

ORIGINAL ARTICLE**THE DIFFERENCES BETWEEN THE QUALITY OF LIFE OF MALAYS AND NON-MALAYS BREAST CANCER SURVIVORS WOMEN FROM A TEACHING HOSPITAL, KUALA LUMPUR: A QUALITATIVE STUDY**

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ABSTRACT

Introduction : The purpose of this study is to explore the differences of quality of life (QOL) of Malay and non-Malay breast cancer survivors using qualitative method.

Methods : Data was collected using in-depth face to face interview. List of the patients were obtained from Oncology & Surgery Departments and contact numbers were obtained from the medical record. The interviews were conducted either in their home or in the hospital after the appointment has been made.

Results : The majority of the Malays were unable to fulfill the needs of their families. However, the non-Malays were able to fulfill the needs of their families. The majority were satisfied with social interaction and the relationships with their families and friends. In terms of feelings, most survivors felt sad, angry and sometimes they feel like they were going to die early. However the majority coped well with their illness. Regarding sleep, all Malays did not have any sleeping problems, but most of the non-Malays reported serious problems. All survivors were worried about the other female members of the family of getting the same illness. Most survivors did not have any problems with altered body image.

Conclusion : Malays did not have any sleeping problems, but most of the non-Malays reported serious problems. However, the majority of survivors coped well with their illnesses.

Keywords : Quality Of Life, Breast Cancer, Qualitative, Malaysia.

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INTRODUCTION

Breast cancer is the commonest cancer worldwide and the second commonest cancer among Malaysian women⁽¹⁾. In the year 2002, the number of newly diagnosed cases was estimated to be more than a million, and there were more than 400,000 deaths worldwide. Mortality rates from breast cancer have increased in the past 60 years in every country⁽²⁾. Almost one third (32%) of all new cancer cases and 18% of cancer death in women were related to breast cancer³. In Malaysia, the incidence rate of breast cancer in Malaysian women was 46.2 per 100,000 population¹. Breast cancer is commoner amongst Chinese and Indian women compared to Malays in Malaysia. Breast cancer in Malaysia could be considered as the leading cause of cancer death among women⁴. However the rate differs between the three main races. The age-standardized rate in Chinese was the highest at 59.7 per 100,000 followed by the Indians at 55.8 per 100,000. The Malays have the lowest incidence rate of 33.9 per 100,000. This figure translates as 1:14 among Chinese women, 1:15 among Indians, and 1:24 among Malays will develop breast cancer at some stage in their lives¹. Overall, 1 in 20 women in Malaysia will develop breast cancer in their lifetime.

Quality of life (QOL) is a multidimensional concept that assesses physical, functional, psychological/emotional, and social well-being in relation to health^{5&6}. Studies that include ethnic minority women (African American) have found that breast cancer and its treatments result in physical, economic and employment problems, familial and marital relationships challenges, and concerns with body image and sexuality⁷. Additionally, studies investigating Latino cancer patients' QOL found that cultural beliefs, family and religion have significant impact on QOL, including pain expression and management^{8&9}. Cultural beliefs regarding family role, women's roles, perceptions of husband support, and concepts of self-image differentially impacted Asian American and Caucasian women's experience with cancer⁸⁻¹³. Studies concerning patients with breast cancer found a decrease in QOL due to side effects of treatments and pain^{14&15}. Other studies found that depression is correlated with reduced QOL in cancer patients^{16&17}. However, psychological problems and inadequate role functioning appear to have a greater influence on QOL compared with the effects of physical problems¹⁸. For instance, in a study of cancer patients, Redeker et al¹⁹ found that insomnia, fatigue, anxiety, and depression were negatively correlated with QOL. Other studies found that high levels of depression or distress appeared to

be related not only to QOL, but also to increasing the costs of health care^{20&21}. A quantitative study on QOL among Malaysian breast cancer patients have been conducted by Redhwan et al²². No previous study conducted about the perceptions of QOL among different ethnic groups in Malaysia. The purpose of this study is to explore the differences of quality of life of Malay and non-Malay breast cancer survivors.

