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Surgical treatment decision making: how Chinese women with breast cancer choose treatment

Key Messages

1. Most women are so overwhelmed by the diagnosis of breast cancer that they feel paralysed.
2. Chinese women liken treatment decision making (TDM) to gambling—they feel uncertain during the TDM process and suffer from indecisiveness.
3. Chinese women make trade-offs for survival, which is considered the highest stake. Many reported they were choosing between cosmesis and survival.
4. Coping with uncertainty during and after the treatment was an ongoing problem for many women.

Introduction

Modified radical mastectomy (MRM) yields similar survival rates to breast conservation therapy (BCT) in early-stage breast cancer (BC),¹ hence quality of life often dictates treatment choice. Multiple treatment alternatives and increasing expectations of patient participation in medical care² mean that women diagnosed with BC are confronted with difficult surgical treatment choices. A diagnosis of BC forces a woman to take several extremely stressful decisions: treatment or no treatment, MRM or BCT, and if MRM, then breast reconstruction or not. Each decision is complicated by uncertainties regarding tumour stage and type and likely adjuvant therapies, among others. Women must decide quickly while struggling with fear, uncertainty, and ambiguity.

Two paradigms have been used to examine perceptions in women confronting BC³: normative approaches, which assume rationality (analytic processing) as the gold standard for how individuals should make decisions and hold that rational processes lead to optimal decisions. In contrast, naturalistic approaches argue that people use automatic, intuitive processing to make real-life decisions and study decision making in real-world contexts.

Most studies are based on analytic processing assumptions³⁻⁵ and consistently indicate exceptions to logical, deliberative decision making. Using rational treatment decision making (TDM) in BC can be more cognitively and emotionally taxing, error prone, thus causing guilt and lowering satisfaction.⁶

Alternative perspectives on how people make decisions in real-world contexts, such as medical decisions, describe TDM processes as opposed to optimal decisions,⁶ using in-depth knowledge and understanding of the lived experience of TDM. This study describes the TDM process in Chinese women with BC.

Methods

This study was conducted from October 2000 to June 2003. A grounded theory approach was chosen because it explores experiential aspects of human behaviour and the underlying processes.⁷ Grounded theory is most useful for developing new theoretic starting points.

Sample and procedure

This study involved the two public breast centres in Hong Kong, following ethics approval. Cantonese-speaking Hong Kong Chinese resident women 21 years or older who had recently been diagnosed with BC were targeted. These inclusion criteria for interviewees gave an initial starting point for data collection. Samples in grounded theory studies should not be totally pre-specified, but allowed to evolve once fieldwork begins.⁶ Constant comparison (comparing new data to the emerging categories) is used to refine the categories. A heterogeneous sample is therefore essential for confirming or disconfirming the working hypotheses under which the theory holds. Theoretic saturation (no new material generated over four consecutive interviews) determines sample size, and was reached in this study, with 22 women.

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The purpose and scope of the study were explained and informed voluntary consent was obtained. Each of the 22 women subsequently participated in a tape-recorded, private, 45- to 60-minute, in-depth, semi-structured interview on the hospital ward, which began with the general question "please tell me how you decided to agree to have this particular surgery", followed by prompts encouraging elaboration.

Analysis

Analytic rigour was maintained by focusing the initial coding and classification on the research topic, close adherence to the research process, the evolution of codes, categories, and theory in order to allow others to understand how analytic decisions were made. Two researchers independently coded the data and held joint interpretive discussions. Disagreement was resolved by repeated textual reference, comparison, plausibility, and discussion. Validation involved sharing interpretations with, and reviewing of the data by, the participants through ongoing telephone follow-up interviews over the study period. All transcripts were analysed in their original Cantonese form. Illustrative quotes were translated subsequently.

Results

All except one woman were interviewed within 3 days postoperatively. Five women had stage 0 (ductal carcinoma in situ), four had stage I, eight had stage II, and five had stage III disease. Of the 22 participants, 15 had been offered a choice of surgical interventions: four were offered MRM only, two were offered BCT only, and one was offered MRM but requested BCT. Of the 15 women who had a treatment choice, seven chose MRM, one chose MRM with a concurrent TRAM-flap breast reconstruction, and seven chose BCT. Of the seven who chose BCT, two had MRM later because of tumour infiltration.

Of 22 participants aged between 23 and 88 years, none had a family history of BC, 13 were married, six single, and three widowed. Eleven had children aged from 5 to 40 years. Five were housewives, nine were currently employed, four were retired, one was a student, one was currently unemployed, and two had to stop working after the cancer.

