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Assessment of Knowledge and Attitude of Breast and Ovarian Cancer Patients Regarding Hereditary Breast-Ovarian Cancer Syndrome at a Tertiary Cancer Institute: A Cross-Sectional Observational Study

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Abstract

Introduction Hereditary breast and ovarian cancer (HBOC) syndrome affects a significant proportion of our breast and ovarian cancer patients. Mutations in genes, for example, BRCA1 and 2, confer a high risk of acquiring certain malignancies, including breast cancer in both men and women, and ovarian cancer in women. Mutation carriers provide a unique opportunity for healthcare professionals to intensively screen and detect malignancy at an early and curable stage. But, patient awareness and acceptance are the keys to the success of these strategies.

Objective There is a need to assess the awareness of the patients in this field as the patients come from varied backgrounds, and differ in their socioeconomic profiles, educational backdrop, and cultures. In this study, done prior to establishing our cancer genetics clinic, we evaluated the knowledge and attitude toward HBOC in patients with breast cancer and ovarian cancer.

Materials and Methods This cross-sectional observational study was conducted on patients registered in IRCH-AIIMS, who has a diagnosis of breast cancer or ovarian cancer using a self-administered questionnaire based on knowledge and attitude. The sample population included 84 women aged between 25 and 80 years. A binary response was given to knowledge questions, whereas a categorical response was given to attitude questions. The overall data was computed using STATA v13 software.

Results According to the findings of the study, 39.3% (5.11/13) of the patients were aware of hereditary cancer. Knowledge among the targeted population was poor, but 72.1% (37.5/52) of the population had a neutral attitude toward learning more about

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- mutation
- genetic counseling

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hereditary cancer tests. Only 23/84 (27%) people had heard of genetic counseling. Seventy of eighty-four (83%) patients agreed that they would opt for a genetic test if indicated. While 60/84 (72%) of the population wanted to interact with a counselor over a telephonic call, only 41/84 (49%) wanted to interact in person.

Conclusion We concluded from the study that breast and ovarian cancer patients in our clinic have little understanding of HBOC syndrome but have a neutral attitude toward learning more about it.

Introduction

Breast and ovarian cancers are among the most common cancers in women across the world.[1] In the Indian population, the healthcare burden of breast and ovarian cancers has been steadily rising, thus stressing the need for early detection, surveillance, and disease management measures. In Delhi, breast and ovarian cancers rank first and fourth among the most common malignancies in females with an age-standardized incidence rate of 32.25 and 8.8 per 100,000 population.[2] A family history of cancer is one of the most important risk factors for developing breast cancer and ovarian cancer. Hereditary breast and ovarian cancer (HBOC) syndrome is characterized by an early age of onset, overrepresentation of bilateral breast cancers, and familial congregation of ovarian and breast cancers. HBOC constitutes 21 to 30.5% of ovarian cancers[3,4] and 8 to 18% of breast cancers in India.[2,5] Mittal et al's, in contrast, studies from the Western population have shown a prevalence of 5 to 9% of germline BRCA1 and 2 mutations among patients with breast and ovarian cancers.[6–8] Pathogenic mutations in the *BRCA1* and *BRCA2* genes, which operate as tumor suppressors, appear to account for the majority of these cases. Carriers of germline mutations in BRCA1 are believed to have a 57 to 85% lifetime risk of developing breast cancer, while those with the BRCA2 mutation have 49 to 85% by the age of 70 years.[2] The average risk of ovarian cancer in women with a BRCA1 and 2 mutation is 40 and 18%, respectively.[2,5,9,10] Identification of these germline mutations has profound implications in the management of these patients as well as their first-degree relatives who then qualify for single site-specific mutation testing. For the patient, it opens a cafeteria choice for prophylactic risk-reducing surgeries like RRSO (risk-reducing salpingo-oophorectomy), RRM (risk-reducing mastectomies) as well as newer therapeutic agents like PARP inhibitors like olaparib, niraparib. Prophylactic surgeries (like oophorectomy and mastectomy) substantially reduce the risk of otherwise inevitable cancer and mortality.[11] The previvors with these mutations are yet another cohort who will benefit from prophylactic surgeries like RRM and RRSO.[12,13] The National Comprehensive Cancer Network guidelines have elaborately given recommendations for managing these patients according to the specific mutation detected.

