

Decision Making in Breast Cancer Treatment: A Qualitative Inquiry

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ABSTRACT

For breast cancer patients, making decisions are integral to cancer diagnosis, treatment and prevention of recurrence. In order to make these decisions, cancer patients require appropriate and relevant information or guide. These decisions can also be influenced by external and internal factors. To get an insight into decision making related to breast cancer treatment from the perspective of breast cancer patients and survivors, a series of focus group discussions (FGD) were conducted with 36 informants of the Chinese and Malay ethnicities. The informants were recruited from breast cancer support groups in the northern, central, southern and eastern regions of Peninsular Malaysia. The following research questions guided the FGD. These were (1) Who make (s) decision on cancer treatments?, (2) What guide (s) the decision making?, and (3) What influence (s) the decision? For most informants, the primary decision maker in their cancer treatment was themselves. However, these decisions were made upon advice and support from the physicians, family members and friends. The informants stated that information from physicians, family members, friends, internet, books and magazines also served as guidance to decision making on cancer treatment and management. Following the physicians' advice, having the knowledge on breast cancer, taking care of family members and wanting to live longer to fulfil personal goals were also mentioned by these informants as factors which had influenced their treatment decision making. Further research using a quantitative approach is therefore recommended to confirm the findings of this study.

Keywords: Decision-making, breast cancer treatment, breast cancer management, cancer information

INTRODUCTION

Breast cancer is becoming a major health challenge for women all over the world, including Malaysia. It is among the leading causes of cancer morbidity and mortality among women worldwide. Although Malaysia is among countries with the lowest age-specific incidences of breast cancer, it is the commonest disease among the women in Malaysia and this accounted for 31.0% of all the female cancers in 2003 (Lim and Halimah, 2004). In the same year, the incidence rate of breast cancer was 39.5% per 100,000, with the

highest incidence rates found among the Chinese (64.8%), followed by Indians (46.4%) and Malays (26.3%). At present, there is no national data on the survival rate for breast cancer patients. However, the 5-year survival rate for patients gathered in Universiti Malaya Medical Centre, between 1993 to 1997, showed that the incidence was lowest in the Malays (46%), followed by Indians (57%) and the highest was found among the Chinese (63%) (Yip *et al.*, 2006). The ethnic differentials in survival rate could be explained by the fact that Malay women tended to present

with later stages of breast cancer, perhaps due to pervasive cultural perception of the disease and its treatment which eventually delayed their diagnosis (Hisham and Yip, 2003).

For breast cancer patients, making decisions is an integral part in their cancer diagnosis, treatment and prevention of recurrence. The process is rather complex, as it can be influenced by many factors such as the involvement of other individuals in decision making, the availability and accessibility of diagnostic and treatment options, the availability of information and resources to assist decision making, as well as patients' own perceptions and beliefs in relation to the disease or treatment, and whether the disease is life-threatening. However, in today's environment, as well as the fact that patients are increasingly assuming the role as consumers of health care, many want to have the rights to information and active participation in medical decision making (Mills and Sullivan, 1999).

Charles and colleagues (1999) outlined three models of decision making involving the participation of mainly the physicians and patients. The paternalistic model is physician-centred, shared model stressed on joint decisions of patient and physicians and informed model is patient-centred. These models may differ in relation to the analytical stages of the decision making process, namely the information exchange, deliberation and decision on the treatment to implement. According to the paternalistic model, patients preferred having their physicians to make decisions for them (Beaver and Luker, 1998; Butow, Maclean, Dunn, Tattersall, and Boyer, 1997). The model also assumes that physicians know best and will make the best treatment decisions for the patients. In the shared model, the patients make decisions jointly with their physicians (Masood, 2002; Keating, Guadagnoli, Landrum, Borbas, and Weeks, 2002). As such, both the physicians and patients participate in a two-way discussion which may involve negotiations. However, in the Asian context, the shared model is extended to include family in the decision making processes (Blackhall, Murphy, Frank, Michel, and Azen, 1995; Ruhnke, Wilson, Akamatsu, and Kinoue, 2000). Several studies have also supported the informed model on treatment decision, in that patients made their own decisions independent of other individuals, including physicians and family members (Janz, Wren, Copeland, Lowery, Goldfarb and Wilkins, 2004; Leight, Butow, and

Tattersall, 2004). The physicians' role is limited to only as providers of information, with no further participation in the decision making process.

