, 258(62.2%), indicated that the 'preferred term' for the condition is Disorder of Sex Development (DSD). In assessing the proper management of intersex persons, the majority of the respondents agreed that their families need that comprehensive education 375(90.4%). They also stated that it is essential for a healthcare worker to know a patient's gender identity 352(84.8%). The respondents indicated that while intersex persons have unique health risks and needs 324(78.1%), hormonal and surgical treatment is necessary and represent the only efficient management for intersex persons 279(67.2%). 184(44.3%) respondents agreed that waiting for the child to be old enough to participate in decision making is a management option.

Regarding "corrective" surgery, many respondents 180(43.4%) did not think that surgery carried out on intersex children violated the right to autonomy and physical integrity. In comparison, 127(30.6%) were indifferent about carrying out corrective surgery in the first year of life.

Interestingly, more than three-quarters of respondents, 326(78.7%), admitted that they needed more information on intersex to provide better medical care.

Table 6: Respondents' knowledge of medical management of intersex persons

	Yes (%)	No (%)	Maybe (%)	Don't Know (%)
General knowledge of Intersex persons				
Cannot get pregnant or have children	82(19.8)	114(27.4)	90(21.7)	129(31.1)
DSD is the preferred term for intersex	258(62.2)	11(2.7)	56(13.5)	90(21.6)
Intersex can be cured	115(27.7)	71(17.1)	106(25.6)	123(29.6)
Intersex is a third sex	46(11.1)	161(38.8)	44(10.6)	164(39.5)
Knowledge of Management of Intersex persons				
As a health care provider, knowledge of my patients' gender identity is important	352(84.8)	16(3.9)	28(6.7)	19(4.6)
Intersex persons have unique health risks and needs	324(78.1)	14(3.4)	42(10.1)	35(8.4)
Corrective surgery should be carried out in the first year of life	117(28.2)	83(20.0)	127(30.6)	83(20.0)
Waiting for the child to be of age to participate in decision making is a management option	184(44.3)	82(19.8)	109(26.3)	40(9.6)
Surgery carried out on intersex children is a violation of right to autonomy and physical integrity	95(22.9)	180(43.4)	101(24.3)	39(9.4)
Comprehensive education is required by families of intersex children	375(90.4)	7(1.7)	19(4.6)	14(3.3)
Hormonal and surgical treatment are necessary and represent the only efficient management for intersex person	279(67.2)	49(11.8)	69(16.6)	18 (4.4)
Need more information on intersex to provide better medical care	326(78.7)	21(5.0)	40(9.6)	28(6.7)

Findings on attitudes of healthcare professionals towards intersex persons

A more significant proportion of the healthcare professionals surveyed did not know whether to classify intersex persons as normal 135(32.5%) and 175(42.2%) were indifferent about this. Meanwhile, more respondents, 176(42.4%), perceived that intersex persons were 'abnormal' and 199(48.0%) did not think they were cursed.

More of the respondents in the study agreed that intersex persons should have access to healthcare free of discrimination 329(79.2%). They also agreed that healthcare professionals' attitudes could constitute a barrier to care 237(57.1%) and that imposing gender and sex can have harmful and fatal consequences to intersex children 276(66.8%). However, a little above three-fifths of the health professionals interviewed, 258(62.2%) disagreed with feeling uncomfortable when providing care to an intersex person. On discovering a person is intersex, 128(30.8%) health professionals reported that they would be indifferent about any changes in their notion towards them, and 150(36.0%) reported feeling uncomfortable about having an intersex colleague.

Attitudes of healthcare professionals towards intersex persons

The attitudes of healthcare professionals towards intersex persons are as presented in **Figure 4**, with a vast majority (90.6%) of the respondents reporting positive attitudes towards intersex persons, based on the findings of the quantitative research. Respondents in the qualitative survey stated to the contrary - that most healthcare professionals had a poor attitude (discrimination, insensitivity, lack of knowledge and awareness, abuse of rights and autonomy) in dealing with intersex persons.

Summarily, there are many negative societal attitudes held against intersex persons, and healthcare providers also have and exhibit some of these discriminatory beliefs.