From the analysis of these women's experiences, we derived a four-stage decision making model. The four decision stages are: causal conditions, gamble of treatment choice, anticipated consequences of choice, and influence of coping activities.

Causal conditions influencing the treatment decision making process

Two TDM causal conditions emerged: discovery of a breast abnormality and emotional responses to the diagnosis of BC.

Discovery of a breast abnormality, usually a lump, pain or nipple discharge, was the beginning of the BC experience

for some women. Their initial responses varied depending on how they made sense of their symptom(s). Their own and others' experiences, along with media information influenced symptom interpretation. Women knowledgeable about BC were more sensitive to the symptom implications, prompting earlier consultation. A woman with recurrent BC said, "*I felt the lump in my breast when examining my breast. So I made an appointment to see my doctor the next day.*" (Mrs L, 35 years). One woman said her decision to seek medical opinion was related to the current social marketing of BC awareness in Hong Kong, "*I found a lump in my breast.... I've heard so many stories (in the media). Therefore, I decided to seek medical help.*" (Mrs Q, 57 years). However, personal experiences also led to some delaying medical consultation. Previous benign breast disease particularly desensitised several women to their symptoms, delaying treatment: "*The symptom started a year ago. I found a lump in my breast.... I had a benign tumour 3 years ago.... So I didn't pay any attention.*" (Miss N, 23 years). Significant patient delay limited treatment options available to the doctor and hence TDM choices. "*I was so worried that (the cancer) had already spread.... I waited for too long to seek medical advice.... I thought BCT is not good enough to control breast cancer.... I was worried so I decided to have MRM.*" (Mrs K, 43 years). Early detection (including early medical consultation) increased treatment options for these women because of their early-stage BC and enhanced confidence in BCT. One woman who opted for BCT said, "*I want to be able to preserve my breast.... It was discovered at a very early stage... therefore I believed it's...unnecessary to have MRM....*" (Mrs T, 50 years)

The second causal condition influencing TDM was the emotional response to the breast cancer diagnosis. Women were usually provided with information about available surgical options immediately after receiving the diagnosis, a time when emotion impairs information processing.³ Emotional responses included shock and fear of death. "*At first, I couldn't believe it. My surgeon (indicated) it was benign.... She didn't say it could be malignant.... But it turned out that it was.... I couldn't believe it. I was totally shocked.*" (Mrs M, 27 years). Some women were at a loss to understand how they could have BC: "*I kept asking myself: 'why this is happening to me?' I couldn't understand. I had no family history of breast cancer. I didn't experience any signs and symptoms, apart from the lump.*" (Miss C, 53 years). So overwhelmed were they by the unanticipated diagnosis that many women were paralysed by the choices confronting them and could not respond: "*My mind was totally blank. I was shocked as I never thought I would have cancer.... I found it really strange.... I couldn't register any further information, my mind was blank.... My doctor tried to explain the treatment options but I couldn't hear a single word.*" (Mrs J, 59 years)

The process of treatment decision making

Deciding as gambling: because many factors could not be adequately estimated, the TDM process became a gamble

with life. *"I was quite confused. It's like going to a casino to gamble. It's all dependant on your luck."* (Mrs L, 35 years)

Discrepancies between women's perceptions of 'rational' choice and the rationalist models suggest these women reached their decisions based on informal, heuristic decision processes.⁸ This is exemplified by the experiential elements below.

Indecisiveness

- Uncertainty regarding the seriousness of the disease, together with the unanticipated threat of death from BC, made treatment choices very difficult to make: *"I couldn't make up my mind. I kept asking myself whether I should keep the breast or not. This was a constant struggle."* (Mrs A, 60 years)
- Asking responsibility for the treatment decision: women described their surgeons as opting out of the decision-making process by not expressing a treatment opinion, simply asking them to choose between the given options. *"The surgeon was unhelpful...they only told me the (treatment) consequences...then told me to choose one of the options...It was very impersonal."* (Mrs A, 60 years)
- Inability to assimilate information: difficulties assimilating the surgeon's information were common: *"I was so confused. I didn't pay attention.... To be honest, I wasn't sure if my surgeon had explained the treatment options to me...because I didn't listen. I was so frightened, I wasn't interested to listen to the details."* (Mrs V, 40 years)
- Less distraught women also had problems asking questions, selecting, assimilating and clarifying the information given by their surgeons: *"I didn't know how to ask questions. I was listening to the biopsy report, as well as the surgeon's advice. She kept asking me whether I understood or not. Of course, I understood what she was saying in that moment. But then I was overwhelmed with all the information. I was very confused."* (Miss P, 46 years)
- Uncertainty about survival hindered these women's abilities to identify the best treatment, further obstructing treatment decision information: *"I asked my doctor about the chance of cancer recurrence (with) MRM.... She could only emphasise that my case is an early-stage disease. Then I asked her whether I need radiation therapy.... She told me that I had to wait for the... pathology report. It wasn't very clear."* (Miss P, 46 years)
- Uncertainty about the necessity of surgery: some women doubted the necessity of surgery. Doubts about the necessity of the surgery were associated with loss of trust in the surgeon, due, for example, to concerns about experimental treatments or the financial motives of private surgeons. *"I had second thoughts about the doctor's advice.... I don't entirely trust the doctors as I am worried that they would want to use me to test new treatments."* (Miss N, 23 years)