To be active participants in making decisions related to their care, cancer patients must be knowledgeable on the disease, treatment options and disease management. This requires them to have relevant and accurate information, as well as good comprehension of the information. Patients may obtain the necessary information from various sources, which can be categorized into three groups, namely the mass media, groups and organizations and health professionals. Among the sources of media-type information, sought by cancer patients, are printed materials (Rager, 2003), books (Satturlund, McCaul, and Sandgren, 2003), radio advertisements (Sent, Ballem, Paluck, Yelland and Vogel, 1998), videos (Satturlund *et al.*, 2003) and television commercials (Davis, Lee, Jarvis, Zorbas and Redman, 2003). As internet is increasingly accessible, it is becoming a popular source of unlimited health and medical information to many people, including breast cancer patients (Norum, Moen, Balteskerd, Holthe, 2003; Rotmovits and Ziebland, 2004; Satturlund *et al.*, 2003; Thomas, Stamler, Lafrieniére, Out and Delahunt, 2002; Williamson and Manaszewics, 2003; Ziebland, 2004). Community programs, support groups and cancer organizations have also been reported to be important sources of information to cancer patients (Davis *et al.*, 2003; Rager, 2003; Klemm, Bunnell, Cullen, Soneji, Gibbons and Holecek, 2003). Among health professionals, physicians (Chen and Siu, 2001; Davis *et al.*, 2003; Schaffner, 2002) and nurses (Norum *et al.*, 2003) had also been identified as important providers of cancer treatment information.

By drawing upon Janis and Mann's (1977) Conflict Theory of Decision Making, the literature review on factors influencing treatment decision making of breast cancer patients can be categorized into internal and external factors. While the internal factors are related to the individuals' attitude, knowledge, values and emotions, the external factors include culture, religion, availability of and accessibility to resources and health care, disease condition as well as socio-economic and demographic variables (Rager, 2003; Weinberger and Schmae, 1996).

Despite the increasing prevalence of breast cancer in Malaysia and the importance of decision making for breast cancer patients, there is no

documented empirical data on the subjects in the Malaysian context. Thus, this study aimed to address the need, and for this, it was guided by the following research questions: (1) Who make(s) the decision on cancer treatments?, (2) What guide(s) the decision making?, and (3) What influence(s) the decision?

METHODS

To understand breast cancer patients and survivors' treatment decision making from their perspectives, a qualitative research design was employed. The qualitative research focuses on inductively uncovering meaning from the informants' viewpoint (Bogdan and Biklen, 1998; Merriam, 1998). While various modes may be utilized to capture evidence in a qualitative study, this present study employed focus group discussion (FGD). This section gives a brief description of the methodology, which includes the development of question guide, the data collection, and analytical procedure.

Focus Group and Questions

A series of five focus group discussions were conducted with 36 breast cancer patients and survivors from the breast cancer support groups, in four states representing the East, Central, North, and South Peninsular Malaysia: Kelantan (Kelantan Family Planning Association), Selangor (Kanser Network), Pulau Pinang (Lam Wah Ee Hospital Breast Cancer Support Group) and Johor (Johor Bahru Breast Cancer Support Group). A focus group discussion was conducted in each state, except for Pulau Pinang, in which 2 focus group discussions were conducted.

Upon the approval from the Ethics Committee of the Faculty of Medicine and Health Sciences, all the 4 breast cancer support groups were contacted so as to obtain their permission to conduct the focus group discussions. The support group leaders invited the group members and made arrangements for the focus group interviews. Prior to each discussion, the informants were briefed on the topics and procedures of the discussion, and were informed that their participation was voluntary. Each informant was requested to sign a consent form before participating in the focus group discussion.

As the purpose of a qualitative research is to obtain the perspectives of the informants, the selection criterion for the focus group

informants was based on the rich experience of each informant who could provide answers to the research questions outlined in the present research. The number of informants, in each focus group, was kept in the range of 6-9, as the range only permitted a dynamic group interaction, yet allowed for the moderator to effectively manage both the discourse and the informants. Each focus group was homogenous only in relation to the informants' breast cancer experience, but not in other characteristics (e.g. age, ethnicity, education level and stage of cancer). In a qualitative research, data are collected until saturation point is achieved or no new information emerges. Thus, in this study, conducting five focus group discussions was deemed as adequate in providing the required information.

Each focus group was facilitated by trained moderators and it ran for approximately 2 hours. Discussions were conducted in Bahasa Melayu. To ensure clarity, Chinese speaking translators assisted the Chinese informants who were not proficient in Bahasa Melayu. All focus groups discussions were audio-taped. To complement the recorded discussion, the moderators cum researchers also took field notes of their observations and findings.

The focus group question guide was developed by the research team so as to address the following research questions:

1. Who make(s) decision on breast cancer treatment or management?
2. How do women with breast cancer make decision on breast cancer treatment?
3. What influences their decision on breast cancer treatment?

