Original Article

Genetic counseling and testing for gynecological cancers: Perception of female undergraduates of universities in Ibadan, Nigeria

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ABSTRACT

Introduction: Genetic education and counseling give individuals an opportunity to make informed choices related to risks, benefits, and limitations of genetic testing for social and medical purposes. We aimed to assess the perception of female undergraduates of universities in Ibadan to genetic counseling and testing (GCT) for gynecological cancers and their willingness to participate in the twin procedure.

Materials and Methods: This was a cross-sectional study involving consented female students from the two universities within Ibadan metropolis – University of Ibadan and Lead City University, Ibadan. Using a self-administered, semi-structured questionnaire, information on their understanding of GCT, perception of implications, and willingness to participate in the procedure were obtained.

Results: There were 943 respondents with mean age of 20.0 ± 3.4 years, 908 (96.3%) had ever heard of cancers, but only 252 (26.7%) provided proper definition. Overall, 484 (51.3%) were aware of GCT although three-quarters, 712 (75.5%), wished to know their inheritable risk of developing gynecologic cancer. All the respondents were willing to participate in the counseling procedure, but only 815 (86.4%) would be willing to proceed with testing if indicated. Possible surgical intervention reduced willingness to test from 82.3% to 45.7%.

Conclusion: The female undergraduates of universities in Ibadan were willing to partake in GCT provided there are no surgical interventions. There is a need for an increased awareness and encouragement of GCT for at-risk groups and also in the prevention and/or early detection to reduce the burden of familial gynecologic cancers.

Key words: Counseling; genetic; gynecologic cancers; testing; university.

Introduction

The incidence of gynecologic cancers has been growing in recent years along with the related mortality rates.[1] Genetic risk assessment, counseling, and testing is generally a multistep process involving identification of individuals who may be at increased risk for potentially harmful mutations, followed by genetic counseling from suitably trained health-care providers and genetic testing of selected high-risk individuals as indicated. Most familial gynecologic cancers tend to occur in younger age groups compared to similar sporadic cases.

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Although the causes of gynecologic cancers are not fully understood, the genetics of hereditary gynecologic cancers are continually evolving, and our understanding of the molecular basis of inherited susceptibility to gynecologic cancers has improved considerably.[2] Factors such as family history, genetic predisposition, risky sexual behavior, viral infections such as human papillomavirus, early menarche and coitarche, parity, and in utero exposure to diethylstilbestrol are among the many risk factors screened for although it is now noted that identifying mutation carriers has important implications for management, long-term surveillance, and risk reduction of gynecologic cancers. In addition, at-risk relatives can be offered testing and appropriate risk management if found to be mutation carriers or reassured if not. Gynecologists and gynecologic oncologists have major roles to play in not only identifying women at risk of inherited cancer syndromes and referring such patients to genetic services but also in managing them appropriately.[1,3] It has been documented that women with germ line mutations in the cancer susceptibility genes, BRCA1 and/or BRCA2, associated with hereditary breast and ovarian cancer syndrome have up to an 85% lifetime risk of breast cancer and up to a 46% lifetime risk of ovarian, tubal, and peritoneal cancers.[4]

Genetic counseling has been described by the National Society of Genetic Counselors as the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease.[5] Individuals are considered to be candidates for cancer risk assessment if they have a personal and/or family history (maternal lineage) with features suggestive of hereditary cancers.[6] Such candidates for genetic testing receive genetic education and counseling before testing to facilitate informed decision-making and adaptation to the risk or condition. On the other hand, genetic testing is recommended or offered when a risk assessment suggests the presence of an inherited cancer syndrome for which specific genes have been identified.[7] Pertinent conditions for offering the test include: (1) an individual has a personal or family history suggestive of a genetic cancer susceptibility syndrome, (2) the result of the test can be interpreted, and (3) testing will influence medical management. In general, genetic testing is performed when there is evidence of an inherited susceptibility that had neither been tested nor had identifiable mutation and also in families with a documented deleterious mutation.[7-10] Genetic counseling increases the accuracy of risk perception, decreases intention for mutation testing among women who are unlikely carriers, and decreases cancer-related worry, anxiety, and depression.[7]

Genetic testing has the potential to provide information about cancer risk, thereby significantly contributing to measures of cancer prevention.[1] However, genetic testing raises a lot of ethical issues as it is only ethical and useful if combined with counseling and implementation of risk management strategies. Cancer prevention and screening practices have been documented to improve outcome greatly among women at risk for hereditary breast and ovarian cancer after genetic counseling in the community setting.[11-14] The main thrusts of this study were to assess the perception of female undergraduates of universities in Ibadan about genetic counseling and testing (GCT) for gynecological cancers, determine their willingness to be counseled and tested for inherited traits of some gynecological cancers, and assess their willingness to undertake any necessary preventive strategy that may be advised.

