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Factors influencing delayed presentation with symptomatic breast cancer in Hong Kong Chinese women

Key Messages

1. Women knew about breast cancer symptoms, but atypical and painless presentation was more common among women delaying presentation.
2. Utilisation barriers included cost, uncertainty about referral pathways, competing priorities and embarrassment.
3. Education should emphasise atypical symptoms, a high cure rate and the need for early presentation.
4. Reduced cost and easy access to clinics would enhance early consultation.

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Introduction

Delayed presentation of symptoms of breast cancer (BC) means that advanced, disseminated disease is more likely and treatment therefore less effective. This is one of the main contributors to mortality in BC.[1] Early treatment is associated with a much higher cure rate. It is therefore important to understand the reasons for delayed presentation and referral of symptoms for investigation. Several components of treatment delay have been noted, including patient-delay factors such as ignorance of symptom meaning, and delay between symptom detection and presentation, and doctor-delay factors such as diagnostic error and referral delay. Help seeking is influenced by illness cognitions, the way women make sense of their symptoms and the way they cope with the responses resulting from their symptom perceptions.[2,3] There are no such data for Hong Kong Chinese women. We sought to identify factors determining delayed presentation of BC symptoms in Hong Kong Chinese women.

Methods

This study was conducted from February 2005 to January 2006.

Study design

A grounded theory-based qualitative approach addressed four questions: (1) What information do women seek and attend to? (2) How do they interpret that information? (3) What decision rules do they use? (4) How do they justify their choices?

Sample

Following ethics committee approval, participants were recruited at surgery clinics in Kwong Wah Hospital, United Christian Hosptial, and Pamela Youde Nethersole Eastern Hospital from women consulting for self-identified BC symptoms. Chinese women, 21 years or older, residing in Hong Kong, and who could communicate in Cantonese were eligible. Women were excluded if they had a prior BC diagnosis, or if their breast abnormality was discovered through breast screening. Women interviewed were chosen, using theoretical sampling, to capture a wide range of perspectives.[4] Sample size was determined by data saturation, occuring with 37 women. Each woman participated in an in-depth, semi-structured interview, prior to their consultation, beginning with the question "please tell me how you decided to bring the particular breast problem to the attention of a doctor". Probing questions followed to encourage response elaboration. All of the interviews were tape-recorded.

Data analysis

All interviews were transcribed and then analysed using the grounded theory approach.[5]

Results

The Table summarises the characteristics of the participants. We derived a two-stage help-seeking decision model explaining the process of medical help-seeking decision by Chinese women with BC symptoms. The two stages were