The development of the focus group questions was initially guided by the 'Health Belief Model' (HBM) (Becker, Drachman, and Kirscht, 1974). The HBM has frequently been used in health behaviour applications to help explain a variety of factors which influence health behaviours and actions. This model was supplemented by the conceptual framework, as reported in the 'Introduction' section of this paper. The refinement was also based on the feedback gathered from four informants (breast cancer survivors not included in any of the focus group discussions) before the actual focus group interview was carried out. A semi-structured focus group question guide was utilized in the discussions to ensure consistency in the

responses among groups and to allow flexibility for the informants to share their perceptions and experiences. Below are some of questions which were used to guide the focus group discussion:

“For each treatment that you received, who made the decision?”

“How did you decide for your own treatment?”

“What made you go for the treatment?”

“How did you obtain information on breast cancer?”

“What types of information on breast cancer did you seek for?”

“What made you obtain the information on breast cancer?”

Data Analysis

The taped focus group discussions were transcribed verbatim by a research assistant. For completeness and accuracy of the transcripts, another research assistant listened to the tapes and reviewed the transcripts. Finally, the focus group moderators reviewed the edited transcripts. For each focus group, the responses to each question were grouped together and read for emerging themes. Themes within a group were defined as responses agreed by half or more of the group members. The key findings were themes which arose in majority (≥ 3) of the groups.

RESULTS

This section reports on the informants' perspectives on their decision making in breast cancer treatment. The presentation is organized according to three themes, namely (1) Persons involved in decision making, (2) Sources and forms of information in decision making, and (3) Factors that influence decision making. The informants' brief profile was also included. The responses gathered from the informants, quoted in this section, were then translated from Bahasa Malaysia.

The Informants

The FGD was attended by 36 informants – 10 (Johor Bahru Breast Cancer Support Group), 8 (Kelantan Family Planning Association), 12 (Lam Wah Ee Hospital Breast Cancer Support Group) and 6 (Kanser Network). These informants were from two ethnic groups, Chinese (56.3%) and Malay (43.7%). The mean age of the informants was 50.9 ± 7.6 years and these ranged from 36 to

65 years old. All the informants received some forms of education (primary school-18.8%, lower secondary-18.8%, upper secondary-28.1% and college or university-33.3%). A majority (79.3%) of the respondents reported that they were diagnosed with an early stage cancer (27.6% stage 1 and 51.7% stage 2). The remaining 20.7% (n=6) were in stage three. In addition, all the informants had undergone surgery (lumpectomy/mastectomy) and radiotherapy. A majority (93%) of these informants had also received chemotherapy, while 50% were on hormonal treatment. The survival period ranged from 12 to 128 months, with a mean of 43.6 ± 29.0 months.

Persons Involved in Decision Making

All groups indicated that decisions on breast cancer treatment were mostly done by the women themselves, based on the recommendations and/or discussions with their physicians. Many of these women also reported that they had discussed with their family members (husbands and children), after the consultation with their physicians. There were, however, several women who made the decisions independent of their family members, or they let the physicians or husbands to make the decisions for them. Below are some examples of their responses:

“I decide myself. ...For surgery at first I discuss with Dr. A. After he explained I feel OK. I also discuss with my husband”

“I felt that if you are on your own, without the doctor's advice, you still cannot decide”

“Dr. B explained ... and recommended surgery. ... I asked my three children. They said it is up to mama. ... I think about it for two weeks. I went back to see Doctor B. Doctor, I will do the surgery. (The doctor said) Aaa... very good, very good”

“My husband said lets discuss... But I made the decision. I do not want them to make the decision because if there is any mistake, they will blame themselves”.

“I made the decision myself because I am the one who is sick. My husband has no medical knowledge so if I were to discuss with him, he may not understand”

“Doctor decided for me. But I did asked what treatment he gives. He said ... I agreed”

“The doctor decided for me and I did not decide for myself. I know I am a nurse and I know about cancer but I am scared to come forward”

“My husband made the decision without asking me. He came with me to the hospital to see the physician but he made the decision and not me”

Sources and Forms of Information in Decision Making

Physicians, printed materials (books, magazines, newspapers, and pamphlets) and family members or friends with cancers were cited as the primary sources of information on breast cancer by almost all groups. Professional training in nursing, internet, exhibitions, and seminars on breast cancer were also mentioned as the sources of breast cancer information by several women. There were a few women who mentioned that their physicians had only instructed them to go through the treatment without giving any information on breast cancer. Moreover, they also did not attempt to find information on breast cancer on their own. Samples of the responses given by these women are listed below:

“I went to the internet to look for information and also read magazines and newspapers. And my doctor is very good because he explained all my options.”

