

RESEARCH ARTICLE

The Decision-Making Journey of Malaysian Women with Early Breast Cancer: A Qualitative Study

Adina Abdullah^{1*}, Khatijah Lim Abdullah², Cheng Har Yip^{3,4}, Soo-Hwang Teo^{3,4}, Nur Aishah Taib³, Chirk Jenn Ng¹

Abstract

Background: The survival outcomes for women presenting with early breast cancer are influenced by treatment decisions. In Malaysia, survival outcome is generally poor due to late presentation. Of those who present early, many refuse treatment for complementary therapy. **Objective:** This study aimed to explore the decision making experiences of women with early breast cancer. **Materials and Methods:** A qualitative study using individual in-depth interviews was conducted to capture the decision making process of women with early breast cancer in Malaysia. We used purposive sampling to recruit women yet to undergo surgical treatment. A total of eight participants consented and were interviewed using a semi-structured interview guide. These women were recruited from a period of one week after they were informed of their diagnoses. A topic guide, based on the Ottawa decision support framework (ODSF), was used to facilitate the interviews, which were audio recorded, transcribed and analysed using a thematic approach. **Results:** We identified four phases in the decision-making process of women with early breast cancer: discovery (pre-diagnosis); confirmatory ('receiving bad news'); deliberation; and decision (making a decision). These phases ranged from when women first discovered abnormalities in their breasts to them making final surgical treatment decisions. Information was vital in guiding these women. Support from family members, friends, healthcare professionals as well as survivors also has an influencing role. However, the final say on treatment decision was from themselves. **Conclusions:** The treatment decision for women with early breast cancer in Malaysia is a result of information they gather on their decision making journey. This journey starts with diagnosis. The women's spouses, friends, family members and healthcare professionals play different roles as information providers and supporters at different stages of treatment decisions. However, the final treatment decision is influenced mainly by women's own experiences, knowledge and understanding.

Keywords: Decision making - in-depth interviews - early breast cancer - qualitative study - Malaysia

Asian Pac J Cancer Prev, 14 (12), 7143-7147

Introduction

It is estimated that of the 1.4 million new cases of breast cancer worldwide in 2012, at least 50% will occur in low and middle income countries such as Malaysia (Porter et al., 2008). In many developed countries where population-based screening programmes are the norm, many newly diagnosed breast cancer patients present at an early stage and have a high chance of survival (The Lancet, 2009). By contrast, the majority of women in low and middle income countries present with late stage disease and face poorer survival.

In Malaysia, breast cancer is the most common cancer among women and it comprises 31% of all female cancers (Yip et al., 2011). The 5-year survival ranges from 43.5% to 75.7% (Taib et al., 2011; Ibrahim et al., 2012) in large partly because of late presentation (Taib et al., 2008). From clinical experience, when women do present early,

many do not complete treatment. The reasons for this have not been explored. However a published study, which looked at late presentation, reported one major factor is the patient's belief in complementary and alternative medicine (CAM) in favour of hospital-based treatments (Taib et al., 2008). It was found that 15.5% of women with breast cancer in Malaysia sought CAM, such as nutritional and herbal medicine, traditional Chinese medicine and spiritual healing, prior to visiting a breast cancer clinic (Taib et al., 2007).

Research in predominantly Caucasian women in developed countries has shown that patients want to be involved in treatment decision making (Nakashima et al., 2012) and that attaining their preferred role in decision making leads to better quality of life (Hack et al., 2006). For example, women diagnosed with early stage breast cancer can choose either mastectomy or wide local excision, because these two options have similar survival

¹Department of Primary Care Medicine, ²Department of Nursing Sciences, Faculty of Medicine, ³Department of Surgery, Faculty of Medicine, University of Malaya, Kuala Lumpur, ⁴Cancer Research Initiatives Foundation, Sime Darby Medical Centre, Subang Jaya, Malaysia, ⁵Sime Darby Medical Centre, Subang Jaya, Malaysia *For correspondence: adina@ummc.edu.my

rates, and the choice often depends on patients' preference, such as whether to conserve the breast (Morris et al., 1988; Fallowfield et al., 1994). Studies have found that there is a wide variation in the extent to which patients are involved in decision making (Coulter et al., 2005) and often, patients want to be involved in decision making but are not given the option to do so. In order to involve patients in making treatment decisions, a number of patient decision support interventions, such as patient decision aids, have been developed and these improve decisional quality and patient involvement in decision making (Coulter et al., 2005).