Fig 4: Attitudes of healthcare professionals towards intersex persons

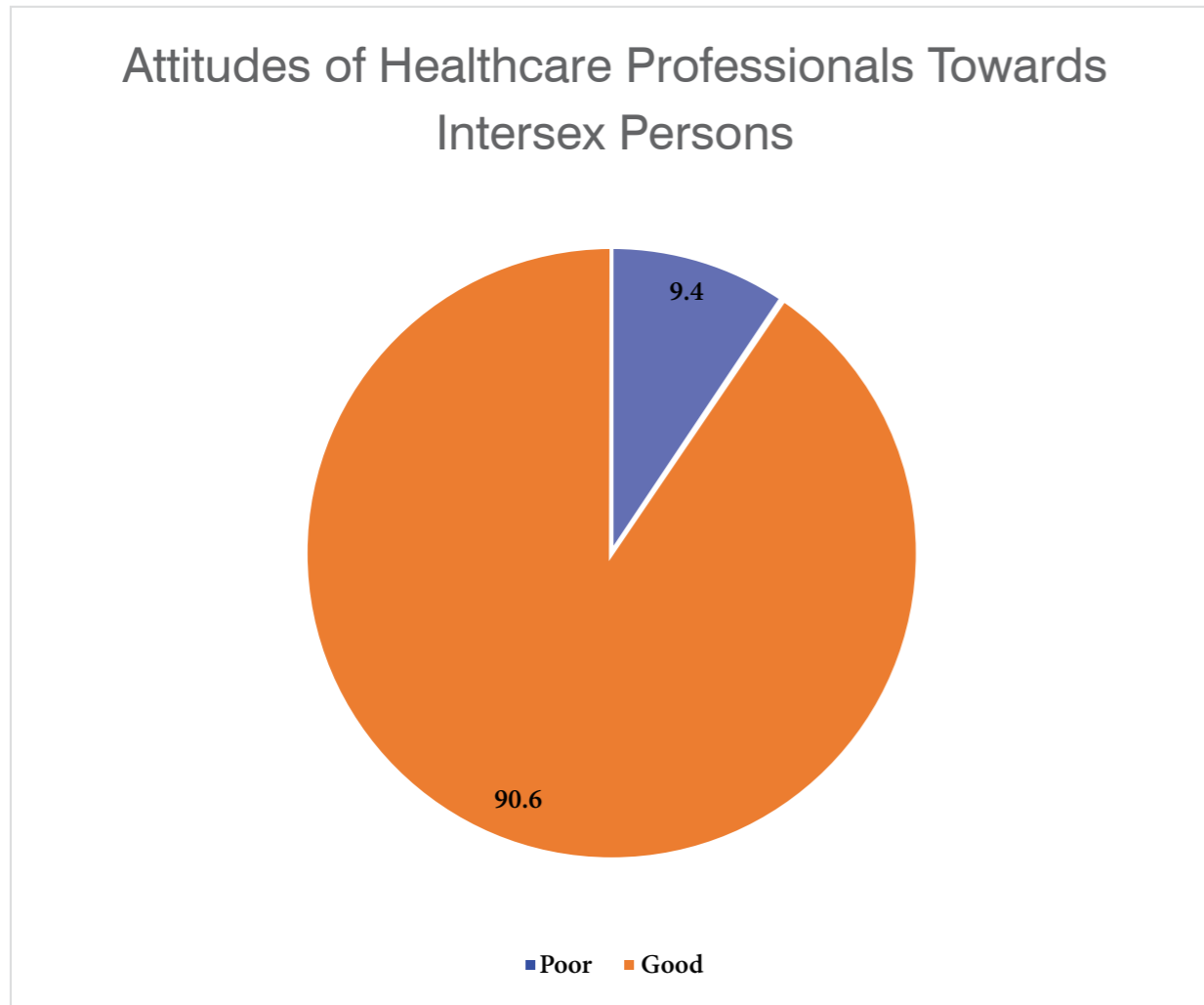


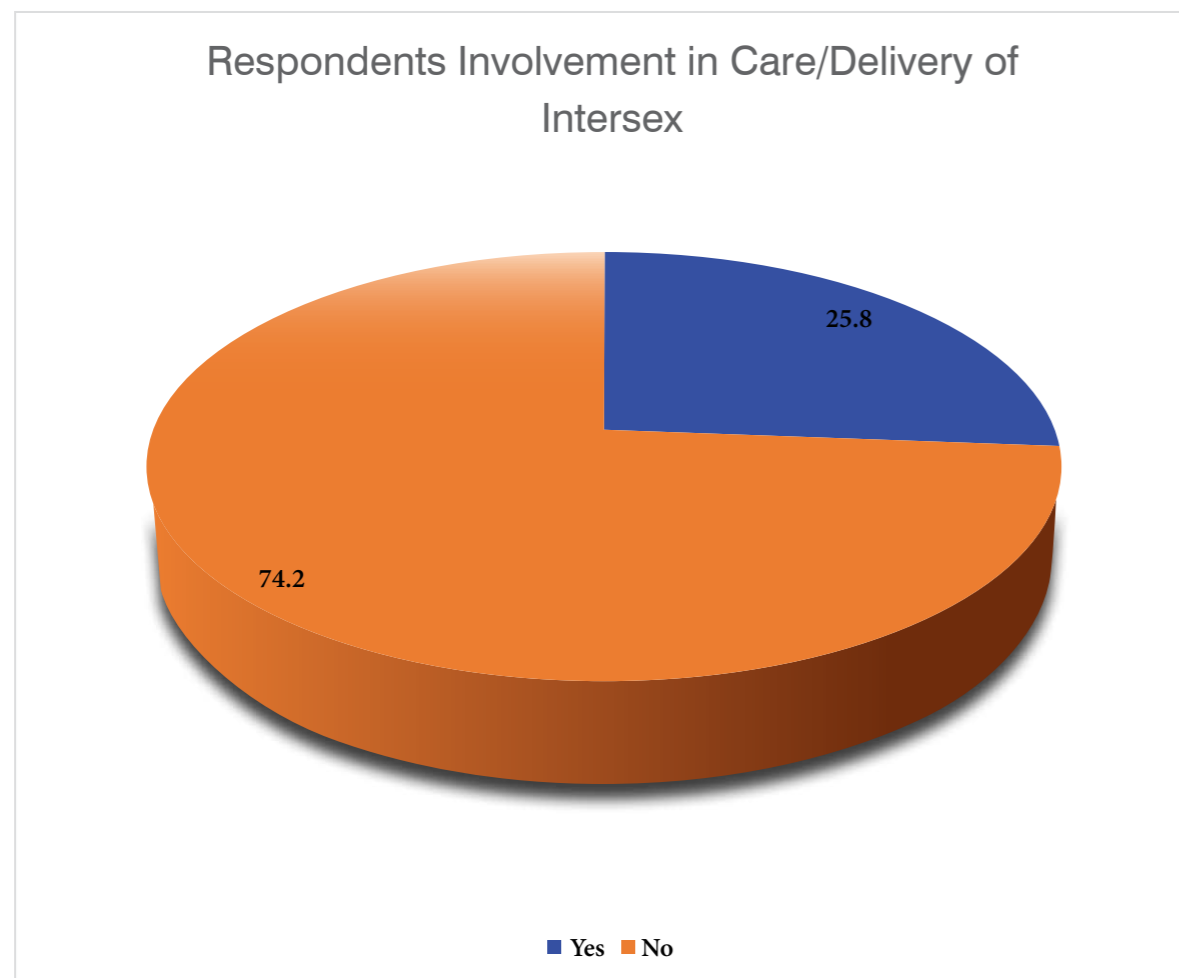
Table 7: Findings on attitudes of healthcare professionals towards intersex persons

	Yes (%)	No (%)	Maybe (%)	Don't Know (%)	
What are your views of intersex					
Normal	126(30.4)	127(30.6)	27(6.5)	135(32.5)	
Abnormal	176(42.4)	92(22.2)	34(8.2)	113(27.2)	
Cursed	13(3.1)	199(48.0)	23(5.5)	180(43.4)	
Indifferent	70(16.9)	135(32.5)	35(8.4)	175(42.2)	
	Strongly Agree	Agree	Indifferent	Disagree	
When I meet someone for the first time I assume they cannot be intersex	21(5.1)	168(40.5)	121(29.1)	101(24.3)	4(1.0)
On discovering a person is intersex, my notion about them changes	38(9.2)	92(22.2)	128(30.8)	116(28.0)	41(9.9)
I will feel comfortable having an intersex colleague	75(18.1)	104(25.1)	150(36.0)	60(14.5)	26(6.3)
I feel uncomfortable providing care to an intersex person	54(13.0)	39(9.4)	64(15.4)	171(41.2)	87(21.0)
Intersex persons should have access to health care free of discrimination	187(45.0)	142(34.2)	71(17.1)	11(2.7)	4(1.0)
Health care professionals' attitude could constitute a barrier to care	69(16.6)	168(40.5)	88(21.2)	64(15.4)	26(6.3)
Imposing gender and sex can have a negative and fatal consequence to intersex children	102(24.6)	174(42.2)	101(24.3)	28(6.7)	9(2.2)

Provision of care or management of intersex persons by respondents

Only 25.8% of the persons surveyed have been involved in providing care to intersex persons.

Fig 5: Provision of care or management of Intersex persons by respondents



Experiences of healthcare professionals engaged in caring for intersex persons

84(79.2%) of these healthcare professionals experienced in caring for intersex persons revealed that most of the parents attended to in their facilities accepted the treatment options that they were given. They also stated that parents had a poor understanding of intersex 84(79.2%), have a fear of the unknown 86(81.3%) and fear of surgery 62(58.5%).

Regarding the management of intersex persons, a higher proportion of the healthcare professionals 191(46.0%) indicated that following diagnosis, detailed information on intersex and management options is provided to families of intersex children. They also stated that informed consent for interventions is given to parents 267(64.3%) and agreed that information should be shared by parents when the children come of age 274(66.0%). These professionals also disclosed that there could be post-surgery consequences on a person's physical and psychological development 210(50.6%). On the contrary, more health professionals, 201(48.4%) believed that parents did not fully understand the health implications and risks associated with surgery and there was an absence of medical protocols for managing intersex in their respective health facilities 248(59.8%).

During surgery, a larger proportion of health professionals reported that the gender of a child is determined by parents 182(43.9%) and health care providers 159(38.3%) while less than a tenth 14(3.4%) mentioned religious leaders as responsible for determining the gender of the child.

In most cases, unnecessary surgeries on intersex children are carried out by healthcare professionals using arbitrary determinations of what the child's anatomy and gender should be. Persons interviewed for this research also shared that when they developed at puberty, their bodies developed contrary to what the healthcare professionals or parents chose.

Table 8: Experiences of healthcare professionals engaged in management of intersex persons

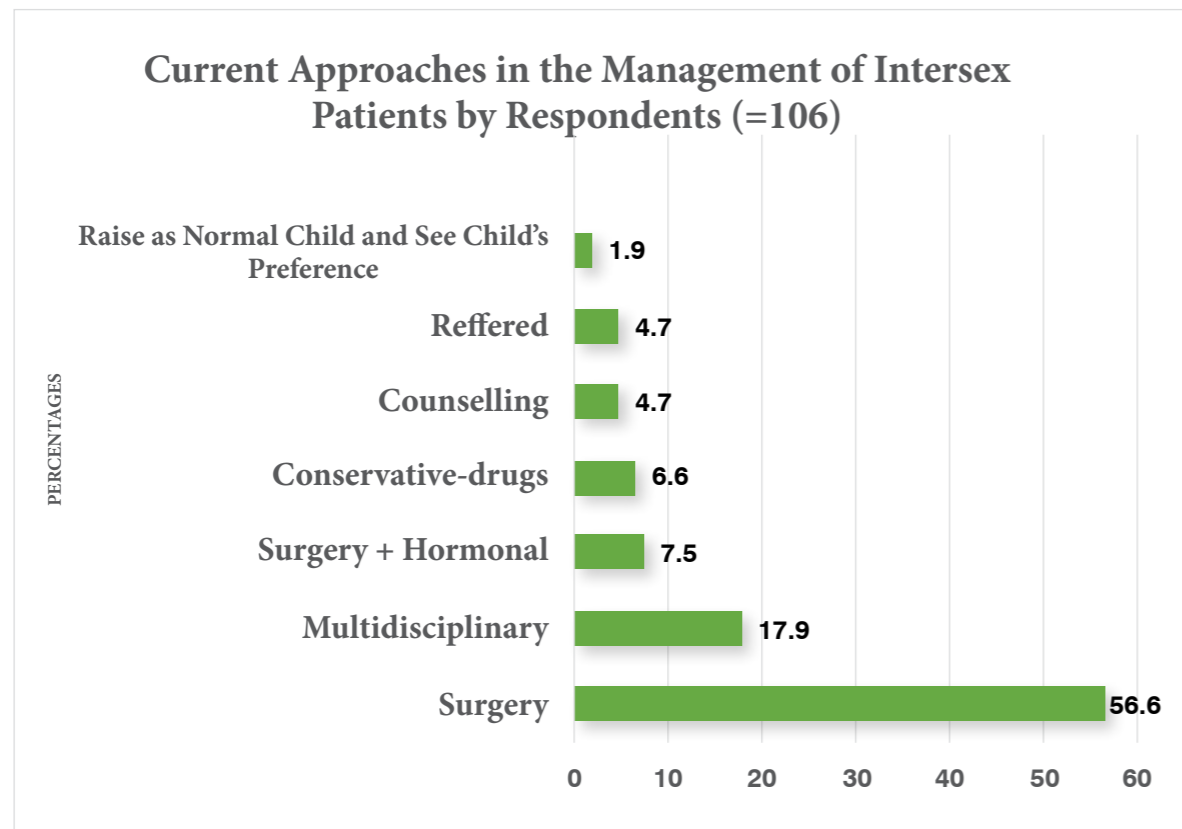
Practices	Yes (%)	No (%)	Maybe (%)	Don't Know (%)
Parents response to management (N=106)				
Accepted	84(79.2)	22(20.8)		
Barriers encountered in delivery of care(N=106)				
Poor understanding of parents	77(72.6)	16(15.2)	13(12.2)	
Fear of the unknown	86(81.3)	5(4.7)	15(14.0)	
Fear of surgery	62(58.5)	35(33.0)	9(8.5)	
Practice proper (n=451)				
Availability of Medical protocols for managing intersex in my work place	61(14.7)	248(59.8)	2(0.5)	104(25.1)
Following diagnosis, Provision of detailed information on intersex and management options to families of intersex is done	191(46.0)	28(6.7)	50(12.1)	146(35.2)
Do parents fully understand the health implications and risks associated with surgery?	43(10.4)	201(48.4)	95(22.9)	76(18.3)
Informed consent for intervention is given by parents based on information provided by Health professional	267(64.3)	13(3.1)	38(9.2)	97(23.4)
Parents should share information about intersex with children when they come of age	274(66.0)	20(4.8)	102(24.6)	19(4.6)

