



Original Research Article

SURVEY OF PATIENT CAREGIVERS' OPINION ON CANCER AWARENESS MATERIAL ON CERVICAL CANCER DISPLAYED IN AN OPD SETTING

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Received : 05/10/2023
 Received in revised form : 22/11/2023
 Accepted : 06/12/2023

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DOI: 10.5530/ijmedph.2023.4.2

Source of Support: Nil,
 Conflict of Interest: None declared

Int J Med Pub Health
 2023; 13 (4); 8-11

ABSTRACT

Background: The uptake of preventive and treatment measures for cancers by the public significantly depends on the level of awareness generated in the population at risk. Cervical cancer is a common preventable cancer and a public health problem of the Indian subcontinent, including the state of Uttar Pradesh, the most populous and geographically diverse part of the country, which is largely unscreened and unvaccinated for the disease, with patients presenting in advanced stages. The cancer awareness measure studies performed most frequently are aimed at women in the eligible age group for screening or healthcare workers, often in a formal setting. Pictorial information is also disseminated as IEC material by various agencies which have not been evaluated for the impact on awareness generation in the public. Awareness programs incur costs and are time consuming, requiring significant human resource. Most cancer awareness measures are meant for public in general, not for the specific population of patient attendants or caregivers and studies on their opinion on devising cancer awareness material could be relevant in terms of understanding and identifying barriers in uptake of screening, early detection and treatment for cervical cancer.

Materials and Methods: The cross-sectional qualitative observational pilot survey study was undertaken with the objective of improving the uptake of screening services and understanding the reason for the low uptake of screening for cervical cancer, even when offered to those who accompany patients suffering from the disease. A poster of 70x50 cm was affixed in the gynecological oncology OPD and a survey questionnaire for self-administration was shared with the attendants or family members of the patients attending OPD services in the month of September which is observed as the gynecological cancer awareness month.

Results: There were sixty-five respondents with significant participation of male respondents for a gynecological cancer. All respondents found the information important, relevant, thought provoking and there were seven themes generated from the opinions/suggestions shared by them, which could be further utilised for qualitative studies to improve awareness measures and uptake of screening and early detection.

Conclusion: Those attending to a patient with cancer may not be adequately aware of the disease causation and availability of prevention strategies, therefore the information material such as that used in this study can be a well-accepted source of information without incurring significant additional costs and time on the healthcare provider while encouraging public participation in improving the IEC material and services.

Keywords: Cancer Awareness Measures, Surveys, Cervical Cancer.

INTRODUCTION

The uptake of preventive and treatment measures for cancers by the public significantly depends on the level of awareness generated in the population at risk.^[1] Cervical cancer is a common preventable cancer and a public health problem of the Indian subcontinent, including the state of Uttar Pradesh, the most populous and geographically diverse part of the country, which is largely unscreened and unvaccinated for the disease.^[2] Common risk factors for cervical cancer, such as early childbearing, multiple child births, poor nutritional status leading to compromised immunity and increased susceptibility to persistent infection, are prevalent.^[3] There are awareness activities organized by several public and private agencies; however, the impact of these programs resulting in the uptake of screening is not significant.^[4] Most often the information is didactically disseminated and is not interactive or response generating. The cancer awareness measure studies performed most frequently are aimed at women in the eligible age group for screening or healthcare workers, often in a formal setting. Posters and pictorial information are also freely available on websites of various agencies such as the National Health Mission in India, the World Health Organization and several nongovernment organizations working for cancers for a considerable time, but most of these require voluntary effort by the interested individuals who wish to participate, with the screening being opportunistic in the absence of a program. There is a gap in the understanding of information on the disease condition into uptake of screening or preventive services, where there are available, which is also impacted by the socioeconomic and educational background of the population.^[5,6] Therefore, we hypothesized that awareness material created by trained nurses or technicians can be a useful source of information and reduce time spent educating patients and caregivers for cancer screening, early detection and treatment of cervical cancer. A competitive poster-making event was organized on World Cancer Day to involve healthcare support staff from the nursing and technician cadres, and the best awareness material was displayed for information of patient caregivers in the outpatient department of a tertiary care cancer hospital and teaching institute in Uttar Pradesh.

