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Pattern of Help Seeking Behaviour in Female Breast Cancer Patients

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Abstract
Introduction: *Incidence of breast cancer has been increasing in Kerala over the past decade and has overtaken cervical cancer. Early detection and treatment can completely cure breast cancer. Delay of more than 3 months results in poor prognosis. Nevertheless, delayed help seeking is seen among the majority of women who come to clinics. Patient delay can occur at three levels (delay due to not disclosing to another person, delay in consulting a doctor and delay in starting treatment).*
Objectives: *To study the pattern of delay in help seeking behavior among female breast cancer patients and to find out reasons for delay.*
Methodology: *Study was conducted in the female wards of Surgery and Radiotherapy Departments, in a tertiary care centre in South Kerala. 60 patients were interviewed and data collected using semi-structured questionnaire.*
Results: *The study was conducted in 60 patients who were diagnosed as breast cancer and were under treatment in a tertiary care centre in South Kerala. The mean age was 50.15 years (9.725). 73.3% were rural residents, 43.3% APL, 63.3% housewives, 83.3% married. 26.7% knew about screening, of which 56.2% knew mammogram and 81.2%, self-breast examination. Of the latter, 83.3% practiced it while others did not, due to ignorance. Lump was the commonest symptom detected, in 75%. 50% reported at early stage. 55.6% of those who sought help at first symptom reported to their husbands. 51.7% had delay of more than 3 months, 5.0%, less than 3 months and 43.3% had no delay. The median help seeking delay in disclosing to another person was 8.0 months (6.0-24.0), in consulting a doctor, 6.0 months (2.0-19.5) and in starting treatment, 1.5 months (1.0-3.0). Median total delay was 11.0 months (6.0-31.5).*
Conclusion: *In spite of Kerala having high female literacy, the majority of women delayed due to ignorance and lack of awareness about disease itself and screening practices. Ironically, many who are aware do not take proper steps to detect breast cancer early. Programmes targeted at increasing the awareness among women are necessary so that they present early and have a better chance of survival.*
Keywords: *Breast cancer, Delay, Awareness, Help seeking, Breast cancer in Kerala.*

Introduction

Breast cancer is a type of cancer originating from breast tissue and is the most common non-skin cancer in women worldwide. Before the 20th century, breast cancer was feared and discussed in hushed tones, as if it were shameful, and women

tended to suffer silently rather than seeking care. However, today, even though this scenario is different, compared to other diseases or cancers, breast cancer receives only a disproportionate share of resources and attention. The emotional impact of symptoms, diagnosis, treatment and related issues can be severe as in any other cancer. Increasing awareness of the disease and possibility of treatment by surgery, chemotherapy and radiotherapy have increased the survival rates. In developing countries, however, survival rates are poorer. Prognosis and survival rates for breast cancer vary greatly depending on the cancer type, stage, treatment and geographical location of the patient.

The primary risk factors for breast cancer are sex and age; older females are more prone. Other potential risk factors include genetic factors, lack of childbearing or breastfeeding, higher hormone (estrogen) levels, family history of breast cancer, high fat-low fibre diet and obesity, to name a few. The stage of the cancer is the most important component of traditional classification methods of breast cancer as it has a greater effect on prognosis than any other factor. Staging takes into consideration the size, local involvement, lymph node status and whether metastasis has set in. The higher the stage, the poorer the prognosis.

A clinical or self-breast examination (SBE) involves feeling the breast for lumps or abnormalities. Clinical breast examination is performed by doctors or nurses, while self-breast examination is performed when a person checks herself. Mammography, ultrasound, or fine-needle aspiration cytology are the essential diagnostic procedures to perform a work-up on suspicious lumps in the breast. An early visit to the physician is sometimes a matter of life or death. The question is, what is 'late' and what is 'on time' in health care? It has been found that the prognosis for breast cancer and melanoma is better for patients if the problem is diagnosed within 3 months. Early help-seeking has an impact on the success of treatment related to the moment of intervention for a particular disease. Women with delayed presentation often have larger tumours and poor survival. There is evidence that smaller tumors are more likely to be treated successfully with breast conservation surgery, and perhaps, ensures, a better quality of life.

In quantitative and qualitative studies to date, a number of potential risk factors for delayed presentation of breast cancer have been identified. Reasons for delay have been broadly categorized as "presentation/illness delay" (*i.e.*, because of psychological or social factors specific to the patient), "utilization delay" (*i.e.*, because of issues in the health care system), and "system delay" (*i.e.*, the interval between first presentation to a medical professional and initial treatment). The present study deals with presentation delay, designated here as "patient's delay", which is most frequently described as "the length of delay between the onset/discovery/recognition of signs and symptoms, confiding in another person and a patient's first visit to a health care/medical provider". But more simple descriptions like "time to first presentation of signs or symptoms to a physician" can be found as well. In addition, the terms 'help-seeking delay' or 'help-seeking behavior' are frequently used in the literature as a synonym for 'patient's delay'.

