An assessment of informational needs of breast cancer among patients and adults in general publicand the effectiveness of a tailor-made information package for patients in Sri Lanka

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Introduction

Breast cancer (BC) is the commonest cancer in Sri Lanka. The provision of relevant and accurate information in a social-culturally appropriate manner will lead to proper understanding of the disease, treatment options, and BC management.

Objectives

To determine the knowledge, attitudes/beliefs and practices on BC among adults in general public; to develop and validate an instrument; to assess information needs of BC patients and to assess the effectiveness of an educational intervention to fulfill the information needs of the BC patients.

Methodology

The study comprised four phases. The first phase was a descriptive cross-sectional household survey among a representative sample of adults [n=1500] living in Colombo district. An interviewer-administered questionnaire was used to assess knowledge. In the second phase, Sri Lankan BC patients' Informational Needs Assessment Questionnaire of Breast Cancer (SINAQ-BC) was developed. Construct validity and reliability was evaluated among BC patients [n=150]. The third phase was a hospital based cross-sectional survey to determine the informational needs of BC patients using the validated SINAQ-BC. The education package was developed in the form of a pamphlet in the last phase andits effectiveness was evaluated in an experimental study with an intervention (n=104) and acontrol group [n=104].

Result

The results revealed that only 207 [13.8%] [95% CI-12.1–15.6] adults have a 'good' overall knowledge on breast cancer. Validation of the SINAQ BC showed that 58 items are best organized into five domains, disease, diagnosis, treatment, physical care and psychosocial service and good internal consistency with Cronbach's alpha of 0.76 to 0.93. All patients indicated a strong need for information. BC patients gave highest important to the domains: disease, treatment, and psychosocial service. In the intervention study, the level of fulfillment of information needs in the intervention group was 'met' in only 13.5% while the corresponding proportion was 12.5% in the control group ((p>0.05). Four weeks after the education intervention, the 'met' level of fulfillment of information needs has significantly increased to 79.8% at the post-assessment from 13.5% at the pre-assessment stage (p<0.0001) while in control group the increase was marginally from 12.5% (pre-assessment) to 22.1% (post-assessment) which was not statistically significant (p>0.05).

Discussion

This study confirmed that overall knowledge on BC among adults of the general public is inadequate. The SINAQ-BC was found to be a valid and reliable tool to assess informational needs of BC patients. The educational intervention was found to be an effective to improve fulfillment of information needs of BC patients and to improve the knowledge and the pamphlet is recommended to be used further.

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