METHODOLOGY

In-depth semi-structured face-to-face interviews were conducted with 10 Malaysian women (5 Malays and 5 non-Malays). The samples include Malaysian women who were diagnosed with breast cancer at any stage, one year or more after diagnosis. They were no longer on active treatment such as chemotherapy, surgery, or radiation therapy i.e. one year since initial diagnosis. Women taking tamoxifen (n = 4 non-Malay) (n = 5 Malays) were included in this study because it's considered a noninvasive treatment. List of survivors were obtained from the Oncology & Radiotherapy Department and Surgery Department. Then the patient's files were traced in the Medical Record Department to obtain their contact numbers. They were contacted through phone and were asked to be interviewed. Those who volunteered were explained of the purpose of the study, and a written informed consent was obtained. At the beginning of the meeting, the interviewer introduced himself, briefly repeated the study purpose, reviewed the elements of informed consent, and asks the patient to sign the informed consent document. They were explained that their voice was going to be recorded, and that the interview will take approximately 60 minutes. The patients were interviewed between March and July 2007. Once a patient was screened for eligibility and had verbally given their consent by phone to the interview, an appointment for a face to face in-depth interview was arranged. Participants were interviewed in their own home or in hospital. The interview was conducted solely by the main researcher using a semi-structured interview format. A semi-structured interview was used to guide the participants in a discussion about the following topics: (1) How do you perform your daily physical activities? (2) What were your feelings during diagnosis, treatment and now? (3) What are your thoughts about enjoying your life and about accepting your illness? (4) What do you think about your body image? Probing was used to obtain additional information and get the specific examples from the participants. Participants were given a token of appreciation to compensate for

their time. This study was approved by the ethical committee of National University of Malaysia Medical Centre. The data obtained were sorted into various categories.

RESULTS

The in-depth interview sample included 10 women (5 Malays and 5 non-Malays), and their sociodemographic factors are presented in Table

1. More than half of the participants were ≥ 50 years old, been married, had completed secondary education and were house wife. The majority of the participants have three or more children. Half of the participants had monthly income of more than RM 1000. The majority do not have a history of using contraceptives. All women except one had received more than one treatment modality Table 2.

Table 1 Socio-demographic characteristic of breast cancer patients

Variable	Malay	Non-Malay
Age (years)		
< 50	1	1
≥ 50	4	4
Marital status		
Single	0	1
Married	2	2
Widowed	3	2
Number of children		
< 3	2	1
≥ 3	3	3
Educational status		
Primary education	2	2
Secondary education	2	1
Tertiary education	1	2
Occupation		
House wife	4	3
Professional	1	2
Monthly income (RM)		
< 1000	3	2
$\geq 1000-3000$	2	3

Table 2 Clinical characteristics of breast cancer patients

Variables	Malay	Non-Malay
History of contraceptive use		
No history	3	5
Have history	2	0
Type of treatments ***		
Mastectomy	3	4
Lumpectomy	3	1
Chemotherapy	3	4
Tamoxifen	5	4
Traditional medicine	2	2

*** Some survivors received more than one type of treatment

Stress during the treatment

The majority of survivors felt stressed all the time, starting from when they were first diagnosed and were told that they had the cancer, until the time of the interviews. Two of the Malays reported that they were not stressed much even during chemotherapy, surgery and radiotherapy. One of them said:

▪ *"I just [redha] (give my trust) to Allah."*

However, three others reported that they were stressed during the treatments: some of them said:

▪ *"I felt stressed during the treatment... but I just fight and not thinking much."*

▪ *"I was terrified over it... but I just go through it... the pain like more than pregnant women... I can't even smell the laundry in the house."*

Four of non-Malays felt very worried during the treatments due to different reasons such as losing weight and depression:

▪ *"After chemotherapy treatment... I don't feel like want to see anybody."*

▪ *"I do felt stress... because I lost weight."*

One non-Malay had reported less stress because she had only surgery done because she diagnosed with breast cancer in very early stage.