But the core of success for all these interventions lies in the awareness of the patients and their acceptance of these interventions. This highlights the importance of the availability of cancer genetic counseling services in the different oncology centers in the country. Cancer genetic counseling should be incorporated in all the centers providing breast oncology and gynecology oncology services. In order to successfully start any "High risk familial /cancer genetic clinic," it is essential to understand the ground realities of the targeted population, their understanding of the subject, what it means to them, and the attitude they have in their minds toward these tests. The Indian population is diverse with multiple levels of ethnic, cultural, linguistic, and religious groups that contribute to this diversity. These factors along with the level of education make the Indian population very heterogeneous. Patients visiting the breast cancer clinic and gynecology oncology clinic comes from diverse backgrounds, rural and urban, with varying levels of education and a variety of religious and cultural backgrounds from different parts of northern India.[14]

This study was planned as a survey to assess the knowledge of our patients with breast and ovarian cancers about HBOC, and their attitude and acceptance of genetic tests and possible interventions.

Objectives

The main aim of this study was to assess the knowledge and attitude of breast and ovarian cancer patients about HBOC.

Materials and Methods

In this cross-sectional observational study conducted in our breast cancer and gynecological cancer clinics of Dr. BRA-IRCH, All India Institute of Medical Sciences (AIIMS), New Delhi, from January 2018 to December 2018, patients with a diagnosis of breast or ovarian cancer attending clinics for treatment or follow-up were invited to participate with a patient information sheet and informed consent form. This was done during a personal meeting in the outpatient department (OPD). We included patients aged 18 years and above with an Eastern Cooperative Oncology Group Performance Status (ECOG PS) of 0 to 3 and who gave informed consent. Acutely sick patients and ECOG PS4 were excluded. Those consenting were asked to fill up the questionnaire using tick marks that took 5 to 7 minutes. Data collection variables included demographic details, diagnosis, family history of cancer, and responses to short questions assessing the knowledge about hereditary

cancers and attitudes toward genetic counseling and testing. Illiterate patients were interviewed by translating and reading out each question and their response was recorded in the proforma (see supplementary file). The primary outcome of the study was to determine the average knowledge score and average attitude score of these patients using an in-house validated questionnaire. No formal sample size calculation was done. We intended to do the study as a pilot survey as there is no data available in the literature. We included as many patients as available during this time period.

An in-house expert-validated questionnaire was developed for the study. This questionnaire consisted of two parts: knowledge assessment and attitude assessment. The KAP survey was interviewer-administered and quantitative. The 27 questions covered knowledge and attitude aspects. The knowledge section consisted of 13 questions. (minimum possible score 0 and maximum possible score 13). Based on the score, the knowledge assessment was evaluated as follows: excellent knowledge more than 75%; good knowledge 45 to 75%; poor knowledge less than 45%. The attitude section consisted of 14 questions, with each question formatted to have five possible choices (strongly agree, agree, not sure, disagree, strongly disagree). The total marks for the attitude assessment were 60 (maximum possible score = 60, minimum possible score = 0). Based on the score, the attitude assessment was evaluated as follows: favorable attitude-attitude score more than 75%; neutral attitude-attitude score between 50 and 75%; unfavorable attitude-attitude score less than 50%.

Preliminary Work on Quality Control

To optimize the scientific rigor of this research, the following processes were done: *Translation and back translation:* Questionnaire questions were developed first in English with a panel of medical experts. These questions were then translated into Hindi by specialist medical translators and then back into English again by a separate, nonmedical translator before they were finally checked for consistency by the research team.

Peer and expert review: A panel of medical and research experts was formed to review the research design and questionnaire development.

Pretesting using cognitive interviewing: A process of cognitive interviewing was used to study the interpretation of the questionnaire questions on lay volunteers. This involves verbalizing the thought processes occurring while reading the questions.