Materials and Methods

This study was conducted among selected, consenting full-time undergraduate students of the two universities within Ibadan metropolis – the University of Ibadan and the Lead City University, Ibadan. Using convenience sampling technique, a semi-structured, self-administered questionnaire was used to obtain necessary data. The questionnaire consisted of sections on the respondents' sociodemographic characteristics, knowledge about gynecologic cancers, awareness of the risk factors for gynecologic cancers, perception on GCT for cancers, and willingness to be tested.

Confidentiality and anonymity of the participants were ensured as the questionnaires lacked means of identification and thus cannot be traced. The study was adequately explained to respondents, and informed consent obtained before administering the questionnaire. In addition, participation was voluntary and data obtained were treated with confidentiality. The data collected were cleaned, coded, and entered into the computer. Analysis was done using the Statistical Package for the Social Sciences version 20.0 (SPSS Inc, Chicago IL, USA). Data were presented using frequency distribution, percentages, and charts.

Results

A total of 943 consenting female undergraduates satisfactorily responded to the survey. The mean age of the respondents was 20.0 ± 3.4 years; about two-fifths, 380 (40.3%), were in their 1st year of study while single women were 906 (96.1%). Other sociodemographic characteristics are presented in Table 1. The majority, 908 (96.3%), of them had heard about cancers before this study although only 252 (26.7%) properly understood what cancer meant [Figure 1].

Most of the respondents were aware of breast (86%), cervical (82.6%), and ovarian (63%) cancers with the

Table 1: Sociodemographic characteristics of the respondents

Variable	Frequency (%)
Age group (years)	
≤20	662 (70.2)
21-25	228 (24.2)
26-30	41 (4.4)
31-35	7 (0.7)
≥36	5 (0.5)
Mean age (years)	20.0±3.4
Level of study	
100 level	380 (40.3)
200 level	185 (19.6)
300 level	157 (16.6)
400 level	164 (17.4)
500 level	21 (2.2)
600 level	36 (3.8)
Marital Status	
Single	906 (96.1)
Married	37 (3.9)
Ever heard of cancer	
Yes	908 (96.3)
No	35 (3.7)
Ever heard of genetic counseling and testing	
Yes	484 (51.3)
No	459 (48.7)
Willingness to have genetic counseling and testing	
Yes	594 (63.0)
No	125 (13.3)
Undecided	224 (23.7)
Willing to know about personal risk for cancer	
Yes	712 (75.5)
No	231 (24.5)
Willingness to have necessary intervention	
Yes	776 (82.3)
No	167 (17.7)
Willingness to have surgical intervention	
Yes	431 (45.7)
No	512 (54.3)
Will recommend genetic counseling to others	
Yes	857 (90.9)
No	86 (9.1)

main sources of information being media (67.7%) and internet (60.9%) [Table 2]. The perception of the respondents about the risk factors for gynecologic cancers is presented in Table 3 while their awareness of various gynecologic cancers is presented in Figure 2. Overall, almost half, 431 (45.7%), of our respondents have relations and friends who have been previously diagnosed with cancers, especially breast (49.4%) and gynecological cancers (15.7%), while 484 (51.3%) were aware of both GCT and additional two people were aware of counseling alone. Only two-thirds, 595 (63.1%), of our respondents thought that cancers can be prevented generally [Figure 3] while 11.6% were of the opinion that cancers were mere superstitious beliefs [Table 3].

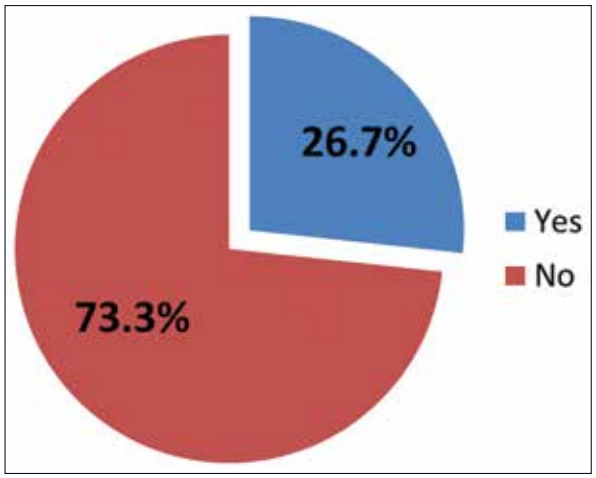

Figure 1: Pie chart showing the percentage of respondents that properly defined cancers

The attitude toward GCT was good in 644 (68.3%) of the respondents while 877 (93%) of them agreed that it should be encouraged, especially among the at-risk group, and 715 (75.8%) believed that the procedure will result in a more favorable outcome in terms of survival from gynecologic cancers. About three-quarters, 712 (75.5%), wished to know their personal risk of developing gynecologic cancers [Table 1]. When the possibility of psychological and emotional disturbance of knowing one's susceptibility to developing gynecologic cancers was mentioned, 696 (73.8%) believed that this would have an insignificant negative effect on willingness. All our respondents were willing to have genetic counseling for gynecologic cancers, but 13.6% opted out of possible follow-up genetic testing if indicated.