Table . Personal and medical characteristics of the participants

Case	Age (years)	Martial status	Employment	Education level	Years of residence in Hong Kong	Type of symptoms	Duration of delay
1	44	Married	Full-time	Tertiary	>7	Breast lump	<1 week
2	52	Married	Housewife	Primary	>7	Breast lump	>6 months
3	48	Married	Part-time	Secondary	>7	Breast lump	<3 months
4	36	Married	Full-time	Secondary	4-7	Breast lump	>6 months
5	32	Married	Full-time	Primary	1-3	Breast lump	<1 week
6	44	Single	Full-time	Secondary	>7	Breast lump	<3 months
7	58	Married	Housewife	Primary	>7	Breast lump	>3 months
8	23	Single	Full-time	Secondary	>7	Breast lump	>3 months
9	78	Widowed	Retired	No formal	>7	Breast lump	>3 months
10	42	Married	Housewife	Secondary	1-3	Breast lump	<3 months
11	20	Single	Student	Tertiary	>7	Breast lump	>3 months
12	51	Married	Housewife	Secondary	>7	Breast lump	<1 week
13	48	Married	Full-time	Secondary	>7	Breast lump	<3 months
14	45	Married	Housewife	No formal	4-7	Breast lump	<1 week
15	46	Single	Unemployed	Secondary	>7	Breast lump	<1 week
16	47	Single	Full-time	Secondary	>7	Breast lump	>6 months
17	52	Single	Full-time	Primary	>7	Breast lump	<3 months
18	49	Married	Unemployed	Secondary	>7	Breast lump	>6 months
19	65	Married	Housewife	No formal	>7	Breast lump	>6 months
20	46	Widowed	Part-time	Secondary	<1	Breast lump	>3 months
21	35	Married	Housewife	Secondary	>7	Breast lump	<1 week
22	50	Married	Part-time	Primary	>7	Breast lump	<1 week
23	45	Single	Full-time	Secondary	>7	Breast lump	<1 week
24	52	Married	Part-time	Secondary	>7	Breast lump	<1 week
25	44	Divorced	Full-time	Secondary	>7	Nipple discharge	<3 months
26	70	Widowed	Retired	Primary	>7	Breast lump	>3 months
27	35	Single	Full-time	Secondary	>7	Breast lump	<1 week
28	44	Married	Housewife	Secondary	>7	Breast lump	<1 month
29	69	Married	Retired	Primary	>7	Breast lump	<1 week
30	56	Married	Part-time	Secondary	>7	Breast lump	<1 week
31	33	Married	Full-time	Secondary	>7	Breast lump	<3 months
32	81	Widowed	Housewife	No formal	>7	Breast lump	>6 months
33	54	Married	Full-time	Primary	>7	Breast lump	<1 week
34	42	Married	Full-time	Tertiary	>7	Breast lump	<3 months
35	40	Married	Full-time	Secondary	4-7	Breast lump	<1 month
36	47	Married	Full-time	Primary	>7	Breast lump	>6 months
37	21	Single	Full-time	Secondary	>7	Breast lump	>6 months

(1) symptom recognition and (2) service utilisation.

Symptom recognition

Three factors triggered symptom recognition—symptom interpretation, symptom progression, and social messages.

Symptom interpretation

- Interpretation influenced women's subsequent help-seeking behaviours: "*I didn't pay much attention to the lump. I just ignored it. But then recently, it was painful when I touched it. So I thought I shouldn't wait anymore. Then I went to see a doctor.*" (case 2, age 52, >6 months delay).
- If symptoms failed to match women's illness representation of BC, delay in seeking medical attention was more likely, suggesting women's symptom understanding was imprecise. Additionally, traditional Chinese medicine elements created ambiguity: "*I thought it's (the lump was caused by) re qi. So I took some cooling food….*" (case 6, age 44, <3 months delay).

Symptom progression

- For several women, symptom persistence triggered their consultation: "*(The lump) was still there every time I felt it. And it's the same as the first time I felt it. So I think it needs to be seen by a doctor.*" (case 20, age 46, >3 months delay)

Social messages

- Knowing someone who had cancer or breast disease that prompted women to attribute the symptom as a signal of health threat applied to both prompt and delaying appraisers. Women with relatives or friends who had BC promptly appraised the breast symptom as a threat. "*I am quite aware of BC as many of my friends had BC. So I know.*" (case 23, age 45, prompt seeker)
- Some women who initially dismissed the presence of symptoms were later prompted by others who had had BC: "*I didn't know what (the lump) meant…. Then my sister-in-law was diagnosed with BC. So I realised I was in trouble*." (case 32, age 81, >6 months delay)
- News reports of the prevalence of BC heightened women's awareness of the potential seriousness of breast symptoms: "*I was really worried (when I felt a lump in the breast). I made an appointment…straight away… I read a lot about cervical cancer and breast cancer from the newspapers, also from TV adverts. So I was scared that I might have cancer.*" (case 5, age 32,

prompt seeker)

Service utilisation

Once the breast symptom was recognised as a potential health threat, women moved into the second stage and made the decision to seek medical care. Six triggers for medical help seeking emerged.