“I bought many books. There is one book which condemns chemotherapy ... it says that chemotherapy is not medicine to treat you but to make your condition worst.”

“My niece, sister and friends have cancers. I know about cancer because I have a lot of experience.”

“I know already about cancer as I am a nurse ... so I did not go and find other information.”

“The doctor removed the cancer but did not tell me that it was breast cancer until I joined this support group.”

Most of these women reported that the information on cancer treatment options (lumpectomy, mastectomy, chemotherapy, radiotherapy) as well as their side-effects and nutrition (types of food which are allowed and to be avoided during treatment, food that causes cancer) were important to assist them in making decisions related to breast cancer treatment or management. However, there were few informants who mentioned that they shunned detailed information on their disease condition

and management. Motivation, prayers, care for breast cancer patients and survivors (surviving cancer), cure or remedies for cancer, about breast cancer (what is it, what causes it) and exercises were also mentioned by many women. Below are some examples of these women's responses:

“As for me, I want to know what the disease is all about. And then what is the treatment. I read as much as I can on all the different types of treatment. I want to be prepared.”

“During and after treatment ... what should I eat and what foods cannot be eaten.”

“From a book on motivation, it says that cancer does not mean you will have a short life. Instead, it gives you hope to live.”

“I read on how women with breast cancer can live long and healthy.”

“I want to know how to take care of myself and how to cure this cancer.”

Factors Which Influence Decision Making

All groups identified wanting to lead a longer, healthier and enjoyable life as their primary motivator for them to undergo the breast cancer treatment. They wanted to prevent recurrence and be able to see their children grow, get married and have their own children, pay more attention to their family members, visit places and people, and help other people (e.g. breast cancer patients). Other than these, trust in their physicians that the medical treatment is the best choice for them, knowledge on breast cancer and experience with friends and family members with cancers were also reported by many women as factors which had influenced their treatment decisions and behaviours. Below are some excerpts of the informants' perspectives on what had influenced them in their decision making:

“I want to live longer ... I want to see my children go to universities and get married.”

“I have to take care of my self, my body, my health so that I can do a lot of things I can share with everyone.”

“When I have cancer, I see death and it reminded me of what I have done for the past 20 years. Anything can happen to me. I want to live. I want to have a more meaningful life.”

"From my experience looking at friends and people with cancer:when they came in too late to get treatment and I thought long about it I felt that I just want to get rid of my cancer as fast as I can."

DISCUSSION

The discourse is presented according to the themes which address the research questions of the current study; (1) Persons involved in decision making, (2) Sources and forms of information which assist decision making, and (3) Factors that influence decision making.

Persons Involved in Decision Making

Even though the majority of these informants reported that they made cancer treatment decisions themselves, these decisions were actually guided by their physicians' recommendations and discussions with them and family members. The findings gathered in the current study seemed to support the 'shared model' in which the decisions were made as collective efforts of the patients, physicians and family members (Masood, 2002; Keating *et al.*, 2002; Ruhnke *et al.*, 2000). There were also several informants who reported that the decisions on the cancer treatment were made by their physicians or husbands. This paternalistic approach was also reported by Beaver and Luker (1998) and Butow *et al.* (1997).

Due to its qualitative design, this study did not attempt to examine the association between the patients' socioeconomic and demographic profile, and cancer stage with the types of decision making. However, the 'shared model' prevalent among the informants could possibly be explained by the informants' relatively younger mean age and the high percentage of informants with moderate to high education level (61%) and with early stage cancer (79.3%). Several other studies have shown that older and less educated patients and those with worsening disease conditions were less likely to participate in active decision making (Butow *et al.*, 1997; Sekimoto, Asai, Ohnishi, Nishigaki, Fukui, Shimbo and Imanaka, 2004).

Sources and Forms of Information in Decision Making

The study revealed that the informants did draw upon available information on cancer treatment and management when making decisions. Most of the sources of information reported are similar to those documented in the literature. Informants who could draw upon available printed materials,

almost all of them had received some forms of education. The role of family members and friends, as the primary sources of information, suggests the informants' reliance on close inter-personal communication network. Other sources, such as professional training in nursing, and exhibitions and seminars on breast cancer identified in the study, reflect the role of the non-formal education in decision making. The fact that some physicians instruct patients to go through treatment without giving them relevant information suggests the presence of paternalistic model in treatment decision making (Charles *et al.*, 1999).