Breast cancer is the most common cancer among Indian women and the majority of cases are locally advanced at presentation. The majority of the population in India lives in villages and, in the rural set-up, the unregistered medical practitioner (quack) acts as the gatekeeper to medical services. He is often the first 'medical' person to see and examine cases. These quacks, due to their limited understanding of cancers, cause significant delay in the diagnosis and in the management of breast cancer patients. Women delayed longer when initial breast symptoms did not include a lump and women who detected a breast lump waited significantly lesser. The connection of fear with patient's delay is significant and was identified as fear of embarrassment, fear of loss of breast and fear of cancer. Other factors causing delay include competing life demands, belief in alternative

therapies, lower level of education, failure to disclose concerns to a friend or a relative, social stigma and spiritual beliefs, associated anxiety or depressive symptoms, reservations about seeing the family physician and presenting to the family physician with a non-breast problem.

Family physicians are often the first point of contact for women with breast concerns. But the concepts of a family physician and routine check-up and screening for various common medical conditions are still alien to a developing country like India. This project envisages finding out the different aspects of this "Indian problem".

Materials and Methods

Our study was a hospital based cross sectional study which was done in the female wards of the Departments of Surgery and Radiotherapy, in a tertiary care hospital in South Kerala over a period of six months.60 patients were included in the study. Inclusion criteria for the study was patients who were diagnosed with breast cancer and admitted in wards for surgery, chemotherapy or radiotherapy.

The only exclusion criteria applied was patients who do not give consent for interview and examination.

Informed consent was obtained from each patient. A semi structured questionnaire (Annexure I) was used for data collection by interview method and detailed proforma was filled up for each patient, which included age, sex, presence of risk factors like hypertension, diabetes, family history of cancers in first degree relatives, lack of awareness, delay in seeking help and fear of treatment. Ethical consent for conducting the study was obtained from the Heads of the Departments of Surgery and Radiotherapy.

Convenient, non-random sampling was done. Data were entered in Excel and analysed using appropriate statistical software. Quantitative variables as mean and SD, qualitative variables using proportion, for analysis of statistical significance, the tests used were Chi-square, t-test, and Mann- Whitney U test. Odds ratio (OR) was used for strength of association and binary logistic regression for multivariate analysis.

Results

The total population had mean age (SD) - 50.15 (9.725) years.

Baseline characteristics

Religion – 66.7% Hindus; rural residents - 73.3%; BPL category - 56.7%; married - 83.3% (staying with their spouse); housewives - 63.3%; education of 10th standard and above - 51.7%; employed - 36.7% (Fig. 1).

Though 61.7% of the population knew that breast cancer is treatable and curable, 50% did not believe that early detection and treatment of breast cancer can lead to a better outcome than the present scenario (Table. 3).

Just over one-fourth of the population (26.7%) knew about at least one method of screening for breast cancer. Of those who knew, 15% knew about mammogram and 23.3%, SBE. Of those who knew about SBE, 83.3% practiced it.

The first symptom detected was lump, in 75% of the respondents. 58.3% sought help at the earliest. Those who knew about at least any one of the screening test were protected (OR = 0.231), so also were patients who knew about SBE (OR = 0.071) and those who practised SBE (OR = 0.091). In the majority of cases, the first person approached was the husband ($p < 0.003$, OR = 0.16) (Table 3; Figs. 3, 6).

Prolonged delay was recorded in 51.7% cases (median total delay - 11.0 months). Significant delay in help seeking (time from discovery of symptoms till confiding in another person), was noticed in 41.7% patients (median delay - 8 months; $p < 0.01$ by Mann-Whitney U test) (Table 1; Fig. 7).

Reasons for patient delay were ignorance of the disease (23%), inhibition (11%) and social stigma (8%) (Table 2; Fig. 4). Further, patients, whose husbands were educated below 10th standard, showed significant delay ($p < 0.010$) (Table 3; Fig. 4).

The knowledge of the patients about risk factors for breast cancer in the population studied is summarized in Fig. 5. The reasons for delay in reporting is given in Table 2.The results of statistical analyses are presented in Table 3.

