

# Breast Cancer Patients' Experiences with Information and Communication in Cancer Disease Trajectories

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**Abstract.** Patients' experiences have been used as an indicator for hospital quality for a long time. The concept of patient experiences has many facets. One aspect of particular importance for optimal treatment and patients' quality of life is efficient and understandable information and communication between patients and health professionals. In this paper, we look closer into patients' experiences in breast cancer care by following patients through their narratives related to their treatment trajectory 7–8 years after diagnosis. The specific aim has been to explore their perceptions and experiences regarding received information from and communication with health professionals during their breast cancer disease trajectory in a long-term perspective. Findings show that even though the participants expressed high levels of satisfaction with care, they also highlighted elements that they experienced as problematic during their treatment trajectory. Three major themes emerged: 1) the need to be taken seriously and for immediate action; 2) evolving information needs across stages of treatment; and 3) finding the right network.

## 1 Introduction

Patient experiences are one of the key elements of quality in health care [1]. They have long been used as indicators for hospital quality to inform clinical practice about treatment effects and as a valuable source for quality improvement processes [2-4]. Cancer care specifically emphasizes patient experiences as an important instrument for improving care quality and for reducing the future burden of cancer [5, 6]. The concept of patient experiences is, however, multifaceted, including aspects such as organizational issues, care staff and therapeutic variation [7]. One aspect of particular importance is the provision of efficient and understandable

information and communication between patients and health professionals [5]. When patients are well informed about disease, therapies and related effects, they can play an important role in increasing the effectiveness of the health-care system [8]. The patient and citizen role in communication with health-care personnel (HCP) has changed over recent decades; it is now expected by the patients as well as the health-care providers that patients should be actively involved in communication and decisions about their own health [9]. This may improve the sense of empowerment, the patient's understanding of personal health condition and provide them with insight sufficient to take medication or undergo treatment.

Technology is likely to be one of the enduring pillars of future health and care services. Information technology is expected to enhance the quality of care and patient safety further. New online digital services will give patients more opportunities to make active choices regarding their own health and thereby influence what kind of health services are available [10]. Previous studies on information and communication throughout the cancer care trajectory show - among others - that the Internet has become an important source for providing information to cancer patients [11-15].

Breast cancer is the most common cancer among women, representing with around 3,400 new cases in Norway each year. There are several studies on breast cancer addressing late effects of cancer treatment [16], quality of life/health-related quality of life [17, 18] and patient safety [1] as well as challenges related to information and communication [19-22]. Moreover, many studies emphasize the importance of learning from patients' experiences [23-25] by showing that breast cancer patients who are actively involved in making health decisions report higher satisfaction with care, increased quality of life and functioning, and fewer side effects.

When investigating communication and information in breast cancer care, it seems relevant to use the term 'disease trajectory' in a more extended way than is usually done. The actual follow-up phase lasts from five to ten years. However, many patients experience late effects, such as fatigue and impaired physical- and mental functioning [26], resulting in difficulties in returning to work [27]. Consequently, the disease trajectory can actually be lifelong and one anticipates that experiences, evaluations, needs and preferences are likely to change throughout this period. Thus, in this paper, cancer disease trajectory is defined as the period from the initial signs, symptoms or concerns regarding breast cancer; through the diagnostic workup, treatment, and follow-up in specialist and primary health care; to after the follow-up period is completed and daily life as a permanent cancer survivor appears [28]. Recommendations or instructions regarding patient information throughout the disease trajectory are to a limited degree included in the Norwegian national guidelines for breast cancer. Only one paragraph is specifically addressing patient information, and this information is about breast reconstruction surgery, and scheduled to the first follow-up appointment after surgery [29]. Thus, it is a need for further knowledge on patient information in lifelong disease trajectories.

The aim of this study has been to investigate patients' experiences regarding information from and communication with health professionals during their breast cancer disease trajectory, from a long-term perspective.

## 2 Material and method

**Health-care setting:** The present study is a sub-study from a larger prospective cohort study including 250 breast cancer patients enrolled in an 8-year follow-up programme at a cancer outpatient facility located at Trondheim University hospital owned by Central Regional Health Authority, Norway.

**Study design:** For this sub-study, we followed an explorative, qualitative approach with the use of semi-structured interviews. The purpose was to encourage the women to talk about the issues related to information and communication, but also to allow them to reflect freely upon their experiences.

**Data collection and analysis:** In total, we conducted 37 interviews between December 2012 and August 2015. The interview guide was worded to bring out the women's views of and experiences with their prior breast cancer treatment trajectory through questions on how and when the cancer was detected, the type of treatment received, and how they experienced the care they received during different stages of the treatment trajectory, including the time after hospital discharge. Each interview lasted 30–100 minutes and was tape-recorded and later transcribed for analysis.