Statistical Analysis

Demographic characteristics were analyzed using mean and median (range). Each knowledge question has a binary response, and each attitude question has a categorical response. The total score was also calculated for knowledge and attitude separately. The association of these scores with demographic and disease factors was determined using Student's *t*-test. STATA v13 software was used for analysis and *p*-value less than 0.05 was considered significant.

Ethics

The procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation and with the Helsinki Declaration of 1964, as revised in 2013. Ethical Approval was obtained from the Institutional Ethics Committee vide letter no. IEC- 186/3/2018 dated 19.03.18 (see supplementary material). Informed consent was taken from all the participants.

Results

A total of 84 women patients participated in the study aged between 25 and 75 years among which 69/84 (82%) had breast cancer and 15/84 (18%) had ovarian cancer (see ►**Table 1**). Among the sample population, 77/84 (92%) did not recall having any relatives with cancer. Twenty-six of eighty-four (31%) patients reported that they feared that cancer may run in their family (►**Supplementary Fig. S1**, available in the online version).

The knowledge part of the questionnaire had 13 questions, and the binary responses to which have been tabulated in ►**Table 2**. Briefly, 55/84 (65%) of the sample population were unaware that some cancers run in families. Only around 13/84 (15%) of respondents were aware that specific genes are responsible for cancer. *BRCA* genes were unknown to 78/84 (93%) of the population. Fifty-four of eighty-four (64%) patients were unaware that breast and ovarian cancer can coexist in certain cases. Only 23/84 (27%) of patients had heard of genetic counseling. Around 54/84 (64%) had the notion that genetic counseling was required prior to genetic testing (►**Fig. 1**). About 19/84 (23%) of the participant had the idea that genetic test reports are kept confidential and not disclosed to anyone else. The mean knowledge score of the patients was 5.11 ± 2.54. With a maximum possible score of 13, this amounted to $39.3 \pm 19.5\%$. This correlated with poor knowledge about HBOC in this patient's cohort.

Table 1 Baseline characteristics of patients who participated in the survey

Baseline characteristics		
	Females	**Males**
1. Sex of patients	84 (100%)	0
	Breast cancer	Ovarian cancer
2. Diagnosis of patients	69 (82%)	15 (18%)
	Yes	No
3. Do you have any other relatives with cancer?	7 (8%)	77 (92%)
	Yes	No
4. Are they related to you by blood?	6 (7%)	78(93%)
	Yes	No
5. Do you fear that cancer may run in your family?	58 (69%)	26 (31%)

Table 2 Question-wise responses to the knowledge part of the questionnaire

Knowledge questionnaires	Yes	No
KQ1: Do you know certain cancers run in the family?	29 (35%)	55 (65%)
KQ2: Do you know that breast, ovary, or colorectal cancer may run in certain families?	18 (21%)	66 (79%)
KQ3: Do you know that certain genes may be responsible for cancer?	13 (15%)	71 (85%)
KQ4: Have you heard of BRCA genes?	6 (7%)	78 (93%)
KQ5: Do you think some cancers are preventable?	64 (76%)	20 (24%)
KQ6: Do you think breast cancer and ovary cancer can occur together in certain cases?	30 (36%)	54 (64%)
KQ7: Have you heard of preventive surgery to prevent familial ovarian cancer/ breast cancer?	71 (85%)	13 (15%)
KQ8: Do you know preventive ovarian surgery is done after completion of the family generally after 40 years of age?	35 (42%)	49 (58%)
KQ9: Have you heard of genetic counseling?	23 (27%)	61 (73%)
KQ10: Do you know blood tests are available to detect whether cancer runs in your family or not?	62 (74%)	22 (26%)
KQ11: Do you know both blood and saliva samples are taken for cancer tests?	6 (7%)	78 (93%)
KQ12: Do you know that the result of this test will be disclosed only to you and no one else?	19 (23%)	65 (77%)
KQ13: Do you think genetic counseling is essential before genetic testing?	54 (64%)	30 (36%)