Table 1 Delay in presentation of the patient to another person, to doctor and to start treatment

Type of delay	Proportion of patients having the delay N (%)	Median delay (min-max) in months	P value (Mann-Whitney U test) (early *vs* late stage)
Help seeking delay	25 (41.7)	8 (2 - 240)	< 0.01
Consultation delay	22 (36.7)	6 (0.25 - 60)	0. 089
Treatment delay	7 (11.7)	1.5 (0.5 - 2)	0.852

Table 2 Reasons for delay in reporting

Reasons for delay	Number of patients having this reason
Ignorance	23 (38.3)
Inhibition	11 (18.3)
Social stigma	8 (13.3)
Lack of family support	7 (11.7)
Financial	7 (11.7)
No pain	7 (11.7)
Fear of treatment	6 (10.0)
Indigenous treatment	5 (8.3)
Fear of loss of breast	3 (5.0)
Lack of time	2 (3.3)
Job	2 (3.3)
Loss of hope	0
Mentally ill	0

Table 3 Factors of significance found by the study

Characteristics	P value	OR
Education (< 10th Std.)	0.002	5.61 (1.817-17.326)
Husband's education (< 10th Std.)	0.010	4.07 (1.366-12.143)
Know about some screening test	0.030	0.231 (0.058-0.924)
Know about SBE	0.003	0.071 (0.009-0.584)
Know to practice SBE	0.009	0.091 (0.011-0.760)
First person approached (husband *vs* others)	0.003	0.16 (0.046-0.565)

Fig. 1 Baseline characteristics of study population

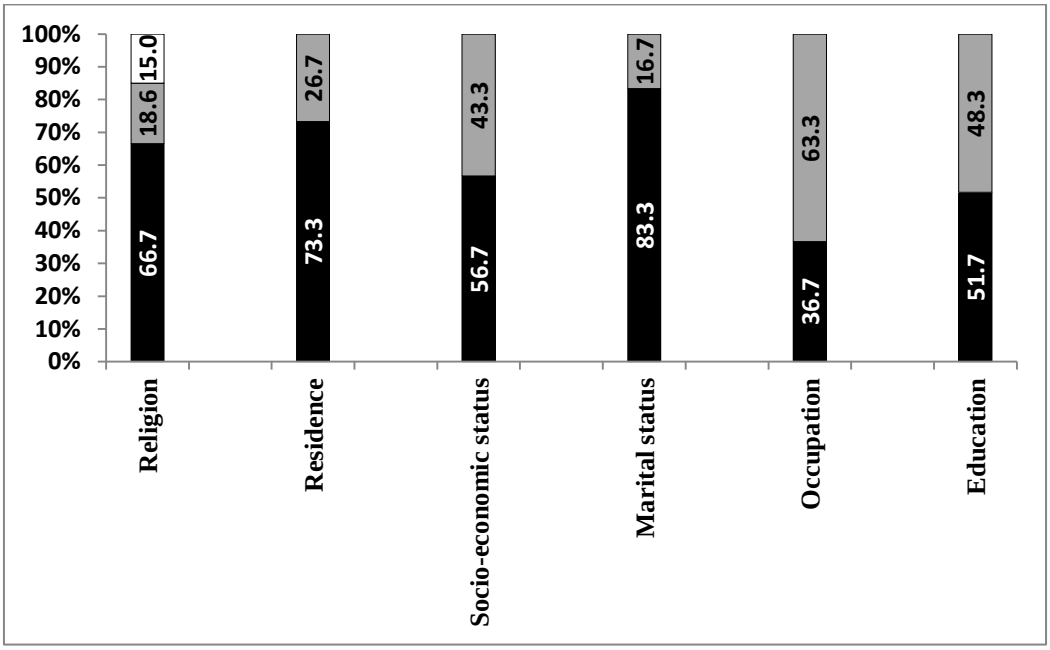


Fig. 2 Knowledge of the patients about the modes of treatment (in %)

