



Not feeling sick from breast cancer: A framework on health status perceptions transition process



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ABSTRACT

Purpose: In what state of health do women with breast cancer consider themselves to be? Health professionals classify them as cancer victims but few studies have examined women's perceptions of their own health following a breast cancer diagnosis. We looked at the transition in health status perceptions between before and after receiving the diagnosis.

Methods: A grounded theory design was chosen to develop a framework.

Results: From an analysis of semi-structured individual interviews with 32 women, it emerged that 1) over a two-year period, the participants went through four iterative steps between receipt of the official diagnosis and the return of the level of energy once the treatments are done. These four steps are: reacting emotionally, facing the situation, constructing a new identity and reacting to social representations of cancer, 2) the participants did not feel sick from breast cancer.

Conclusion: This study shows learning to live with a sword of Damocles over the head during the transition process. The emergent steps of the health status perceptions transition process in breast cancer trajectory give direction for care.

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1. Introduction

Each year, nearly 1.38 million women worldwide are diagnosed with breast cancer, which makes it by far the most common type of cancer in women, in both western and developing countries (World Health Organization (WHO), 2013). According to the latest statistics, in 2014, 24,400 Canadian women were diagnosed with breast cancer, which is 64 women per day (Canadian Cancer Society, 2014). At present, over 88% of women who have been diagnosed with breast cancer have a life expectancy of five years or more, which puts breast cancer in the chronic disease category (WHO, 2013). In addition, breast cancer often occurs in women between 40 and 60 years of age (Canadian Breast Cancer Foundation, 2013). The impacts on family, community and society are devastating, especially because of the association of breast cancer with death and dubious statistics about hypothetical cures (Banning and Tanzeem, 2013; Saillant, 1988). Also, the social roles of women who receive this

diagnosis are often disrupted because cancer has an impact on energy level (Al-Azri et al., 2009; Arathuzik, 2009; Denieffe and Gooney, 2011), body image and sexuality (Cebeci et al., 2010; Özalp et al., 2015; Raggio et al., 2014). While struggling with the physical and psychological effects of cancer, women with breast cancer go through a process of internal changes between health and illness. The health perceptions of women with breast cancer determine the intensity of the transition between health and illness (Meleis, 2010) and affects how they cope (Karademas et al., 2011) with chronic illness. Therefore, it is vital to explore changes in perceptions between health and illness.

This transition has received little attention since studies on women with breast cancer have taken a transversal view of four main phases in the trajectory of the disease: 1) the waiting period before getting the official diagnosis and needs at that time (Doré et al., 2013; Drageset et al., 2010; Montgomery, 2010); 2) the period of shock following the breast cancer diagnosis (Al-Azri et al., 2009; Beckjord et al., 2009) and treatment interventions during that phase (Lu et al., 2014; Vargas et al., 2014); 3) chronicity and coping (Brandão et al., 2014; Silva et al., 2012); and 4) recurrence and palliative care (Dalgaard et al., 2010; Maheu et al., 2015; Sand et al., 2009).

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We also identified some studies that had preconceptions of the disease (Boehmke and Dickerson, 2006; McCann et al., 2010). Hence the authors of these two studies did not investigate the health perceptions of the women interviewed and, from the outset, considered them sick. We believe that the choice made in these studies to explore perceptions from a transversal perspective, i.e., when the women were in the phase following the breast cancer diagnosis, rather than explore the transition process in perceptions between health and illness, accounts for the small number of studies documenting the health perceptions and illness perceptions of healthy women, as highlighted by Baril et al. (2008).

No framework on transition perceptions of women's health with breast cancer has been identified. What is needed is a theoretical framework grounded in empirical data obtained from women at different phases on the breast cancer trajectory that guides health professionals to provide direction in patient-centered care, to obtain insight and understanding of the health status process their patients are experiencing and to further develop teaching, research and policy interventions. The objective of this study was to explore and to develop a conceptual framework of the transition process between perceptions of health statuses during the breast cancer trajectory.