Feeling full of Energy

Most of the Malays got tired easily, and had lack of energy. However two of them had no problems with lack of energy. Three of the non-Malays felt tired, but two of them did not.

Physical conditions and needs of the family

Four of the Malays were unable to fulfill the needs of their families after being diagnosed with the breast cancer and underwent surgery, chemotherapy and radiotherapy, except one said:

▪ *"I still cook... do housekeeping and gardening by myself."*

Most of the non-Malays were able to fulfill the needs of their families such as cooking, washing the clothes and climbing the stairs.

Side effects of treatment

Most of the Malays were not too bothered by the side effects of the treatments.

▪ *"No side effects on me because of the treatment...only want to rest."*

Two of the non-Malays did not bother by the side effects of the treatments because both of them did not receive chemotherapy treatment due to the early detection.

Three of the non –Malays were bothered with losing weight and hair loss.

▪ *"I lost about 5-6 kg and became quite thin."*

▪ *"Very sad because my hair start falling down... one day I'm taking showerand quite big amount hair falls out... and I cried."*

Social & Family well-being

In terms of social and relationship interaction with family and friends, the majority of survivors were satisfied with their relationships; some even expressed that their relationships became stronger. Most of the Malays reported that the relationships with their families after diagnosis became stronger. One of them said:

▪ *"They support me very much...and they visit me all the weekends."*

One Malay woman said that the relationships remained as before.

Most of the non-Malays reported that their relationship with their families was strong, and one contributed to the strong support of her husband.

Regarding the relationships with friends, the majority of the Malays reported that their relationships with their friends were good. One of them said:

▪ *"All my friends and neighbors always come and visit me ...and spend time to talk to me...they support me much."*

Most of the non-Malays reported that they had good support from friends.

Regarding the relationship with the husband, all Malays reported that the relationship with their husbands remained as usual. Two of the non-Malays reported that their relationship with their husbands remained the same. One reported that it was not as before.

▪ *"Not as active as before."* (In terms of sexual relationship).

▪ *"My husband is like my best friend...we were close and after being diagnosed...we were even closer... for sex... just once in a while."*

Emotional well-being

In terms of feelings, most survivors felt sad, angry and sometimes they felt like they are going to die early. However, the majority coped well with their illness by making themselves busy all the time and thus they didn't think much about it. They hoped that they can fight the cancer and that would be the first and the last time. Most Malays felt sad or angry. Two of them said:

▪ *"I feel sad and scared if die early."*

▪ *"Not a very shock or sad time."*

Three non-Malays felt like they were going to die.

- *"I felt like I am dead."*
- *"I thought I am going to die."*

Two felt worried during diagnosis but not anymore.

Coping with the illness

Most Malays coped well with the illness by making themselves busy all the time, such as keeping busy with the kids, so they did not have to think much about their illness. Most non-Malays accepted their illnesses and do not think much about it, but one tried to ignore everything, and said:

- *"I know already what's going to happen... May be I couldn't survive... so I just ignore everything... that's how I survive."*

Hope in fighting the illness

All Malays hoped to fight their illness.

- *"I hope to be healthy and it won't repeat again... hope this is the first and the last time...but if I have it again what to do, it's from ALLAH."*

Most of the non-Malays did not want any recurrence and trying any traditional medicine to prevent them from the recurrence. One of them believed that the coffee with herbs (anti-cancer) would help and said:

- *"I would like to highlight that... by taking this coffee herb give me the hope."*

Thinking about dying or the condition will getting worse

The fear of dying made the survivors more careful about their health and concerned about treatments and some of them took extra traditional supplement beside the medicine like (Gamat, vitamins, and coffee herbs).

Most the Malays thought about dying, one of them said:

- *"Yes, of course I think of dying... even some people said this kind of illness not long to live... until now I survived for nearly 7 years already... as long we can do treatment do it... that's why I take Gamat also."*

Most of non-Malays thought about dying. One of them said:

- *"One time yes... I felt like want to die... but not because of the cancer... but because of difficulties of sleepingbecause always hearing things like people talk to me."*

Functional well-being

In terms of functional well-being, the majority of the patients enjoyed their lives by going out with the family and friends, shopping, gardening, enjoying vacation, and singing.

