

## Original Article

# Breast Cancer Patients' Experience about Involvement in Health Care: A Qualitative Study

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## Abstract

**Background:** Patient involvement in health care is a basic patient's right. Effective communication between the health care professional and the patient is associated with improved psychological functioning of the patient, adherence to treatment, and higher quality of life.

**Objective(s):** This study aims to explore qualitatively breast cancer patients' experience and satisfaction with their involvement in cancer care.

**Methods:** This study was carried out among 30 women in different breast cancer care stages through in-depth-interviews. The patients were purposively selected from surgery and oncology outpatient clinics and surgery inpatient wards in Medical Research Institute Hospital- Alexandria University, and in Ayadi El-Mostakbal Cancer Care Center - Ayadi El-Mostakbal Charity Foundation, Alexandria, Egypt.

**Results:** Some patients mentioned that they did not know their diagnosis until late, others complained of the harsh non-empathetic way of breaking the news of their disease. Patients, generally, reported a little understanding of their treatment plan, they just followed physician's instructions without receiving enough explanation. Patients on chemotherapy and radiotherapy expressed their unsatisfied need for information. Patients' source of information was mainly other patients who suffered from the same disease. Patients, in general, were not familiar with the concept of giving feedback, it was perceived by the majority of them as equivalent to complaining. Some patients believed that complaining could put them in trouble such as receiving harsh blame or even delaying their medication.

**Conclusion:** Patients' narratives revealed poor involvement in health care and showed dissatisfaction of the majority of patients with their level of involvement.

**Keywords:** Patient involvement; breast cancer; Egypt; qualitative research; decision-making

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## INTRODUCTION

Breast cancer (BC) is the most common cancer among women in both high-income countries (HICs) and low- and middle-income countries (LMICs).<sup>(1)</sup>

Effective communication between the health professional and the patient is associated with improved psychological functioning of the patient, adherence to treatment, satisfaction and higher quality of life.<sup>(2)</sup>

Prior studies showed that cancer patients who felt they were not given enough responsibility for treatment decision-making reported lower satisfaction and worse quality of life.<sup>(3,4)</sup>

Involvement of patient (PI) is a basic patient's right. Involvement of people in their care means supporting people to manage their health and wellbeing on daily basis.<sup>(5,6)</sup> Involvement signifies

that a person is engaged in a process through which he harmonizes robust information and professional advice with his own needs, preferences and abilities to prevent, manage and cure disease.<sup>(7)</sup>

In Egypt, hospital accreditation standards stated that "Patient and family (as appropriate) are involved in all care and treatment decisions".<sup>(8)</sup> However, across all regions in Egypt, hospitals were particularly low in measures of community and patient involvement (PI).<sup>(9)</sup>

The present qualitative study aims to explore breast cancer patients' experience and satisfaction with involvement in their cancer care.

## METHODS

### Study Setting

The study was conducted in surgery and oncology outpatient clinics and Surgery inpatient wards at

Medical Research Institute Hospital - Alexandria University, and in Ayadi El-Mostakbal Cancer Care Center - Ayadi El-Mostakbal Charity Foundation, Alexandria, Egypt.

### **Study population**

Breast cancer female patients at different stages of BC care. Patients with a communication difficulty or at a critical state were excluded.

### **Study design**

An exploratory inductive qualitative study (phenomenology) was done to gain in-depth detailed insight into the experience of patients about their involvement in BC care.

### **Sampling**

Purposive sample was used. The sample consisted of 30 female patients at different stages of BC care (6 newly diagnosed, 6 post-surgical, 6 on chemotherapy, 6 on radiotherapy and 6 under follow up).