The following factors were identified as positively affecting the willingness of the respondents to accept GCT: knowing other available measures of treatment of the cancers (68.3%), knowing the risks associated with the cancers (67%), making the testing free (64.1%), and past experience with cancer survivors (63.3%). On the other hand, fear of the unknown (63.9%) and emotional disturbance (61.7%) will have negative effect on acceptance of the procedure while 355 (37.6%) said that they were not convinced of its necessity [Table 4].

In the absence of surgery, 776 (82.3%) of our respondents are willing to have necessary intervention, but this number reduced by almost half when willingness for surgical intervention was assessed (from 82.3% to 45.7%). This reduction was mostly attributed to fear (58.0%) and religious beliefs (36.0%) about surgeries generally.

Discussion

Genetic testing may enable targeted surveillance, effective

Table 2: Sources of information on gynecologic cancers*

Source of information	Percentage
Parents	34.3
Friends	39.1
Internet	60.9
Media	67.7
Social network	48.6
Health professionals	50.6
School lectures	35.3

*Multiple responses

Table 3: Perceived risk factors for gynecologic cancers

Variable	Frequency (%)
Early age at menarche	
Yes	186 (19.7)
No	757 (80.3)
Early age at coitarche	
Yes	465 (49.3)
No	478 (50.7)
Use of oral contraceptive pills	
Yes	177 (18.8)
No	766 (81.2)
Unprotected sexual intercourse	
Yes	444 (47.1)
No	499 (52.9)
Multiple sexual partners	
Yes	525 (55.7)
No	418 (44.3)
Smoking	
Yes	535 (56.7)
No	409 (43.3)
Alcohol consumption	
Yes	525 (55.7)
No	418 (44.3)
Type of diet	
Yes	496 (52.6)
No	447 (47.4)
Exposure to radiation	
Yes	636 (67.4)
No	307 (32.6)
Superstitious beliefs	
Yes	109 (11.6)
No	834 (88.4)

prevention strategies, early disease detection, and treatment of localized cancer cases with the possibility of cure or long-term survival. Knowledge of risk enables behavioral change as it has been stated that specific cognitive and motivational factors appear to influence risk perception.[15] Despite limited knowledge, a high interest level in genetic testing has been reported among high-risk African–American women with cultural beliefs and values influencing genetic testing decisions.[16,17] A study reported in 1999 by Durfy *et al*.[15] showed that women favored ready access to testing, believed decision to be tested should be a personal choice,

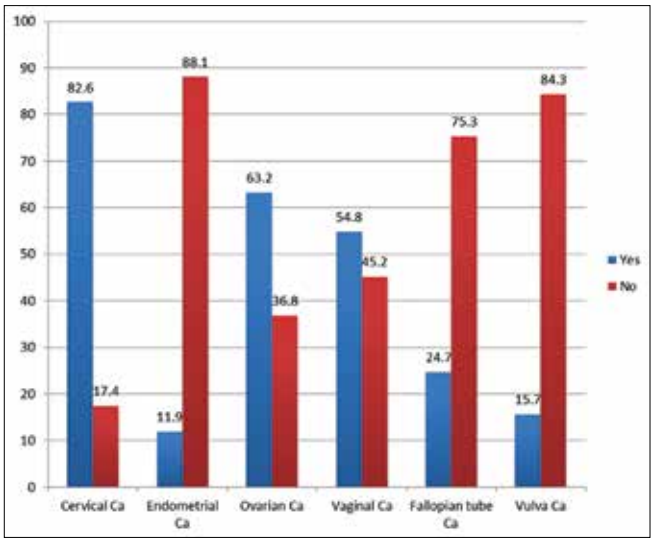

Figure 2: Bar chart showing the awareness of various types of gynecological cancers (in percentages)

believed that genetic results should stay confidential, and were not greatly concerned that all these might be impossible.

