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Physical and psychosocial adjustment of Chinese women and their significant others to the impact of breast cancer and treatments

Key Messages

1. Changes in the meaning of breast cancer and the demands of adaptation to breast cancer can present significant difficulties to women.
2. Spouses also experience significant demands in supporting their wife but may not have as much support available to them.

Introduction

Breast cancer (BC) is the most common cancer and the second leading cause of cancer death among Hong Kong women, with an estimated 1787 new cases reported annually—equivalent to 17.5% of all newly diagnosed female cancers.¹

Diagnosis and treatment for BC have significant implications, are highly stressful, and often cause a range of physical and psychosocial sequelae. During diagnosis and treatment, 31-51% of women experience moderately high levels of depression and anxiety,² compared with well women.³ In addition, psychological morbidity among women with BC is significantly greater than that seen in women with benign breast disease.⁴

Identifying important influences on psychosocial function that affect adaptation to cancer and its treatment is essential if we are to efficiently allocate services to women at risk for poor adjustment. Most information on biopsychosocial adjustment in BC is from western countries. Little is known about Chinese women's responses to BC. Culture is an important consideration in any attempt to understand behaviour. Illness meanings affect adjustment. Attitudes, culture, and personal meanings ascribed to a disease influence how an illness is embodied, lived, and coped with, thereby ultimately dictating adjustment. These cultural and social contexts within which we live converge with our Life Contexts (developmental stage, personal and family past experiences, knowledge, and beliefs).⁵ It is unknown whether BC holds the same meanings for Chinese women as for western women, or if they experience the same physical and psychosocial difficulties in response to the impact of BC and its treatments.

No studies have examined the impact of BC and its treatment on Chinese family members. Western studies of BC patients and their significant others report significantly higher distress than found in the normal population,⁶ but family members perceived significantly less support from friends and health professionals than did patients.⁷

Reductions in length of acute care stay and out-patient treatment protocols have shifted responsibilities for the physical and emotional care of patients to family members. Family availability, willingness, and ability dictate capacity to meet patient needs and provide for their care. Therefore, a clear understanding of the impact of BC and its treatment from Chinese women's and their significant others' perspectives is essential to provide direction for future interventions to manage the identified physical and psychosocial difficulties associated with BC.

Aims and objectives

To explore (illness meanings held by Hong Kong Chinese women recovering from BC, and those of their significant others, thereby understanding their physical and psychosocial adjustment to the impact of BC and its treatments.

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Methods

This study was conducted from April 1999 to March 2000. A qualitative study using a phenomenological analytic approach derived from interviews with female participants selected on a broad range of disease characteristics, BC treatments, experiences, age, marital and employment status, and their spouses or partners. Sample size, determined by theoretical saturation, was 17 women. Only seven of the 17 women agreed to their significant others participating. All were interviewed immediately on completion of treatment (6 to 8 months after diagnosis). Data were analysed by parallel independent interpretive reading of interview transcripts using a phenomenological approach with repeated discussion and reiterative reviews of content to identify repetitive elements and combine these into thematic units.

Results

Eleven had stage III and the rest stage I or II disease. All women had surgery: 14 modified radical mastectomy (one with TRAM-flap breast reconstruction), and three lumpectomy. Eleven women had chemotherapy (CT) only, one radiation therapy (RT) only and five both CT and RT. One woman with recurrent BC in the remaining breast had undergone her second mastectomy. The women were aged 30 to 65 years, two had a family history of BC, 15 were married, one was single, and one divorced. All married women had children (aged from 5 to 39 years). Four women were housewives, 10 were currently employed, two were forced to stop working after the cancer and one took early retirement. Of the seven participating husbands (aged 42 to 66 years), one was unemployed, and the others were salesmen, technicians, taxi drivers, businessmen, or civil servants.