Prioritising personal aims

The process of reviewing and weighing factors considered significant influences in the treatment decision.

Three key illness context factors influenced TDM:

- Perceived seriousness: none of the women considered refusing surgery. Their decision situation was, starkly, a choice between life and death: *"...you have to do something...for example if you know you are carrying a bomb, you would want to get rid of it."* (Miss E, 36 years). Secondly, women needed to select BCT or MRM. Evaluating the seriousness of their disease was one of the strategies women used to assess the necessity of having MRM. *"If I was really worried, I could have the entire breast removed. But I thought my condition was not that bad. I'm not sure...that is what I believed. Now, I just have to wait for the (clinical pathology) report."* (Miss E, 36 years)
- Surviving is the highest stake: survival was assigned the highest priority by these women. *"I found a lump in October, then I had surgery in November. The only thing in my mind was preserving my life."* (Mrs L, 35 years). Losing a breast was an acceptable trade-off for survival, freedom from both cancer and the organ in which it arose. Several women incorrectly believed that no breast meant that recurrence was impossible. This desire for cure contributed to formulating a tolerable choice: *"Having the entire breast removed could prevent cancer recurrence."* (Miss P, 46 years)
- The extent of suffering: weighing the extent of suffering also influenced TDM: *"I was very hesitant about accepting the surgery. I didn't want to suffer. I thought the operation would be very painful."* (Mrs I, 63 years). Minimising suffering by avoiding subsequent treatments was an influential TDM consideration. *"If I want to preserve my breast, I needed to have chemotherapy first. I didn't want to have chemotherapy.... So I decided to have MRM as it is possible that I might not need chemotherapy."* (Miss N, 23 years)

Three social contextual factors influenced the TDM process:

- Preserving personal identity: our sense of self is physically embodied. Body image is a key facet of self-representation. Although many women traded-off their breast for health and survival, disfigurement significantly threatened their sense of self. Therefore, the surgical decision created a psychological dilemma between cosmesis and survival. The distress of the anticipated body disfigurement, the stigma that the scar represents forever separates these women from those who are normal: *"It was very tough to make the decision. I didn't want to lose my breast. I didn't want to look like an alien. I don't want to be different from those who are normal."* (Miss N, 23 years). In contrast, concerns about a poor cosmetic outcome after BCT discouraged other women: *"I've looked at pictures (of the cosmetic effects with BCT, as well as MRM).... The appearance looks*

rough.... It actually looks better without the breast.” (Miss P, 46 years)

- Preserving personal relationships with significant others: partners' opinions on the treatment options were particularly influential: *“My husband gave me a lot of confidence (in deciding to have bilateral mastectomy). It was very important to know how he thought about the effects of the surgery on our sex life. He reassured me that it was the right decision.”* (Mrs U, 41 years). Older and/or widowed women showed less interest in preserving their breasts and felt 'too old' to worry about their body image and their husband's opinions. *“I am too old to worry about my appearance.... Being attractive is unimportant to me.... It's more important for me to look normal.”* (Mrs A, 60 years)
- Minimising life disruption: many women chose treatment options that were least disruptive to their routines. Most simply wanted to return to normal as soon as possible. *“I chose the surgery based on the one that had the least disruption to my life.”* (Miss E, 36 years)

Adjuvant therapy was viewed as an obstacle to regaining normality and they gambled that MRM minimised their chances of having adjuvant therapy. *“I really don't want to have chemotherapy. I am hoping that having MRM would be good enough.... I'm just hoping for the best.”* (Mrs A, 60 years)

Treatment impact on the family was another consideration. Family obligations dictated decisions considered best for their families.