### **Data collection**

A semi-structured face to face interview guide was

used. The interview guide was developed based on that designed by the Directorate-General for Health and Consumer Protection -European Commission, <sup>(10)</sup> after making some modifications to suit the purpose of the study and the Egyptian health care system. It consisted of open-ended and probing questions. It was translated into Arabic. The guide was used to collect some personal data such as; patients' age, educational level and employment status, and to explore:

- Current level of PI in health care.
- Patient satisfaction with their current involvement in health care.
- Patient's experience of involvement as regards certain areas of health care which are; awareness and knowledge of the diagnosis, knowledge and understanding of the treatment plan, sharing in decision making about treatment and giving feedback about received medical care to medical personnel.

The interview guide (Table 1) was piloted, some probing statements were added based on the pilot results. The interview took 45-60 minutes.

**Table 1: Interview guide**

Main sections of the interview	Subsections	Examples
<b>Introduction</b>	The interviewer introduces herself, establishes the principles of interview, and develops rapport with respondents.	Interview principles include: <ul style="list-style-type: none"> <li>• Audio recording</li> <li>• No right / wrong answers</li> <li>• Confidentiality</li> </ul>
<b>Overall current level of PI</b>		To what extent would you say that the medical team allows you to be involved in your health care? How willing are you to be involved in healthcare? How satisfied are you with the current level of your involvement in your own healthcare? Why do you say that?
<b>Patient satisfaction with current level of PI</b>		Did the health team inform you of the diagnosis of your disease and help you understand your condition? Why/why not? Who told you about your disease and how? What did he/she say? How did you respond to the news and how did he/she react to your response?
<b>Patients' experience of involvement.</b>	Patients know and understand the diagnosis and nature of disease	Were you given information about your surgery before undergoing the operation? What did they say? Did they explain your treatment plan? What did they say? Did you share in putting your treatment plan? How? Did you share in decision about type of surgery (partial/total mastectomy)? Were you given information about breast reconstructive surgery? What type of information? Were you asked about performing breast reconstructive surgery?
	Patients know and understand the treatment they receive, and are aware of possible alternative treatments. (patients were interviewed about surgery, chemotherapy, radiotherapy and follow up plan)	Have you ever given any comments (positive or negative) about the medical care you receive to any of the medical personnel? Did you find it easy to say your comments? What was their response to your comments? Did they listen to you? If not why? If you want to complain about any of the medical personnel, do you know what to do or whom to go to?
	Giving feedback	Have you actually shared in making decision about your treatment? Why/why not? Would you like more participation in decision making? Do you feel you can object to or refuse the recommended treatment? Why/why not?
	Patients share in decision making about their treatment	

### **Data management**

Verbatim transcriptions of audio recordings were made using Microsoft Word (Microsoft, 2010). Both interviewer and interviewee whole statements were captured in the transcription. Transcribed data were analyzed using the qualitative data analysis software Atlas ti.

### **Steps of data analysis**

The analysis of interview transcripts was based on an inductive approach where the patterns and themes of analysis come from the data rather than being imposed before data collection and analysis.<sup>(11)</sup>

#### **1. Immersion in data**

Participants' responses to each question were read many times for a detailed examination of what was said.

#### **2. Coding of data**

Two of the researchers independently read and coded three interviews extracting common themes, the themes were merged to develop a coding list. This process was repeated until no new themes emerged (saturation).

#### **3. Creating themes**

Each research objective represented a category and each category –as appropriate- was divided into subcategories. The initial codes were grouped under relevant subthemes that were fitted under a major theme, Table 2.

#### **4. Analyzing themes**

Each theme was narratively described.

#### **5. Producing the report**

A report was written for each theme with enough data extracts (quotes) to demonstrate the theme.

