



Lived Experience of Women Living with Breast Cancer in the Maldives: A Case Study

Salma Hassan¹(✉) and Nazeera Najeeb²

¹ School of Nursing, The Maldives National University, Malé, Republic of Maldives
Salma.hassan@mnu.edu.mv

² Tree Top Hospital, Malé, Republic of Maldives

Abstract. Breast cancer affects the lives of women, and this is also the most common cancer for women in the Maldives. This study **aims to** understand the lived experience of a Maldivian woman undergoing breast cancer treatment. A single case of breast cancer was purposely chosen among the women receiving chemotherapy from Hulhumale' Hospital. **A semi-structured questionnaire** was used to gather data. Five themes emerged through thematic analysis. *Feeling sick*, feeling weak due to chemotherapy; *Being hopeful*, religious with a positive attitude; *Satisfied with support*, grateful for assistance from her children, health professionals, and from the community; *Fear of dependency*, she had a preconceived fear of being dependent during radiation therapy; *Out-of-pocket expenditure*, expenses incurred for travel. **Findings** revealed that the participant was hopeful with her positive attitude and religious practice; It was a burden to spend to travel for chemotherapy and believed that financial support or free traveling arrangement should avail through the social support system. There was uncertainty about the consequences of radiation therapy based on her current information and assumed that she would be sick and depend on others. Support and empathetic relationships are important for breast cancer patients to enhance positivity and hopefulness. There is also a need to strengthen awareness programs and existing support systems. The experience associated with this study may not be the same for others in the Maldives. However, the findings direct future research and interventions.

Keywords: Breast Cancer · Case Study · Cancer Treatment · Lived Experiences

1 Introduction

Breast cancer is a devastating disease among women all over the world. It is also the most common cancer diagnosed in women in the United States (U.S.), and the second leading cause of cancer death in women [5]. In accordance with the WHO cancer country profile [4], the breast cancer incidence in the year 2018 was 17.3% and the mortality rate was recorded as 11.9%, denoting the highest among all other types of cancers. Breast cancer among Maldivian women is also increasing at an alarming rate. Women with breast cancer suffer from the physical disease burden and psychological challenges. As a result, women have to alter their lifestyle as well as their career opportunities and lack

confidence and live with fear [13]. However, advances in diagnosing and treating breast cancer have led to vast improvements in patient survival and quality of life. As per the researcher's knowledge, this is the first study of this kind in the Maldives. Therefore, this study aims to understand the current situation and challenges that Maldivian women face undergoing breast cancer treatment and the rehabilitative process from the woman's perspective.

1.1 Significance of the Study

The diagnosis of breast cancer at any stage deeply affects the individual and family members. It affects the total quality of life for a prolonged time or lifetime, depending on the circumstances. Cancer is one of the leading morbidity conditions which was noted to be rapidly increasing in the Maldives [12]. Women diagnosed with breast cancer will need continuous support during all stages from the time of diagnosis and beyond. As an island state, Maldives faces major challenges in the high cost of delivering services to people in greatly dispersed and remote locations [22]. Though there is an improvement to access to curative health services at the island and atoll levels, unequal access to health services remains a great challenge [2]. Furthermore, healthcare services in the islands do not provide a focused range of services related to breast cancer at the primary care level.

There is a need to learn about the experiences of women living with breast cancer in order to generate evidence-based information. This study identifies the real-life experiences of women living with breast cancer in the Maldives. The information derived from this study will contribute to the existing knowledge related to providing care for breast cancer patients and will identify a whole range of support for women undergoing breast cancer treatment. Furthermore, the study will enlighten the specific areas for further research. It will help to highlight common issues and existing challenges to accessing care and aid in addressing the gaps in the system.

1.2 Literature Review

Breast cancer survivors have increased over the years due to improved care [3, 7]. Evidence-based innovations are required to improve the quality of life of survivors [7]. In addition, a phenomenological study conducted in India on lived experiences of women with breast cancer revealed two main themes 1) challenges encountered (embarrassment, altered body image, financial constraints, perceived worries, dealing with negative attitudes and stigma) and 2) coping strategies (reliance on religion and spirituality, social support, living, as usual, optimistic attitude and will to recover, and venting out).

Similarly, it has been noted that employers should understand and support cancer patients at work [16]. A recent qualitative inquiry on the experiences of Filipino women revealed that cancer patients' journey encounters several aspects that led to preventable adjustments [11]. Moreover, a study also found that it was obvious that the pain, fear, distress, as well as cultural barriers, were blocks to obtaining timely professional support which ultimately leads to mortality [9]. Also, the analysis of three personal blog documents by breast cancer survivors from Malaysia, indicated that accounts of illness

were heavy with emotional talk since the bloggers were documenting an important event in their life into perspectives [15].

