Uptake of Premarital Genetic Counselling: Awareness and Demand

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Abstract

The prevalence of genetic disorders in Nigeria has become a concern to medical practitioners. Premarital genetic counselling is crucial in the prevention of hereditary disorders, congenital abnormalities and different health problems. This study therefore investigated the correlation between awareness and the need for the uptake of genetic counselling among the students of the University of Ilorin, Nigeria. A quantitative correlational research design was adopted for this study using the questionnaire, Awareness and Need for the Uptake of Genetic Counselling Scale (ANUGCS), as a data collection tool. The instrument had 3 sections; Section A contained information on the demographic characteristics of the respondents, Section B had 5 items on students' awareness, and Section C had 15 items on the need for the uptake of genetic counselling. The purposive sampling technique was adopted in choosing 4 faculties while proportionate sampling was used in selecting 249 respondents across the university. The data obtained were analysed using percentages and mean scores. The Pearson product moment correlation and a regression analysis were used to test the null hypotheses and a *p*-value of < 0.05 was considered statistically significant. This study would be of significance to students, intending couples, medical personnel and parents. The results of this study show that (1) the respondents were fully aware of genetic counselling; (2) the need for the uptake of premarital genetic counselling by the respondents was high; and (3) gender significantly influenced the need for the uptake of premarital genetic counselling while age did not. It was therefore recommended that school clinics employ the services of trained genetic counsellors. These counsellors can assist medical practitioners whose clients need counselling about their genetic status.

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Background

Genetic counsellors are experts in genetic therapy; they assist clients to become aware of their medical condition in relationship to how their genetic make-up predisposes the occurrence of diseases (Alabek, Mohan, and Raia 2015; Georgia Association of Genetic Counselors 2018). Clients are counselled through the outcome of medical reports obtained from clinics or hospitals. This process includes an analysis of the medical history of the family which in turn explains the possibility of the occurrence or recurrence of diseases such as sickle-cell anaemia (SCA), thalassaemia, hepatitis B and C, and HIV/AIDS infections (David et al. 2018). Genetic counselling could also be defined as the process by which patients and relatives are educated on the risk of inherited disorders and the possibility of transmitting such disorders to the next unborn generation (Aneke and Okocha 2016). This process offers information that permits the clients to make an informed decision about their health status and that of their relatives. According to Medicine Net (2016), this therapeutic process exposes the client to the complexity in genetic formation, and the likely health risk factor that could occur as a result of an inherited disorder. Azuka (2014) explained that the genetic counsellor gives complete information to clients about their health fitness and at the same time assists in the process of choosing a life partner that matches the inherent make-up. Counselling is a helping relationship in which the counsellor assists clients in a face-to-face interaction with the aim of supporting them to achieve a greater level of self-awareness and satisfaction (Umoh 2016). The participants must value the relationship and must endeavour to achieve the attained goal.

Premarital genetic counselling (PGC) is an enlightenment process that involves the transfer of information by helping the intending couple or would-be partners (i.e. partners who are in courtship and planning to get married in the future) to understand their genetic condition. This is a process by which the clients receive counselling before marriage on their health status in order to prevent the transference of possible infectious disease or disorder to each other or the next generation (Adeyemo et al. 2018).

A premarital genetic counsellor supports partners who are not genetically compatible to accept the outcome of the test and to make a wise decision. The therapist also assists clients by giving psychological support, especially when the test result is not favourable. The results of premarital screening could be complex and traumatic when such information is not well-managed. The therapeutic process provides practical lifestyle information to ease tension and to ensure acceptability of inherited risks (Siani and Ben-ZviAssaraf 2015).

With the advancement in diagnosis and diverse campaign through social media on the need for premarital counselling, Azuka (2014) revealed that there is high prevalence of genetic disorder in Nigeria, with sickle-cell disease (SCD) being the most common

serious genetic ailment in the country, of which two to three per cent of the newborns are carriers of this disorder. In fact, genetic disorders such as glucose-6-phosphate dehydrogenase (G6PD) deficiency (which manifests primarily as an increased risk of neonatal jaundice) and congenital malformations are reasonably common and account for the substantial morbidity and mortality of children (Adeyemo et al. 2018).