Practices	Yes (%)	No (%)	Maybe (%)	Don't Know (%)
During surgery the gender of the child is determined by				
Parents	182(43.9)	48(11.6)	46(11.0)	139(33.5)
Health care professionals	159(38.3)	53(12.8)	55(13.3)	148(35.7)
Religious leaders	14(3.4)	148(35.7)	27(6.5)	226(54.5)
Post-surgery consequences on the persons physical and psychological development	210(50.6)	20(4.8)	87(21.0)	98(23.6)

Current approaches in the management of intersex patients by respondents involved in care and management

Our findings show that, currently, the commonest management options used include corrective surgery (56.6%) followed by adopting a multidisciplinary approach (17.9%) and a combination of corrective surgery and hormonal treatment (7.5%).

Fig. 6: Current approaches in the management of intersex patients by respondents

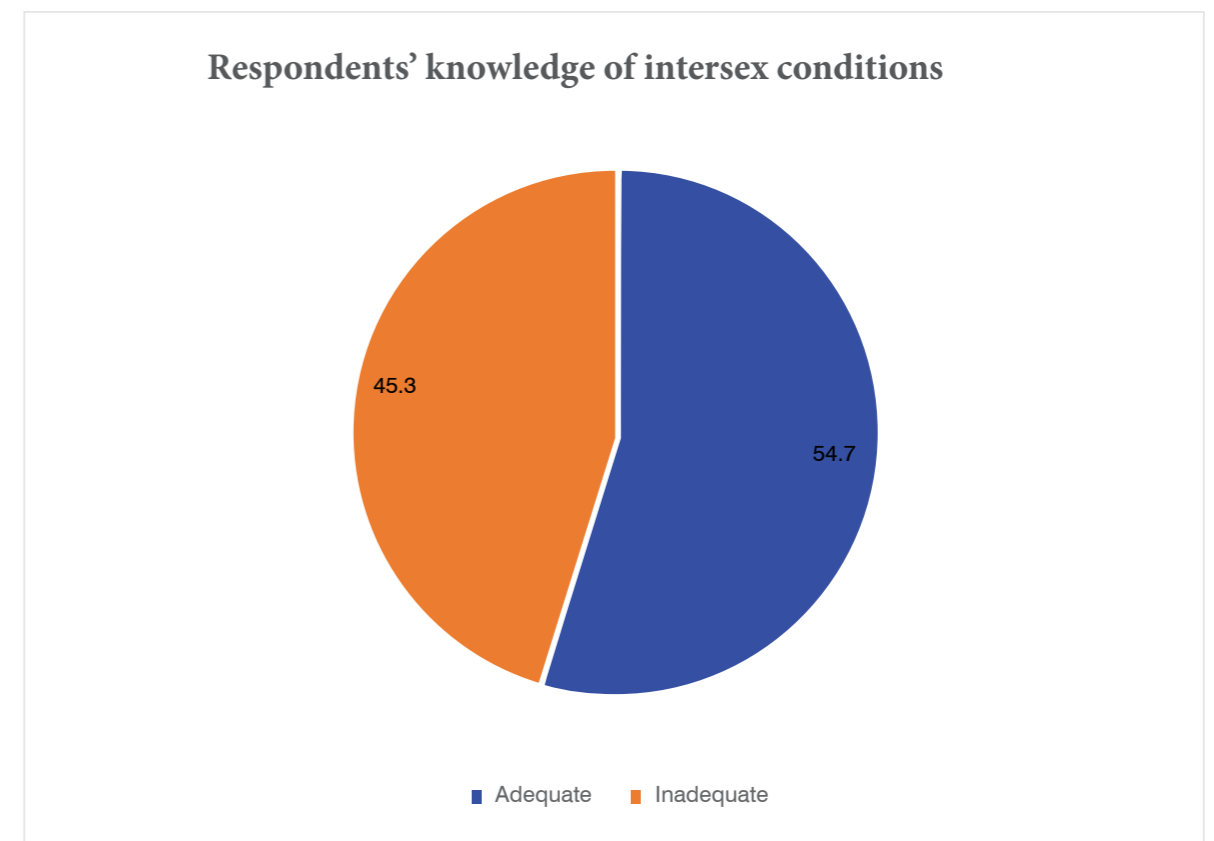


Assessment of healthcare professionals' knowledge of intersex conditions

This section of the quantitative survey examined healthcare providers' knowledge of clinical presentation, risk factors/ causes, investigations, management and general questions on intersex. A little above half (54.7%) of the health professionals interviewed had sufficient knowledge of intersex, while 45.3% had a poor understanding of the condition.

For this study, we categorised knowledge into two groups to show adequate and inadequate knowledge with a total of 40 questions. A score of 1 was given to a correct response and 0 for an incorrect answer, and 50% was taken as the cut-off mark for good knowledge. Therefore, a respondent with a total score of 20 and above out of 40 questions bordering on their knowledge of intersex indicated good knowledge, while < 50% ≤ 19 demonstrated poor knowledge.

Fig. 7: Respondents' knowledge of intersex conditions



Association between healthcare professionals' socio-demographic characteristics and knowledge of the intersex condition

A significantly higher proportion of health professionals who were aged ≤ 29 years 64(60.4%), attained Post tertiary level of education 76(69.7%), were Muslims 36(64.3%), of the nursing profession 102(75%) and house officers 43(53.8%) were more likely to have limited knowledge of intersex among the health professionals in the study.

Based on geopolitical zones, knowledge on intersex was limited in the northeast zone 31(100%), followed by the southeast 57(51.8%) and the northcentral zones 56(48.3%).

Table 9: Association between healthcare professionals' socio-demographic characteristics and knowledge of the intersex condition

Variable	Knowledge of intersex		Test -statistic	p-value
	Good Frequency (%)	Poor Frequency (%)		
Age of respondent (years)				
≤ 29	42(39.6)	64(60.4)	14.1	0.003
30-39	100(59.2)	69(40.8)		
40-49	61(63.5)	35(36.5)		
≥ 50	24(54.5)	20(45.5)		
Level of education				
Tertiary	155(50.7)	151(49.3)	13.5	<0.001
Post Tertiary	33(30.3)	76(69.7)		
Profession				
Medical Practitioner	193(69.2)	86(30.8)	72.1	<0.001
Nursing	34(25.0)	102(75.0)		

Variable	Knowledge of intersex		Test -statistic	p-value
	Good Frequency (%)	Poor Frequency (%)		
Designation for Doctors (N=258)				
House officers	37(46.2)	43(53.8)	31.8	<0.001
Medical officer	18(94.7)	1(5.3)		
Registrar	61(71.8)	24(28.2)		
Senior registrar	41(75.9)	13(24.1)		
Consultant	35(85.4)	6(14.6)		
Health facility				
Teaching Hospital	154(54.6)	128(45.4)	0.001	0.99
Others	54(54.5)	45(45.5)		
State/ Geopolitical zone				
Bauchi/ North East	0(0.0)	31(100)	54.7	<0.001
Kaduna /North west	36(70.6)	15(29.4)		
Abuja/ North central zone	60(51.7)	56(48.3)		
Cross River/ South -south	50(70.4)	21(29.6)		
Enugu / South East	53(48.2)	57(51.8)		
Lagos and Oyo/ South west	27(75.0)	8(22.0)		
Religion				
Christianity	207(57.7)	152(42.3)	9.42	0.002
Islam	20(35.7)	36(64.3)		

Association between respondents' designation, facility and training and knowledge of intersex conditions

A significantly higher proportion of health professionals who did not attend seminars on intersex issues 163(49.8%) or receive formal training 158(50.5%) and did not want more information on the condition were more likely to have inadequate knowledge on intersex issues 50(56.2%) compared to their counterparts ($p < 0.05$).

