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Original Research Article

FEASIBILITY OF PRIMARY CARE NURSE BASED GENETIC INFORMATION AND COUNSELLING SERVICE DELIVERY FOR MAINSTREAMING IN OVARIAN CANCER PATIENTS- A MIXED METHOD STUDY

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ABSTRACT

Background: Genetic testing for Breast Cancer (BRCA) gene 1 and 2 mutations in epithelial ovarian cancers is recommended to guide prognosis, adjuvant treatment and prevention of second malignancies in the patient and in the carrier family members or relatives. Prevalence of BRCA and other cancer- causing mutations is not known in most regions in India and is inadequately explored. Main-streaming genetic testing has the potential to increase uptake of testing in patients and identify at-risk carrier population in whom primordial or primary prevention of genetic cancers can be implemented with good outcomes.

Materials and Methods: A mixed method study was conducted with aim to explore feasibility of a primary care nurse based genetic counselling modality for ovarian cancer patients, along with exploration of factors affecting its uptake, using a structured objective survey questionnaire followed by key informant interviews to develop qualitative questionnaire for further phase of the study.

Results: The uptake of genetic testing among patients was good and among healthy relatives was negligible. The affecting factors were lack of awareness and economic. The qualitative study interview explored reasons for low uptake of tests, satisfaction with the counselling and impact of test results on patients.

Conclusion: The pretest counselling was effective and post-test counselling necessitated counselling by specialist oncologist. The uptake of genetic testing was affected by level of awareness and costs.

Keywords: Mainstreaming genetic testing, Nurse led counselling, Ovarian cancer.

INTRODUCTION

Genetic testing for Breast Cancer (BRCA) gene 1 and 2 mutations in epithelial ovarian cancers is recommended to guide prognosis, adjuvant treatment and prevention of second malignancies in the patient and in the carrier family members or relatives.[1] The national institute of health care excellence UK, recently published their guidelines on identifying and managing familial and genetic cancer risk for ovarian cancer, which includes guidance on setting up genetic cancer clinics based on the type or level of healthcare facility.[2] Targeted therapy such as the Poly Adenosine Di Phosphate Ribose Polymerase (PARP) inhibitors has revolutionized the treatment for BRCA mutated patients, improving survival, while risk reducing surgeries for breast and ovarian cancer are the effective low cost and safe preventive strategies for healthy carriers.[3,4] Prevalence of BRCA and other cancer- causing mutations is not known in most regions in India and is inadequately explored.[5] This is attributable to various factors and obscures patients and healthy mutation carriers from receiving better treatment and risk reducing modalities for familial carriers.[5,7] Main-streaming

genetic testing has the potential to increase uptake of testing in patients and identify at-risk carrier population in whom primordial or primary prevention of genetic cancers can be implemented with good outcomes.[2,8] Success of mainstreaming genetic testing depends on convenient and cost-effective counselling and testing strategies along with the appropriate comprehension, understanding and acceptance of genetic tests by patients and healthy individuals in the population.[6,8]

The tests results have psychological and social ramifications on the family as does the diagnosis of cancer. The low resource regions especially suffer from less knowledge about diseases such as cancer and thus any prevention strategy which requires follow-up or is costly, is not well accepted. Thus, operations or implementation research studies that focus on understanding and thereby mitigating such impediments are relevant at all times.[6,9] The time investment in counselling is significant if left to the specialist oncologists. Nurse practitioner led genetic counselling services have been found to be effective and the implementation of this strategy is recommended.[1,2,10,11] The qualifications and experience of the nurse delivering the services is essential, therefore, specialized training of nurses is also recommended.[12-14] The training of nurses to deliver basic information about cancers and genetics which is socially sensitive and not time consuming, including nurses who work in primary care settings, can be effective in delivering information and counselling patients for the mainstreaming at the time of diagnosis and treatment planning.[10-14] Thus, this study was conducted for exploring feasibility of implementing mainstreaming of genetic testing for patients of ovarian cancer, by training a primary care level nurse, in a subspecialty hospital setting.