Seeking and evaluating information

- Family discussions: BC was a family matter. Family members, particularly husbands, played a significant role in the decision making process. *“I mainly discussed with my family. I asked my sisters...as both are nurses. I had great confidence in (them). I was so confused.”* (Mrs U, 41 years)
- Identifying surgeons' preference: those who trusted their surgeons' knowledge and expertise tended to adopt their surgeon's treatment recommendation. *“I followed my surgeon's advice. This was probably the best approach. Nobody knows better than your doctor.”* (Mrs F, 39 years)
- Relating to previous memories: past experiences of friends and relatives who had faced cancer influenced some women's treatment choices. *“My daughter's friend had bilateral mastectomy. She was only 30 years old. I thought if she could accept the surgery, I figured that I could...so I decided to have the MRM.”* (Mrs Q, 57 years)
- Seeking a second expert opinion: second opinions from medical friends or family physicians provided reassurance. *“I asked my surgeon to give me the clinical report and showed it to my medical friend...who is a gynaecologist, as well as my Chinese herbalist. Both of them told me to have the surgery.”* (Mrs I, 63 years)

- Reviewing written materials: written information provided by the hospital was considered impersonal by some women and did not facilitate TDM, *“You couldn't make a decision based on the information (in the pamphlet). It only explained different treatments and the possible effects of the treatments.”* (Mrs B, 36 years)

Time pressure

- All women in the present study felt that they made the decision very quickly. Some women said they were pressured to make a quick decision by health professionals or their families. *“The staff told me to make the decision as soon as possible, the sooner, the better. So I called back within a week.... It was a bit rushed.”* (Mrs B, 36 years)
- Some women wanted the operation as soon as possible, to get rid of the cancer and to return to normal. *“My surgeon told me to take time to think about the options. It was a hard decision. I wanted to have the operation as soon as possible, while I couldn't decide between the options.”* (Mrs J, 59 years)

Consequences of making the treatment decision

Many women were emotionally overwhelmed while waiting for the surgery and their postoperative clinical pathology results.

- Fear of death: Once the decision was made, waiting lists often delayed surgery for 2 to 4 weeks. Preoccupation with fear of death made treatment delays especially difficult to cope with: *“I was very down. I felt hopeless. I thought I didn't have a chance to recover. I was worried that the cancer had spread. I felt very sick. I had pain and hot flushes. I felt that I was waiting for a death sentence.”* (Mrs K, 43 years)
- Paying the price of the treatment choice: women choosing MRM talked about their unwillingness to relinquish their breast. *“I would caress my breasts from time to time. I didn't want to let them go.”* (Mrs U, 41 years). Women who chose BCT suffered greater uncertainty about firstly, whether they would have to undergo MRM due to failed BCT operative margins and secondly, risk of disease recurrence. *“I'm worried about what is going to happen next...the (pathology) report is really the final diagnosis. I know all of the possible outcomes. I heard from other women during the hospitalisation.... It's just worrying.”* (Miss O, 38 years)
- Living in uncertainty: confirmation of the disease stage usually depends on the pathology report, which is not available for several weeks after surgery, forcing women to wait and live in uncertainty. *“I am really worried about my (pathology) report. I didn't ask my surgeon, as I was so afraid that she would tell me bad news.... The prognosis couldn't be confirmed without the report.”* (Mrs K, 43 years)

Coping with the uncertainty

In order to keep from being overwhelmed by fear and uncertainty, women utilised emotion-focused coping strategies.

- Keeping busy: distraction, for instance through work or companionship, was a common strategy. *“(While waiting for the operation,) I continued to go to work. I didn’t let myself think about it. I kept myself very busy. If I stayed at home, I would think a lot of things...all kinds of terrible scenes.”* (Mrs Q, 57 years)
- Being optimistic: a few women described how they managed to think positively: *“I am feeling better after the operation. I told myself that at least I would live for another 5 years. I thought I wouldn’t be that unlucky.”* (Mrs K, 43 years)
- Fatalism: another common strategy used to manage emotions was to adopt a fatalistic stance. *“If it happens, it happens. I am very calm.”* (Mrs A, 60 years)
- Social comparison: upward comparisons with others who seemed to be coping well provided reassurance that they too would be able to cope. *“I met a woman in the hospital. She was having chemotherapy. She seemed to be coping well with the side effects.... She had hair loss and was nauseated as well. But she handled the side-effects very well. I thought if she could cope well, so can I.”* (Mrs Q, 57 years)

Discussion

These data expose the processes women endure in their journey through the breast cancer treatment decision-making process. Deciding on treatment is like gambling, Russian roulette, where the outcome is either death or survival. The implications for clinical practice in the management of women facing breast cancer are that more can be done in the clinical consultation to minimise unnecessary stress and difficulties by ‘tuning’ how women are given information and when this information is given. The data illustrate very clearly that the doctor-patient relationship is at the heart of the provision of

optimal care for these women at this most difficult time.

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