2. Method

The few empirical studies on this subject and the lack of theoretical framework justify using an inductive approach. A grounded theory design appeared to be the best method because it deepens our understanding and sheds light on social processes while developing an empirically-founded theory based on the views of the people experiencing this health transformation process (Corbin and Strauss, 2008). This research design can be used to examine the diverse situations of women with breast cancer at different steps in the progress of the disease since none of them experience this diagnosis in the same way. Thus it is appropriate to use the approach of Strauss and Corbin (1998) to explore the internal change process that women go through following a breast cancer diagnosis.

3. Sample

The population of interest was all women with breast cancer in the administrative region of Mauricie-Centre-du-Québec (Canada). The initial sample was composed of women with breast cancer who volunteered to take part in the study and who attended one of the eight hospitals in this area of Québec, which has a population of 505,787 and covers 42,368 km² (Institut de la statistique Québec, 2014).

3.1. Recruitment of the participants

Following approval from the various research ethics committees, the women were recruited in two hospitals, one providing tertiary care and the other secondary care, from the staff of the university where the first author teaches and from the general public in the region where the study took place. Posters were put up in ambulatory chemotherapy and radiation clinics and in the offices of the pivot nurses and oncologists at the two hospitals. Posters were also distributed by the university communications service in an attempt to reach staff and students. Finally, local newspapers and the local radio station publicized the research project with the general public in the region.

Grounded theory is characterized by an iterative approach as the research progresses (Corbin and Strauss, 2008). This aspect can be seen in theoretical sampling, the aim of which is to select

participants based on their relevance to the development of the conceptual categories and their relationships, and not for the purpose of maximizing population representativeness (Corbin and Strauss, 2008; Glaser and Strauss, 1967; Strauss and Corbin, 1998). Thus the convenience sample used in the initial phase of the study evolved towards a theoretical sampling strategy. Based on these principles, the participants retained were women who met the following inclusion criteria: be between 40 and 60 years of age, have started or finished chemotherapy and/or radiation or have had surgery, not have been diagnosed with another type of cancer, not suffer from aphasia or disabling psychological disorders, and speak French. All women who volunteered to participate and who filled the inclusion criteria were recruited. Then, the author was selective by choosing people who could add to certain emerging categories in a manner to reach the theoretical saturation.

The theoretical sampling process continued until theoretical saturation was reached, i.e., when new data did not add more information to the different conceptual categories of the current theory (Strauss and Corbin, 1998). We interviewed women newly diagnosed with cancer and others with up to three recurrences, women who had had a lumpectomy and others who had had complete removal of the breasts as well as chemotherapy and radiation, women diagnosed with microcalcifications and others in palliative care. The sample was continually reworked in response to the analyses. Again with the aim of varying the theoretical sample and obtaining extreme cases, interviews were conducted with healthy women who carried the BRCA1 or BRCA2 gene cf. Table 1 that put them at risk of developing breast cancer. With a varied sample, the data collected enhance understanding and theorization of the phenomenon under study (Corbin, 1998).

3.2. Data collection

We conducted 32 semi-structured individual interviews. Throughout the data collection and analysis process, we wrote field notes about how the interviews were progressing and memos concerning each new methodological idea.

Before starting the fieldwork, a pilot interview was done to verify the clarity, relevance and accuracy of the questions. The interview guide included open-ended questions that evolved as the interviews progressed. For example, in the first interview, questions such as "What steps have you gone through to get to the point of viewing health and illness as you view them today?" were asked. Throughout the interview, inductive hypotheses were verified with the participants and the questions evolved along with the understanding of the phenomenon, to be ultimately framed as follows: "In your view, what is an illness?" and "What may explain that you don't feel sick from breast cancer?" If necessary, clarification questions such as "What do you mean by ... ?" and "Can you explain a little more ... ?" were asked to get a better understanding of what the participants' comments meant.

The first author interviewed the women at one repetition at a location of their choice (their home, the interviewer's office at the university, coffee shop or public park). The interviews lasted 90 min on average and were recorded on digital audiotape. It was impossible to predict with any accuracy the number of interviews to be done since that depended on theoretical saturation. Also, to increase the women's participation and thus the credibility of the results, the first author checked her understanding of the information with the participants during the interviews as well as validating the data model created once each interview was finished (Charmaz, 2006; Corbin, 1998). Also, one participant phoned the author to complete her answer to the interview and the interviewer reached an other participant to lighten some information after the analysis.

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