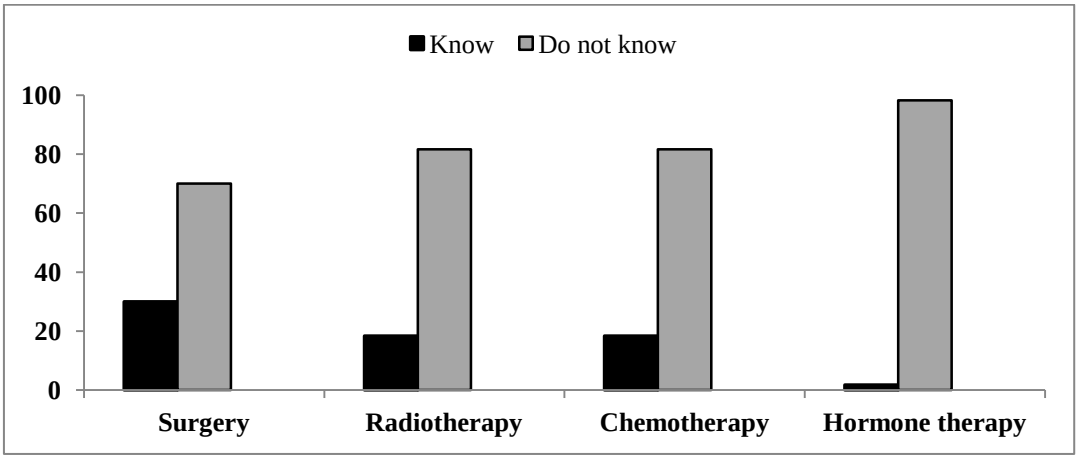


Fig. 3 The first person informed by the patient on discovery of symptom (in %)

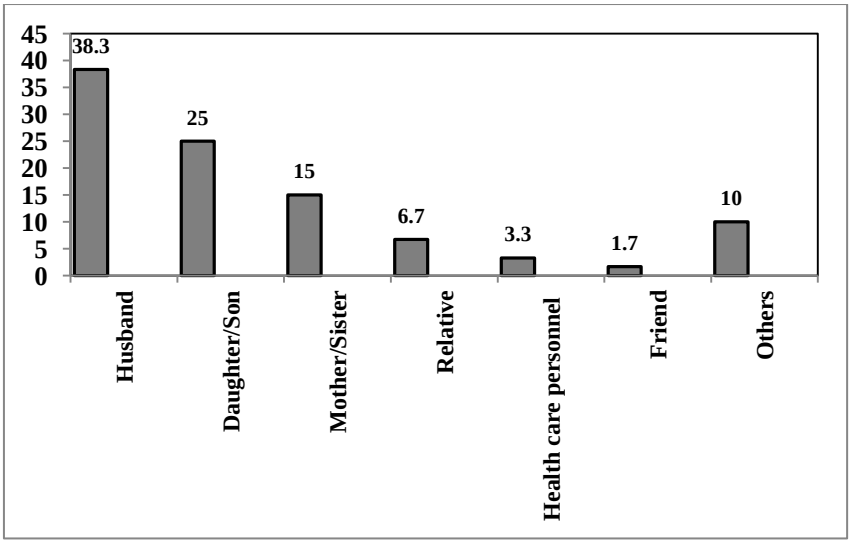


Fig. 4 Various reasons for help seeking delay of the patients (in %)

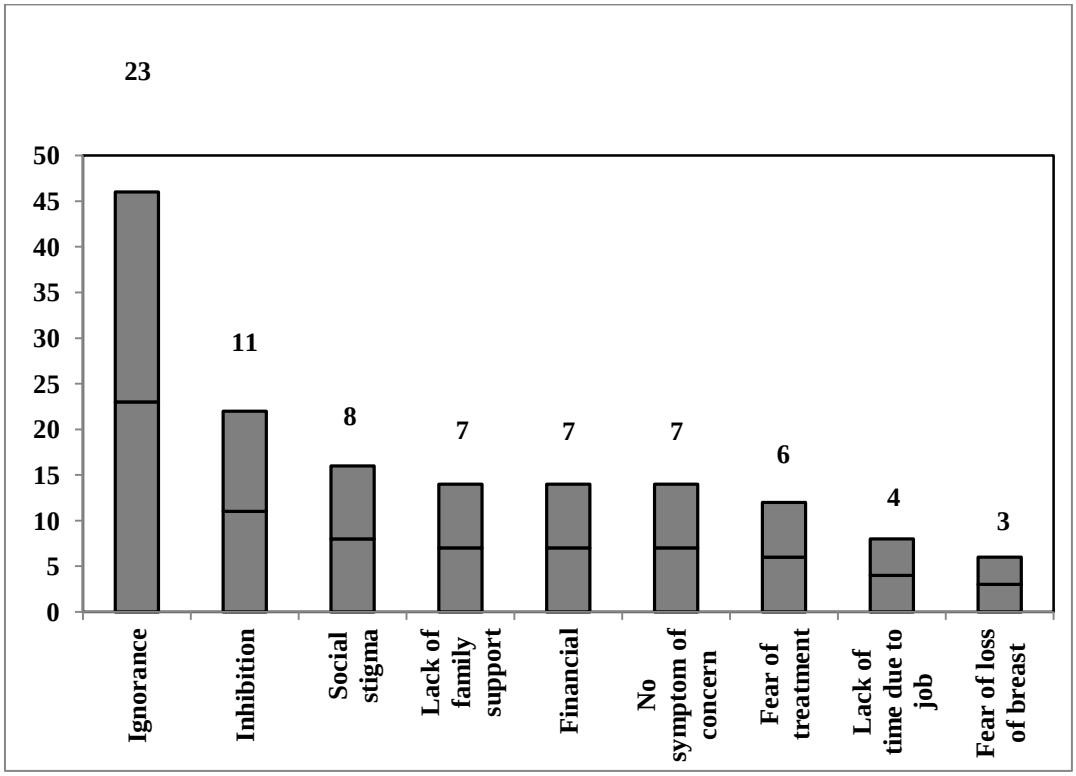


Fig. 5 Knowledge of the patients about risk factors for breast cancer (in %)