Perception differs among communities and this affects the management and support required for women diagnosed with breast cancer. Thus programs should be mapped with evidence-based information, contextualized to the culture and geographic location of women living with breast cancer.

1.3 Study Aim

This study aims to understand the lived experience of a Maldivian woman undergoing breast cancer treatment.

2 Methodology

2.1 Study Design

The case study approach will help to generate an in-depth multifaceted understanding of this complex issue in a real-life setting. This will in turn better understand the reality of the patient's perspective. A single case study or intrinsic approach can be used to understand the unique phenomena of women living with breast cancer [5]. Additionally, a case study provides the researcher with an opportunity of having intimate knowledge of the client's condition [18].

2.2 Sample

Purposive sampling was used to select the case for this study. One case was selected from the group of women visiting the Cancer Center of HMM, to obtain treatment. The case was identified with the support of the staff of the center. This is one of the hospitals where oncology services are established in the country. The case selected was a woman of age between 40 – 65 years with at least one child as per the inclusion criteria.

2.3 Data Collection

In-depth interviews were conducted using a semi-structured questionnaire. The interviews were recorded after obtaining written consent. Privacy and confidentiality were ensured during the interview process. Three subsequent interviews were conducted to gain saturation. She was grateful for contacting her and expressed her readiness to provide any information required. The first interview was translated and transcribed verbatim.

2.4 Data Analysis

The interviews were transcribed and translated into English. Transcripts were checked against the recordings by the two researchers independently. All the data were then analyzed using interpretive phenomenology. The interpretive phenomenological approach (IPA) allows us to understand the lived experiences of individuals that have their

meaning that occurs in relation to those experiences [21]. Moreover, IPA involves an iterative, inductive process in which data analysis is taken a step further than pure description, as the researchers take an active role in interpreting participants' perspectives and experiences [22]. Transcripts were read and re-read to get immersed in the data and to make sense of the data for meaning and clarification. The participant was contacted for checking the accuracy of the information and meanings.

3 Results and Discussion

This case study has explored the lived experiences of a woman living with breast cancer in the Maldives. The participant discussed and expressed positive and negative experiences during the different phases of her journey. **Satisfied Support.** Support from the family members was strongly acknowledged by the participant and she believes that the love and support from her family members keep her happy and that is one of her blessings during this journey. Especially her children and grandchildren, every child of her own was involved in her care. *"my children are always on the lookout for me. When I was talking to they were here to check on me... Just now they left... They made sure that I was talking to people from the hospital". "So kids will come out and will stay with me, they won't go away from me. That is why I am happy and satisfied..."*

The participant also discussed and expressed her sadness at remembering her late husband while acknowledging the significance of her husband. This finding was very similar to the study done in Thailand. According to their findings, all of the women in their study had support from their family members, particularly their husbands, children, and sisters [6]. Furthermore, van [23], reported that many women from their study enjoyed and received support from family members, friends, and people from the Church. Additionally, previous studies had identified that family support was an important factor and was associated with a lower risk of depression [19]. The same study also highlights the importance of having a spouse during the care of breast cancer women [1, 21]. Therefore, our study supports previous studies on having family support in the care of patients suffering from breast cancer. In terms of support from the health care providers, especially from the nurses working in the chemotherapy department, the participant discussed their compassionate care, friendly communication skills, and caring attitude towards her during the treatment process. She said it was very satisfying for her to see when nurses talk to her in a polite and friendly manner. *"when I come here I get all the help, care and support I need, very supportive, compassionate, helpful, these are things a patient needs the most ... caring, compassion is what the patients need the most. What do you say? Isn't it?". "That is why I am very satisfied; I am very satisfied due to that."*

This finding is also similar to the study conducted in Thailand perhaps reflecting the social value orientation of Asian communities [6]. The small community of the island is aware of her situation as the participant was a well-known person in the community. She was also happy with the support received from the community members. Previous studies have also reported social support as an important factor for women living with breast cancer [6]. Furthermore, **being hopeful**, the participant had a very hopeful attitude toward her recovery, the participant found hope and comfort in her prayers, and she believes in her faith and her prayers. Therefore, she paid careful attention to her daily

obligatory prayers, she was prepared before the prayer time and never missed a moment. *... I feel very satisfied with prayers and dhuaas... I very much look forward to the prayer time... Even now I am ready for my prayers before it's time... This makes me very happy and satisfied*". Similar findings were identified in other studies [13]. Participants from this particular study talked about their God and finding peace from god. Moreover, a recent study reports that patients' religious beliefs and spirituality had made it easier for patients to tolerate cancer and made it part of their life [17]. Thus, regardless of religion, spirituality is one of the elements to cope with chronic diseases [10, 17].