Also, we observed limited and inadequate knowledge of intersex conditions among healthcare professionals in Abubakar Tafawa Balewa University Teaching Hospital Bauchi 31(100%), University of Nigeria Teaching Hospital Enugu 30(75.0%) and National Hospital Abuja 20(66.7%) compared to the other health facilities ($p < 0.05$).

Association between respondents' designation, facility and training and knowledge of intersex conditions

Variable	Knowledge of intersex		Test -statistic	p-value
	Good Frequency (%)	Poor Frequency (%)		
Designation of Nurses (N=123)				
Nursing officer	10(18.9)	43(81.1)	5.29	0.39
Senior Nursing Officer	9(24.3)	28(75.7)		
Principal Nursing officer	5(26.3)	14(73.7)		
Assistant Chief Nursing officer	1(50.0)	1(50.0)		
Chief Nursing officer	9(42.9)	12(57.1)		
Director	1(25.0)	3(75.0)		
Attended Seminars on Intersex				
No	164(50.2)	163(49.8)	12.9	<0.001
Yes	63(71.6)	25(28.4)		
Received formal training on intersex				
Yes	72(70.6)	30(29.4)	13.8	<0.001
No	155(49.5)	158(50.5)		

Variable	Knowledge of intersex		Test -statistic	p-value
	Good Frequency (%)	Poor Frequency (%)		
Needs more information on intersex				
No	39(43.8)	50(56.2)	5.41	0.02
Yes	188(57.7)	138(42.3)		
Health Facility				
University of Calabar Teaching Hospital (UCTH)	50(70.4)	21(29.6)	83.4	<0.001
University Of Abuja teaching Hospital	15(44.1)	19(55.9)		
University of Nigeria Teaching Hospital (UNTH)	10(25.0)	30(75.0)		
Baura Dikko Teaching Hospital, Kaduna	24(70.6)	10(29.4)		
Enugu State University of Technology (ESUT)	43(61.4)	27(38.6)		
St Nicholas Hospital Lagos	35(67.3)	17(32.7)		
University College Hospital Ibadan	28(77.8)	8(22.2)		
St. Gerald's Catholic Hospital, Kaduna	12(70.6)	5(29.4)		
National Hospital Abuja	10(33.3)	20(66.7)		
Abubakar Tafawa Balewa University Teaching Hospital Bauchi	0(0)	31(100)		

Associations between healthcare professionals' Knowledge and Practice, Knowledge and Attitude

A higher proportion of respondents, 78(34.4%), who were knowledgeable about intersex were more likely to be involved in the management of intersex compared with health professionals 29(15.4%) with inadequate knowledge on the condition. Also, a significantly higher proportion of respondents, 21(75%) with inadequate knowledge on the intersex nature, were more likely to manage the condition using corrective surgery alone compared to those 39(50%) who were knowledgeable on the subject matter ($p < 0.05$).

Knowledge was, however, not significantly associated with attitude towards intersex persons ($p > 0.05$).

Table 11: Associations between healthcare professionals' Knowledge and Practice, Knowledge and Attitude

Variable	Attitude		Test -statistic	p-value
	Poor Frequency (%)	Good Frequency (%)		
Knowledge				
Adequate	22(11.7)	166(88.3)	2.14	0.14
Inadequate	17(7.5)	210(92.5)		
	PRACTICE			
	Yes	No		
	Frequency (%)	Frequency (%)		
Knowledge				
Adequate	78(34.4)	149(65.6)	19.3	<0.001
Inadequate	29(15.4)	159(84.6)		
	Treatment options			
	Surgery	Others		
	Frequency (%)	Frequency (%)		
Knowledge				
Adequate	39(50.0)	39(50.0)	5.24	0.02
Inadequate	21(75.0)	7(25.0)		

Findings on the knowledge of Medical Students on intersex conditions

The overall mean age of medical students was 24.6 ± 3.43 years, with more respondents 134(53.6%) in the 20-24 age bracket followed by 98(39.2%) in the 25-29 age group. Most of the respondents were males 148 (59.2%), in their fifth year of study 151(60.4%) and Christians 191(75.4%). Regarding their training institutions, more respondents were from UNTH 60(24%), followed by UATH 44(17.6%) and ABUTH 41(16.4%). Of these, more students indicated that their studies introduced them to intersex issues in their fourth 103(41.2%) and fifth 117(46.8%) levels of study (**Table 1**).

A vast majority of the medical students recruited into the study, 210(84%), had heard of the term intersex, and their most typical source of information was the internet 74%. This source was followed by medical books 59.6% and journals 26.4%. (**Fig 1 and 2**)

Table 1: Socio-demographic characteristics of medical students

Variable	Frequency	Percentage
Age (years)		
≤19	5	2.0
20-24	134	53.6
25-29	98	39.2
≥ 30	13	5.2
Mean age ± SD	24.6 ± 3.43	years
Sex		
Male	148	59.2
Female	102	40.8
Religion		
Christianity	191	75.4
Islam	56	22.4
Others*	3	1.2

Variable	Frequency	Percentage
Year of Study		
Fourth	14	5.6
Fifth	151	60.4
Sixth	85	34.0
Training Institutions		
University College Hospital Ibadan, Oyo state	31	12.4
University of Calabar Teaching Hospital, CRS	30	12.0
University of Nigeria Teaching Hospital Enugu	60	24.0
Enugu State University Enugu	30	12.0
Barrau Dikko Teaching Hospital Kaduna	14	5.6
University Of Abuja Teaching Hospital	44	17.6
Abubakar Tafawa Balewa University Teaching Hospital, Bauchi	41	16.4
What year in the medical school was intersex introduced		
4th	103	41.2
5th	117	46.8
6th	15	6.0
Not at all	15	6.0

Students' Knowledge of Intersex conditions

Most of the respondents, 216(86.4%), supported this definition of 'intersex': a person born with reproductive or sexual anatomy that doesn't seem to fit the typical definitions of female or male. More respondents were unsure of classifying intersex persons as either male 125(50%), female 129(51.6%) or neither male nor female 140(56%). However, almost half of the medical students, 122(48.8%), reported that intersex persons are both male and female. The surveyed medical students correctly identified Congenital Adrenal hyperplasia 154(61.8%) and Androgen insensitivity syndrome 148(59.2%) as intersex variants. However, they did not know about Klinefelter syndrome 105(42%), Turners syndrome 111(44%), Swyer syndrome 175(70%) and Mayer-Rokitansky-Küster-Hauser syndrome 153(61.2%). **Table 5**

Regarding the students' knowledge of common forms of presentation of intersex persons, more than half of the respondents identified the following as features of intersex persons: small penis 168(67.2%), excessive body hairs 203(81.2%), undescended testis 152(60.8%) and large clitoris 156(62.4%). Less than a third 72(28.8%) identified the webbed neck as a presentation of an intersex person. (Table 3)

Knowledge of Possible risk factors

More of the respondents in the study identified the following as possible risk factors for intersex, Exposure of mother to alcohol or tobacco during pregnancy 114(45.6%), exposure to harmful chemical agents when pregnant 131(52.4%), exposure to harmful drugs during pregnancy 121(48.4%) and family history of genital abnormalities 155(62%). In contrast, 111(44.4%) did not know if consuming certain foods when pregnant could result in birthing an intersex baby. Additionally, more medical students felt that intersex persons could not get pregnant or have children 100(40%). They also chose 'Disorder of Sexual Development' as the preferred name for intersex conditions, and 114(45.6%) 106(42.4%) stated that the intersex condition could be cured. Less than half 111(44.4%) did not know whether to refer to intersex persons as a/the third sex.

Knowledge of Management Options

The common forms of management of intersex persons the surveyed students know include corrective surgery 154(61.6%), followed by hormonal therapy 135(54.0%) and observing and waiting 77(30.8%).