The analysis used a combination of deductive and inductive reasoning. Initial inductive analyses revealed that information and communication were recurrent themes in all interviews; hence, we decided to pursue this further. The specific analysis for this paper first identified all passages of the transcripts in which participants told about their experiences regarding information and communication. Thereafter, we deductively analysed these passages following a preliminary topical structure based on the disease trajectory phases the participants referred to. Finally, we worked on meaning condensation/coding and categorized the material carefully into broad themes.

**Ethical issues:** The main study obtained approval from the Regional Committee for Medical and Health Research Ethics (REC Central 2009/108.4.2006.2856) and by the Norwegian Data Inspectorate. The responsible oncologist at the outpatient clinic recruited the participants for this interview study. All participants signed an informed consent form.

### 2.1 Participant characteristics

The age of the participants ranged from 45 to 86 years at the time of the interview, and most of them were married or cohabited. Former or current professional affiliation included cleaning, sales, service, associate professionals, academic professionals and executives. Cancer treatment varied widely across the interviewees (see Table 1).

The informants are referred to as («A»), («B»), («C») etc. in the text below to maintain their anonymity.

**Table 1: Treatment characteristics of the 37 participants**

Types of therapy	N (%)
Surgery	
Breast conserving	20 (54)
Radical (mastectomy)	17 (46)
Chemotherapy	25 (68)
Endocrine (anti-hormonal) treatment	13 (35)
Immunotherapy (Herceptin)	12 (32)

### 3 Findings

In our study, most women were satisfied with the patient–staff relationship and the care they received. Despite this positive attitude, the women highlighted communication-related issues that they evaluated as problematic or challenging regarding interactions with the health-care services. Moreover, they reported problems or challenges from various or all phases of the disease trajectory (Table 2): from the detection of initial symptoms, through the mammography screening, biopsies, receiving bad news, primary and adjuvant treatment at the hospital, to the follow-up care at the hospital or with the GP, rehabilitation programmes and daily life afterwards. Three major themes that emerged from the analysis of our interview data will be further addressed in this paper: 1) the need to be taken seriously and for immediate action; 2) evolving information needs across the stages of treatment; and 3) finding the right network.

**Table 2: Information needs throughout the disease trajectory**

Patients' information and communication needs	To be taken seriously
	Perfect timing of information – not too soon and not too late
	Unambiguous and accurate information, about diagnosis, treatment plan, side effects (acute and late), follow-up and rehabilitation
	HCP to talk to, face to face, in various phases of the disease trajectory
	Help by family/partner to remember information
	Coordinated information between HCP
How patients meet information needs	Actively: If you need information, you ask and receive answers from HCP
	Passively: You wait for someone to

	inform you/You do as you are told
	Information by coincidences

### 3.1 The need to be taken seriously and for immediate action

The informants reported that it is important that they are taken seriously by the HCPs early in the trajectory, i.e. during the diagnostic workup. This means that HCP pay attention to the patient's symptoms and concerns, and provide information and messages as scheduled. Many of the participants experienced individual delays before the initiation of diagnosis and treatment, as illustrated by the following quote:

*'It was a bit difficult to get in [to the health-care system], because I went to my GP and he didn't want to refer me to the hospital, so I had to go to a private clinic (...). He was not in a hurry. He didn't take it seriously enough to even examine the lumps'* («A»).

One of the participants had experienced two doctors who claimed that the lump in her breast was not a tumour. However, *'there was something in the back of my head telling me to not give up on this'*. She called the hospital several times, and finally she received the breast cancer diagnosis. The period from mammography to surgery was 79 days, and she said:

*'I had to fight to get there, and it is bloody disappointing (...) if they had taken me seriously back then, it probably wouldn't have hit me this hard now'* («B»).

The feeling of not being taken seriously could lead to an overall negative experience of interaction with HCP. For instance, one woman characterized the meeting with the health-care system as negative, seemingly because she felt she was not taken seriously in the initial phase of the disease trajectory:

*'I went to see my GP and found the lump ... or I found the lump myself. But she [the GP] said this does not look like a typical cancer tumour. She still referred me to hospital. And I had a mammography and ultrasound and no ... it was nothing, so they sent me home ... and I had to live with the lump. My grandmother died of breast cancer, and my aunt got breast cancer last year. This is not normal'* («C»).

