PERSPECTIVE OF BREAST CANCER PATIENTS ON BREAST CANCER SURVIVORSHIP CARE IN INDIA

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Table-1: Themes and verbatims on the needs and priorities of breast cancer survivors

Themes	Verbatims
Survivors relationship with primary care practitioner and oncologist specialists	*"The gynaecologist I visit is just like a family. As she gave birth to my daughter's children, so whatever issue I use to have, I use to go to her. So, she suggested for oncologist when I get to know about breast cancer."* *"We go to him for the small health issues but not for my breast cancer"*
Knowledge on diagnostic, treatment and side-effects	*"What is chemo, what is radiation, how much it will cost all these information should be shared by the doctor, should be discussed with the family."* *"I did 6 chemo's, 3 weeks of radiation and 10 years of HRT. It was very long time and my third chemo leaked out and the port was done, which could have been possibly done during my surgery. So, there were no explanation before surgery or at the time of surgery that these are your options"*
Knowledge on available resource, and counselling like support group, exercise, nutrition	*"I didn't know that any support group of breast cancer exits in hospitals. I came to know from one of my friends. So, it will be good if information regarding support group is available in most of the hospitals"* *"What exercise we should do; how much walking should be done. A radiation doctor just asked me that why you don't go for walk. But I didn't know about it until he asked. So, that information should be given clearly."*
Follow-up information and expectation	*"During follow-up basically what happen the major thought the survivors has that even I am sneezing then did I had cancer. If anything happens in the whole body, we relate it with cancer, so the doctor should clarify these things to the survivor during the follow-up"* *"During the chemo the doctor should be accessible and response from the physician is also important either via WhatsApp or call"*
Unmet needs of Survivors	*"During my chemo I never saw my oncologist ever, she gave me the medicine but I never saw her during my treatment duration, rather I met another oncologist and he gave me his number, held my hand. I love that support and joy, which I never got from my own oncologist"* *"There are few things other than health issues I prefer to ask or discuss, like can I have sex with my husband, but these things I am unable to discuss. I think doctor need to look into these things and give importance to it"*

INTRODUCTION

According to Globocan report 2020, incidence of breast cancer is most common in India. The western world has developed some guidelines on the long-term care of breast cancer survivors; however, India has limited evidence in this area. Also, limited research available on breast cancer patients needs and their perception regarding breast cancer survivorship care.

METHODS

Two Focus group discussions were conducted with survivors (7 each in 2 groups). Data was gathered using semi-structured guide, transcribed verbatim, and then analysed using thematic framework of approach. Major themes explored were relationship with primary care providers and oncologists, follow-up, communication, patient needs, and provider roles.

RESULTS

Survivors form intense relationships and has dependency towards the specialists and expertise. Few also believed primary care providers are for minor ailments. Majority of the survivors reported concerns about access to care and limited time provided by specialists during treatment and follow-up. More concise and written information about cancer diagnosis, treatment, nutrition, physical activity (including dos and don'ts), side effects, and counselling were also expected by survivors. The majority of survivors recommended doctor's assistant, but the patient must be told first. The majority of survivors reported psychosocial difficulties and anticipated oncologists' referrals and counselling support. Similarly, many of them found it difficult to talk to experts about their mental and sexual issues.

CONCLUSIONS

Patients with breast cancer may have trouble making the transition to survival and are frequently found to be dependent on specialists. During therapy and follow-up, they shared a consistent preference for accessibility, time, support, and written information. These results states that survivorship care guidelines and a plan should be developed using a holistic approach comprising specialists, primary care physicians, and survivors.

REFERENCES

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