**Table 2: Themes and subthemes emerging from patients' narrative**

<b>Category</b>	<b>Subcategory</b>	<b>Themes and Subthemes</b>
<b>Patients' experience of involvement</b>	<i>Understand diagnosis</i>	<b>Factors influencing patients' understanding of diagnosis:</b> <i>Communication styles</i> <i>Willing to understand</i> <i>Emotional reactions</i>
	<i>Understanding treatment</i>	<b>Lack of understanding treatment</b> <b>Patients' sources for seeking information</b> <b>Decision-making experience</b>
	<i>Sharing in decision-making</i>	<i>Negative experience (passive receiver)</i> <i>Positive experience (Shared decision)</i> <b>Benefits of shared decision</b> <b>Challenges of shared decision</b>
	<i>Experience of giving feedback and complaining</i>	<b>Patients' way of delivering feedback or complaints</b> <b>Perceived barriers</b> <b>Perceived benefits</b>
<b>Current level of PI</b>	<i>Level of PI</i> <i>Current aspects of PI</i>	
<b>Satisfaction with the current level of PI</b>		

### **Ethical considerations**

The study protocol received ethical approval from the Ethics Committee of the High Institute of Public Health, Alexandria University. The researchers complied with the International Guidelines for Research Ethics. Verbal consent for audio recording was obtained from all participants after explaining the aim of the study.

Participants were able to skip any question they did not feel comfortable with and each participant was able to withdraw from the study at any time. Confidentiality of data was assured and maintained and each participant was given a code to protect her identity.

## **RESULTS**

More than half the participants were above 50 years old (17) and moderately educated (16). Most of them were married (27) and not working (26), 14 of them had stage II cancer breast, (Table 3).

### **Category 1: Patients' experience of involvement in a range of breast cancer care areas**

#### **Sub-category 1: Understanding diagnosis**

Many patients followed the physician's instructions about making investigations without knowing the reason beyond doing them.

"They did not explain anything" (Case 8).

Some patients went into surgical operation without being explicitly told the real reason for surgical intervention, and some others did not know about their disease until they had finished many sessions of chemotherapy and radiotherapy.

Several patients revealed that at the time of the diagnosis, rather than talking to the patient herself, the physician addressed the closest relative.

*"He did not explain to me, he asked me to wait outside and explained to my husband"* (Case 23).

**Table 3: Characteristics of the studied breast cancer patients**

Patients' characteristics	No. (n=30)
<b>Age</b>	
18-	2
36-	11
>50	17
<b>Social status</b>	
Married	27
Divorced	3
<b>Employment status</b>	
Employed	4
Not employed	26
<b>Education*</b>	
High	8
Moderate	16
Not educated	6
<b>Stage of disease</b>	
Stage I	4
Stage II	14
Stage III	6
Stage IV	6

\*High: university or higher      Moderate: below university

### Factors influencing patients' understanding of diagnosis

#### Communication styles

Some patients appreciated the tactful, empathetic manner physicians followed in breaking the disease news.

*"The doctor was cheerful and he was talking to me about my children and other life matters"* (Case 26).

Other patients indicated that the physicians threw the diagnosis into their faces and sometimes even blamed them for coming in a late stage.

*"He shouted at me and told me that it was a second degree with four lymph nodes infiltrated"* (Case 16).

#### Willing to understand

Most patients expressed their need for understanding their condition. Some patients, however, expressed their fear to ask for further information.

*"No, I don't want to know anything, I am not even able to look at my breasts"* (Case 19).

#### Emotional reactions

Patients' emotional reactions at the time of hearing the diagnosis ranged from feelings of shock, fear, despair,

confusion and sense of loss of control to feelings of acceptance.

*"I felt lost and confused "* (Case 2).

*"I was shocked"* (Case 10).

*"I left it all to Allah and did not say anything"* (Case 25).

### Sub-category 2: Understanding Treatment

#### Lack of understanding treatment

Most patients seemed to experience a little understanding of their treatment plan.

*"They did not give me information about chemotherapy, I was astonished that my hair was falling"* (Case 23).

#### Patients' sources for seeking information

Most patients declared that their source of information was mainly other patients who had similar experiences.

*" I was asking a friend of mine who had a similar experience"* (Case 11).

### Sub-category 3: Sharing in Decision-making

#### Decision-making experience

##### Negative experience

Some patients revealed that they were not asked about their opinion/decision.

*"I did not know I had mastectomy until after the operation when I did not find my breast"* (Case 8).

##### Positive experiences

Some others were asked to choose between different types of surgery.