To date, there has been a paucity of information on local women's desire to be involved in treatment decision-making and tools for patient decision support. This has resulted in wide variation on how patients are being supported during decision-making, which may have an impact on their choice of cancer treatment.

We aimed to explore the decision making process of Malaysian women diagnosed with early breast cancer. In particular, we sought to understand how they made decisions regarding different treatment options namely surgery or CAM therapy, and who influenced their decisions and their views. The findings from this study had been used to inform the development of a treatment decision support tool for Malaysian women with early breast cancer.

Materials and Methods

Design

We used a qualitative study methodology to gain an in-depth understanding of the decision making process of a group of multi-ethnic women diagnosed with early breast cancer. A qualitative approach was chosen because it allows us to probe women's beliefs, experiences and views on the complex health issue of decision making (Pope et al., 1995). Women's accounts were captured using individual in-depth interviews. The one to one interview set-up provided a safe environment for the participants to discuss personal and sensitive issues and to express their emotions more freely if necessary.

Setting

The study was carried out at two breast surgical units in Klang Valley, an urban area in Malaysia. One unit was located at a university-based tertiary hospital and the other at a busy Ministry of Health secondary hospital.

Participants, recruitment, sampling

We recruited women who were diagnosed with early breast cancer (Stage 1 or 2) by a breast surgeon; were aware of the diagnosis; and had not undergone surgery, chemotherapy or radiotherapy. The reasons for selecting this specific group of women were to ensure that the information gathered is current and not subjected to recall bias. These also reduce the possibility of rationalization of the decisions by the women once they have undergone the treatments. The background of the women ranged from middle to lower socio-economic class. We used purposive sampling method to recruit women who were at different

stages of decision making (decided vs. undecided) and who preferred different treatment options (surgery vs. CAM therapy). Breast surgeons and nurses from the two hospitals helped to recruit the participants. Sample size was determined by data saturation and interviews were stopped when consensus was reached amongst three researchers that data categories were established and any new data fit into categories already devised.

Data collection

An interview topic guide was developed based on the Ottawa Decision Support Framework (ODSF). We used the factors considered in the decisional needs such as knowledge and expectations, patient values, support and resources to outline the topic guide. Information from other literatures, researchers' clinical knowledge and research experience also informed the topic guide. The interviews were carried out by at least one of the researchers who are trained to conduct qualitative interviews. Interviews were conducted either in the researcher's department or the women's own homes. A research assistant took detailed notes and observed non-verbal cues during the interviews which were used as field notes. We conducted the interviews in Malay, Mandarin and English to capture the experiences of women from different ethnicities. Each interview lasted 40-60 minutes and they were audio-recorded, transcribed verbatim and managed using NVivo 9 software (Richards, 2002). Each transcript was checked for accuracy by another transcriber and used as data for analysis.

Data analysis

Three researchers read the transcripts repeatedly to scrutinise the data before applying the thematic approach to identify the main themes. All three researchers coded two transcripts independently to identify the coding frame. This framework was then used to code two other transcripts individually. This was followed by discussion until a consensus on the common emerging themes was reached.

Ethics approval

This study received ethics approval from the University of Malaya Medical Ethics Committee and Ministry of Health, Malaysia. (MEC Ref. No: 841.6 dated 18th March 2011).

Results

Eight women with early breast cancer participated in this study (Table 1). The findings from our interviews identified four phases that women experienced prior to making a treatment decision. They can be divided into: discovery (pre-diagnosis) phase; confirmation ('receiving bad news') phase; deliberation phase; and decision (making a surgical treatment decision) phase.

Phases towards making a treatment decision

a). **Discovery phase:** this study found that the process of making a treatment decision began before the diagnosis of breast cancer was made. Women started to suspect

Table 1. Sociodemographic Profiles of Eight Women with Early Breast Cancer, Their Decisions and Preferred Roles in Decision Making

	Age	Ethnicity	Marital status	Job	Treatment choice	Preferred role in decision making
Mrs. A	47	Malay	Married	Teacher	Surgery	Shared decision making
Ms. B	64	Chinese	Divorced	Housewife	Surgery	Shared decision making
Mrs. C	55	Indian	Married	Housewife	Surgery	Doctor to make decision
Ms. D	53	Chinese	Divorced	Clerk	Complementary and alternative medicine	Own decision
Mrs. E	41	Malay	Married	Accounts executive	Complementary and alternative medicine	Own decision
Mrs. F	48	Chinese	Married	Teacher	No treatment	Own decision
Mrs. G	50	Malay	Married	Clerk	Complementary and alternative medicine	Shared decision making
Mrs. H	58	Malay	Married	Housewife	Surgery	Family making decision

they might have breast cancer and consider the possible treatment options upon discovering a breast lump or an abnormal mammogram. Some women in our study made a decision to seek alternative medicine before the diagnosis of breast cancer was made. Their decisions were shaped by the positive experiences of their friends or family members who had undergone the treatment successfully.