Some patients also felt they were not being taken seriously during treatment, as exemplified by one woman who was not informed that she was about to receive Herceptin (adjuvant treatment, given after surgery): *'Perhaps one physician thought the other one had told me (...). No one told me that I needed subsequent treatment, and this was a slip-up. I felt that this affected me'* («D»). She believed that unclear information routines caused this lack of information about Herceptin, but eventually she met an oncologist who took her seriously and told her about Herceptin, making her feel safe again.

### 3.2 Evolving information needs across stages of treatment

The informants reported that in the early phases of the disease trajectory it could be challenging to receive too much information too soon, but also to have to wait too long to get the information. For some of the patients, the period from diagnosis to surgery was short, but mostly evaluated as very positive. During this short period, the women presented with a breast cancer diagnosis underwent surgery and received information about adjuvant chemotherapy and radiotherapy. Being very vulnerable at this stage, patients like those quoted below felt overloaded with information and unable to process it:

*'When I had surgery, when my breast was removed, a nurse waited for me outside my door. She had to talk to me. No, I don't want to talk to anyone. Yes, you have to take all these brochures so you know what to do. Then I felt, no, I don't want the brochures (...). But I was polite, and took them, brought them back home and threw them in a drawer. It was a bit too much information (...) I had to process the situation first, because, the period from the diagnosis to the completed surgery was too short'* («E»).

On the other hand, if information was provided later than the patient had expected, it was regarded as extremely negative, as waiting time most often led to insecurity and frustration: *'My cancer results came through in November, but I didn't receive the message until Christmas. I think this was unfortunate, because we phoned and phoned and there was no one there that could give me an answer'* («F»).

Throughout the entire disease trajectory, there was a clear preference for unambiguous and accurate information, about the diagnosis, treatment plan, side effects (acute and late effects), follow-up and rehabilitation. The women's stories reflected both active and passive ways of meeting information needs. Their active approach included asking questions. *'I'm satisfied [with the information]. I was made aware of what I wanted to know, and I was not afraid to ask'* («G»). However, some of the women were not satisfied with the fact that they had to ask to get information: *'I had to contact him [the GP] myself if I wanted anything. They took some tests, but I never got the results before I called them and asked. I'm used to it now, but I'm not always cheerful when I visit the GP'* («H»). Quite a few met their information needs passively, meaning they waited for someone to inform them instead of seeking the information themselves. These patients did not like to ask questions, and they did as they were told: *'I didn't ask. I didn't nag. I just suddenly received a letter'* («I»), and *'I don't understand, and I don't ask. I do what I'm told to do'* («J»).

For some patients, the passive stance towards information needs resulted in surprises regarding treatment and/or follow-up procedures, as illustrated in the following quote from a patient who was unaware that she was going to have chemotherapy and radiotherapy: *'I thought the treatment was done when I had surgery, because no one mentioned anything else'* («H»). Another patient got an infection that led to hospitalization during chemotherapy because no one had told her she could get a sick note during this therapy phase: *'There was a doctor, who wagged his finger at me (saying): "Are you aware of how sick you are, woman?" Yes, I know that I am sick, I said, I am aware of that. "But why, in heaven's name, didn't you stay home from work?" No one told me to stay home, I said'* («K»).

The patients preferred to receive information from the HCP verbally. Ideally, this would be the oncologist, and the same one each time, as meeting different physicians telling different things could make the patients insecure, as illustrated in the following quote:

*'And I had a lot of expectations when I arrived (at the hospital). I had so many questions, and I wanted to ask about so many things that I had gradually discovered. And I didn't know whom to ask or who could give me the answers, because (...) I didn't meet one permanent physician at the hospital, there were so many saying different things' («D»).*

At the end of the treatment when the patients realized they might never meet the oncologist again, they felt alone and left to their own devices. Regular and prolonged interaction with the oncologist was a pronounced wish as it would make them feel safe and be helpful when new questions emerged after the treatment period was over. One of the participants described it like this: *'You shouldn't be kicked out of the cancer department on the last day of your treatment. There should have been someone to talk to [at the hospital], some peers (...) and a consultation with an oncologist a year afterwards, because I had so many questions, and I still have' («L»).*

In general, the GP had the responsibility for follow-up care after cancer treatment. However, in our study, participants rarely referred to the GP as the contact person they needed or preferred. The women experienced that the GP lacked knowledge about cancer survivorship follow-up care. Some of them said that they had to tell the GP what to do, as in the following quotes: *'I have to ask (the GP) about everything: Shouldn't I have an appointment for follow-up care? Shouldn't I be referred?' («H»).* And: *'But she (the GP) didn't even know what Herceptin was, she didn't know anything about cancer treatment (...) I got the impression that she hadn't even been informed about what tests she was supposed to perform' («D»).* This participant did not have confidence in the expertise of the doctor, which influenced her total experience of the post-treatment period.