Resources

Some of the resources available as indicated by the students include a library with books and journals on intersex issues 139(55.6%). Some students also noted that the formal curriculum in their school adequately covers intersex and its variants 110(44%). However, the majority, 196 (78.4%), admitted that the standard curriculum did not prepare them adequately to serve intersex persons comfortably and competently. Most of the students had not attended any training or seminars 219(87.6%) and did not have the opportunity to interact with intersex persons 224(89.6%). Table 3

Fig. 1: Awareness of intersex variations by medical students

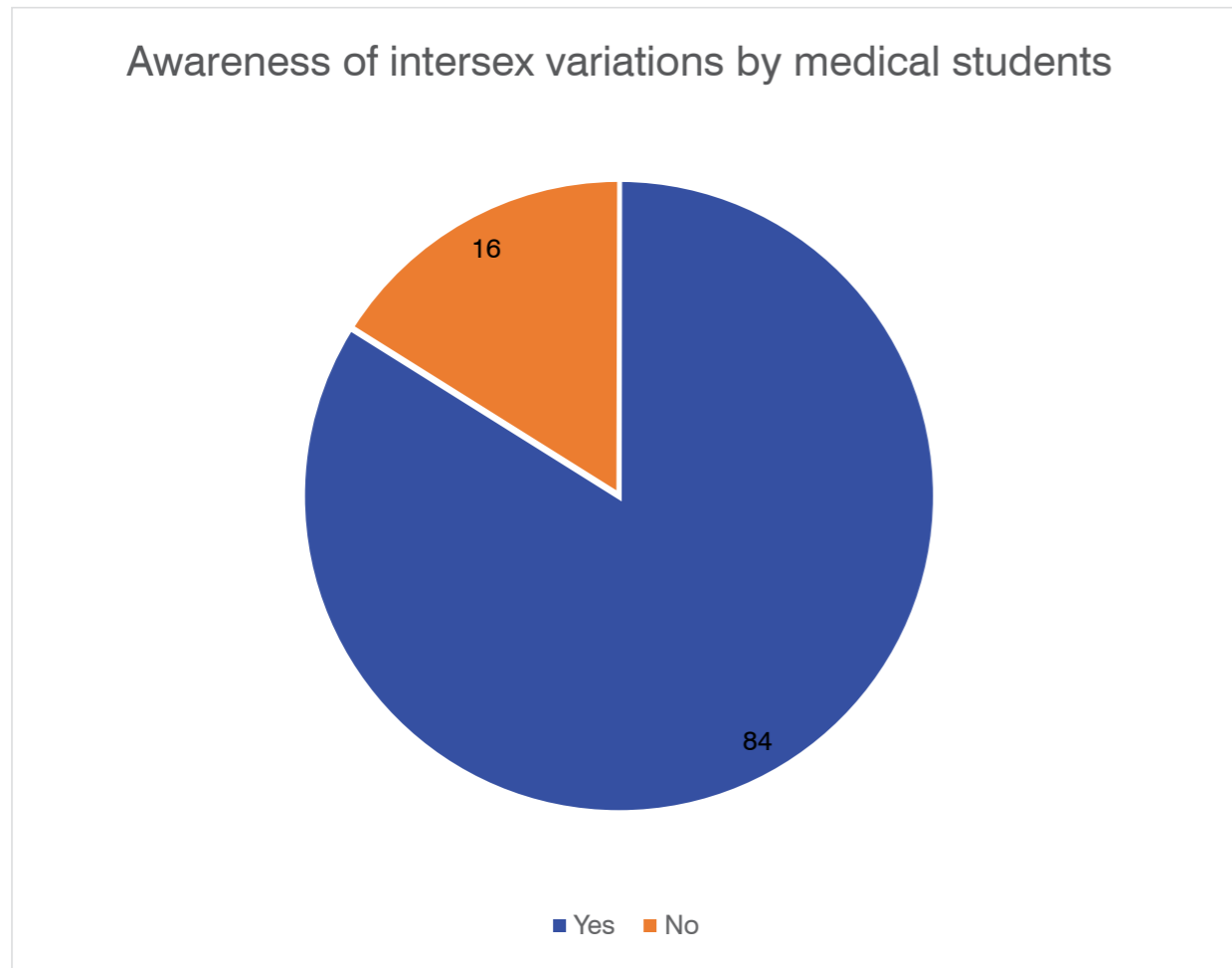


Fig 2: Source of Information on intersex issues

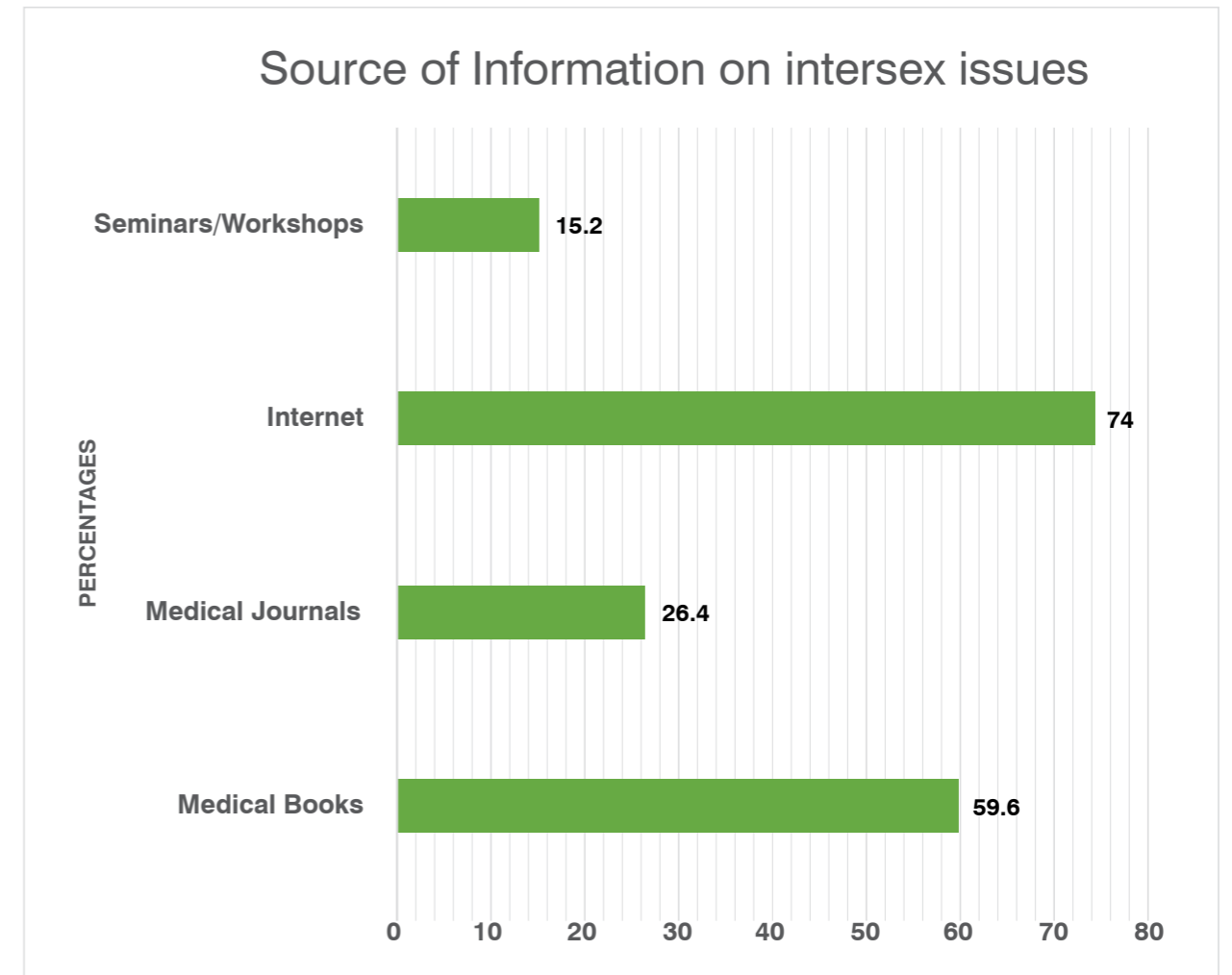


Table 2: Knowledge of Intersex variants, presentation by medical students

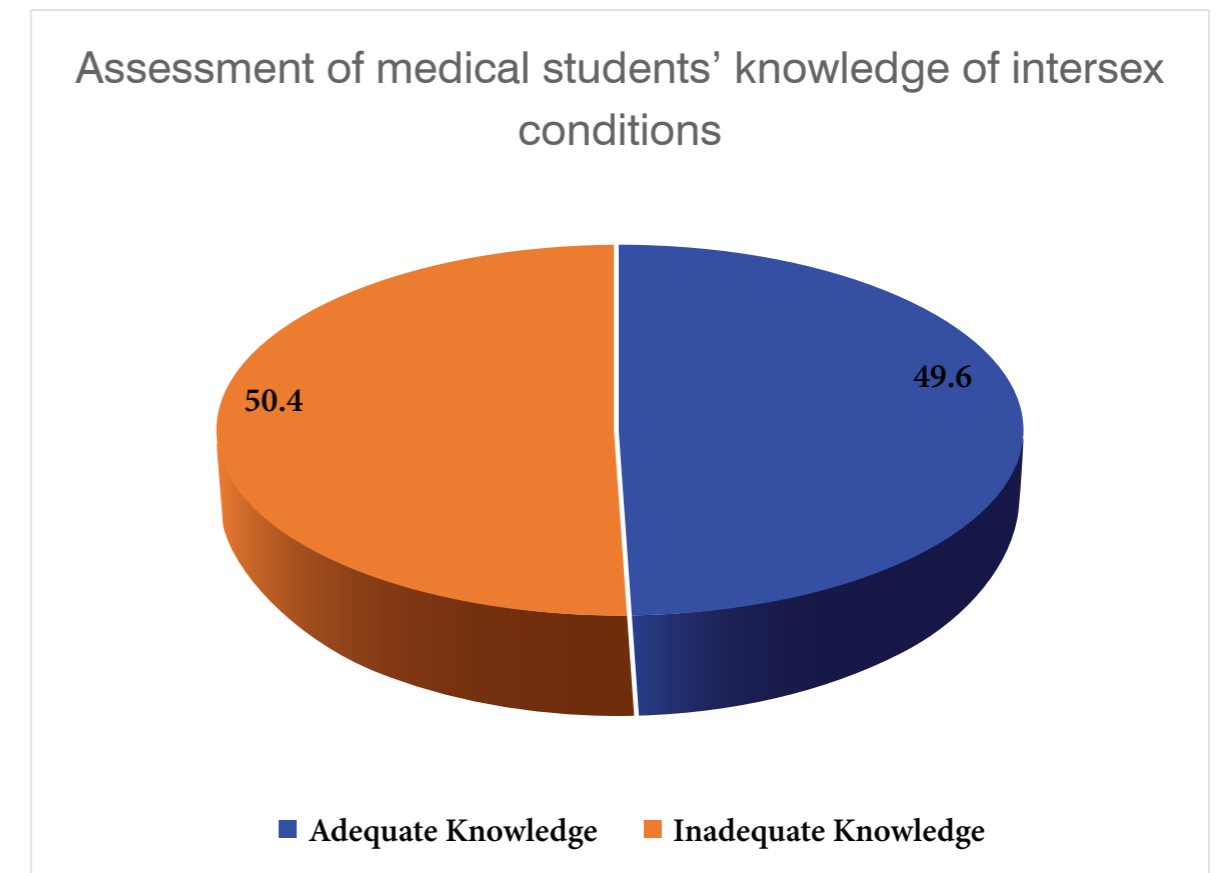
	Yes (%)	No (%)	Maybe (%)	Don't Know (%)
An intersex person is a person born with a reproductive or sexual anatomy that doesn't seem to fit the typical definitions of female or male.	216(86.4%)	5(2.0)	29(11.6)	
An Intersex person can be classified as				
Male	70(28.0)	20(8.0)	35(14.0)	125(50.0)
Female	69(27.6)	21(8.4)	31(12.4)	129(51.6)
Both male and female	122(48.8)	20(8.0)	32(12.8)	76(30.4)
Neither male nor female	57(22.8)	34(13.6)	19(7.6)	140(56.0)
Intersex variant				
Congenital Adrenal Hyperplasia	154(61.8)	28(11.2)		68(27.2)
Androgen insensitivity syndrome	148(59.2)	6(2.4)		96(38.4)
Klinefelter syndrome	100(40.0)	45(18.0)		105(42.0)
Turner syndrome	79(31.6)	60(24.0)		111(44.4)
Swyer syndrome	55(22.0)	20(8.0)		175(70.0)
Mayer-Rokitansky-Küster-Hauser syndrome	68(27.2)	29(11.6)		153(61.2)
An intersex person can present with				
Small penis	168(67.2)	7(2.8)		75(30.0)
Excessive body hair	203(81.2)	18(7.2)		29(11.6)
Undescended Testis	152(60.8)	7(2.8)		91(36.4)
Large Clitoris	156(62.4)	4(1.6)		90(36.0)
Webbed neck	72(28.8)	35(14.0)		143(57.2)

Table 3: Knowledge of risk factors, features, management options and resources available

	Yes (%)	No (%)	Maybe (%)	Don't Know (%)
Possible risk factors for intersex could include				
Mother being exposed to alcohol/tobacco during pregnancy	114(45.6)	32(12.8)		104(41.6)
Mother being exposed to harmful chemical agents during pregnancy	131(52.4)	13(5.2)		106(42.4)
Mother being exposed to harmful drugs during pregnancy	121(48.4)	13(5.2)	26(10.4)	90(36.0)
Family history of genital abnormalities	155(62.0)	8(3.2)		87(34.8)
Consumption of certain foods during pregnancy	43(17.2)	55(22.0)	41(16.4)	111(44.4)
Knowledge of intersex				
Intersex people cannot get pregnant, or have children	100(40.0)	59(23.6)	55(22.0)	36(14.4)
Disorders of Sex Development, or DSD, is the preferred term for intersex	114(45.6)	23(9.2)		113(45.2)
Intersex is a "condition" which can be cured	106(42.4)		53(21.2)	91(36.4)
Intersex is a third sex	33(13.2)	79(31.6)	27(10.8)	111(44.4)
Were you taught other names for intersex	134(53.6)	66(26.4)		50(20.0)

	Yes (%)	No (%)	Maybe (%)	Don't Know (%)
Management options for intersex persons				
Corrective Surgery	154(61.6)	96(38.4)		
Stem Cell Transplantation	29(11.6)	221(88.4)		
Hormonal Therapy	135(54.0)	115(46.0)		
Watch and wait	77(30.8)	173(69.2)		
Resources available				