Women's illness experience—a number of core themes were identified from the transcripts:

(i) Meaning: BC meaning began evolving and proliferating as soon as women discovered their breast abnormality:

"a mosquito bite" (Mrs. I)

"a scratch" (Mrs. A, Mrs. O)

"re qi" (an excess of Yin energy) (Mrs. P) or

"too small to signify a problem" (Mrs. D)

(ii) Detection of a breast lump:

"While checking my breast, I found a lump. It aroused my suspicion, but I was unsure. So I asked my husband to take a look and then we decided to seek help from our general practitioner immediately." (Mrs. C)

(iii) Facing the threat of diagnosis was followed in quick succession by (iv) Denial and fear

"When I heard the word 'cancer', I felt frightened. A lot of people say that cancer is incurable. I was filled with fear of death." (Mrs. B) and, rapidly,

(v) Searching for meaning to explain why cancer has occurred:

"I was wondering whether I'm going to die. I thought, 'Oh god! How come I would have this kind of disease?'"

(Mrs. C)

(vi) Uncertainty: Locked into the diagnostic process the level of uncertainty rises rapidly until the diagnosis is confirmed.

"The surgeon told me that the report should be ready in two weeks. But it wasn't the case. I thought this is not a good sign as other patients had received their reports within two weeks. There must be some problems with my results. At that time, I was worried and frightened. I was not sure whether the cancer cells have spread to the lymph nodes or not." (Mrs. D)

"I went into the room and the doctor was trying to explain to me. I couldn't remember what they had discussed with me. I only remembered that I had to have the surgery. My mind was totally blank. I really didn't know what to do. I didn't want to think about this. I let the doctor decide for me." (Mrs. G)

Once treatment began a further set of thematic meanings emerged, including (i) the struggle to decide between cosmesis and the pragmatics of survival, which was mostly driven by fear:

"The surgery (mastectomy) set me free. I feel that I have taken out the bomb. This was what I must do and I did it." (Mrs. C)

"I had no choice. I was afraid that keeping the breast would lead to cancer recurrence." (Mrs. E)

(ii) disturbances to the sense of identity (I don't know who I am anymore),

"I feel that I'm different from others. I'm different from those who are normal. That is, those women whose appearance or bodies are perfect. For myself, I'm imperfect. I had the surgery and lost one side (of the breast)." (Mrs. A)

(iii) "Doing chemo", having chemotherapy:

"I hardly had any outings. I feel that I had changed into another person. I used to be quite slim. I didn't belong to the group of fat people. Everything changed. I have changed into another person. I feel like I am not in the shape of mankind. I am very fat. I feel that I'm very ugly. Now when I look at myself from the mirror, I want to throw up." (Mrs. B)

and, when it became apparent that death was not imminent and cure seemed possible, (iv) the question of how patients could regain a normal life became a key issue.

"My friends didn't know I had cancer. I didn't want to tell them. I don't want them to pay attention to me. If they don't know you are sick, they'll treat you as a normal person. They will ask you out. Otherwise, I would be left out as they thought you can't do anything since you are sick." (Mrs. G)

Finally, the meaning of surviving BC must be faced, and is associated (v) with a process of re-appraising life's priorities.

"I have gone through so many things in the past six months. I used to be very stubborn. I used to worry so much about what would happen in the future. I was worried about things such as buying a flat and saving money for the future. Then it turns out that no matter

how hard you planned for your future, you would never know whether you could achieve your goals. Now I think that the most important thing to be concerned about is today's happiness." (Mrs. I)

Among the spouses, seven men aged 42-66 years said that the role of providing support to their wife was the main theme. The man's duty was to support his wife:

"The husband is the closest person to her. The most important thing is that when the wife is ill, the support from (the) husband cannot be replaced by support from friends." (Mr. E)

and this was primarily by the provision of instrumental support around the home:

"Back then I wouldn't care so much about her, such as I would only clean up the table after she went home and cooked herself dinner. But now I will care much more about her. I don't want her to be too tired." (Mr. L)

By adopting a care-taking role, family was foremost and the man's own immediate emotional needs were often put aside, sometimes voluntarily,

"When she is ill, I try my best to take care of her. The children have to study, there is not much, for friends, relatives, they can't help because they have to go to work. We deal with this matter ourselves." (Mr. F)

and sometimes because of prohibitions from spouses:

"I don't have anyone to talk to about my problems. Nobody knows what I have gone through. (Q: Do you talk to your friends?) No, no, I don't dare tell them, she told me not to tell anybody." (Mr. K)

Men suppressed their feelings and focused on supporting their wife:

"She was admitted to a public hospital (so) we felt much better. I started to comfort my wife because my wife was also very frightened. (laughing) You could not let her know that you were frightened too!" (Mr. E)

