Breast Cancer: Mixed Methods Study to Create a Preference-Based Measure Utility Module

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It is known that breast cancer is one of the world's most advanced and also one of the most common cancers occurring in women today. Preference-based measures (PBM) may not be the most optimal in economic evaluations of breast cancer interventions. There is no breast cancer specific PBM that currently exists. Many generic PBMs are unable to adequately summarize the many unparalleled concerns of women with breast cancer. Examples of this include physical appearance and treatment-specific unfavorable effects. The overall objective of this study is to create a breast cancer specific PBM, called the BREAST-Q Utility Module. The method of this study was that fifty-seven women were recruited from two hospitals in Canada and one in the United States, who were diagnosed with breast cancer at any stage and in any treatment. The methods used followed a sequential mixed methods approach which included semi-structured interviews. At the end of each interview, the women were asked to list, in their opinion, what their top five "health-related quality of life" (HRQOL) concerns were. While doing so, they were also asked to rate the importance of each item on the BREAST-Q. Results included the top five HRQOL were appearance, physical, psychological, social, and sexual well-being. BREAST-Q item ratings were used to create ten unique dimensions. This extensive approach was used to ensure that the quality of BREAST-Q was comprehensive, relevant, and thorough to highlight the main concerns of women diagnosed with breast cancer.

Introduction

Breast cancer is one of the most common cancers among women. It has also become one of the most advanced. In generic preference-based measures, it would be optimal for the use in economic evaluations of the intervention of breast cancer. Additionally, no breast cancer specific preference-based measures exist currently. The overall objective of the study was to create or develop a type of specific breast cancer preference-based measure (PBM). The methods of this experiment include women who were diagnosed with breast cancer within stages zero to four were recruited for this study to participate. The study took a mixed

methods approach. Therefore, the interviews were conducted with each of the fifty-seven participants and at the end of each interview the participants were asked to choose their top five "health-related quality of life" (HRQOL) concerns and then to rate the importance of each of them on the BREAST-Q. The interviews conducted were also audio recorded, then transcribed verbatim, and then coded. To develop a solidified conceptual framework, the interviews were refined and then compared.

Recent Progress

The data was analyzed from the interviews to add new topics to the interview guide for developing subsequent interviews. Transcripts were coded using a combination of inductive and deductive approaches. Top codes were broad to prevent any redundancy of concepts obtained during the interviews. Additionally, the conceptual framework was developed throughout the study. The interviews continued until the researchers saw there was enough redundancy to have themes. The data on the top five HRQOL concerns were summarized accordingly.

In total, fifty-seven interviews were conducted starting from January 2017 to June 2018. Each interview lasted from thirty minutes to an hour and a half long. The average age of the participants were twenty-two to seventy-five years old.

The BREAST-Q was concocted from 3,948 different codes. The top five level domains were appearance, physical, psychological, social, and sexual well-being.

The response options for appearance asked about body image, breast appearance, as well as sensation which was identified based on severity.

Physical options were divided into different parts, such as fatigue, pain and discomfort, breast sensation and emotional distress. These were ranked based on severity and

Patient input consisted of women's interviews and the interviewers asked them to utilize the "think aloud" technique to obtain even more feedback on the process. The Utility module was revised from two rounds of interviews. The researchers continued interviews until there were no more recommended changes from participants about the level of the items.

Expert input included the research team's professional network. They were all invited and were asked to review the Utility module using "REDCap." REDCap was developed via refining the survey by developing it from consistent participant feedback. Feedback included wording of the instructions, the various items, and the response options.

Additionally, the experts were asked to rate the importance of the items on a "5-scale Libert scale," and were then asked to point out which items were missing. Later, a reminder email was sent out two weeks later. This was to refresh the description of expert feedback to sufficiently revise the Utility Module.

Discussion

how each of these would interfere with their normal daily activities and mobility. In the final field set there were a total of twenty-one items. Many women reported a lot of pain on the surgical side of their body, reduced arm mobility, and an interference with their personal hygiene. Women also reported their concerns about their average amount and quality of sleep. Many had trouble falling asleep on a daily basis. Some had difficulty staying asleep and reported that they often have interrupted sleep due to hot flashes, nausea, pain, discomfort, and fatigue.

Psychological well-being included emotional distress. In many interviews of participants of post-surgery or treatment, women highlighted feelings of anxiousness, fear, and worry. In interviews of women who were newly diagnosed with breast cancer there was a pattern

of feeling angry, frustrated, irritated, or even disappointed.

Social well-being consisted of social issues in regard to their diagnosis, personal experience of treatment, and their various survivorship phases. Some women reported in their interviews that there were limitations and interference of their ability to actively participate in their normal social roles such as, being with family, at work, and in their community. Many of the participants side effects of fatigue and pain limited them of their work-life participation during their recovery and survivorship phases. These women also attempted to make accommodations for themselves such as reducing their work hours or temporarily taking a leave of absence. Women also reported needing assistance with childcare and house chores which contributed to the financial burden of their families. Furthermore, some participants described their feelings in social isolation which is necessary to avoid any infection. But this led to symptoms of body image issues and fatigue. The daily routine of attending radiation therapy was also a factor of isolation because it limited any socialization with friend and family. The lack of social participation with family, friends, work, and their community contributed to their sense of loneliness throughout their breast cancer experience. It was found that many women struggled with their newfound role as a dependent instead of caregiver after being diagnosed with breast cancer.

Sexual well-being consisted of the women's sexual self-image, functioning, and appearance. Sexual self-image can be defined as changes in their body image due to their breast cancer treatment which affects the women's perspective of her body and her sexual interactions. The majority of the women admitted to feeling much less attractive and sexy. This was highlighted in their intimate scenarios and reduced feelings of satisfaction because of pain or lack of sensation in their breasts. Some women reported being annoyed, bothered, or uncomfortable with their partner looking at or touching their breast area. These women mentioned covering up during these scenarios. Sexual functioning can be defined as women who expressed concerns when sexually active because of fatigue, irritation, or vaginal dryness. These factors impacted their ability to experience sexual pleasure with their partner. In regards to how often they engage in sexual interactions, many women reported they were not very interested it in, or do not engage often, or just much less frequently. Many breast cancer survivors reported that they were consistently in a depressed or sad mood. Some further explained they had anxiety which lasted beyond the treatment phase, which led to fear. These feelings ultimately impacted their family and partners. Furthermore, these feelings and factors affected some women's ability to have an orgasm which led to have less frequent intimacy with their partner.

This research was able to develop a new BREAST-Q Utility Module which can be used to better comprehensively understand the concerns of women diagnosed with breast cancer.

The BREAST-Q Utility module will be available in clinical research as well as economic evaluations of breast cancer medical interventions.

References

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