My school library contains books and journal on Intersex	139(55.6)	20(8.0)		91(36.4)
I have attended seminars on intersex	31(12.4)	219(87.6)		
The formal curriculum in my school adequately covers intersex and its variants	110(44.0)	64(25.6)		76(30.4)
The formal curriculum in my school had adequately prepared me to comfortably and competently serve intersex persons	54(21.6)	196(78.4)		
Over the course of my medical education and clinical rotation, I have had the opportunity to practice interacting with intersex persons	26(10.4)	224(89.6)		

Figure 3: Assessment of medical students' knowledge of intersex conditions



In assessing knowledge of medical students regarding intersex and its variants, about half (50.4%) had adequate knowledge, while 49.6% had insufficient knowledge of intersex

Association between socio-demographic characteristics and knowledge of intersex issues by medical students

A significantly higher proportion of medical students aged ≤ 19 years 5(100%) and in their fourth year 13(92.9%) were more likely to have insufficient knowledge of intersex compared to their counterparts. Also, based on geopolitical zones, a significantly higher proportion of medical students from Abubakar Tafawa Balewa University Teaching Hospital, Bauchi 41 (100%), followed by the University College Hospital Ibadan 22(71.0%) and Barrau Dikko Teaching Hospital Kaduna 7(50%) had comparatively limited knowledge on intersex issues.

Table 4: Association between socio-demographic characteristics and knowledge of intersex by medical students

Variable	Knowledge of intersex		Test -statistic	p-value
	Inadequate Frequency (%)	Adequate Frequency (%)		
Age of respondent (years)				
≤ 19	5(100)	0(0)		
20-24	77(57.5)	57(42.5)		
25-29	40(40.8)	58(59.2)		
≥ 30	4(30.8)	9(69.2)	13.2	0.003
Sex				
Male	76(51.4)	72(48.6)		
Female	50(49.0)	52(51.0)	0.13	0.72
Religion				
Christianity		78(40.8)	113(59.2)	
Islam	46(82.1)	10(17.9)	31.8	<0.001
Others*	2(66.7)	1(33.3)		

Variable	Knowledge of intersex		Test -statistic	p-value
	Inadequate Frequency (%)	Adequate Frequency (%)		
Year of Study				
Fourth	13(92.9)	1(7.1)		
Fifth	97(64.2)	54(35.8)	16.7	<0.001
Sixth	37(43.5)	48(56.5)		
Training Institutions				
University College Hospital Ibadan, Oyo state	22(71.0)	9(29.0)		
University of Calabar Teaching Hospital, CRS	3(10.0)	27(90.0)		
University of Nigeria Teaching Hospital Enugu	26(43.3)	34(56.7)	77.6	<0.001
Enugu State University Enugu	6(20.0)	24(80.0)		
Barrau Dikko Teaching Hospital Kaduna	7(50.0)	7(50.0)		
University Of Abuja Teaching Hospital	21(47.7)	23(52.3)		
Abubakar Tafawa Balewa University Teaching Hospital, Bauchi	41(100)	0(0)		

Association between practice and knowledge of intersex issues among medical students

We found certain groups of medical students to have limited information on intersex issues. These are medical students in the study who admitted that they had not been introduced to intersex and its variants; those not aware of the term intersex 26(65%), those who did not want an inclusive curriculum on intersex and its management 86(65.2%); those who felt it was unnecessary for doctors to have adequate information on intersex issues 79(66.9%); and even those who did not think the formal curriculum prepared them to adequately manage intersex patients (55.1%).