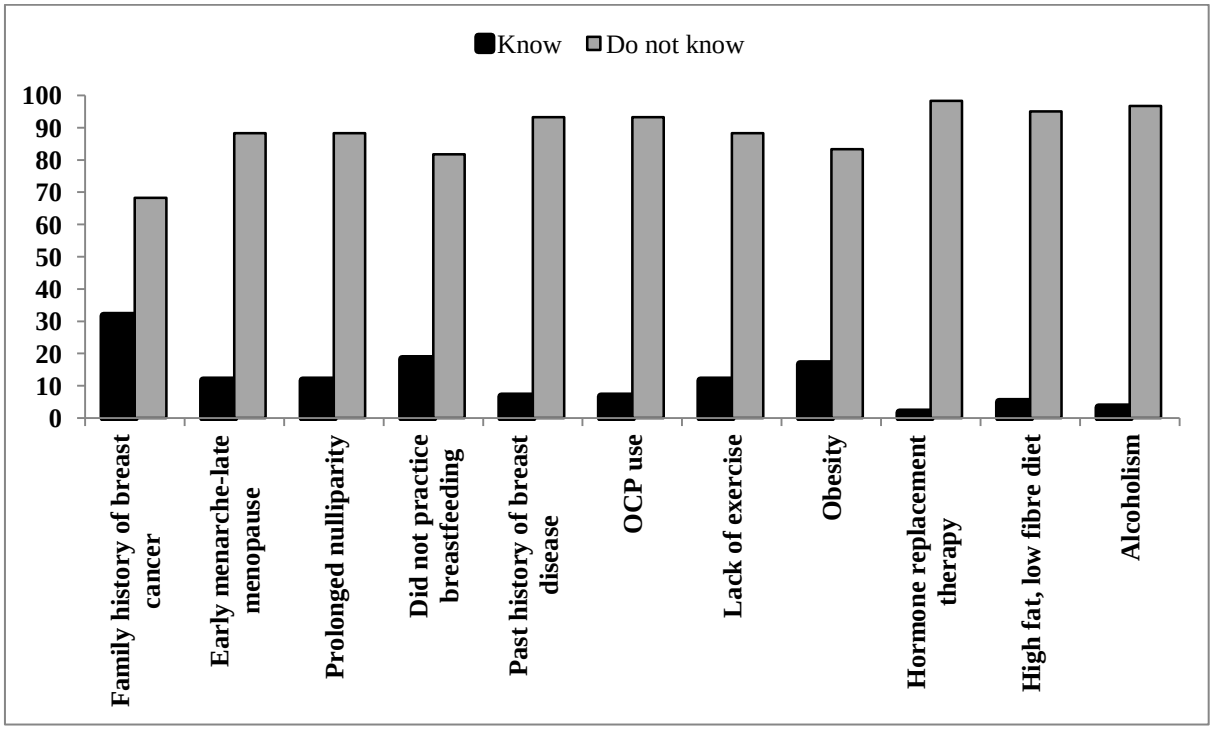


Fig. 6 Delay in reporting symptoms and to whom the symptoms are reported to

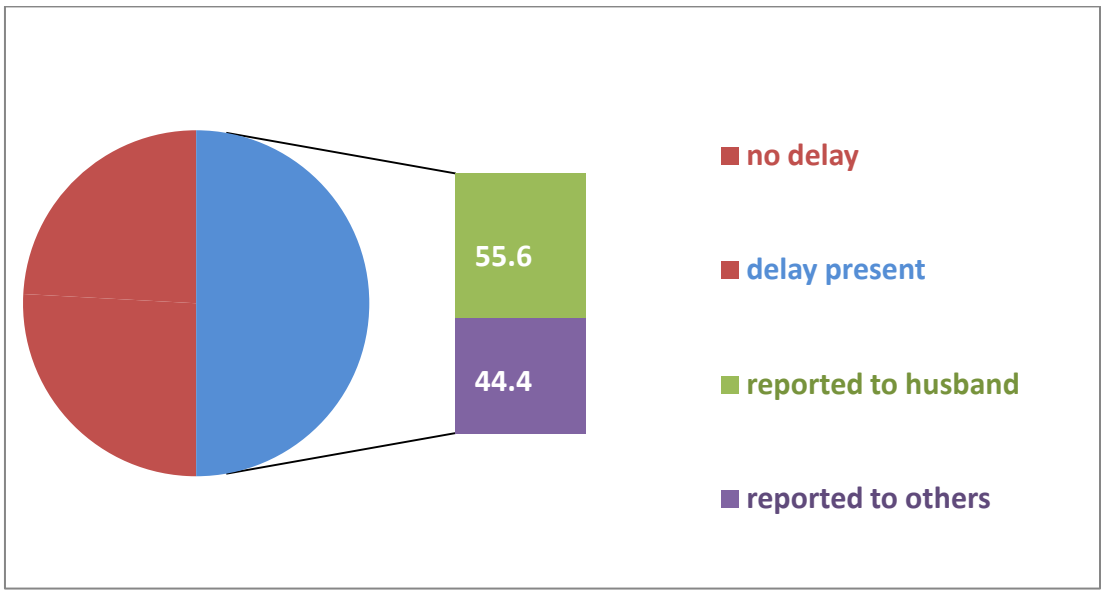


Fig. 7 Delay in reporting symptoms (%)

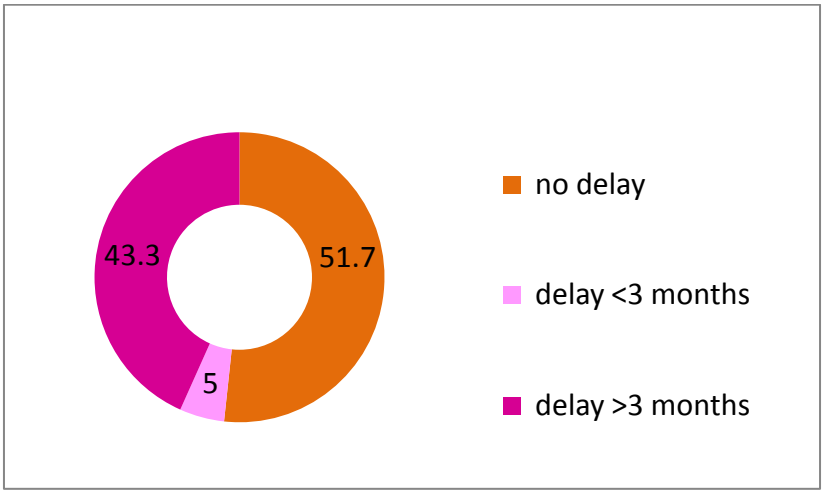
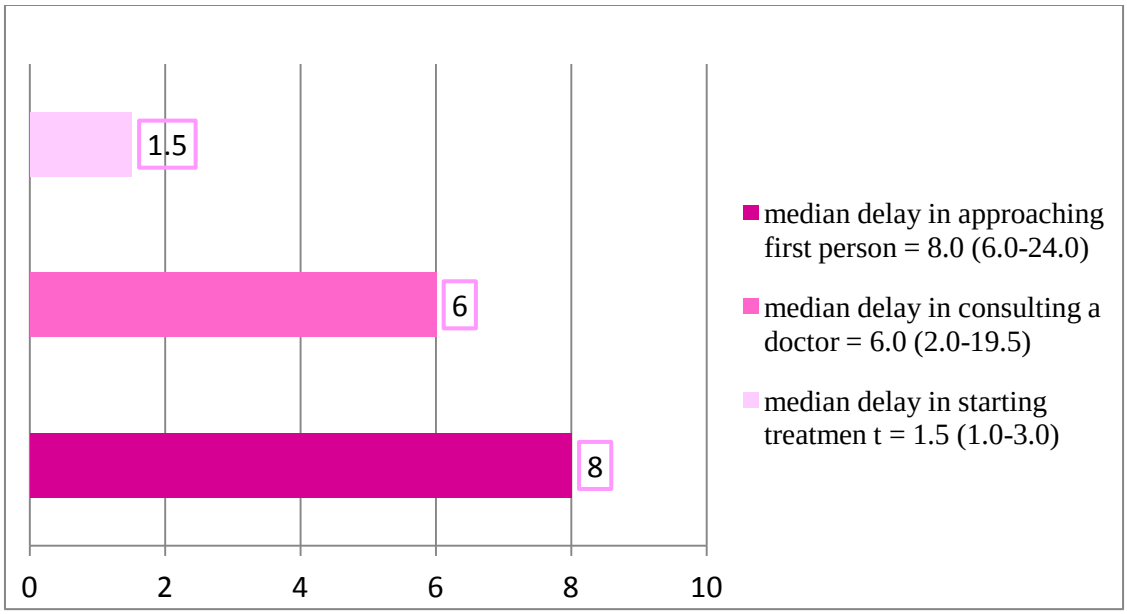


Fig. 8 Median delay in reporting symptoms (in months)



Discussion

Rural respondents had more of a negative attitude and delayed seeking help more compared to urban (Grunfeld et al., 2010) but this was not significant according to our study. In a study in Iranian women by Ali Montazeri et al., 2003, the mean ages of patients were 47.0 (SD 11.3) years and most were married (80%).