It is clear that youths of marriageable age are not well informed about what genetic counselling entails while many are ignorant of the fact that there is the high tendency of mating with someone who has defective recessive genes (Siegal 2018). Bolu-Steve (2017) revealed that the attitude of youths to premarital genetic screening and counselling in Nigeria shows that they are ignorant of the importance of genetic counselling. Most youths of marriageable age who are aware of this process are reluctant in checking their genetic status until there is a serious health challenge. The awareness about one's carrier state gives the would-be couple an opportunity to have a healthy marriage. The uptake of PGC is key in the prevention of the spread of some genetic diseases (King 2017). This suggests that many people are likely to be ignorant despite its benefits (Azuka 2014). Al Kindi, Al Rujaibi, and Al Kendi (2012) explained that many youths lack awareness about their health status. The World Health Organization (2010) revealed that about 90 per cent of youths infected with HIV are not aware of their status before marriage.

The Georgia Association of Genetic Counselors (2018) explained that it is important for all students to voluntarily submit themselves for genetic counselling before marriage. PGC helps in identifying the onset of genetic conditions such as neurological problems (Huntington's disease, ALS, frontotemporal dementia), haematologic conditions (clotting or bleeding disorder), and cardiological conditions (inexplicable sudden cardiac arrest, cardiomyopathy, congenital heart defect) (Kohne 2011). Multiple pregnancy losses and infertility problems could also occur. According to Boadu and Addoah (2018), a large proportion of the world population have one form of genetic disease or the other, and many people are ignorant of their status. PGC is crucial in the prevention of hereditary disorders, congenital abnormalities and different health problems (CDC 2014).

Kelani (2017) explained that it is important for youths to voluntarily submit themselves for genetic testing and counselling before marriage. This is because the genetic make-up of the would-be couple is essential in determining whether the intending couple would have a healthy family. The counselling process offers information to the clients about inherent genes and chromosomes and at the same time identifies the genetic traits or chromosomal condition that could negatively affect the intending couple. Genetic counselling process gives insight into the epidemiology of disorders and the impact it could have on the unborn generation when the infected intending couple marry (Abd Al-Azeem et al. 2011).

Statement of the Research Problem

The choice of a marriage partner among the youths is usually based on love thereby neglecting other crucial issues. The increase in genetic disorders among youths has become a concern to stakeholders despite the efforts of medical personnel in preventing the occurrence of genetic diseases. Many students of marriageable age do not see the need for PGC. When the researcher was serving the questionnaire, some attested to the fact that they got married without the knowledge of their health status. Al Kindi, Al Rujaibi, and Al Kendi (2012) revealed that many students are ignorant of their genetic status. The incidence of SCA and other inherited diseases has continued to increase in Africa despite the fact that it can be prevented (Long et al. 2011). Kelani (2017) stated that Nigeria has the highest population of people living with SCDs. Non-adherence to PGC has led to the birth of children with various disorders. The involvement of youths in consanguineous marriages has become a major factor in raising the incidence of genetic diseases, hence the need to raise awareness of the need for genetic counselling.

Abd Al-Azeem et al. (2011) carried out a research project among medical students on knowledge and attitude of university students regarding premarital screening programmes. Aneke and Okocha (2016) worked on the genetic counselling and testing of SCDs, while Gharaibe and Mater (2009) carried out a study on young adults' knowledge of and attitude to premarital testing. Despite the various researches on PGC, there is a high rate of genetic disorder among our youths. This was why the researcher deemed it fit to carry out a study on the awareness and need for the uptake of PGC among the students of the University of Ilorin in Nigeria. Hence, there was the need for this study.

Purpose of the Study

The purpose of this study is to carry out a research on the awareness and need for the uptake of PGC as perceived by students at a Nigerian university.