According to the participant she had never received any information or heard about breast cancer before the diagnosis. However, she believes if she had known the signs and symptoms or information regarding breast cancer it would have made a difference in contacting healthcare workers and getting tested earlier. This indicates an important gap in the interventions on cancer awareness, prevention and early detection by the public healthcare system. The perception of breast cancer screening and diagnosis have an important role in the early diagnosis of breast cancer [20].

The participant was undergoing chemotherapy and she discussed about her experiences. Chemotherapy is one of the therapies that is frequently used to treat cancer but its side effects make it challenging for patients [13]. The administration of chemotherapeutic agents causes numerous side effects including short and long-term effects [4]. The study participant completed eight rounds of chemotherapy. She described her *feeling sick* with the side effects of breast cancer and she believes that it is a different type of sickness as her cancer got better. She explained what was happening to her *"Look at my skin, it has become so dark, Subha na Allah. Actually, it is very painful...."* *... "It hurts a lot, I can't even close my fingers. My nails are falling."*.. This is akin to the findings of a study conducted in Hong Kong that looked at patients' responses to chemotherapy before and after treatment. It revealed that some participants had a relatively normal life before chemotherapy but observed others have significant impairment in their daily life after the chemotherapy and describe this as suffering [12].

The participant expressed high levels of anxiety, concern, and worry about becoming physically dependent and the *fear of dependency* on others as she got ready for radiotherapy. *"..... But I am concerned about getting sick and people having to look after me, they have to carry me like a child"* Based on what she had observed in cancer patients and what she had learned from her friends, this was one of her greatest worries. Previous studies have reported the same issues with a few patients feeling worried and anxious if they have heard frightening stories from friends or family members who have experienced breast cancer radiation therapy [14]. This reflects a lack of appropriate information regarding radiation therapy and misconceptions about radiation therapy. It is imperative that education programs are specifically planned and developed to suit the needs of patients and address radiation and chemotherapy [8]. Previous studies in other settings have also reported significantly low levels of knowledge related to breast cancer radiation therapy [14].

Another challenge that she talked about was the *out-of-pocket spending out-of-pocket expenditure* for transportation, and the trips to and fro to receive chemotherapy. In an island nation of an archipelago like Maldives, transportation is a costly challenge, especially during stormy weather. The participant had to travel from her own island

where they have only a health center with minimal health care facilities. *“Actually we are coming to Male’ for chemo every time spending 550 rufiyaa. For a launch I am spending each time 550 rufiyaa on these big issues”*. Also she talked about the need for continued treatment visits. *“It’s so common and this is not something we can do like one day give chemo and we can omit it the next time. It’s like that. we are supposed to take the full course of treatment. The needed treatment should be given. It’s a big thing what can I say about it? We should get it”*.

The Maldives has a four-tiered health care system, but only the capital city of Male, where there are tertiary-level hospitals, offers specialized treatment facilities for cancer. Although chemotherapy and other health care costs such as admission, and other medications are covered by the National Health Insurance Scheme called “Aasandha, she is burdened by the out-of-pocket payment incurred to access the treatment. It was assumed that all the women in the Maldives are aware of breast cancer and its symptoms, nevertheless, this study revealed that this assumption is wrong as the participant who is working in a health facility has not heard of breast cancer signs and symptoms prior to her diagnosis.

4 Ethical Consideration

To maintain anonymity and confidentiality participant’s name and islands are not disclosed. Privacy and confidentiality were maintained throughout the data collection process. Information regarding the study was provided to the participant and informed written consent was obtained. Permission from HMH was officially received. Ethical approval was obtained from the National Health Research Council of the Ministry of Health.

5 Strengths and Limitations

A major strength of this study is the in-depth information obtained from the case involved in the study regarding the phenomenon of living with breast cancer. In addition, the transparency and soundness of the data gathered will direct further research. However, the study results cannot be generalized as the study used a single case study approach.

6 Recommendation for Future

As the findings indicate general awareness among the public is still low there is a need to strengthen awareness among the general public regarding the early signs and importance of early detection of cancer. Including misconceptions about various treatment modalities regarding cancer as well as breast cancer. Training of health care providers at all levels to educate and support patients with breast cancer is needed. Further research should also be conducted with cancer patients at different stages of cancer at the time of diagnosis and different socio-economic status. It is important to further assess out-of-pocket spending on breast cancer patients in the Maldives in order to best address the issues.

7 Conclusion

This case study has explored women's lived experiences with breast cancer in the Maldives. According to this case study, having faith and a positive attitude toward recovery was very helpful to cope with breast cancer. This study also supported the immense help from family, healthcare providers, and the community helps to keep women encouraged towards healing.

This study revealed that breast cancer awareness programs have not reached all women in the country. Thus these programs need to be strengthened. There is also a need to educate women who go through different phases of treatment to keep them well-informed about implications and management. Out-of-pocket expenditure to access treatment is a concern. Further research can be done to learn more about the factors identified in this study.

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