The average time lapse before diagnosis for rural patients was higher (67.5 days) compared to urban patients (53.7 days) (Chintamani et al., 2011). The delay in illiterates was 60.6 days compared to 49.5 days for literates (Chintamani et al., 2011). Women delayed longer when initial breast symptoms did not include a lump (Burgess et al., 1998) compared to women who detected a breast lump, the latter group waiting significantly less time. One in four women reported that they would delay telling for at least one month after discovering the symptom (Grunfeld et al., 2010). One quarter of the patients delayed seeking help for more than three months according to the study by Mor et al. (1990.

The key variables linked to delayed help seeking were denial, fear, social factors and knowledge and beliefs as reported by O'Mahony, et al. (2011). In the Leicester review, it was identified that the reasons for delay were two types of fear, i.e., fear of embarrassment and fear of cancer (Smith et al., 2005).

Patient delay ranged from less than one week to 60 months (Mean 3.8, SD 8.6 months) and delay of more than three months was reported by 25% of patients (Montazeri Ali et al., 2003). In multivariate regression analysis Montazeri Ali et al. (2003) found that there was a risk for longer delay in widowed or divorced women (OR 3.7, 95% CI 1.5-9.7), women with a positive family history of breast cancer (OR 2.8, 95% CI 1.1-7.7), and less educated patients (illiterate: OR 5.2, 95% CI 1.5-17.7; primary schooling: OR 4.6, 95% CI 1.4-14.7). Significant associations also were found between delay in presentation and the late stage of disease (P = 0.01) and bigger tumor size (P = 0.004).

Many participants relied on indigenous medicines for a cure in a study on Chinese-American women (Fancione et al., 2000), but our study showed no such trend. Unregistered medical practitioners or quacks were responsible for delay in large numbers according to Chintamani et al. (2011) but we did not encounter such a scenario.

Conclusion

Delay in help seeking was found in 41.7% of the patients; the significant delay was that in confiding in a person. The common reasons for patient delay are ignorance of the symptoms (23%), inhibition (11%) and social stigma (8%). Even in the state of Kerala, which is as good as a developed nation, with a female literacy of 92%, the awareness of screening methods is poor.

After regression, seeking help to husband was protective (OR = 0.238) against the help seeking delay.

Recommendations

Lack of awareness of the disease should be addressed with awareness programmes for a brighter outcome. Awareness should be imparted to men and women on the,

- symptoms of breast cancer,
- screening measures and their role in early detection of the disease,
- available treatment options and
- outcome of early detection and treatment.

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Ethical Approval: The study was approved by Institutional Ethics Committee.

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Annexure-1

Questionnaire for Studying the Pattern of Help-Seeking Behaviour in Breast Cancer Patients

Medical College, Trivandrum

1. Name :
2. Age :
3. Address :
4. Area of Residence
   ⇧ Urban ⇧ Rural
5. Religion
   ⇧Hindu ⇧ Christian ⇧ Muslim
6. Occupation
   ⇧ Housewife ⇧ Unskilled ⇧ Semi-skilled
   ⇧ Skilled ⇧ Professional ⇧ Others
7. Education

(i) ⇧ Illiterate ⇧ High School ⇧ SSLC
⇧ +2 ⇧Under-Graduate ⇧ Postgraduate

(ii) Husband's education
⇧ Illiterate ⇧ High School ⇧ SSLC
⇧ +2 ⇧Under-Graduate ⇧ Postgraduate

8. Socio Economic Status
   ⇧ APL ⇧ BPL
9. Type of Family
   ⇧ Nuclear ⇧ Extended ⇧ Joint
10. Marital Status
    ⇧ Married ⇧Unmarried ⇧ Divorce ⇧ Separated ⇧ Widowed
11. Age of Menarche :
12. Age of Marriage :
13. Obstetric score :
14. Age at first child birth :
15. No. of years of marriage after which first child was born:
16. Breast-feeding practiced or not
    ⇧ Yes ⇧ No ⇧ NA

(i) *If YES*, how long breast feeding was practiced?