Objectives

The objectives of this study are to

- determine the level of awareness regarding PGC among the students of the University of Ilorin;
- identify the need for the uptake of PGC as perceived by the university students;
- investigate the relationship between the students' awareness of genetic counselling and need for the uptake of PGC; and

- identify the moderating role of respondents' profile on the relationship between awareness of genetic counselling and PGC as perceived by the university students.

Definitions and Operationalisation of Key Concepts

Genetic counselling is the process in which the counsellor assists the students to understand and be familiar with their hereditary make-up.

Premarital genetic counselling is the process of assisting people to understand their hereditary make-up before marriage.

Uptake of genetic counselling is the willingness to seek and use the genetic counselling process.

Research Methodology

The research design adopted for this study was a quantitative, correlational and cross-sectional design. According to Soeters, Shields, and Rietjens (2014), correlation research designs are used to determine the relationship between two or more variables and the extent to which such a relationship exists. The researcher considered this method appropriate for this study because it looks at the relationship that exists between variables.

Study Setting

The study was conducted at the University of Ilorin, Nigeria. There are 15 faculties in the university. For this study, faculties with a large population of students were purposively selected. The university is unique because it is located in the transition zone between the South and North confluence of cultures of Nigeria (Bolu-Steve and Atinuke 2011).

Study Population

The study population consisted of students of the University of Ilorin, Nigeria. The major reasons that motivated the researcher for the choice of this sample were that most of these students are at the verge of marriage while some are in courtship, and the students are ignorant of their genetic status. The purposive sampling technique was adopted in choosing four faculties while the proportionate sampling technique was used in selecting students from each of these faculties. The proportionate sampling technique is a method used when the population consists of several subgroups that are different in number, as the number of participants is determined by the size of each group.

Eligibility Criteria

The following participation criteria were set up: (1) those students that were willing to take part in the study should voluntarily accept the questionnaire; (2) the participants must be students of the University of Ilorin; and (3) the participants must be 15 years and older. This is because in most universities in Nigeria, students are not admitted until they are 15 years old. Based on these criteria, the proportional sampling technique was used in selecting the respondents from each of the faculties.

Measurement Instrument

The students were asked to complete the Awareness and Need for the Uptake of Genetic and Counselling Scale (ANUGCS), which was developed by the researcher. The instrument was a 4-point Likert type scale, which had three sections. Section A consisted of information on the demographic characteristics of the respondents, Section B contained 5 items on the students' awareness, and Section C had 15 items on the need for the uptake of genetic testing and counselling.

Validity of the Measurement Instrument

To ascertain the validity of the instrument, copies of the questionnaire were given to experts in the related field of study. After their suggestions, the necessary amendments were made and the instrument was finally adjudged valid for the study.

Reliability of the Measurement Instrument

The reliability of the instrument was determined using Cronbach's alpha. The result of the factor analysis for awareness of genetic counselling indicated that all 5 items measuring awareness of genetic counselling were valid and had loadings above 0.5, which is greater than the threshold value of 0.4. Also, the result of the reliability test as shown also revealed that Cronbach's alpha was 0.750, which is greater than the threshold value of 0.6. Thus, the items were said to be valid and reliable. The loadings for all the items measuring the need for the uptake of genetic counselling had loadings above 0.4, except the third item and its Cronbach alpha was 0.823. Thus, these results showed that the items measuring the two constructs were valid and reliable.

Data Collection

The researcher with the help of a research assistant personally administered the questionnaire to the students. The study started on 10 August 2018 when the letter of clearance was granted, permitting the researcher to distribute the questionnaire among the students of the University of Ilorin. The researcher gave those willing to participate in the study time to complete the questionnaire while some completed their copies on the spot. By the end of September 2018 all the copies of the questionnaire were retrieved from the respondents.

Data Analysis

The statistical analysis used for this study was the Statistical Package for Social Sciences (SPSS) version 22. The data obtained were analysed using percentages and mean scores, while the Pearson product moment correlation was used to test the null hypotheses generated and a *p*-value of < 0.05 was considered statistically significant.

Ethical Consideration

A letter of permission was issued by student affairs granting the researcher permission to distribute the questionnaire to students who were willing to participate in the study. The students were assured that their responses were primarily for research purposes and that all information supplied would be treated with the utmost confidentiality.