Regarding to the sleep, most of the Malays don't have any problem regarding sleep, but most of the non-Malay had serious problem about sleep, they can't sleep well.

Enjoying the life

Most of the Malays enjoyed their lives as before (e.g. go eating outside, picnic, shopping, vacation, and gardening, watching TV, reading magazines ...) one of them said:

- *"I enjoy as much as I can...when you know you have limited time you will try to enjoy as you could... when I have extra money I will go for holiday with my son and husband."*

All non-Malay enjoyed their lives as before and created some hobbies such as singing and other hobbies to enjoy themselves and did not think much about the illness.

One of them said:

- *"I like to go to my friends house and other places...I enjoy my time with my friends so much...I like to sing so much...I always go karaoke with my friends and ...also go singing in the church."*

Other described herself as she coming out from the shell and said:

- *"Now I accepted the illness and enjoy my time with my children ...I am coming out from the shell ...I go shopping, dinner and show with my kids ...the first year I got it I don't even go to the market because I am worry people think and know I ve cancer...I am a widow ...it took me more than a year to overcome it."*

Sleeping

Most Malays did not have any problems regarding sleep. One declared that she has a problem and said:

- *"Yes...difficult to sleep...even now may be 11 o'clock or 2 am only feel sleepy...sleeping at night is difficult...at day time didn't sleep at all."*

Most of non Malays reported serious problems regarding sleep (i.e. can't sleep well).

- *"Sleep is ok...as long as I take the medicine until now."*

- *"I cannot sleep well until now...I didn't seek any help...I just read the book until I feel sleepy...I sleep 5 hours but I don't feel its enough."*

Additional Concern

All survivors worried about the other female members of the family (grandmother, mother, sister, daughter, niece, aunt and grand daughter) to get the same problem (breast cancer). All Malays worried about other female members of the family get the same illness, but the perception was different from one patient to another. Some of the patients advised her relatives to take care of the type of the food. However, other patient advice their relatives to do regular check-ups and mammograms and others suggested to their relative to do breast self-examination. Non-Malays also worried about the other female members of the family can get the illness, some of them concerned about the genetic, other patient concerned about the coffee with herbs and others suggest for the family to maintain healthy lifestyle; one of them said:

▪ *“Yes, I’m worry...that’s why we try to promote the coffee herb to the people to take it...even the healthy people also can take it.”*

Body image

Most of the survivors did not have any problem with the body image and they did not think about it. Three out five Malays did not have any problem with the body image and they did not think about it; one of them said:

▪ *“I don’t have any problem with it...I still can wear fashionable clothes like I used to.”* The others thought a bit about the body image.

▪ *“I felt a bit odd...but when asked the husband ...he don’t mind...I know some of the patients after being diagnosed the husband divorced them...but I am lucky because my husband still with me.”*

All non-Malays did not have any problem with the body image; one of them said:

▪ *“I don’t feel anything to shy about...my husband pass away long time already...its already been 4 years since the first day I got to know I have the lump.”*

DISCUSSION

The study findings suggest important differences between Malay and non-Malay breast cancer survivors in their beliefs and perceptions about QOL. Most survivors felt stressed all the time, starting from when they were first diagnosed. They reported that they had the stress until the time of the interviews because they did not knew what they could do. This may due to the lack of information given by health care workers. Similar finding was reported by Jones²³. Other similar studies found that depression reduced

QOL in cancer patients^{16&17}. Psychological aspects showed to have a superior influence on QOL compared with the effects of physical problems¹⁸. Redeker et al⁽¹⁹⁾ found that anxiety, and depression negatively correlated with QOL. Similar other studies found that increased levels of distress among breast cancer survivors appeared to be related not only to QOL, but also increasing the costs of health care^{20&21}.

Most of the Malays got tired easily and have lack of energy but the Non-Malays did not. The difference might be due to the difference in the culture, since the Chinese practice the meditations and regular exercises, like Yoga, qi-gong, tai-chi. Both groups were not too concerned by the side effects of the treatments. They were able to fulfill the needs of their families. Redeker et al¹⁹ reported that fatigue was negatively correlated with QOL.