(ii) Do you think breast feeding has any relation with development of breast cancer?
⇧ Yes ⇧ No ⇧ don't know

17. Whether OCP were used?
    ⇧ Yes ⇧ No
    If YES, duration of use of OCP
18. Do you think there is any connection between OCP use and breast cancer?
    ⇧ Yes ⇧ No ⇧ don't know
19. Have you attained menopause?
    ⇧ Yes ⇧ No ⇧ hysterectomy
    (i) *If YES*, age of menopause

20. Any HRT done?
    ⇧ Yes ⇧ No
    If YES, how long?
21. Do you know about screening for breast cancer?
    ⇧ Yes ⇧ No

(i) What do you know about screening for breast cancer?
⇧ Mammogram ⇧ SBE ⇧don't know

(ii) Was it done?
⇧ Yes ⇧ No

(iii) *If NO*, why?
⇧ Fear ⇧ Financial ⇧ Lack of family support
⇧ Ignorance ⇧ Inhibition

22. Have you heard of SBE?
    ⇧ Yes ⇧ No

(i) *If YES*, source of knowledge
⇧ Friends ⇧ Relatives ⇧ Books

⇧ Awareness programmes by medical personnel
⇧ Media ⇧ Internet ⇧ any other source

(ii) Do you know how to do SBE?
⇧ Yes ⇧ No

(iii) *If YES*, do you practice it?
⇧ Yes ⇧ No

(iv) *If YES*, frequency of practice

(v) Do you know when to do SBE? ⇧ 2 days before menses ⇧ after menses ⇧no specific time ⇧a day of the month in hysterectomy patients

(v) *If NO*, why?
⇧lack of knowledge ⇧ embarrassment
⇧lack of privacy ⇧lack of confidence
⇧lack of time ⇧fear of finding
⇧belief that you are not at risk

23. What was the first symptom detected
⇧ Lump ⇧ Pain ⇧ Breast Discharge
⇧ Nipple Retraction ⇧ Others
24. Did you seek help on first symptom?
⇧ Yes ⇧ No
25. First person approached on discovery of symptom
⇧ Husband ⇧ Daughter/Son/daughter-in-law ⇧ Mother/sister ⇧ Friend ⇧ Colleagues ⇧ Cousin/other relative ⇧ Health care personnel ⇧did not approach anyone
26. Time period between detection and approach to first person:
27. Time lapse from detection till medical consultation:
28. Time lapse from diagnosis till start of treatment:
29. Reasons for delay in any of the above
⇧ Lack of family support ⇧ Financial ⇧Social stigma ⇧ Loss of hope ⇧ Job ⇧ no pain ⇧ Ignorance ⇧inhibition/shyness ⇧Lack of time ⇧Fear of treatment ⇧Fear of loss of breast ⇧ Indigenous treatment ⇧mentally ill
30. Do you know about the risk factors for breast cancer?
⇧Yes ⇧No

(i)*If YES*, which all do you know about?

FACTORS	YES	NO
Family history of breast disease		
Early menarche - late menopause		
Prolonged nulliparity		
Did not practice breast feeding		
Past history of breast disease, surgery		
OCP use		
Lack of exercise or physical inactivity		
obesity		
HRT		
Inadequate fruits and vegetables (low dietary fibre, high fat diet)		
Alcoholism		

(ii)Which of the above factors do you have?

FACTORS	YES	NO
Family history of breast disease		
Early menarche - late menopause		
Prolonged nulliparity		
Did not practice breast feeding		
Past history of breast disease, surgery		
OCP use		
Lack of exercise or physical inactivity		
HRT		
Obesity		
Inadequate fruits and vegetables (low dietary fibre, high fat diet)		
Alcoholism		
Chest irradiation		

31. Stage of presentation

⇧ Early ⇧ Locally advanced ⇧ Advanced (Metastatic)

32. Any previous history of breast disease?

⇧ Yes ⇧ No

(i) *If YES*, history of any surgery on breast

⇧ Yes ⇧ No

33. Any history of breast disease/breast cancer in family?

⇧ Yes ⇧ No

If YES, ⇧ 1st degree ⇧ 2nd degree

34. Any history of any other cancer in family?

⇧ Yes ⇧ No

If YES, ⇧ 1st degree ⇧ 2nd degree

35. Do you know about the treatment of breast cancer?

⇧ Yes ⇧ No

If YES, which of the following?

⇧ Surgery ⇧ Radiotherapy ⇧ Chemotherapy ⇧ Hormone therapy

36. Do you think if you had sought help early the outcome would have been better?

⇧ Yes ⇧ No ⇧ don't know

37. Do you know that breast cancer can be treated and cured if discovered in early stage?

⇧ Yes ⇧ No ⇧ don't know