### **3.3 Finding the right network**

As mentioned before, the different types of breast cancer treatments and the combination thereof can cause several complications such as nausea, loss of appetite and fatigue in addition to emotional stress and anxiety [26]. The interviews reflected that for many women, the illness itself, the treatment and the related complications imposed great changes in their lives. Hospital care also incorporated support to the individual affected. From the accounts, we observed that HCP organized different group activities including physical activities, and discussion of practical information, such as strategies of how to cope with different side effects (Table 3). Most of the women communicated appreciation with these support group activities:

*'I joined a group, with other women with a breast cancer diagnosis, and I think that was good, because we met a physician, a physiotherapist and an occupational therapist, and we could ask questions, this was after the surgery' («M»).*

However, in the time after hospital discharge, some women took a different view on participating in support groups. While some emphasized the support and activities offered by formal support groups, like the specialized rehabilitation programme and the non-profit breast cancer society, others were not that eager to seek contact with other cancer patients. Moreover, the latter wanted distance from the disease itself, including organized social contact with other women in the same situation:

*‘It was ok to talk to someone who has had it (breast cancer) themselves and who knows what they are talking about, but I don’t want to take part in a breast cancer group or things like that. I sort of pretend that I have recovered’ («N»).*

Instead, they built a network of various informal groups (Table 3). Some women focused on their social network with family members, one or several ‘old friends’, or new friend(s) whom they had met occasionally, for instance through social media or physical activity. Examples from the accounts illustrate that these new friends might have experienced a serious illness themselves – *‘Because, I thought that when I had fought for five years I was safe. So, those who experience this for the first time, they get terrified [in group discussions]. I have to contact girlfriends who feel the same’* («B») – or were able to advise our informants on medication: for instance, on alternative medicine that could possibly benefit their breast cancer condition.

**Table 3: Types of hospital and post-hospital communication networks**

Formal/informal	Network types	Purpose
Formal	Group care organized and led by hospital staff	Physical activity, information
Formal	Support groups	Social: bringing together patients facing similar challenges
Formal	Rehabilitation groups	The way back to normal life: physical activity, nutrition, individual counselling, support
Informal	Family	Social/ physical activities
Informal	Friends	Social/ physical activities, advice on medication
Informal	‘Similar patient group’	Social/ physical activities, advice on medication

## 4 Discussion

In this paper, we used data from a sub-study within a follow-up programme of patients treated for breast cancer to investigate patients’ experiences regarding the information from and communication with health professionals across various stages of their cancer trajectory from a long-term perspective.



Even though the participants expressed a high level of satisfaction with care, they also highlighted communication-related issues that they experienced as problematic – or challenging – during their treatment trajectory. They particularly linked these issues to delays in initial referral to the breast cancer facility, information needs that varied throughout the trajectory, and differences in how they met their information needs during hospital care as well as after hospital discharge. The information needs identified in this study include several other aspects besides the content of information, which has been the focus of attention in the majority of previous studies of information needs (for example in [30-32]). In addition to *what* the participants needed to be told, this analysis revealed needs concerning *how* the information was given, *when* and by *whom*. All these aspects are of relevance for preparing the best conditions for well-informed, satisfied patients who are truly able to participate in shared decision-making.

In line with previous work, we found that women who presented with symptoms at their GP, experienced diagnostic delays which made them feel that they were not being taken seriously [33-35]. Regarding *how* the information was given, it is important to have a health service in place that takes patients seriously to avoid making them feel insecure, which can lead to the risk of creating distrust in the HCP [36]. As such, health policies expect that the recent introduction of standardized cancer care pathways (CCP) in Norway will ensure more timely diagnosis and treatment as well as creating greater predictability for the patients [37]. CCPs are supposed to ensure patient participation and the provision of adequate information and communication, i.e. ensuring standardized and adjusted instructions for *when* the provision of information should take place, and by *whom*. However, the Norwegian CCPs first started in 2015 and it is too early to evaluate their effects on GP-related delays.

Cancer patients' information needs in later stages of the hospital therapy period obviously deserve more attention. One major reason, as identified by our study findings and other work [38], is that the cancer patients' information and communication needs evolve throughout the treatment trajectory: the longer the trajectory, the more questions the patients have. In addition, HCP should take into consideration that even if some patients meet their information needs actively, others might take a more passive stance. This is important because well-informed patients are pivotal for participating in shared decision-making about treatment [39] as well as for ensuring compliance to post-hospital treatment [40]. Policies should consider the possibility of standardizing procedures for long-term interaction with HCP in care pathways, for instance through the upgrading of GP skills or arranging for HCP to participate as experts in support groups.

