



Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Research paper

Patients' learning and understanding during their breast cancer trajectory

Lena Engqvist Boman^{a,*}, Kerstin Sandelin^b, Yvonne Wengström^c, Charlotte Silén^a

^a Department of Learning, Informatics, Management and Ethics, Karolinska Institutet, Tomtebodavägen 18 A, 171 77 Stockholm, Sweden

^b Department of Molecular Medicine and Surgery, Karolinska Institutet, Karolinska University Hospital, Solna, P9:03, 171 76 Stockholm, Sweden

^c Breast and Sarcoma Unit, Radiumhemmet, Karolinska University Hospital, 171 77, Karolinska Universitetssjukhuset and Department of Neurobiology, Care Sciences and Society, Division of Nursing, 141 83 Huddinge, Sweden

ARTICLE INFO

Article history:

Received 24 March 2016

Received in revised form 19 December 2016

Accepted 21 December 2016

Keywords:

Patients' learning

Understanding breast cancer

Learning for participation in breast cancer care

ABSTRACT

Objective: To explore how women learn and understand their disease, treatment, care, and life-situation during a breast cancer trajectory.

Method: Semi-structured individual interviews were performed with 16 women suffering from breast cancer. Qualitative content analysis of data was performed.

Results: Three themes describe the women's learning; *Interacting with a diversity of information:* women interact with a vast amount of information, including perceptions of bodily sensations and events. *Concealed and expressed understandings:* women interpret information that results in understanding which is either concealed or expressed. *Struggling to understand and manage the new life situation:* pre-understanding, driving forces to learn, contemplation and dialogue with healthcare staff influence the women's learning.

Conclusions: General theories of learning are applicable to learning during a breast cancer trajectory. Significant features of learning during a life-threatening illness are strong personal drivers to understand and deal with all that occurs. Vulnerability remains a challenge in developing understanding as a cancer diagnosis infers uncertainty.

Practical implications: Patients need time to assimilate and process complex bodies of information in dialogue with health care staff. Patients' understanding needs to be assessed and pedagogical competence in the interprofessional team is assumed to facilitate patients' learning and participation in treatment and care.

© 2016 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

During the last decades, hospital stay after breast cancer surgery has been shortened and the need for patient support has been emphasized [1–3]. Breast cancer surgery is frequently performed as day surgery in many countries including Sweden where this study was carried out. The short hospital stay puts new and high demands on patients' knowledge, understanding and engagement in self-care [4–6]. Patient participation has become fundamental for safe care; achieving this goal urgently requires a better understanding of how to effectively support the individual to cope with, comprehend and make decisions about their disease [7–9].

The need for improved information and communication in cancer care has long been emphasized [10–15]. Breast cancer is an overwhelming transitional experience for any individual, with long-term implications on personal life and identity. Women with breast cancer have considerable information needs and positive associations have been found between high satisfaction with information and health related quality of life [15–17]. A recent literature review revealed that information is still one of the most unmet needs among women diagnosed with breast cancer [18]. This is in accordance with findings from recent studies in Sweden demonstrating patients' ratings of information during breast cancer treatment as insufficient [16,19].

Education for cancer patients has been evaluated primarily in terms of its effects on knowledge and emotions [20–24]. Research about patients' learning during cancer treatment has mostly focused on *what* a person learns [20,25–27] but only rarely on *how* this learning proceeds. Studies on patients' learning about breast cancer have focused on women who use self-directed learning or

* Corresponding author.

E-mail address: lena.boman@ki.se (L. Engqvist Boman).

computer-based systems [28–30]. Ventura et al. [30] found no effect of a computer-based educational program on breast cancer patients' health self-efficacy, their healthcare participation or on anxiety and depression levels compared to controls. They concluded that the program might not have been relevant or useful for the participants as the information was delivered one-way which is not enough to influence multi-dimensional outcomes. Their findings are in accordance with a systematic review of online interventions for cancer patients which showed unclear efficacy [31].