Results

This section presents the demographic data of the respondents and the results of this study. A total of 249 students participated in the study.

Table 1: Demographic data of the respondents

Demographic data		**Frequency**	**Percentage**	**Cumulative percentage**
Age	15–17 years	17	6.8	6.8
	18–20 years	15	6.0	12.9
	21 years and above	217	87.1	100.0
	Total	**249**	**100.0**	
Religion	African traditional religion	12	4.8	4.8
	Christianity	154	61.8	66.7
	Islam	83	33.3	100.0
	Total	**249**	**100.0**	
Gender	Male	124	49.8	49.8
	Female	125	50.2	100.0
	Total	**249**	**100.0**	
Level of education	100–300	96	38.6	38.6
	400–600	138	55.4	94.0
	Master's degree	14	5.6	99.6
	PhD	1	.4	100.0
	Total	**249**	**100.0**	
Faculty	Sciences	52	20.9	20.9
	Arts	13	5.2	26.1
	Social Sciences	65	26.1	52.2
	Education	119	47.8	100.0
	Total	**249**	**100.0**	

The analysis of the sample by age revealed that most of the respondents for this study were 21 years and above (87.1%), 154 (68.1%) of them were Christians, and the

percentage of the respondents who practiced Islam and African traditional religions were 33.3 per cent and 4.8 per cent respectively. Furthermore, the analysis of the respondents' gender revealed that 50.2 per cent of them were female students, while 49.8 per cent were male students. In terms of percentage, 55.4 per cent (n = 138) of the sample were between 400 and 600 level students. (See Table 1.)

Table 2: Descriptive statistics of the respondents' awareness of genetic counselling

Awareness of genetic counselling	**N**	**Mean**	**Std deviation**
1. Have you ever heard of PGC?	249	.62	.495
2. Are you aware of premarital genetic testing?	249	.43	.495
3. Are you aware of someone that went for genetic screening before marriage?	249	.48	.501
4. Do you have a good understanding of genetic counselling?	249	.51	.501
5. Do you agree that premarital genetic testing and counselling are necessary?	249	.80	.404
Total	249	.57	.340

Note: 0–0.33 = not aware, 0.34–0.67 = fairly aware, 0.68–1.00 = fully aware

Table 3: Descriptive statistics of respondents' need for the uptake of premarital genetic testing and counselling

In my view, premarital genetic counselling can help in:	**N**	**Mean**	**Std Deviation**
1. the early recognition of genetic disorders	249	3.43	.644
2. ensuring the optimal management of a disorder	249	3.26	.671
3. preventing the transmission of genetic diseases	249	3.29	.716
4. ensuring partners' genetic fitness	249	3.29	.698
5. preventing the spread of diseases	249	3.28	.740
6. serving as a source of enlightenment to partners before marriage	249	3.57	.645
7. correcting some irrational beliefs about premarital screening	249	3.27	.703
8. exposing the intending couple to their reproductive health status	249	3.49	.602
9. giving information on the methods of preventing genetic diseases	249	3.35	.679
10. exposing the intending couple to the risk attached to genotype incompatibility	249	3.41	.725
11. giving psychosocial support to the client	249	3.21	.716

In my view, premarital genetic counselling can help in:	N	Mean	Std Deviation
12. providing premarital counselling to the couple	249	3.39	.704
13. screening genetic conditions of the intending couple	249	3.35	.649
14. checking the haemoglobin genotype relationship before finally choosing a life partner	249	3.38	.591
15. making clients discuss matters relating to the reproductive health in marriage	249	3.30	.643
Total	249	3.35	0.37

1.00–2.00 = Low, 2.01–3.00 = moderate, 3.00–4.00 = high

Tables 2 and 3 show the overall means of the respondents' awareness of genetic counselling and need for the uptake of PGC in this study. The analysis indicated that, except for Item 5 (mean = 0.80) which suggests that the respondents are fully aware of genetic counselling, most of the items revealed that the respondents were fairly aware of genetic counselling with the mean values ranging from 0.43 to 0.62.