MATERIAL AND METHODS

The cross-sectional qualitative observational pilot survey study was undertaken with the objective of improving the uptake of screening services and understanding the reason for the low uptake of screening for cervical cancer, even when offered to those who accompany patients suffering from the disease. Paucity of time to counsel or motivate apparently healthy patient caregivers to undergo screening or vaccination in the OPD was thought to

be obviated by affixing a poster (70x 50 cm) in the gynecological oncology OPD area where the attendants or kin of the patient often wait. The poster illustrated the anatomy of the uterus and cervix, risk factors, symptoms, prevention and treatment methods of cervical cancer, which was posted in the waiting area of the gynecological oncology OPD. It was handmade, in the Hindi language, using colloquial terms, by a paramedical staff member of the radiation oncology department in a competition organized on World Cancer Day. The location was a shared waiting area for patient attendants and caregivers for the gynecological oncology OPD and colposcopy room, where patients are given treatment consultation and undergo minor procedures. After one month of posting the awareness material, the survey was performed for those who accompanied the gynecological cancer patients, and the forms were provided for self-administration before or after the consultation for the patient was completed. It was offered to attendants of all the patients who consulted in the OPD for voluntary participation. The survey document contained five close-ended and one open-ended question for sharing opinions or suggestions on the illustration. (table 1). The survey documents were provided by the nursing staff and the hospital attendant who were posted in the gynecological oncology OPD, who are involved in assisting with patient consultation and informing patients regarding various service areas, maintenance of department records and postprocedure patient counseling and assistance, for which they have been trained postinduction in the department, and any questions regarding filling them were answered by the junior resident doctors working in the department, who are qualified medical graduates.

RESULTS

This survey was conducted in September 2023, during the international gynecological cancer awareness month, and there were seventy-seven women registered with a diagnosis of cervical cancer, either visiting for the first time or on posttreatment follow-up accompanied by a family member or caregiver, among whom sixty-five agreed to participate. Among these, thirty-four were female respondents, twenty-one were male, and ten responses were anonymous. All respondents affirmed that the information given in the awareness material was important and relevant, and none of the respondents felt that the information was wrong or objectionable. The information generated more questions pertaining to the disease for fifty respondents, and fifty-five respondents affirmed that they would share information about screening and vaccination for cervical cancer with other people. Seven themes were generated when the participants were asked to share their opinions regarding the method of information dissemination being used by the investigators and the contents of the awareness

material. The most common and recurring thoughts were ‘cancer screening should be done regularly’ and ‘doctors must be consulted regarding the disease diagnosis, treatment and screening’ followed by ‘vaccination is essential for prevention of cervical cancer’. The participants also thought that ‘all eligible/at risk should get tested’ and ‘a campaign for

elimination of cervical cancer must be undertaken similar to that done for polio’. That ‘there should be similar information material for other cancers’ was shared by one respondent, while there were verbal queries on the availability of the screening tests in the hospital.

Table 1: Tabulated Responses to questions & themes of opinions/suggestions

S. No	Questions	Number of (yes)affirmative responses	Number of (no) negative responses	No response
1	Does this poster contain important information	65	0	0
2	Do you have more questions about cervical cancer disease after reading this poster	50	15	0
3	Do you think any wrong information is given in this poster	65	0	0
4	Does this poster contain some objectionable information	65	0	0
5	After reading this will you suggest cervical cancer or Human Papilloma Virus screening and Vaccination to anyone	55	0	10
6	Suggestions/queries obtained- 7 themes	‘All eligible/at risk should get tested’		
		‘There should be similar posters with information on other cancers’		
		‘Cancer screening should be done regularly’- by 3 respondents		
		‘Doctors should be consulted for more information on screening and treatment’- by 3 respondents		
		‘Where is the testing & vaccination facility available’- by 4 respondents		
		‘Vaccination is very important’-by 2 respondents		
		‘An awareness mission and a campaign for elimination of cervical cancer must be initiated, just as was done for polio’		