In comparison with the findings of Jedy-Agba *et al*. in 2012[18] that awareness levels about breast and cervical cancers were the most common among women, our study also found this trend to apply among the study population. However, the awareness about the risk factors associated with gynecologic cancers was poor, thus calling for attention on information dissemination about these cancers. Majority of our respondents were willing to know their personal risk of developing gynecologic cancers unlike in a similar, but hospital-based study conducted by Dekker *et al*., 2007, among patients with gynecologic cancers where 36% and 63% of patients with endometrial and ovarian cancers, respectively, accepted genetic counseling mainly to receive risk assessment for themselves and relatives.[19] Moreover, most of our respondents also believed that GCT should be encouraged despite the potential psychological and emotional disturbance of knowing one's possibility of developing one or more gynecologic cancers. Our study also corroborated previous reports that GCT, if widely accepted and properly done, have the chance of offering better prevention and early diagnosis of inheritable gynecologic cancers.[8,19]

Majority of the respondents indicated willingness to participate in GCT if given the opportunity and were willing to have necessary intervention if found to be at risk. However, and rather interestingly, this number dropped by almost 50% if the intervention involves surgery. This reduction resulted from the fear of being unsure of the possible outcomes of such intervention including having to lose body parts, religious beliefs and the fact that as yet, there is no cure for

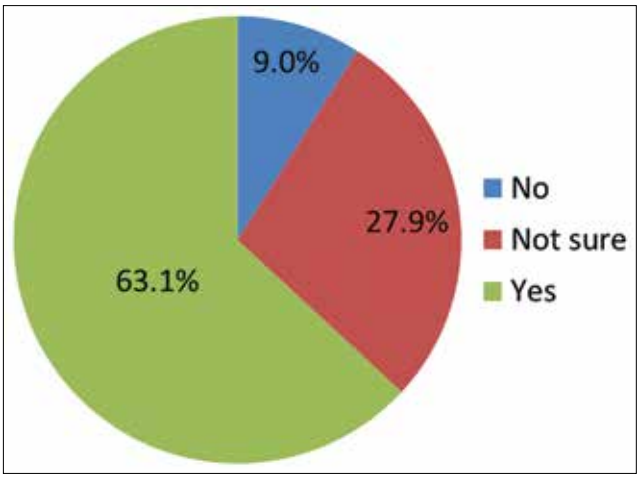

Figure 3: Pie chart showing the perception of respondents to possibility of cancer prevention

Table 4: Factors affecting willingness to have genetic counseling and testing

Factors	Agree (%)	Undecided (%)	Disagree (%)
Fear of unknown	63.9	17.1	19.0
Risk to future life events	67.0	19.2	13.8
Emotional disturbances	61.7	22.1	16.2
Lack of conviction	37.6	37.8	24.6
Cost	42.8	27.1	30.1
Compulsion	41.5	31.3	27.2
Experience of survivors	63.3	20.3	16.4
Knowledge of treatment options	68.3	20.6	11.1
Making it free	64.1	23.2	12.7

cancers. This is similar to a report by TM Wagner *et al*.[20] when the attitude toward prophylactic surgery and effects of genetic counseling in families with BRCA mutations were assessed. The report showed that prophylactic mastectomy was considered by only 21% of the mutation carriers while the majority of affected and nonaffected carriers expected prophylactic mastectomy to impair their quality of lives such that only 50% of carriers agreed to undergo prophylactic oophorectomy instead.[20]

Most of our respondents were unfamiliar with risk factors for gynecological cancers which are similar to an earlier report by Sule and Shehu that only 9.7% of patients in developing countries knew that unusual vaginal discharge or abnormal bleeding could be early symptoms of gynecologic malignancies.[21] In a systematic review of perceived risks, Heshka *et al*. also reported that younger women were less aware of risk factors such as early coitarche, multiple sexual partners, and high parity although they were more informed about gynecologic malignancies contrary to earlier reports.[8] Knowledge of methods of early detection was very low among our respondents, and only 50% agreed that cancer is curable when detected early, thus highlighting a considerable level of ignorance and lack of awareness of cancer among the study population of university undergraduates.

This lack of awareness is principally due to inadequate dissemination of information. It is, however, established that most people favor GCT in our environment despite the psychological effects of a possible positive result. Therefore, it is important to note that performing GCT requires individuals with expertise in cancer genetics, sufficient ability to adequately counsel patients pre- and post-test to encourage possible risk reduction strategies, and reduce the potential psychological impact of the test results. Potential benefits of increased opportunities for and access to screening programs including GCT are enormous and should be explored by developing countries.

Conclusion

Most female undergraduates of universities in Ibadan were willing to participate in GCT provided there are no surgeries involved. There is a need for an increased awareness and encouragement of GCT for at-risk groups and also in prevention and/or early detection to reduce the burden of familial gynecologic cancers. There is an urgent need for processes that will foster an increased awareness of GCT and its benefits.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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