Breast Cancer in Rural India: Knowledge, attitudes, practices; Delays to care and Quality of life

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Akademisk avhandling

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Abstract

Background: Cancer is a major public health problem globally. The incidence of cancer is increasing rapidly in many low- and middle-income countries like India due to the epidemiological transition. At present, breast cancer is the leading cancer in females in many countries including India. In spite of all of the epidemiological evidence pointing towards a surge in breast cancer cases, the National Cancer Control Programme of India has not yet taken sufficient measures to understand the disease burden and to plan a course of action to cope with the increasing cancer burden.

Aim: The aim of this thesis is to explore the knowledge, attitudes, and practices regarding breast cancer in a predominantly rural district of central India along with identifying the determinants of delays to care and quality of life (QoL) in breast cancer patients. This understanding may help to strengthen the health system by improving breast cancer control and management programmes and the delivery of care.

Methods: This thesis combines findings from two cross-sectional studies in the predominantly rural district of Wardha. The first study was a population-based cross-sectional survey conducted on 1000 women, in which face-to-face interviews were conducted with the help of a questionnaire covering demographic and socio-economic information, knowledge, attitudes and practices regarding breast cancer screening and breast cancer. The Chi-square test for proportions and t-test for means were used and multivariable linear regression analysis was performed to study the association between socio-demographic factors and knowledge, attitude and practices. The second study was a patient-based cross-sectional study conducted in 212 breast cancer patients. All 212 breast cancer patients were included for patient delay. However, 208 female breast cancer patients could be included for system delay, quality of life and self-efficacy, as there was some information lacking in 4 patients. Information on socio-demographic characteristics, patient and system delays and also reasons for the delays were collected. The study also utilised WHOQOL–BREF for QoL and self-efficacy measurements in breast cancer patients. Socio-demographic determinants were examined by frequencies and means and multivariable logistic and linear regression analysis to assess the relationship between exposure and outcome variables.

Results: One third of the respondents had not heard about breast cancer, and more than 90% of women from both rural and semi-urban areas were not aware of breast self-examination. Patient delay of more than 3 months was observed in almost half of participants, while a system delay of more than 12 weeks was seen in 23% of the breast cancer patients. The late clinical stage of the disease was also significantly associated with patient delay. The most common reason for patient delay was painlessness of the breast lump. Incorrect initial diagnosis or late reference for diagnosis were the most common reasons for diagnostic delay while the high cost of treatment was the most common reason for treatment delay. Self-efficacy was positively associated with QoL, after adjusting for socio-demographic factors, patient delay and clinical stage of disease.

Conclusions: Our research showed poor awareness and knowledge about breast cancer, its symptoms and risk factors in women in rural India. Breast self-examination was hardly practiced, although the willingness to learn was high. Although the ideal is no delay in diagnosis and treatment, diagnostic and treatment delays observed in the study were not much higher than those reported in the literature, even from countries with good health facilities. However, further research is needed to identify access barriers throughout the process of cancer diagnosis and treatment. The quality of life was moderately good and its strong relationship with self-efficacy makes these two dimensions of breast cancer patients relevant enough to be considered for health workers and policy makers in the future.

Interventions focused on improving breast awareness in women and the breast cancer continuum of care should be implemented at a district level. The role of community social health activists in breast cancer prevention should be encouraged and the implementation of an operational national breast cancer program is urgently required.

Key words: Breast cancer, rural, India, knowledge, attitudes, practices, delay, quality of life, self-efficacy.