*"The doctor asked me to choose between mastectomy and conservative treatment "* (Case 19).

Concerning chemotherapy, they were allowed to choose between injection and tablets.

#### Benefits of shared decision

According to patients, sharing in the treatment decision would help them be aware and in control of their disease and feel cared for and respected.

*" I will be aware of what is going on"* (Case 9).

*"I will feel cared for"* (Case 25).

#### Challenges of shared decision

Inadequate provision of tailored information and weak provider-patient communication were fundamental causes of poor sharing in decision making.

*"Nobody explained anything about treatment so that I could share in the decision making"* (Case 5).

Patients' external locus of control and low self-efficacy were negatively influencing their engagement in decision making.

*"I feel confused when I am asked to share in decision making"* (Case 1).

#### **Sub-category 4: Experience of giving feedback and complaining**

##### **Patients' way of delivering feedback or complaints**

Patients agreed on the unavailability of a defined feedback system.

*"There is nobody I can talk to"* (Case 14).

##### **Perceived barriers**

Patients believed that their feedback was useless.

*"Do you think they are waiting for my opinion?"* (Case 14).

Several patients clarified that they were sick and had no power or will to give feedback.

*"We are coming to take the dose and leave"* (Case 27).

Some patients believed that complaining could put them in trouble like receiving harsh blame or even delaying their medication.

##### **Perceived benefits**

Patients acknowledged the importance of feedback in improving the quality of the provided medical service.

*"When a patient complains, they will know what they did wrong and fix it"* (Case 28).

#### **Category 2: Current level of PI in care**

##### **Subcategory 1: Level of PI.**

Patients in different stages of BC care indicated that they didn't experience real involvement during their healthcare journey.

*"I haven't been given any role in anything"* (Case 8).

##### **Subcategory 2: Current aspects of PI in care.**

Reassuring the patient and giving her some instructions as to avoid stress and smoking were perceived by some newly diagnosed patients as involvement. Similarly, follow up patients viewed having instructions related to medication, physical exercise and nutrition as being involved in health care

*"What I am always told is to take care of my treatment, regulate my diet, do exercise and do not eat sugars"* (Case 14).

One patient mentioned that she was actively involved in monitoring her wound drain.

##### **Category 3: Satisfaction with the current level of PI in care**

Most patients expressed their dissatisfaction with their current level of involvement. Patients' dissatisfaction revolved around hiding the diagnosis from the patient, leaving patients to suffer the long routine procedures before starting treatment, and giving the patient non-precise information about the type of surgical intervention or treatment.

*"No, I am not satisfied as they did not tell me before the operation that they would remove my breast"* (Case 8).

*"They should explain to the patient herself"* (Case 29).

Few patients declared being satisfied and attributed their satisfaction to their belief that nothing better could be done considering the deficient resources of public hospitals.

*"Yes, I am satisfied. For us, the poor, everything they do will be good"* (Case 4).

## **DISCUSSION**

This study described BC female patients' experience about PI in cancer care. When patients were asked directly about their level of involvement in their healthcare, the majority indicated that they had not experienced real involvement and they just complied to physicians' commands. Most of these patients were dissatisfied with their current level of involvement. In effect, patients tend to be more satisfied if their need for information is met and if they have higher levels of patient-clinician information engagement and exchange. <sup>(12,13)</sup> This was observed in the study of Corriere, et al <sup>(14)</sup> who indicated that generally, patients expressed high levels of satisfaction with their understanding of diagnosis, level of involvement in treatment decisions and the number of treatment options discussed. This inconsistency with our findings reflects the discrepancy between physician-centered and patient-centered approaches in health care. Patient-centered approach represents a shift from traditional, paternalistic, provider-driven, approaches towards healthcare systems that ensure patients are fully integrated into every phase of medical consultation, treatment and follow-up. <sup>(15)</sup>

The present study showed that a lot of patients did not know the reality of their disease until later, while others, although told of the diagnosis, were not well informed about the disease. Physicians addressed the closest relative to inform him/her of the patient's condition rather than inform the patient herself. In agreement with these findings, a study on Latin American patients revealed that close to two-thirds of the sample (65%) did not know their stage and the type of tumor. <sup>(16)</sup> Concealing information from the patient and acting on her behalf is part of the paternalistic culture prevailing in some parts of the world. Although it sometimes occurs with good intentions, it is disempowering anyway.