“So because my sister herself took herbal medicine. Her little lump, after she took it (the herbal medication) and went back to see the doctor, he said that it was gone! No need surgery for the lump”
Ms D, Own decision

“Neighbors or friends, asked you to see that one (particular surgeon) then some people also said that you do not need any treatment and just go to see Chinese medicine practitioner, that is it”
Ms B, Shared decision making

b). Confirmation phase: in this phase, the diagnosis of breast cancer was confirmed and the bad news was ‘broken’ to the women. During the consultation, some women wanted to know more about the reasons why they had breast cancer while others did not know what they needed to know. The women mentioned that they received information about the treatment from their healthcare professionals, who focused mainly on the surgical options. Meanwhile, women who were in distress often received emotional support from their spouses and family members. The support from the healthcare professionals was not highlighted.

“It is his job maybe. He seemed more experienced than my usual doctor. He was straightforward and he did not offer false hope of complete cure. Not cured forever”
Mrs E, Own decision

“So you must not wait! No not another minute, you have to go for surgery immediately, then go for chemo and radio, she (her doctor) said”
Mrs E, Own decision

“I felt empty actually. My doctor told me that it is confirmed to be cancerous and that I should not wait long. I was asked to make a decision there and then. I said no doctor! I cannot just make the decision now”
Mrs E, Own decision

“My husband was with me while waiting to see my doctor about the result. My hands were very cold, only god knows. I said to him don’t leave me alone. He said he will come with me into the doctor’s room”
Mrs A, Shared decision making

c). Deliberation phase: the deliberation phase occurred in between visits to the breast clinic. After returning from the hospital, the women started to look

for more information. The women we sampled looked for information themselves, by reading books, accessing information from the internet and/or mass media. In addition, they also received information from friends and family. The information was used to help them cope as well as to guide them to make decisions about their breast cancer treatment.

“Yes, I do read. In fact, once I was informed of the diagnosis, I went straight to the bookstore to buy a book on cancer. I don’t have anybody else to ask”
Mrs E, Own decision

“How did I come across HL (a complementary faith healer)? It was a coincidence actually. At that time I was looking for answers when he appeared (on television) and talked about alternative treatment for breast cancer. After that a local newspaper also runs an article on him. So I immediately look for him.”
Mrs E, Own decision

“Ah... a breast cancer patient. A friend brought her to see me. Those with cancer and had done surgery wished to come and see people like us. They told us not to be afraid and that we must accept the treatment. You must accept it, she said. I felt better and cheered up after that”
Ms B, Shared decision making

“Yeah, my doctor gave me his number so when I came across this (complementary and alternative medicine) I wanted to call him but I didn’t know when would be the right time to call”
Mrs A, Shared decision making

d). Decision phase: after deliberating different treatment options, the women would make a decision whether or not to proceed with surgical treatment offered by the doctor. Those who chose surgery would then face with another decision of whether to do mastectomy or lumpectomy. Some chose CAM and would consider surgery only after CAM had failed. In this study, women themselves seemed to play the main decisional role.

“I must do the necessary to get better and hopefully recover”
Mrs F, Own decision

“It is my decision. I felt it in my heart also the doctor said I am only at stage 1, so he said I could either take it all out or just the lump. I knew I wanted the surgery, just not sure which one.”
Mrs A, Shared decision making

“Actually I have made the decision to have surgery from home. I just want to take it out. If it is positive (for cancer) I want to take it out”
Mrs A, Shared decision making

“I was thinking, the doctor seemed not to let me prepare it mentally and wanted to get me to the hospital to cut it (out). So I

quickly decided and said, I do not want to remove it first, please let me find another treatment option, please can you give me a little time?"

Ms D, Own decision

Discussion

This study offered insight into how women with early breast cancer in Malaysia make treatment decision. We identified four phases in their treatment decision making: discovery; confirmation; deliberation; and decision phase.