No one main source of male support was seen, though the hospital teams helped considerably. For some this was mainly for the wife:

"It was my wife who wanted to ask about the treatment and the procedures of the treatments. I told her to ask Nurse X or Dr. Y or Nurse Z, because I really don't understand any medical stuff. It would be stupid for me to ask" (Mr. L)

For other men, the limitations of staff support and the importance of peers were recognised:

"The nurses are very friendly. The patients talk with each other, comfort each other. I think it's the right choice to have surgery here...(But) the gap between the medical staff and the relatives...is so large. They cannot give much comfort...the medical staff can give the patients confidence and make them think they have no big problem because they have professional knowledge." (Mr. E)

Some men themselves wanted information:

"Q. (So you are saying) the important thing that makes you satisfied is that they can give you the

information, so you know your wife's illness condition. You think this is the most important?"

Mr. O: "Yes".

Coping with the demands of their wife's illness challenged the men. A range of coping patterns was seen, mainly empathy:

"(I get complaints if) something displeases her. So I should be a man and take them without protest. After all, she is sick. I wouldn't be in my sweetest temper either if I was in her shoes." (Mr. L)

sympathy:

"I felt sorry for her when I saw her suffering from the side-effects." (Mr. F)

pragmatism:

"Um, worry? I think she is more worried than me...in this situation she is the one who is going to face the truth, not me. Frankly, if I am the one who is going to have to deal with it I would have a different attitude." (Mr. A)

and helplessness:

"I told her...with this illness, the husband cannot share your (problems) and you are the one who has to deal with the problems, I often said to her that I don't know how to help her. I can't help her even if I wanted to. I don't know how to help..." (Mr. A)

Some men felt that their marital relationship was improved,

"Yes, our relationship is even better than before." (Mr. L)

Others felt things were not changed by BC:

"More or less the same, we are stable in our relationship, nothing special (laughs)." (Mr. E)

while some felt there were new relationship problems,

"Now she only accept things that please her ears and you have to yield to what she wants, but I could talk back and argue with her back then when she wasn't sick. Now I give way to her whenever she is being difficult. I just leave it and let her say whatever she wants to say. I mean she was obstinate back then, but I could still argue with her and opposed what she said. But now I will leave it and let her have the upper hand." (Mr. L)

but these were most prominent among couples that had pre-existing difficulties:

"She doesn't let me see it (the chest), then forget it! Right? Like I want to care for her, I ask her about the condition, she said there are no problems, she said there isn't anything to see! Then forget it!" (Mr. K)

Discussion

Illness meanings are exemplified as evolving, dynamic phenomena changing with situational and relational (life) contexts and the experiences generated by the illness and treatment process. The findings of this study show the process of changes in meanings unfolding from experiencing BC treated in a biomedical context. The ever-changing interruptions imposed by BC over-rode their previous

assumptions about life and ultimately forced the women to re-organise and re-define their personal meanings as functions of the changes comprising the illness trajectory.

Coming to terms with BC as a life-threatening illness meant facing not only the threat of death, but also the threat of rejection. Many women attributed their BC to mundane life events rather than uncontrolled factors such as genetics. This may help the women to minimise future threat.

Breast cancer disrupts the fabric of daily life and profoundly impacts a person's sense of identity. Women in Hong Kong seem to value the breast much less as a sexual feminine or as a functional organ than women in a western culture. Few women expressed concern about their sexuality or the loss of the breast on their marital relationship. Hair loss, weight gain, and facial changes were more important to these women as these could not be hidden and were a visible stigma of illness. Social harmony and keeping the body undamaged is strongly emphasised in Confucianism and daily life. Therefore health and sickness is not merely an individual but also a societal issue.

This study has highlighted the importance of giving women not only tailored information and the opportunity for choice, but also sufficient time and discussion to support treatment decisions. Health providers must listen to and utilise patient stories to better assess and intervene to mitigate the impact of BC on women and their significant

others.

Conclusions

Changes in the meaning of BC and the demands of adaptation to BC present significant difficulties to women and their spouses who also experience significant demands in supporting their wife. This study provides important information on the experience of BC for Hong Kong women and their spouses.

Acknowledgements

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