It is not known how women with breast cancer interpret and understand information and its significance regarding the likelihood for successful participation in treatment and care [32]. Evidence of improved communication is difficult to capture due to the complexity of the encounter between patients and health professionals [33]. Further, there is a call for developing strategies to support patients to engage in their treatment and care and define their learning needs [34,35]. Changing perspective from patients' information needs to their learning is expected to increase our understanding about how participation in their breast cancer care can be supported.

This study focuses on patient learning and is based on the consensus of contemporary learning theories emphasizing that all learning involves active constructive processes in the learner [36]. Receiving information is not enough, learning includes perceiving and processing a variety of stimuli, cognitively, emotionally, and through practice. Learning is about gaining knowledge to understand what you see, hear, read and feel and to be able to approach and handle encountered situations. Understanding is constructed by the individual in interaction with others and the context and contributes to a transformed understanding reflected

Table 1
Demographic data of the 16 participants, numbers are given.

Age	
34–54 years	7
55–94 years	9
Country of origin	
Scandinavian	13
European	2
South America	1
Marital status	
Married/cohabitant	10
Single	6
Children	
Yes	13
No	3
Residential area	
Inner city	7
Low-middle income suburb	3
High-middle income suburb	3
High income suburb	3
Educational level	
Tertiary	5
University	8
Master	1
Licentiate	1
Phd	1
Employment	
Business owner	3
Educator	1
Health and social worker	3
Restaurant worker	1
Manager	5
Specialist/Expert	3

Table 2

Recruitment and treatment data of the 16 participants, numbers are given.

Time for interview	
Before surgery	3
1 month after radio- and/or chemotherapy.	5
1 year after diagnosis	4
2–5 years after diagnosis	4
Surgical treatment	
Partial mastectomy + SN*	8
Partial mastectomy + mastectomy + SN or LND**	3
Mastectomy SN or LND	4
Bilateral mastectomy + SN + LND	1
Adjuvant treatment	
Radiation	13
Anti-hormonal	9
Chemotherapy	4
Anti-bodies	1
Neo-adjuvant chemotherapy	2

* SN = Sentinel node dissection (one lymph node removed).

** LND = Lymph node dissection (several lymph nodes removed).

in actions, thinking, and reactions [37–39]. Merleau-Ponty [40] stresses the importance of not applying a dualistic division of a person into a thinking, feeling being and a physical body since the whole person is involved when we are experiencing and learning. The learner's pre-understanding, what the learner already knows, thinks and feels in relation to a situation or phenomenon, constitutes the basis for learning something new [38,39]. A fundamental driving force of learning is to understand and deal with situations which are perceived as relevant and meaningful [38]. Special circumstances for learning are created during a serious illness as the patient faces an uncertain future with dramatic existential implications. To increase our understanding about this phenomena the aim of this study was to explore how women learn about and understand their disease, treatment, care, and life-situation during their breast cancer trajectory.

2. Material and methods

A qualitative approach was used as it contributes to illuminating human beings' meaning making of experiences [41]. The study was divided in two parts. In part one, the current study, women's learning and understanding during their breast cancer trajectory were explored. Part two (to be published), focuses on the women's participation in treatment and care in relation to their understanding.

2.1. Participants

Female breast cancer patients were recruited from surgical and oncological departments at a university hospital in Sweden and from a survivor group organization. The inclusion criteria were women diagnosed with primary breast cancer and ability to speak and understand Swedish. Purposeful sampling was performed to obtain variation on dimensions of interest and identify diversity and common patterns in the data [41]. Accordingly sixteen women with various demographic backgrounds, treatments and phases of treatment were recruited and accepted inclusion during the fall of 2014 and the spring of 2015 (Tables 1 and 2).

2.2. Data collection

Data collection was performed through individual interviews following an interview guide which was informed by a pre-study. Staff from two cancer helplines, survivors and contact nurses in surgery and oncology were asked about patients' most frequently

Download English Version:

<https://daneshyari.com/en/article/5682089>

Download Persian Version:

<https://daneshyari.com/article/5682089>

[Daneshyari.com](https://daneshyari.com)