In terms of emotional well-being, most survivors felt sad, angry and sometimes felt like they were going to die early. One of the differences between these two groups of survivors is how they think about dying. Most of the Malay women think about dying, however, most of the non-Malays do not. These differences may be due to the different beliefs and religion. However the majority of patients coped well with their illnesses because they accept their illness and they adapt themselves with the illness, and they make themselves busy all the time, so they do not think much about it. One of non-Malays she wore scarf, so no body can see her hair falling. They hoped that they can fight the cancer and that this will be the first and last time that they have to deal with it.

In this study, the majority of survivors were satisfied with their social well-being, may be due to that their relationships with families and friends became stronger after diagnosis. Another reason it may partly due to the Malaysian society have very strong relationships among the family members. As in another study done by Wong-Kim et al²⁴, family support was considered to be an important factor that determines QOL. Regarding the sexual relationships with their husbands, the participants were not open to discuss about this issue. Similar finding was reported by Yan & Sellick⁽²⁵⁾ stated that there were difficulties to discuss about spousal relationships during the interview. However Wong-Kim et al²⁴ reported that there participants were open to discussion about spousal relationships during the interview. Similar finding was reported that families were considered a source of both support and strain for cancer survivors²⁶.

In terms of functional well-being, the majority of survivors enjoyed their lives by going out with family and friends. But there is a

difference by the way they enjoy their life, Malays enjoyed by eating outside the house, picnic, shopping vacation, gardening, watching TV and reading magazines. However non-Malays enjoyed life by dancing, singing and karaoke. These differences may be due to the different culture and background. Regarding sleep, all Malays did not have any problems sleeping, but most of the non-Malays reported serious problems. Similar study reported that inadequate role functioning appear to have a greater influence on QOL compared with the effects of physical problems¹⁸. Redeker et al¹⁹ found that insomnia was negatively correlated with QOL.

All survivors were worried about the other female members of the family of getting the same illness because they do not want the other family members to go through the surgery including losing their breasts, the pain and losing the hair during the chemotherapy and non the least the pain of the radiotherapy. But the perception differs from one to another, some of them advised their relatives to take care of the food. However, others advised their relatives for regular check-up, others suggested to do mammograms, and others suggested to their relatives to do regular breast-examinations.

Most survivors did not have any problems with altered body image and they did not think about it. May be because of all the survivors are old and married or widowed. So they did not think much about the body image. Most survivors were worried about recurrence. Similar to another study done by Yan and Sellick²⁴, we found that the survivors who participate in this study were also not open to discussion about spousal relationships. The findings from this study enhanced our understanding of the quality of life among ethnic groups in Malaysia.

CONCLUSION

Most survivors felt stressed, got tired easily, had lack of energy were able to fulfill the needs of their families. The majority of the survivors were satisfied and some even expressed that their relationships in the family became stronger than before. Most survivors felt sad, angry and sometimes felt like they were going to die early. However the majority coped well with their illnesses. All survivors hoped that they can fight the cancer and that this will be the first and last time that they have to deal with it. In terms of functional well-being, the majority of survivors enjoyed their lives by going out with family and friends. All Malay survivors did not have any sleeping problems, but most of the non-Malays reported serious problems. All survivors were worried about the other female members of the

family getting the same illness. Most survivors did not have any problems with the altered body image and they did not think about it.

RECOMMENDATIONS

Multidisciplinary team management (financial, legal, spiritual, complementary health practitioners, sexual and body image issues) should be conducted to support the breast cancer survivors. Health care should be educated in cross-cultural values, beliefs and practices. Insomnia, sad emotions, recurrence and fear of dying because of the breast cancer should be taken seriously to improve the quality of life of the breast cancer survivors. To educate and bring the awareness to the patients and their relatives through the seminar that will be held by the Oncology and Psychology Department because all the survivors was worried about the other female members of the family of getting breast cancer.

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