MATERIAL AND METHODS

The aim of the study was to explore the feasibility of mainstreaming genetic testing by training a primary care level nurse to provide information and genetic counselling for patients of carcinoma ovary in a subspecialty hospital setting. The objectives were to ascertain the motivating and preventing factors for uptake of genetic testing for BRCA mutation among patients and eligible first-degree relatives of patients of serous carcinoma ovary. It was a mixed method study in the department of gynecological oncology, as part of establishment of a genetic counselling and testing service, in a newly commissioned cancer hospital. A nurse with a 2-year diploma in general nursing and midwifery and 3 years of work-experience in managing a gynecological oncology OPD in a cancer hospital, was trained to administer genetic counselling by a nurse practitioner cum tutor through a 3-day workshop in an implementation research setting. The demographic information of the patients, diagnosis and stage of disease was collected to assess eligibility for genetic counselling and testing. Genetic counselling and germline testing for BRCA mutations was offered to patients of serous ovarian cancer in the outpatient department of gynecological oncology on alternate days of the week. The counselling included basic information on genes, the BRCA gene mutation, information on ovarian cancer symptoms and treatment and an assessment of existing level of awareness regarding the same among the patients. The time consumed for each session was 10 to 15 minutes per patient, which included counselling, filling questionnaires and the willingness to pay assessment. Based on this assessment tests were offered for as low as hundred Indian rupees to eight thousand rupees for the BRCA germline mutation. The post-test counselling by nurse included informing the test result and its implications. This was followed by assessment of patients' satisfaction by decision made to undergo testing. The training of the nurses was supported by the of the Kolkata Gynecological Oncology Trials & Research Group, who trained nurses in delivering the information and the knowledge, attitude questionnaire. The nurse in this study was also trained about ovarian cancer, genetic testing in cancers and follow-up and method of communication in local languages for the patients' convenience and understanding at the study site cancer hospital by the specialist gynecological oncologist.

To assess the feasibility of this service and the motivating and discouraging factors, the patients who had been offered counselling through this service were surveyed for the quantitative assessment of factors with a survey questionnaire that was administered telephonically, 1-3 months following the counselling and testing. It had 3 essential multiple choice and 2 optional single best answer type questions. (Appendix 1) The patients were surveyed by a primary physician, graduate in medicine & surgery. Later for the qualitative study the patients were interviewed by the specialist gynecological oncologist and encouraged to provide their experience and views about the service, where the questions were semi structured and open ended based on the quantitative survey responses. The interviews had questions to ascertain level of understanding and impact of the test reports, satisfaction with the nurses counselling and factors preventing uptake of testing by those who did not get tested and eligible relatives of those who had the BRCA mutation. The consensual qualitative approach was used to develop domains or themes, to develop questions for further study.

RESULTS

Twenty-six patients with a diagnosis of carcinoma ovary, who were previously undiagnosed, attended the gynecological oncology OPD on specified three days of the week, at the hospital between June to

December 2023. Among them 18 patients who underwent treatment at the hospital, were offered genetic counselling by the nurse, 11 patients who participated in the study accepted the testing, while another 7 patients who were counselled, did not accept the tests. Six among those who got tested, consented for the questionnaire-based interview of their experiences. The demographic features of all patients who were counselled are depicted in table1. The reasons revealed after telephonic interview of the patients who did not get tested were i) inability to understand the information by 5 of the patients, ii) inability to afford any further testing and further treatment, even if the genetic tests were offered free of cost, by 2 patients. On being asked which aspect was not understood, the responses obtained were, 'significance of a positive report in terms of further treatment and recurrence'. Three patients among them were lost to post-treatment physical follow-up citing paucity of time and loss of wages of accompanying family member for further testing. Thus, the prominent theme for low uptake of genetic test by the patients was 'inability to bear cost of further treatment'.

Among the 11 patients who got tested 6 responded to the questionnaire and were undergoing treatment and follow-up. The patients were asked whether the specialist doctor's consultation was necessary after the nurse counselled and informed about genetic testing, to which 4 patients selected the option that specialist consultation was necessary for some aspects of the counselling. Further questions were asked on the aspects that required specialist consultation, the responses to which were 'significance of test in treatment and further prognosis by 3 interviewees while 3 responded that they 'trusted the doctor more', therefore wanted to confirm the information obtained from the nurses counselling. They were asked questions on whether they understood the report for which 3 of the patients with BRCA mutation confirmed that they understood the report as explained by the specialist, while 3 patients with positive reports had not understood the significance of the report since it had not been explained by the specialist. The question on uptake of genetic testing by eligible first-degree relatives probed the causes of low uptake for which the responses were 'no benefit in knowing report of healthy family member', 'family member not willing', 'paucity of time to visit hospital'. The common theme that emerged from these interviews was the 'inability to understand benefit in genetic testing of healthy individuals', 'unwillingness to pay for genetic testing' and 'paucity of time to visit health facility'. The patient numbers were not adequate to comment on saturation, however the frequency of the theme was high.