DISCUSSION

Cancer is a chronic disease that is often not curable in advanced stages, and its treatment success is measured by patient survival. Among the various factors affecting survival, early diagnosis and radical treatment performed with curative intent are the most reliable and consistent contributors to longer survival. Generating awareness in the community at large and the population at risk in particular has been seen as an effective strategy in improving uptake of screening or consultation for symptoms by those affected.^[2] While the diagnosis, treatment and follow-up of cancer are expensive, dedicated human resources and infrastructure for population-based awareness programs also incur significant costs. Most awareness programs use one-way didactic methods of communication followed or preceded by cancer awareness measurement using questionnaires. This methodology does improve awareness but may not necessarily result in improved uptake of services if they are not available or if the individual or ethnic beliefs and myths are not addressed, which is one of the barriers to prevention and early detection.^[7,8] The one-to-one method of imparting information about disease has a better impact on improving the knowledge of the target audience.^[9] The population in this study was the attendants or caregivers of patients diagnosed with a gynecological cancer, and we expected them to be more receptive to the information, more aware of symptoms and more inquisitive and concerned about screening and

prevention strategies, along with the treatment modalities and chances of cure of their family member, as corroborated by Sahu et al in their review of Indian studies on cancer awareness measures in India.^[10] The responses reflect that the information was well received, as the majority of the respondents did not find the information in the poster wrong or objectionable, and fifty-five respondents affirmed suggesting cervical cancer screening and vaccination to other people. There were queries by four respondents regarding where the facility was available in the premises. The knowledge of reliable sources of information is important to prevent the spread of misinformation about diseases, and trained doctors are one of them. In addition, health care workers trained in cancer detection, prevention and management can also become good contributors to knowledge and awareness improvement. All respondents found the information useful and important, and there were suggestions for displaying similar information on other cancers. This adds perspective to the existing paucity of knowledge even among those who attend to or are family to the patients.

In a newly commissioned cancer hospital with the services and resources available and limited time in a busy OPD, such information material can be useful for patients and their caregivers in understanding disease causation, prevention and treatment effectively. This population can be a valuable source of information dissemination without incurring any additional costs or time on awareness generation, as

observed in this study. The qualitative feedback surveys performed over time can help improve services, and the quality and quantity of information given can be modified, which is customized not only for a hospital but also for the region or ethnicity. The CAM initiative of the cancer research UK is a systematic, ongoing validated method of assessing knowledge and barriers in cancer prevention and treatment, working since 2008 and is a good example of how consistent and adaptable efforts toward awareness generation are necessary and can produce significant improvement in healthcare uptake and health-improving behavior in various groups of people.^[11]

Public participation in opinion building, awareness generation and health advocacy can potentially make significant improvements in policy as well.^[12] There is a requirement and opportunity for patient advocacy in India, which can happen by well-informed and well-intentioned individuals or groups and the patients' attendants or caregivers, who can be trained to become lay patient advocates if they understand, are conscious and reasonably aware of the circumstances and concerned about patient and public welfare.^[12] The study had considerable participation by men, and their opinions were optimistic toward the information. Qualitative studies from some countries suggest that awareness of cervical cancer among men impacts early detection and treatment uptake for patients and screening for healthy women.^[13]

CONCLUSION

Apparently healthy persons attending to a patient with cancer or accompanying them to a cancer treatment facility, may not be adequately aware of the disease causation and availability of prevention strategy. Therefore, information material such as that used in this study can be a well-accepted source of information without incurring significant additional costs and time on the healthcare provider, while encouraging public participation in improving the IEC material and services.

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