Fearing consequences of delayed help seeking

"*I am afraid of dying. … I often seek medical help straight away whenever I am ill.*" (case 12, age 51, prompt seeker)

Perceived need to confirm the diagnosis

Closely related to this was the need for diagnostic confirmation: "*I decided to seek medical help because I want to have peace of mind. I need to know the diagnosis.*" (case 8, age 23, >3 months delay)

Physical symptom distress

Women experiencing prolonged physical symptom distress, particularly perceived interference with physical or daily activities, sought medical help promptly: "*I had to do housework and cook for my family. But I couldn't lift my hand up because the lump hurt. It affected my daily activities. So I need to seek help. Otherwise, I wouldn't go to see a doctor.*" (case 7, age 58, >3 months delay)

Lay referral system

For some women, the decision to seek medical help was taken by someone else. This is referred to as sanctioning and is a well-recognised feature of the lay referral system: "*My mum and my aunt pressed me to go and see a doctor. They told me that I must go to the doctor. … I know I should seek medical help, but for some reason, I kept putting it off until my mum pushed me to do so.*" (case 8, age 23, >3 months delay)

Media prompts

Some women decided to seek medical attention for the breast symptom as a result of the current social marketing of BC awareness in Hong Kong: "*The information (about BC) on the advert sounds scary. It's about how one in 20 women would get BC. And I had a lump. So I decided to seek medical help.*" (case 21, age 35, prompt seeker)

Opportunistic help seeking

Many women, especially the delayers, presented the doctor with other health problems as their primary concern; the breast symptom was only presented as a secondary concern: "*I didn't seek medical help because it was not painful. I went to see a doctor later on for my chest pain. During the examination, the doctor felt the lump in my breast. So I told him.*" (case 18, age 49, >6 months delay)

Fear of cancer diagnosis

For some women, the possibility of having BC was too frightening, leading them to delay seeking medical attention in order to avoid confronting the bad news: "*I had been struggling for 2 to 3 months whether to go to the doctor or not. I was so frightened of finding out the truth.*" (case 8, age 23, >3 months delay)

Inaccessibility to health services

Unfamiliarity with the medical care system prevented some women from utilising the health service. Older women and new immigrants were particularly likely to have difficulty accessing health services: "*I know I had to see a doctor. But I didn't know where to go. So I waited till the next follow-up appointment at the diabetic clinic. Then I told the doctor.*" (case 26, age 70, >3 months delay)

Financial constraints

Limited household income and health care costs contributed to utilisation delay: "*I can't afford to see a doctor. I live on the government allowance. I don't have money to seek medical help. My daily costs are HK$70. So where am I going to find money to see a doctor? So I have to wait till the follow-up appointment (for another medical concern).*" (case 26, age 70, >3 months delay)

Competing life priorities

Delayers tend to prioritise their other social duties over their own health: "*I have two daughters who are at school. I need to take them to school and help them with their homework. So I thought I should wait till the summer holiday to go to see a doctor.*" (case 10, age 42, <3 months delay)

Embarrassment about having a breast examination

Women who delayed presentation viewed their breasts as private and were reluctant to be examined by a physician, especially a male physician: "*I went to the follow-up appointment to get medications for my hypertension. It was a male doctor. So I didn't tell him about my lump. It's too embarrassing. I didn't want him to look at my breasts. Then I met a female doctor in the following appointment. So I told her about my lump.*" (case 9, age 78, >3 months delay)

Discussion

Symptom interpretation, the initial and most important step in the process of symptom recognition, is largely constructed from pre-existing lay knowledge of BC symptoms. When the symptom is incongruent with women's lay knowledge of BC, women are more likely to attribute minimal symptom significance and delay seeking medical care. Chinese women make sense of breast symptoms using both traditional Chinese (the balance of yin and yang and *qi*) and western (pain associated with illness and injury) decision rules, which might possibly confuse their symptom attributions, resulting in different causes for appraisal delay.

High fear messages can discourage some women and should be avoided in local health education campaigns.

Instead, the favourable prognosis following early detection should be emphasised. Social messages sent via the media facilitate women's prompt utilisation of health services on detecting a symptom.

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