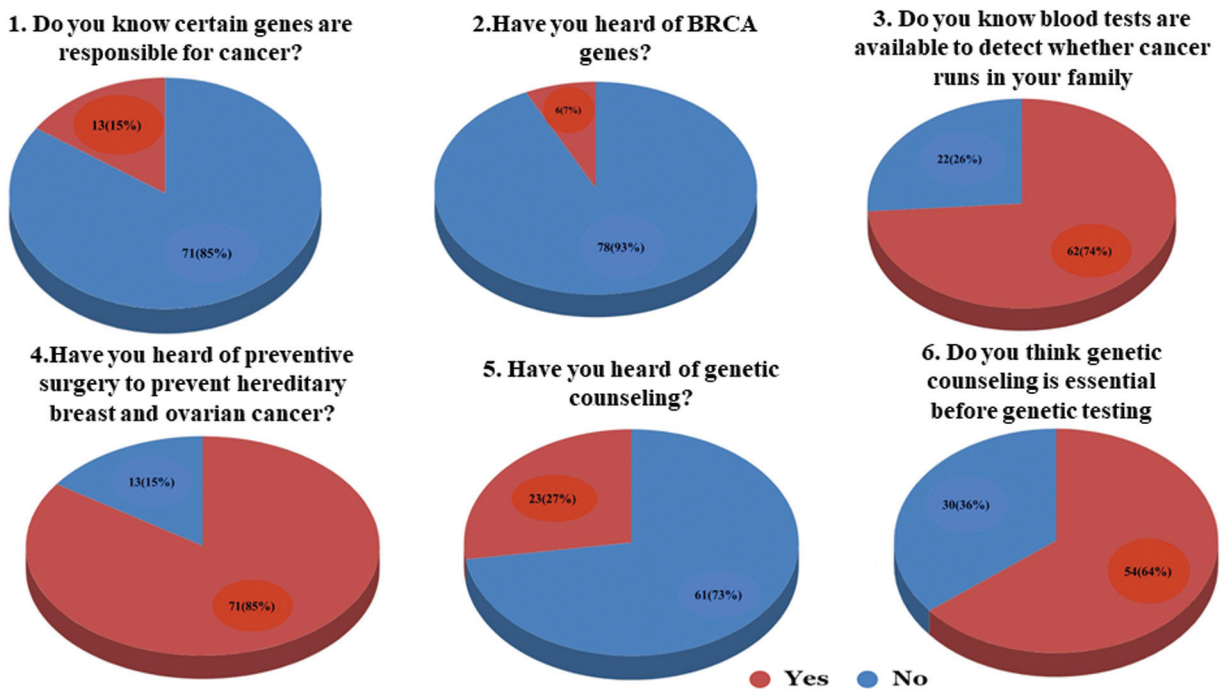

Fig. 1 Pie charts showing binary responses to selected knowledge questions.

Following that, we evaluated the attitudes of the respondents toward genetic testing. In this domain, there were 14 questions, and the responses are tabulated in ►**Supplementary Table S1** (available in the online version).

Briefly, 70/84 (83%) of patients agreed that they would opt for a genetic test if available, and 54/84 (64%) mentioned that they would opt for it even if they had to pay the expenses. A total of 62/84 (74%) of patients believed that these sorts of tests would impact their future decision-making. Around 79/84 (94%) of respondents stated that they would recommend it to their relatives. Given an opportunity, 76/84 (90%) of the participant wanted to interact with a genetic counselor. While 60/84 (72%) of the population wanted to interact with a counselor over a telephonic call, only 41/84 (49%) wanted to interact in person. Approximately 75/84 (89%) of participants were interested in learning more about medical or surgical options for cancer prevention (►**Fig. 2**). The average attitude score of the patients was 40.78 ± 8.05. With a maximum possible score of 52, this amounted to $78.42 \pm 15.48\%$. This meant that the sample population had a neutral attitude toward learning more about genetic testing.