Our findings also indicate that HCP should be more aware of issues related to the small facets of the different treatment options when communicating with patients, as some women reported a lack of detailed and accurate information about what to expect from different types of breast cancer therapies. For instance, more clear communication about subjects like the forthcoming treatment options after surgery or about anti-hormonal therapy use and variations. Of note, recent work by Mullaney et al. reports similar findings [41]. This study investigated cancer patients' interactions with medical technology in treatment situations, showing that lack of adequate preparatory information can affect patient's emotional experiences negatively, for

example creating anxiety [41]. Further to this, patients' confidence in the expertise of the HCP is crucial for their experience and trust in the health service, but also for their perception of receiving good care. Today, the CCP guidelines include directions about providing information to – and having dialogue with – patients about treatment options and outcome. However, one might speculate to what degree the individual cancer patient is aware of these specific patient recommendations.

While helpful for some patients, participating in a post-hospital, specialized breast cancer rehabilitation group did not suit everyone. In our study, several women expressed that they wanted to forget their cancer disease and treatment after hospital discharge. Neither did they feel the need for seeking information or advice from other formal breast cancer networks like the non-profit cancer societies. A few women developed relationships with people they met by coincidence, e.g. through friends or social media, and took the opportunity to seek information on alternative medicine or about their long-term anti-hormonal therapy. However, those who participated in rehabilitation groups expressed satisfaction with the overall programme and activities. This finding indicates that there might be a need for further investigation into which patients benefit most from participating in a specialized rehabilitation group. This includes preparing and disseminating sufficient information of high quality to all patients about rehabilitation services and group education to ensure that the choice they make about joining or not is well informed. Updated, quality-ensured information about breast cancer is available through different web portals (such as the Norwegian Directorate of Health, the Norwegian Cancer Society and the Breast Cancer Society). Specific information about rehabilitation services and group education should be included in these.

It is a specified aim in Norwegian political guidelines to develop shared decision-making tools and to make these tools available on Helsenorge.no [42], which is the Health and Care Services' portal for health information and self-service solutions for the population. Welfare technology, telemedicine, video communication and eHealth promote new ways of involving and treating patients. However, seeking health information can be a complicated process [43]. As shown in the present study, some patients prefer to wait for someone to give them information instead of actively seeking the information they require. This represents a challenge in enabling patients to be actively involved in decisions. Moreover, face-to-face interaction is still the preferred method for receiving information for many patients, not least due to its crucial importance for establishing and maintaining a trustful relationship [44].

### **Limitations of this Study**

This study has some limitations. First, the retrospective nature of the data may be associated with recall bias because the participants had to talk about experiences that took place 7–8 years before the collection of interview data. On the other hand, through their rich accounts, the women give detailed descriptions of specific events, which increase the reliability of our findings. Examples here include, but are not limited to, the date of receiving their cancer diagnosis, the date of hospitalization, the encounters with their oncologist as well as what he/she said during a specific consultation. The retrospective nature of the data could also affect the patients' answers in the interviews, as previous studies have shown that patients tend to be

more critical when evaluating their experiences a longer time after the actual event [45-47]. Second, the design is limited to one breast cancer facility in Norway, and the findings may not be applicable to other facilities and other countries. Third, the context of cancer care has changed after the treatment of our study participants 7–8 years ago. Breast cancer treatment is a dynamic process and has changed a lot over the years: some patients need chemotherapy, but the oncologists do not know whether it will be required until three weeks after surgery. Similarly, the specifics of endocrine therapy vary with patient age (pre-/post-menopausal). In addition, Herceptin was first introduced for treatment in 2006/2007 and obviously, there was less experience with this therapy in 2007. As previously mentioned, the implementation of cancer care pathways (CCPs) occurred in 2015, and as such it is too early to evaluate its impact on patient experiences. Patient-reported experiences should be valuable for future evaluations of information and communication within CCPs.

## 5 Conclusion

This retrospective analysis of breast cancer patients' experiences of information and communication during the breast cancer trajectory showed that the majority of the participants were satisfied with their interaction with health-care personnel. However, in our study, the women addressed information needs' challenges throughout the treatment trajectory and the after-care stage, and we do not know whether current breast cancer patients still face these challenges or not. Moreover, our study shows that time-relevant information and consolation in vulnerable phases may be as important as sufficient information. As such, the presented findings can be useful for developing and improving patient information within the public area and the different breast cancer practices.

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