Table 1

Age of patients in years (n=18)	
20-30 years	2
30-40	2
40-60	12
>60	2
Educational level (n=18)	
Educated	2
Literate	6
illiterate	9
Histopathology (n=18)	
High grade serous ovarian cancer	18
Low-grade serous ovarian cancer	0
Stage of Disease (n=18)	
3c	18
BRCA mutation status	
Positive	6
Negative	5
Treatment given	Upfront surgery f/b platinum-based chemotherapy- 6
	Neoadjuvant chemotherapy f/b interval surgery-12

DISCUSSION

The guidelines such as the NCCN recommend offering genetic counselling to all women diagnosed with epithelial ovarian cancer administered by an oncologist, genetic counsellor or specialist nurse[1]. The results of this study reflect a good uptake of the genetic testing at 61%, after pretest counselling by a primary care level nurse, who was trained for the specific service in a subspeciality department of the hospital. The low-resource settings, which may exist even in high/middle income countries, in terms of trained doctors or counsellors, require simpler and more feasible strategies for preventive healthcare services.[2,11,13,15] This study was conducted to understand whether the nurse with basic nursing training could be coached in a subspecialty setting to offer genetic counselling independently and the patients' satisfaction with the counselling and testing uptake would be optimum. Such a strategy could then be replicated in primary healthcare setting to improve awareness and uptake of genetic

testing for familial cancers. This would also provide for distribution of more demanding and critical responsibilities to specialist nurses, who can be part of multidisciplinary teams.

This is an incipient phase in the service and the uptake of counselling or testing by healthy eligible family members of BRCA mutation carrier patients was found to be negligible, despite a good uptake among patients. The deterrents as observed by the survey and individual patient interviews was the cost of test, along with the indirect costs of travel and loss of wages on visiting hospital, which is commonly observed in many cancer screening and follow-up implementation studies, other than low population awareness and acceptance of diseases.[15,16] The educational level of individuals can influence decision making, therefore, using simple language and only disseminating essential information are the cornerstone of any awareness or counselling service where the patient numbers are high.[2] The patient satisfaction rates have been observed to be superior with specialist based multidisciplinary genetic tumour boards, which was also observed in patients' responses, in this survey and interviews.[17-19] Trained and experienced geneticists and genetic counsellors, who are an essential part of genetic testing and counselling service, are fewer and concentrated in tertiary care centers.[5,6] If and when multigene testing, whole genome sequencing is done or results elicit newer mutations or variants of unknown significance, the results which may be difficult to explain and discuss in lay terms, the geneticists become imperative. The clinical information even when provided by the specialist doctors, is often difficult to process and to comply with by patients and families, for social, psychological and economic reasons.[17,18]

With the testing limited to BRCA mutations, the results of none of the patients' contained variant of unknown significance as diagnosis and it was a small subset of patients, therefore, the post-test counselling was not challenging. Yet, the uptake of testing by first degree relatives of BRCA gene mutation patient was low. This impinges upon requirement of specialist expertise in post-test counselling and developing rapport with patient and the family.[19-20] Preliminary information and conditioning by less time-consuming methods that can be conveniently disseminated to healthy mutation carriers and potential candidates for risk reducing salphingo-ophorectomy (RRSO), such as through social media or tele-genetics, may encourage the visits to healthcare provider for counselling, cascade testing and preventive interventions.[8,9,12] Qualitative studies report better compliance to preventative surgeries, when healthy mutation carriers were counselled by specialists in person.[17,18] The mutation specific risk reduction interventions can be personalised based on the type of mutation and medical and social requirements of the healthy carrier even.[1,2]

The training of nurses having general nursing and midwifery qualifications, for preparing patients to get tested, is effective for specific subset of patients. The nurse led service models are effective in the primary care setting and have been studied for the breast cancer prevention through genetic testing services.[10,11,13] The nurse training and knowledge are crucial determinants for the success of these services. Thus, continued medical education, on-field and dedicatedly, delivered didactically in person, online or as recorded programmes can be considered and can be cost-effective.[14,16]

Implementation studies for improvement of service uptake conducted with obtaining feedback as a methodology are part of basic quality improvement initiatives undertaken to enhance services.[21] This mechanism is seen to be less time consuming and effective if the questions are specific, short and objective and the participants are actively involved, as also observed in this survey. The qualitative part of the study revealed themes that were predominantly social and economic factors that affected patient decision making. This is often the first and most common barrier to healthcare uptake.[13] The other factors as described in studies on genetic testing and preventative services explore emotional and medical factors as well, but the study populations are starkly different, since the regions studied are high income, where affording investigations and treatments is not comparatively difficult.[18-20] Despite this, more patient interviews would be necessary to conclude on the themes after information saturation can be confirmed.[22] This study would provide data on development of interview questionnaires for future consensual qualitative research interviews, by domain generation.[22]

CONCLUSION

The genetic counselling and awareness generation to improve uptake of genetic testing delivered by primary care level nurses is feasible and acceptable to the study population and setting. Post-test counselling requires specialist led multidisciplinary team approach. Community based awareness measures delivered by nurses, about genetic testing may be useful in improving acceptance of testing by the healthy mutation carriers.

Conflict of Interest: None

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