We compared the mean total knowledge marks and mean total attitude marks of our patients dividing them into binary groups according to age ($>/<50$ years), primary diagnosis

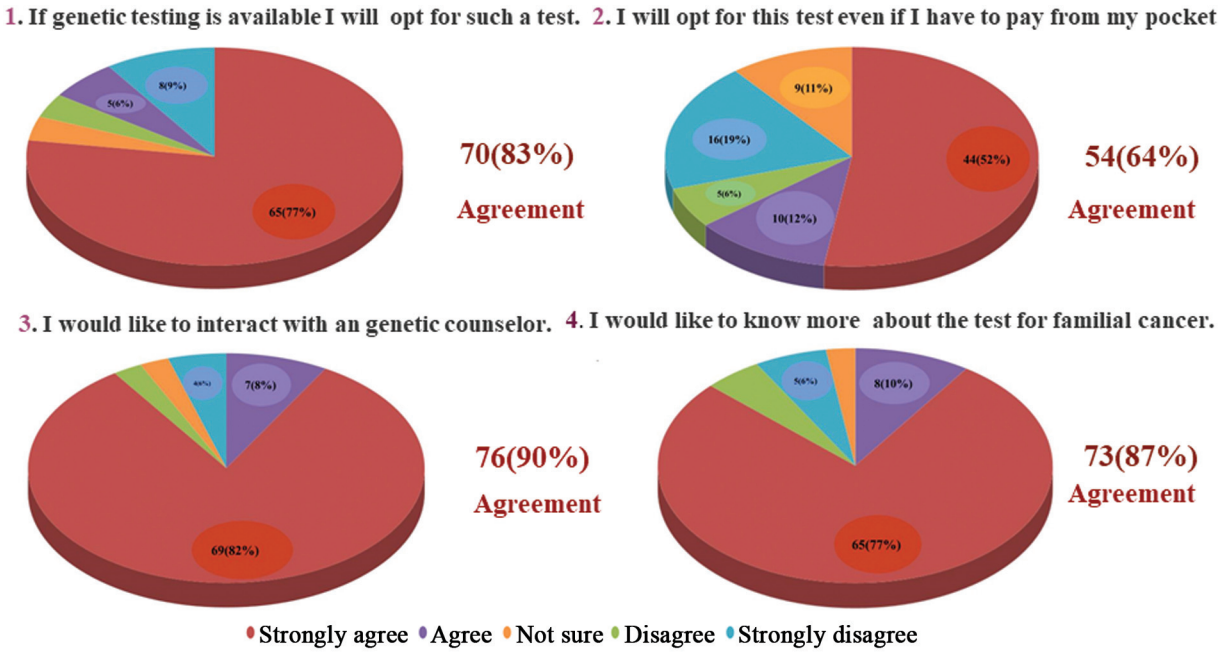

Fig. 2 Pie charts showing categorical responses to questions in the attitude part of the questionnaire.

Table 3 Comparison of knowledge and attitude scores with baseline demographic characteristics

		Knowledge marks			Attitude marks		
Age			*p*-Value			*p*-Value	
≤50	$n=49$	5.08 ± 2.47	0.87	Not significant	40.69 ± 8.07	0.90	Not significant
≥50	$n=35$	5.17 ± 2.68			40.91 ± 8.14		
Diagnosis							
Breast cancer	$n=69$	4.95 ± 2.55	0.21	Not significant	41.44 ± 7.54	0.10	Not significant
Ovarian cancer	$n=15$	5.86 ± 2.47			37.73 ± 9.81		
Relative with cancer							
Yes	$n=7$	4.42 ± 1.18	0.45	Not significant	40.78 ± 7.83	0.98	Not significant
No	$n=77$	5.18 ± 2.60			40.78 ± 11.01		

(breast versus ovary) and whether they had a relative with cancer or not. There were no significant differences between these groups (see ►**Table 3**).

Discussion

We found some interesting results during this study. A large proportion of patients were unaware of hereditary cancers. Most of them were unaware that particular genes are responsible for cancer. Only a small proportion of the participant had heard of genetic counseling. These findings illustrate that public awareness of HBOC is quite low. Interestingly, the study showed that the participants had a neutral attitude toward learning more about genetic testing. More than half agreed to genetic testing, even if they had to pay out of their own pockets. This study was conducted prior to the coronavirus disease 2019 (COVID-19) pandemic, yet it was observed that most individuals preferred to communicate with a genetic counselor over the telephone instead of an in-person visit. A large proportion of those surveyed was interested in learning more about the test for hereditary cancers, as well as the medical or surgical methods for cancer prevention.