The types of information sought by the informants were also similar to those reported in the literature. A systematic review of 18 studies on the information needs of cancer patients (Anken, 2005) revealed that disease-related information (e.g. diagnosis, chances of cure, spread of disease, prognosis and signs of recurrence) and treatment-related information (e.g. treatment options, progress during treatment, treatment side-effects) were indicated as most important to cancer patients. However, priorities for the types of information might also depend on various factors such as age, time since diagnosis, patients' preference for a role in decision making, education level and gender.

There were few informants who reported that they did not want to know detailed information on their cancer condition and management. Leydon and colleagues (2000) found that cancer patients might shun detailed information on their disease condition and treatment as they regarded the information as potentially threatening to them. The authors concluded that not all cancer patients wanted to have detailed information or to know everything about their disease all the time as these might only increase their anxiety and fear or could even challenge their faith and hope.

Factors which Influence Decision Making

As suggested by Janis and Mann (1977), this study identified two factors which might have influenced cancer treatment decision-making, namely internal and external factors. The reported internal factors include motivation to lead a longer and healthier life, to prevent recurrence, and to be able to visit places. Nevertheless, these findings are different from the internal factors suggested in the literature, such as fear (Frisby, 2002), grief and anxiety (Dwyer, 1993). There are several

possible explanations for these different findings. First, emotional distress may be the initial reaction to diagnosis of breast cancer. However, these negative emotions may be overcome once the women become knowledgeable of the disease and its management. Second, the literature, reporting on internal factors such as fear, anxiety, depression and grief, has been on breast cancer patients and survivors in the western culture. Perhaps, cultural values may play a role in influencing treatment decision makings.

Other internal factors observed in the study are related to family values, such as the informants' desire to see their children grow, get married and have their own children. According to Rokeach (1973), the antecedents of human values can also be traced to culture and society. Indeed, culture shapes meaning and decisions people make in their lives. Thus, the finding on family values, as internal factors, suggested the role of culture in the informants' treatment decision making. This finding is congruent with the findings reported by Hisham and Yip (2003), Lee and Wu (2002), Muller and Desmond (1992), Ruhnke *et al.* (2000) and Sent *et al.* (1998).

Perceived credibility of physicians has also been reported as an important external factor in influencing patients' treatment decision making (Fogarty, 1996). In the present study, patients were found to put their trust in the decisions or judgments of physicians which later guided their own decision making due to the physicians' knowledge and experience in medical care. Other external factors reported in this study include knowledge on breast cancer from various sources and the interaction with other breast cancer patients.

This study is not without limitations. As with any qualitative study, generalization of the findings from focus group discussion is rather limited. In particular, the small number of support group members participating in the focus group discussion, at each site and their different demographic and socioeconomic as well as cancer stages, had made it difficult to have homogenous groups based on these variables. Nevertheless, the heterogeneity of the group members contributed to the wealth of information produced from the dynamic discourse. As the participation of the informants was voluntary, there might be a bias in that those participated in the focus group discussions were pro-active than non-participants. This could eventually influence the findings on the

treatment decision making. With the mentioned limitations and the inquiry is qualitative in nature, the findings obtained from this study still need to be confirmed in future research using quantitative approaches.

CONCLUSIONS

In many life-threatening situations where decisions have to be made, individuals are faced with many choices which require conscientious deliberation. However, these decisions are rarely made independently. Similarly, it was found that women with breast cancer in this study made their decisions on breast cancer treatment or management upon the advice and support from other individuals (e.g. physicians, family members and friends) and the possession of information related to breast cancer. In addition, the underlying forces which compelled these women to undergo breast cancer treatment were their desire to live a longer and lead a meaningful life for themselves and their family members. The findings also suggested that the treatment decisions were not made solely by the patients or the physicians, but were done through collective efforts of both parties, which was regarded as appropriate, relevant sources and forms of information contributed to the decision making, and cultural values influenced the decision making process.

One of the factors which was revealed to affect breast cancer survival was treatment. At present, various treatment options are available to breast cancer patients. Thus, for a women diagnosed with breast cancer, her survival is greatly affected by the decision made on the treatment options. The findings from this study could contribute to information on the strategies to assist breast cancer patients and other individuals or stakeholders, involved in cancer treatment and management, in making informed decision related to the disease. These strategies may include strengthening the breast cancer education program for patients, survivors and other stakeholders and improving the communication and interaction between the patients and primary health care providers.

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The stage (extent) of your breast cancer is an important factor in making decisions about your treatment. Most women with breast cancer in stages I, II, or III are treated with surgery, often followed by radiation therapy. Many women also get some kind of drug therapy. In general, the more the breast cancer has spread, the more treatment you will likely need. But your treatment options are affected by your personal preferences and other information about your breast cancer, such as: If the cancer cells contain hormone receptors.