Table 5: Association between practice and knowledge of intersex issues among medical students

Variable	Knowledge of intersex		Test -statistic	p-value
	Inadequate Frequency (%)	Adequate Frequency (%)		
Year of Introduction of intersex				
4th	59(57.3)	44(42.7)	20.2	<0.001
5th	44(37.6)	73(62.4)		
6th	10(66.7)	5(33.3)		
Never heard	13(86.7)	2(13.3)		
The formal curriculum at my school adequately covers intersex and its variants				
Don't know	51(67.1)	25(32.9)	22.9	<0.001
No	38(59.4)	26(40.6)		
Yes	37(33.6)	73(66.4)		
Awareness of Intersex				
No	26(65.0)	14(35.0)	4.06	0.04
Yes	100(47.6)	110(52.4)		

Variable	Knowledge of intersex		Test -statistic	p-value
	Inadequate Frequency (%)	Adequate Frequency (%)		
A more inclusive curriculum on intersex and management option				
No	86(65.2)	46(34.8)	24.3	<0.001
Yes	40(33.9)	78(66.1)		
It is necessary for doctors to have good knowledge on intersex				
No	79(66.9)	39(33.1)	24.5	<0.001
Yes	47(35.6)	85(64.4)		
Attended seminars on intersex				
No	114(52.1)	105(47.9)	1.94	0.16
Yes	12(38.7)	19(61.3)		
The formal curriculum has adequately prepared me to serve intersex persons				
No	108(55.1)	88(44.9)	8.03	0.005
Yes	18(33.3)	36(66.7)		

Case studies and guided in-depth interview findings

In this section, we interviewed five intersex persons on their experiences accessing healthcare in Nigeria. This approach was to fulfil the objective of gaining insights into the experiences of families of intersex persons in Nigeria. We initially aimed to garner more participants for the qualitative survey but were unable despite our best efforts.

This section reflects participants' experiences as intersex persons in Nigeria. Following thematic analysis, we note the following themes from participants' accounts:

- Respondents' views and understanding of the term 'intersex.'
- Respondents' sources of information regarding intersex issues.
- Respondents' opinions on possible causes of the intersex condition.
- Respondents' experiences following the discovery of their being intersex.
- Respondents' experiences with healthcare professionals and the healthcare system in Nigeria.
- Respondents' expectations and recommendations on the management of Intersex persons by healthcare professionals in Nigeria.

Understanding of the term 'intersex'

Almost all interviewees gave their own opinions of what they understood by the term intersex. Some described 'intersex' as a variation in sexual characteristics or disorder in their sexual development, not fitting into the typical binary gender of being either male or female. Many described their condition as unique, with both male and female genitalia and different forms of presentation. According to the interviewees, these could have resulted from chromosomal abnormalities.

"The term intersex is a... disorder in sexual development, and there are different types of intersex conditions. Some have "ambiguous" genitalia, different chromosomes and gonads and the others". (Respondent 1)

"To me, intersex is... it's just like being in between, like having double-gender chromosomes, like it mustn't be chromosomes, it mustn't be genitals or otherwise, is just like having both gender features. You have this feature as a female, and you have this feature as a male, together." (Respondent 4)

"It is a variation or condition, in which a person is born with reproductive sexual anatomy that doesn't seem to fit with the typical recognition of male or female, so to say; variation....so in sex characteristics which includes chromosomes...Sex hormones or genitalia. (Respondent 3)



It is quite understandable and expected that there would be uncertainty among Nigerian respondents on the subject 'intersex' due to the secrecy and shame imposed on intersex persons and the lack of widespread education on these subjects. Most persons interviewed were the first intersex person they were ever aware of until they started conducting independent research when they discovered their intersex nature.

Sources of information on intersex issues

Respondents had varying sources of information on intersex issues. Most participants were of the view that sources of information for the condition was very limited. Some interviewees reported that they depended on medical personnel, their personal experiences and the internet for information. However, some respondents further expressed their dissatisfaction with the level of knowledge of health professionals on the condition. They reported that many health professionals who were relied on to provide information on their intersex nature lacked adequate knowledge and used them for arbitrary experiments.

“Actually, I had to go to the medical centre because they are the ones that will explain more; no other person can do so apart from them. So, I had to start visiting hospitals and native doctors, even the one that knows what they are doing and the one that does not know what they are doing.”

“On a sincere note, in Nigeria, you find it difficult to even meet with people that you could actually get more knowledge about it from. Because even when you go to the hospitals, you just find out that they don't even know about it, and when they see you, they want to experiment with you.” (Respondent 4)

“I get most of the information I know about my condition from [my] personal experiences and research.” (Respondent 5)

There is a lack of information on care for intersex persons and patient-centred management among all healthcare professionals across Nigeria.



Respondents' views on possible causes of the intersex condition

We sought to determine respondents' opinions on this due to the prevalence of wrong information and superstitious beliefs about why a person is born intersex.

A few respondents indicated that their condition may have been due to chromosomal abnormalities during pregnancy. A mother of one of the children perceived that it may have resulted from her not attending antenatal care where the condition could have been detected, while another believed that their condition was a curse from the gods.

“It could actually be as a result of not getting adequate antenatal care because if the pregnancy had been registered in a government hospital, it could have been possible for the condition to be picked up while I was still 2-3 months pregnant with her. It could not have been due to drugs or food in my pregnancy. I am sure it is not due to family curse too.” (Mother of intersex child)

“I feel it is not normal and may be linked to something our forefathers did. I sometimes think it is a curse.” (Respondent 2)

“I think it has to do with the chromosomes. There are times that chromosomes can be higher, chromosomes, different, like for instance the male chromosomes is XY, the female is XX then for some individuals, it is XXY, and then for some it's XY... but when you see the person, the person is physically female.” (Respondent 3)

There must be holistic educational campaigns for persons within and outside the healthcare system in Nigeria to curb the spread of negative beliefs and superstitions about intersex persons. These harmful beliefs contribute to discrimination against and isolation of intersex persons in the country.





Challenges experienced by intersex persons following the discovery

Most respondents reported that they grew up with an assigned gender at birth, but they started manifesting features of a different sex during puberty.

Many interviewees portrayed this phase as a challenging and embarrassing period as they felt awkward and confused because their genitals did not fit into the binary genders. Many respondents admitted living in denial, becoming more reserved, experiencing depression and one even contemplated suicide.

They were subjected to all kinds of tests by health professionals and medical procedures without consent and complete information.

Many complained of being moved from hospital to hospital because many doctors were not adequately trained to care for them. Some reported that doctors performed surgeries very early in their lives to “correct” their external genitalia, but this contributed to their confusion at puberty when they developed traits of a different gender.

“I did not discover it early, but when I did, I was almost depressed at a point because you observed something, you can’t share it with people around you, you don’t even trust who to talk to, because the first time, I actually tried telling someone... and the person just stopped talking to me. So, finding out that thing at first... it was... it was, I won’t lie to you, I was very depressed. Sometimes, I just sit down and start thinking. I will just sit down and start crying like, what is all this. And I think all that was just because I really didn’t understand very well what it was, and my parents didn’t as well.” (Respondent 4)

“I was really confused about these new discoveries and felt really awkward. I was brought up as a female and discovered that I started having some changes which was not there before. So, you know, I have never experienced it and I don’t have a friend that I can explain to, that is like me that will understand. So, I had to rush to the hospital. Then I discovered that it was an ascending and descending testis; testes that will go up and come back down”. (Respondent 1)

“I was assigned to be a female at birth. As I got to the age of puberty, I was expecting all the secondary reproductive things to be... manifesting and developing in me. I’m talking about enlargement of the breast, menstrual flow, but nothing like that happens. Instead, I started developing the opposite sex. I was now having beards all over my face, deep voice, you can hear my deep voice, it doesn’t sound like a female voice, broadening shoulders and so many other things. That’s it. I feel embarrassed every time... I feel embarrassed. Even people embarrass me. I feel timid. I feel inferior. I feel humiliated. Dressing as a female, but with male features. It is really confusing for people.” (Respondent 5)

“I was angry with the whole world, I was angry with everything. There are times where I would just contemplate giving up, most times I was always suicidal and tired.” (Respondent 4)

“Since the discovery of my intersex status, I rarely go out. If I am going out, it’s for a very important purpose. If it’s not anything reasonable, I don’t go out. So, I really felt depressed, sometimes... (sighs) yeah... it’s not easy, it’s not easy. That’s just it; it’s not easy. You receive insults from people. You receive... ahh God, you will see some kind of talk, you will see some kind of manners.” (Respondent 1)

Experience with healthcare professionals and the health system in Nigeria

The experiences with health care professionals varied. While the majority of the intersex persons interviewed were not satisfied with the care received from the health care providers they met, one of the respondents stated that they met one doctor (from one of the hospitals of our quantitative study focus) who was very different.