Results from this study found that treatment decision making process commenced when women discovered an abnormality in their breasts. Some of the women we interviewed were exposed to CAM early on in their help-seeking effort. This may influence their subsequent treatment decisions. We found the women in our study, similar to previous studies went on an information-seeking journey once they confirmed their diagnoses; regardless of their preferred treatment options. Studies show information helps women to understand their diagnoses and to help them make treatment decisions (Butow et al., 1997; Thibodeau et al., 1997; McWilliam et al., 2000). In addition, information also helps women to gain a sense of control over their situation, reduce anxiety, change their behaviour and formulate a plan for the future (Henman et al., 2002).

Another important observation is that women's main source of information and support changes at different phases of the decision making process. Women's spouses, friends, family and healthcare professionals all played different roles at different time their treatment decision. After the women had been told of the diagnosis, the main source of information on the benefit and disadvantages of treatment was from healthcare professionals. This is similar to previous studies in which healthcare professionals are found to be the most common and preferred source of information for cancer patients facing treatment choices (Mills et al., 1999; Rutten et al., 2005). In a 2004 paper, Rutten et al reviewed 112 articles published from 1980 to 2003 summarizing cancer patients' information needs and their sources and they found the most frequent information need was treatment-related (38.1%) and most frequent information source was health care professionals (27.3%) (Rutten et al., 2005). When the bad news is broken, the women looked to their spouse or family members for support. Some women in our study found the information given at diagnosis overwhelming; others were unsure of what they needed to know and, hence were unable to assess the adequacy of the information given by their healthcare professionals.

In between visits to the breast surgeon, women with early breast cancer deliberated on the decision that they had made. In our study setting, surgical treatment dates were given to the women at the time the diagnosis was revealed and the duration between that consultation and the surgery ranged from 2-4 weeks. Women looked to their family, friends, media and internet sources for more information. The women also reported that they received advice from family members and friends without it being solicited. These advices usually pertained to the use of CAM. This finding concurred with other local studies

which found that friends and family play a pivotal role in influencing patients to seek CAM (Hasan et al., 2009; Mazanah et al., 2012). Healthcare professionals did not openly discuss the option of CAM; this might have hindered the women from discussing this treatment option, which is popular in the Asian context (Taib et al., 2007). Another barrier women faced while making treatment decisions, was the lack of timely support from healthcare professionals when the needs arose. Studies have found that patients need time to deliberate, gather information about the pros and cons of the treatment options and be given the opportunity to clarify their doubts to make a more informed decision (Mills et al., 1999). However, health care professionals are not equipped with the skills to provide decisional support to patients due to the lack of awareness, knowledge and skills, concerns about time and resource pressures (Ford et al., 2002).

Findings from this study will help in the development of an intervention that could potentially support women with early breast cancer to make a treatment decision in Malaysia. Recruiting women from two sites also increase the range of views sampled as both sites have different work processes and supporting staff. For example, at one of the breast clinic trained breast surgeons with a team of breast care nurses who were proficient in their interactions with women with breast cancer ran the clinic. Whereas, in the other clinic there was only a non-specialist doctor who performed breast surgery, and there was almost no dedicated breast care nurse to support women with breast cancer. Due to this, we managed to explore the healthcare system factors that could have potentially influenced treatment decision making.

There are a few limitations in this study. Only women from the states of Kuala Lumpur and Selangor were included in this study. The belief and decision making process for women in other states particularly from the East Coast of the peninsula and East Malaysia may be different as women in these states were thought to be more passive in their role of decision making. We attempted to recruit women from these states but the response was poor. This limits the transferability of the study findings. The views from the healthcare professionals would help to further explore the decision making process of women with early breast cancer from doctors' and nurses' perspectives. Information captured from both of these sources could work synergistically to strengthen the intervention such as a Patient Decision Aid that we were planning to develop. A qualitative study has been conducted with the healthcare professionals and the findings will be reported separately.

In conclusion, the process of making a treatment decision is complex. This study offers a preliminary understanding of the factors that influence treatment decision-making in women with early breast cancer. We discovered four phases in which women with early breast cancer go through to arrive at the treatment decision. In each phase, these women are faced with issues of gathering information, garnering support and weighing the pros and cons of the different treatment options. We found that women seek information from different sources to support their final decision. Women's past experience, knowledge

and social influences are important in influencing the treatment decision. These findings would allow us to develop strategies to support women in making a more informed decision in the local context.