Furthermore, the descriptive analysis in Table 3 reveals that the need for the uptake of PGC by the respondents was high as the mean value ranged between 3.21 and 3.49, and the composite mean for the variable was 3.35, which could also be considered high (1.00–2.00 = Low, 2.01–3.00 = moderate, 3.00–4.00 = high).

Correlation between Awareness and the Need for PGC

Table 4: Relationship between students' awareness and need for uptake of premarital genetic counselling

Variables	No.	Mean	r value	Sig.
Awareness of genetic counselling	249	0.57	.285	0.000
PGC needs	249	3.35		

The result of the Pearson product moment correlation test conducted between students' awareness of genetic counselling and their needs for the uptake of premarital genetic testing and counselling as contained in Table 4 showed that there was a significant and positive relationship between students' awareness of genetic counselling and their awareness towards PGC ($r = .285$, $p < .000$). It showed that the high level of students' awareness of genetic counselling was associated with the high level of their needs for PGC among the university students that were sampled in this study. Thus, a 100%

improvement in creating awareness for genetic counselling would bring about a 28.6% improvement in their needs for PGC.

The Moderating Roles of Respondents' Profile on the Relationship between Awareness of Genetic Counselling and Need for the Uptake of Premarital Genetic Counselling

A regression analysis using the SPSS program was done to determine the moderating roles of respondents' age, gender, religion, and level of education on the relationship between awareness of genetic counselling and the need for PGC (see Tables 5 to 7). The analysis was carried out in two stages because of the number of the moderating variables. The first stage examined the moderating roles of age and gender while the second stage examined the moderating roles of the students' religion and level of education.

The first stage of the regression analysis showed that gender ($\beta = 0.2$, $t = 4.58$, $p < 0.05$) significantly influenced the needs for PGC, while age ($\beta = 0.06$, $t = 1.46$, $p > 0.05$) did not. Furthermore, the interaction of age ($\beta = 0.15$, $t = 0.93$, $p > 0.05$) and gender ($\beta = 0.02$, $t = 0.19$, $p > 0.05$) did not account for a significant value in the relationship between awareness of genetic counselling and the need for PGC.

In the second stage of the regression analysis, awareness of genetic counselling, religion and level of education were regressed against the need for PGC. The result of the analysis showed that religion ($\beta = 0.03$, $t = 0.61$, $p > 0.05$) and level of education ($\beta = 0.03$, $t = 0.67$, $p > 0.05$) did not significantly influence the needs for PGC. Furthermore, the interaction of religion ($\beta = 0.03$, $t = 0.28$, $p > 0.05$) and the level of education ($\beta = 0.19$, $t = 1.43$, $p > 0.05$) did not account for a significant value in the relationship between awareness of genetic counselling and the need for PGTC.

Table 5: Summary of models

Model	R	R-sq	MSE	F	df1	df2	P
Model 1	0.40	0.16	0.12	9.28	5.00	243.00	0.00
Model 2	0.30	0.09	0.13	4.90	5.00	243.00	0.00

Table 6: Moderating roles of age and gender on the relationship between awareness and the need for PGC

Variable	Coeff.	Se	*t*	P	LLCI	ULCI
Constant	3.35	0.02	152.06	0.000	3.31	3.40
AGC	0.34	0.07	5.09	0.000	0.21	0.47
Age	0.06	0.04	1.46	0.14	−0.02	0.14

Variable	Coeff.	Se	*t*	P	LLCI	ULCI
Int_1	0.15	0.16	0.93	0.35	−0.17	0.47
Gender	0.2	0.04	4.58	0.000	0.12	0.29
Int_2	0.02	0.13	0.19	0.85	−0.23	0.28

AGC: awareness of genetic counselling
Note: Int_1 (AGC × age), Int_2 (AGC × gender)

Table 7: Moderating roles of religion and level of education on the relationship between awareness and the need for PGC