Individuals at high risk of getting breast or ovarian cancer in most developed nations receive genetic counseling before undergoing BRCA mutation testing. By precisely building their family lineage and acquiring pertinent medical histories, genetic counseling plays a crucial role in choosing individuals suited for genetic testing. However, in many countries, like America, Africa, and Asia, genetic counseling, and genetic testing are still not widely used in cancer management programs.[15] In a systematic review by Hann et al ethnic minority groups, including African Americans, Asian Americans, and Hispanics, had low awareness and understanding of genetic counseling/testing for cancer risk.[16] In a recent study published by our institution, where

we tested 246 consecutive breast cancer patients irrespective of guidelines, and we reported 18.6% pathogenic/likely pathogenic mutations.[2,5] This is almost double what is reported in Western literature.[17] Therefore, there is a high unmet need for genetic counseling and testing in India. In view of the severe scarcity of cancer genetic counseling services, Indian oncologists and breast surgeons have already embarked on the idea of "mainstreaming."[18,19]

But the million-dollar questions that remain unanswered are "How much do the Indian patients know about hereditary cancers, how much are they eager to know about HBOC, what would be their attitude towards these genetic tests, and how would they like to participate in genetic counseling sessions." Unfortunately, to the best of our knowledge, such a survey has not been reported from India. So, the present attempt is a novel step to unearth and bring forward the perspective of Indian patients suffering from breast and ovarian cancers.

India is a multilingual country, and most patients prefer to communicate in their own language. Face-to-face therapy is the conventional counseling style in India. Telephone, video, Skype, and WhatsApp counseling sessions are being increasingly adopted by genetic clinics and counselors to expand their access. This trend has received an impetus during the recent COVID-19 pandemic.[20] It was surprising to know that even in pre-COVID-19 times more patients preferred telegenetic consultation over an in-person visit. Although the reasons remain unclear, we speculate that it might be emotionally less overwhelming for cancer patients to receive the counseling session over the telephone without any visual contact with the counselor, at least for the initial visit. Also navigating busy OPDs and hospital environments for counseling sessions may be challenging. Thus, telegenetic counseling appears acceptable and promising for Indian society.

Another important takeaway from this study may be that the knowledge and information regarding HBOC should be imparted as awareness programs in colleges, workplaces, and primary healthcare centers. It is quite evident that Indian women are receptive and inquisitive to current scientific knowledge about healthcare.

We used a questionnaire evaluated by a panel of experts at AIIMS. This population's general understanding of HBOC was relatively low. Patients, on the other hand, had a neutral attitude toward learning more about genetic testing.

There are some limitations to our study as well. Despite the fact that the questionnaire used in the study was pretested, it may restrict the comparability of our findings to other investigations. Furthermore, because this study was confined to only 84 females, the sample size is quite small hence, additional surveys with larger samples are required. Nevertheless, this study is novel and unique, for it voices the perspective of Indian patients.

Conclusion

This study shows that there is limited knowledge about HBOC among our patients with breast and ovarian cancer. Yet, they have a neutral attitude to learn more about HBOC, medical and surgical risk reduction, and genetic counseling. The report, thus, emphasizes the importance of educational programs to raise knowledge about genetic testing. An increasing number of oncologists in India are projected to utilize genetic counseling and testing. Such studies are intended to improve clinical practices for better patient care.

Ethical Approval

The study was approved by the Institute Ethical Committee vide Letter No. IEC-186/06.04.2018, RP-47/2018.

Availability of Data and Material

Data regarding this study will be available from the corresponding author (R.P.) at reasonable request.

Authors' Contributions

R.P., S.D., L.K. conceptualized the study, S.V. collected data, S.M., R.P., S.K., A.G., and A.B. analyzed data, and R.P. and S. M. drafted the manuscript. The final manuscript was reviewed and edited by all authors.

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None.

Conflict of Interest

None declared.

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