Acknowledgements

This project was funded by CARIF and the HIR Grant UM.C/HIR/MOHE/06 from the Ministry of Higher Education of Malaysia. The authors would like to acknowledge the hard work of Madam Lee Sian Boy in organising the data collection phase of the study, Miss Elaine Seymour for proofreading the manuscript and all the breast surgeons and breast care nurses from University Malaya Medical Centre and Hospital Tengku Ampuan Rahimah, Klang. Very special thanks to all the women involved in this study for allowing us to interview them during the most difficult journey of their lives.

References

- Butow PN, Maclean M, Dunn SM, Tattersall MHN, Boyer MJ (1997). The dynamics of change: Cancer patients' preferences for information, involvement and support. *Ann Oncol*, **8**, 857-63.
- Coulter A, Jenkinson C (2005). European patients' views on the responsiveness of health systems and healthcare providers. *Eur J Pub Hlth*, **15**, 355-60.
- Fallowfield LJ, Hall A, Maguire P, Baum M, A'Hern RP (1994). Psychological effects of being offered choice of surgery for breast cancer. *BMJ*, **309**, 448.
- Ford S, Schofield T, Hope T (2002). Barriers to the evidence-based patient choice (EBPC) consultation. *Patient Educ Couns*, **47**, 179-85.
- Hack TF, Degner LF, Watson P, Sinha L (2006). Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psycho-Oncol*, **15**, 9-19.
- Hasan SS, Ahmed SI, Bukhari NI, Loon WCW (2009). Use of complementary and alternative medicine among patients with chronic diseases at outpatient clinics. *Complement Ther Clin Pract*, **15**, 152-7.
- Henman MJ, Butow PN, Brown RF, Boyle F, Tattersall MHN (2002). Lay constructions of decision-making in cancer. *Psycho-Oncol*, **11**, 295-306.
- Ibrahim NI, Dahlui M, Aina EN, Al-Sadat N (2012). Who are the breast cancer survivors in Malaysia? *Asian Pac J Cancer Prev*, **13**, 2213-8.
- The Lancet (2009). Breast cancer in developing countries. *The Lancet*, **374**, 9701, 1567.
- Mazanah M, Sharan M, Norhasmilia S (2012). Why Breast Cancer Patients Seek Traditional Healers. *Int J Breast Cancer*, **2012**, 689168
- McWilliam CL, Brown JB, Stewart M (2000). Breast cancer patients' experiences of patient-doctor communication: a working relationship. *Patient Educ Couns*, **39**, 191-204.
- Mills ME, Sullivan K (1999). The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *J Clin Nurs*, **8**, 631-42.
- Morris J, Royle GT (1988). Offering patients a choice of surgery for early breast cancer: A reduction in anxiety and depression in patients and their husbands. *Soc Sci Med*, **26**, 583-5.
- Nakashima M, Kuroki S, Shinkoda H, et al (2012). Information-seeking experiences and decision-making roles of Japanese women with breast cancer. *Fukuoka Igaku Zasshi*, **103**, 120-30.
- Pope C, Mays N (1995). Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*, **311**, 42-5.
- Porter P (2008). "Westernizing" Women's Risks? Breast Cancer in Lower-Income Countries. *N Engl J Med*, **358**, 213-6.
- Richards L, Morse JM (2002). *Readme first for a user's guide to qualitative methods*. Thousand Oaks, London, New Delhi: Sage
- Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J (2005). Information needs and sources of information among cancer patients: a systematic review of research. *Patient Educ Couns*, **57**, 250-61.
- Taib NA, Yip CH, Ibrahim M, Ng CJ, Faridah H (2007). Breast cancer in Malaysia: Are our women getting the right message? 10 Year-Experience in a single institution In Malaysia. *Asian Pac J Cancer Prev*, **8**, 141-5.
- Taib NA, Yip CH, Mohamed I (2008). Survival analysis of Malaysian women with breast cancer: Results from The University of Malaya Medical Centre. *Asian Pac J Cancer Prev*, **9**, 197-202.
- Taib NA, Akmal M, Mohamed I, Yip CH (2011). Improvement in survival of breast cancer patients-trends over two time periods in a single institution in an Asia Pacific country, Malaysia. *Asian Pac J Cancer Prev*, **12**, 345-9.
- Thibodeau J and MacRae J (1997). Breast cancer survival: A phenomenological inquiry. *ANS Adv Nurs Sci*, **19**, 65-74.
- Yip CH, Cazap E, Anderson BO, et al (2011). Breast cancer management in middle-resource countries (MRCs): Consensus statement from the Breast Health Global Initiative. *Breast*, **20**, 12-9.