Variable	Coeff.	Se	*t*	P	LLCI	ULCI
Constant	3.34	0.02	146.59	0	3.3	3.39
AGC	0.3	0.07	4.49	0	0.17	0.44
Religion	−0.03	0.04	−0.61	0.55	−0.11	0.06
Int_1	−0.03	0.12	−0.28	0.78	−0.26	0.2
Education	−0.03	0.04	−0.67	0.5	−0.1	0.05
Int_2	0.19	0.13	1.43	0.15	−0.07	0.45

AGC: awareness of genetic counselling
Note: Int_1 (AGC × religion), Int_2 (AGC × level of education)

Discussion

The study examined the awareness of students and the need for the uptake of genetic test and counselling. The findings of the study revealed that many of the students were aware of and agreed that premarital genetic test and counselling were necessary while their responses to other items were fair. According to Teka, Diriba, and Fenet (2016), people understand the need for PGC in the prevention of diseases yet many are not ready to submit themselves to this process before marriage. The findings of this study show that the respondents have heard about genetic counselling but there is the likelihood that they may not understand what it entails. This supports the assertion that students in science-related courses are likely to be more knowledgeable on issues of genetics than other students (Siani and Ben-ZviAssaraf 2015). This is likely to influence the attitude of these students to the uptake of PGC.

Another research question was raised to look at the need for the uptake of genetic counselling and in my view PGC can help in the early recognition of genetic disorders. Most respondents agreed that PGC can help in the early recognition of genetic diseases. This implies that a majority of the respondents are aware of the importance of genetic counselling. With this level of information, one would have expected that people would make themselves available for genetic counselling. However, according to Boadu and Addoah (2018), several people are ignorant of their health status before marriage while those who understand the benefits of genetic counselling are not interested in the process (Ormond et al. 2018).

The first alternative hypothesis showed that there was a positive and significant relationship between the students' awareness of and the need for the uptake of premarital counselling. This means that awareness can lead to the uptake of PGC among the students. This study is consistent with that of Aneke and Okocha (2016) who affirmed that proper understanding can influence students' attitude to genetic testing and counselling.

The study also explored the moderating roles of the respondents' profiles on the relationship between awareness of genetic counselling and the need for the uptake of PGC. The findings of this study revealed that gender significantly influenced the need for the uptake of premarital genetic testing and counselling while age did not. Nahla et al. (2013) also discovered that the knowledge base and attitudes of male and female respondents were not different on issues related to premarital screening and genetic counselling. However, Siani and Ben-ZviAssaraf (2015) observed that gender was least significant in the university students' attitudes to genetic testing.

This research explored the mediating roles of religion and academic level of the respondents in the relationship between awareness of genetic counselling and the need for PGC. The findings showed that the academic level of the respondents did not influence the uptake of genetic counselling. This may be linked to the belief systems of the respondents. Rettig (2017) revealed that the belief systems of people seemed to influence their way of life. However, the religious affiliation of the respondents and their level of education did not influence the relationship between awareness of genetic counselling and the need for PGC. This is in contrast to the findings of Bolu-Steve (2017) who found that a majority of people rejected screening because of their religious beliefs. Long et al. (2011) noted that religious and cultural factors also hinder the uptake of premarital counselling.

Conclusion and Recommendations

The study clearly revealed that the students at the University of Ilorin were aware of PGC. They also agreed that there was a need for the uptake of genetic counselling before marriage. It was also discovered that the level of the students' awareness was associated with the need for the uptake of genetic counselling. The gender of the respondents significantly influenced the uptake of PGC while age did not. Also, religion and academic level had no significant influence on the awareness of genetic counselling and the need for PGC.

The main essence of counselling is to help people live a well-balanced and adjusted life through self-awareness. The trained counsellors through the help of medical personnel such as nurses or doctors can organise seminars that will help to increase the number of students that will be willing to know their genetic status before getting married. Genetic counsellors should be available to assist medical practitioners whose clients need

counselling about their genetic status. School administrators should provide access so that the students can know their genetic status.

Limitations of the Study

The major limitation of this study was that the researcher could not retrieve some of the questionnaire administered.

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