In contrast to the previous findings, a qualitative study conducted by the European Commission (EC) showed that patients, generally, knew and understood the diagnosis and only a few reported receiving insufficient information at the time of diagnosis. <sup>(10)</sup> In the same line, a study in the USA found that about 90% of American cancer patients accurately recalled their clinical stage and whether they had positive lymph nodes. <sup>(17)</sup>

A lot of patients in the current study referred to the experience of hearing their diagnosis as "shocking".

Similar reactions were described by Hébert, et al. <sup>(18)</sup> However, in the current study, patients attributed their reaction not only to the diagnosis itself but to the way they were informed of it as well.

Middle-east societies believe in God and resort to Him in such stressful situations. However, it should not be left only to patients' faith and prayers to get through this painful experience. Working in multi-disciplinary teams, encouraging patients to join support groups and developing patient navigation programs would be of extreme help to those patients. <sup>(19, 20)</sup> Unfortunately, neither one of these approaches was deployed in the studied health care facilities.

The Institute of Medicine recommended providing patients and their families with understandable information about cancer prognosis, treatment benefits and harms. <sup>(21)</sup> However, patients in the present study expressed their lack of understanding of the treatment plan, treatment options, effect and side effects of the prescribed medications. These findings provide support to previous literature demonstrating low patient involvement in public hospitals in Egypt. <sup>(9)</sup> In contradiction to these findings, Smith, et al <sup>(22)</sup> found that overall, the studied BC patients had a nearly complete general knowledge of their treatment where, all 33 participants knew whether they had surgery, chemotherapy, and/or radiation therapy. Nearly all women undergoing surgery had accurate specific knowledge about the type of surgery (30/31) and 73% of women receiving chemotherapy reported all chemotherapy drug names correctly.

A growing emphasis has been placed on physician-patient communication, and information sharing. <sup>(23)</sup> In their study, Corriere, et al <sup>(14)</sup> found that healthcare providers were identified as important sources of medical information by most participants. Similar findings were reported by Engqvist Boman, et al. <sup>(24)</sup>

On the contrary, most patients in the present study were not given the time or chance to reveal their queries, they had to seek answers to their questions from other patients rather than from the medical staff.

Patients in the current study expressed their non-volitional control on treatment decisions. Patients were not dealt with as equal partners in their care and were inconsistently involved in decision making through the various stages of treatment. Results of a study conducted in Uganda were, generally, consonant with our findings, where 80% of patients reported that they were not given a chance to participate in the selection of the treatment they were to receive. <sup>(25)</sup> Physicians in more developed or richer countries seemed to be more likely to involve patients in health care. In Germany, 67% of participants reported that they shared in decision-making with their physician. <sup>(26)</sup> In Saudi Arabia, about 80% felt that they were partners in the treatment plans. <sup>(27)</sup> This contradiction with our

findings sheds important light on the influence of socio-economic conditions on physician-patient communication pattern. Time, money, moral incentives and communication skills are key domains that must be addressed to ultimately impact the ways in which healthcare professionals care for patients. <sup>(28)</sup>

The present study has some limitations. First, the study was conducted in public health facilities only which did not allow for comparison between different health sectors. Second, we used a subjective method (interview) for assessment of PI practices which depended on respondents' perceptions and memory rather than observation.

## CONCLUSION AND RECOMMENDATIONS

Study results revealed poor patient involvement in the studied health facilities and showed dissatisfaction of the majority of patients with their level of involvement. The traditional provider-driven approach still prevails in public hospitals.

### Disclosure statement

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