Interviewees perceived that doctors did not have in-depth knowledge of intersex issues and the proper management of intersex patients and tended to use them as solely experimental objects. Another respondent was unhappy with the lack of privacy, discriminatory treatment received and consultants using them to teach their students. In addition, one of the respondents opined, from their experience, that doctors usually assign genders based on what was easier for them to carry out during surgery which they felt was so wrong. Additionally, most interviewees agree that most doctors in Nigeria need to undergo training on intersex and the best ways to manage it using a patient-centred approach.

“From my experience, most of the doctors in Nigeria lack experience. When they see you, they want to use you for practical purposes. You’ll see all of them start bringing out their camera, start snapping. It’s as if, what they have been seeing in theory, they are just seeing somebody [real] and they want to use you as a life practical, which is not always too good ... I’m not always comfortable with it.”
(Respondent 5)

The intersex persons deserve some privacy during consultation, and it is not that you will be exposing one, and calling your students, maybe you are a consultant, calling your students around and telling them, oh come and see, come and see why this is this, that is why such a person cannot menstruate and all that. No, I think an intersex person deserves to be treated better because you shouldn’t just be exposing one to everyone like that because they are coming to see you, the person had confidence in seeing you because you are a doctor you don’t have to now place them as a tool of experiment. **(Respondent 2)**

“These health workers ... don’t know anything, that’s the truth. I’ve been to different hospitals; they just don’t know anything.” **(Respondent 2)**



The respondent who had shared a positive experience with the health care workers reported:

“I think I have had some good experiences with the females in the sector. Most of the ladies, like I’ve met a matron, I’ve met a female doctor before and one other nurse, oh I remember when I was in school too that I was sick, so there was a nurse too there. So, these people, they were really nice ... even [though they] know. So she was just checking up, so I opened up to her. When I opened up to her, to my greatest shock, even when the doctor came, she didn’t tell him, and she told me I should

not tell any one of them around there so that they would not start misbehaving around me.” **(Respondent 2)**

While many of these hospitals are teaching hospitals, many of the experiences disclosed by respondents are not merely providing medical students with practical knowledge of various medical treatments. They involve making a spectacle and mockery of intersex persons without care for their dignity, privacy, right to information and consent to medical treatment. The discrimination against intersex persons in most of these hospitals across Nigeria is pervasive and must be stopped.

Discriminatory treatment, harassment and maltreatment of intersex patients by healthcare workers

Respondents mirrored their experiences with discrimination, harassment and generally poor treatment in the hospitals because they are intersex. One respondent stressed that they never had any good experience from childhood with hospitals. They shared their experience of feeling very uncomfortable with a family doctor whom they perceived always took advantage of their condition and was in the habit of touching the genital area even if they complained of a headache. This experience led to them avoiding visits to the hospital. They expressed that they were treated unfairly and in a derogatory manner by the healthcare professional.

“There was this particular doctor my dad will always take me to, and each time we go there, he will be tussling with the genitals, and I am like, this is not why I came here. Each time I go to him, even if I complain to him about a headache, he wants me to go naked, probably he finds interest in my genitals, but then when I get home to report, they would be like; Oh,

you’re just trying to make a fuss, what is there. So, at some point, when I was much younger, I stopped going to hospitals. Even if I’m sick, I won’t complain because I know that, definitely, they will take me back to this person.” (Respondent 3)

In addition to these, respondents also shared their experiences with medical practitioners dismissing their needs and withholding information from them. All healthcare professionals must adopt a patient-centred and human rights approach in dealing with all patients, including intersex persons.

Expectations and Recommendations for managing intersex patients

The intersex persons interviewed for this study also made suggestions for health professionals, family members, community members and society, in caring for and interacting with intersex persons. These recommendations directly respond to the unequal treatment, disrespect, discrimination and exclusion meted out against intersex persons across sectors in Nigeria.

Health Professionals

Most interviewees highlighted the need for doctors to receive more training to manage their condition better.

“When I newly discovered my condition, I realised that the doctors don’t really know much about intersex and require training to manage us properly.” (Respondent 5)

Some respondents perceived that doctors usually play the role of God in determining their gender, which they felt should not be so.

The doctors I met gave me a male hormonal drug and did not take into cognisance my gender identity. They didn’t want to respect that. They felt that they had the final say on how this thing should play out. It dawned on me that a lot of doctors assume the position of playing God for an intersex person, assuming that they know the right thing to do for an intersex person, not minding if the gender identity is opposite or the same. They should not impose any sex on anyone (Respondent 4).

Another respondent shared that healthcare professionals should delay the surgeries done on intersex persons until the person is old enough to decide. These surgeries should not be forced on the children.

“I am not in support of, particularly children being subjected to surgery. It’s best we let them make a choice, let them make their own decision, the decision should be left to the individual to make, not the doctor.”

“There’s no need trying to correct any child or mutilate any child for any reason; let the child be. Allow the child to grow up and choose whichever gender they want to. If they want to be like that, it’s their decision to make. If they want to go through surgery, it’s their decision to make. It is not your decision.”

One of the respondents suggested that the training of doctors on intersex should begin early when they are in medical school, and they should be the ones to enlighten others about the condition:

“Teaching of doctors on intersex [issues] should start in the medical school, that people give birth to...as in, it’s something that they should start telling people, enlighten people about it because even the doctors, some of them don’t even know, and it’s something that they are supposed to be teaching them at medical school - as in deeply - so they will know. So that when they see something like that, they will be like, yeah, this is what they have taught us, and it’s true” (Respondent 1)

One of the respondents stressed the need for intersex persons to be given equal and dignified treatment as other patients visiting the hospital and not be subjected to discriminatory or derogatory treatment.

“I think that doctors should attend to intersex persons the way they attend to normal people. The Intersex person deserves some privacy, and they shouldn’t just be exposing one to everyone like that because they are coming to see you. I just want them to realise that ... if they can stop using an intersex person as a tool of experiment, I think we would be more free.” (Respondent 2)

Parents and caregivers

Respondents had suggestions for parents and caregivers on the best approaches to manage a child with the condition

“I will advise the parents that they should allow the child to grow up to choose any gender the child decides, and they should be dressing the child with unisex, and name that both male and female wear. I don’t want them to just capitalise on a particular gender for the child. Supposing they allowed me to be wearing trousers in time, dressing anyhow, it won’t have too much effect on me.” (Respondent 3)

Early education of the intersex child is critical

“I think parents should be able to educate the child right from a very young [age]....., so that anyway the child is feeling inwardly, they should be able to express it physically, not that the child should be doing what or dressing the way they want the child to dress or take a gender that they want the child to take. I also suggest that they give the child a general name, a name that does not pertain to a man or a woman and brings the child up in a way that he doesn’t necessarily need to be a male or female.” (Respondent 2)

Provide Adequate Love, care and support to the child

“My advice to parents/caregivers of such children is to always make them happy and to also labour well over them as one cannot predict their future. One should labour to the point that the children will know that such parents laboured over them whether there is a solution or not. One should not neglect them.” (Respondent 4)

Conclusion and recommendations

This research has extensively examined the levels of information and perception of intersex issues by healthcare professionals and students in Nigeria. We

aimed to assess healthcare professionals’ attitudes towards intersex persons and note their ongoing practices as a form of background to identify gaps and make necessary interventions. In addition, the experiences of intersex persons in Nigeria are crucial in assessing the nature and extent of discrimination faced within the healthcare system, as we have seen.

Based on the outcome of our research, all classes of stakeholders must make efforts to eliminate discrimination against intersex persons within and beyond healthcare institutions and create a more inclusive society. To this end, we make the following additional recommendations.

- Knowledge sharing and awareness-raising for health care workers and students, including compulsory training on sex characteristics and all intersex variants for medical students in Nigeria
- In-depth training for medical and health professionals on sex characteristics, caring for intersex persons, human rights and sexual orientation, gender identity/ expression.

- The Nigerian Medical Association, the Nigerian Medical and Dental Council, the Nursing Council and other professional healthcare associations must hold healthcare practitioners accountable for their discriminatory, abusive and negligent actions in treating and caring for intersex persons in Nigeria.
- Human rights advocates should collaborate for movement building within the civil society space to recognise intersex persons’ rights in Nigeria.



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