

Research Article

Breast Cancer Patients' Experiences on Their Individual Care Pathway: A Qualitative Phenomenographical Study ^{*Corresponding author}Eija Metsälä^{*1}, Siret Kivistik², Kjersti Straume³, Laurent Marmy⁴, José A. Pires Jorge⁵, Bergliot Strom⁶¹Principal Lecturer, Myllypurontie 1, Metropolia University of Applied Sciences, PO BOX 4000,00079 Metropolia²Senior teacher, Tartu Healthcare College, Department of Radiography and Biomedical Laboratory Science, Nooruse 5, 50411, Tartu, Estonia³Stråleterapeut, Avdeling for kreftbehandling og medisinsk fysikk, Haukeland Universitetssjukehus, Post Office Box 1400, N-5021 Bergen⁴Senior Lecturer UAS School of Health Sciences (HESAV), HES-SO University of Applied Sciences and Arts Western Switzerland, Av. de Beaumont 21, 1011 Lausanne⁵Associate Professor UAS, School of Health Sciences (HESAV), HES-SO University of Applied Sciences and Arts Western Switzerland, Avenue de Beaumont 21,1011 Lausanne, Switzerland⁶Associate Professor HVL, Western Norway University of Applied Sciences, Faculty of Health and Social Science, Inndalsveien 28, 5063 Bergen, Norway

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Abstract**Background:** Patients are experts regarding their own individual treatment and care, and they are an important source of valuable information which can lead to an improved care pathway. Patients may see the pathway differently than health care staff, putting emphasis on different concerns.**Purpose:** The purpose of this study is to breast cancer patients' experiences on their individual care pathway.**Methods:** The data was collected with open-ended online questionnaires via the websites and social media of national breast cancer patient organizations in four countries. The recruitment announcement to participate in data collection was targeted at patients who had completed their breast cancer treatments a maximum of six months before responding. Data was analyzed using thematic analysis.**Results:** Women responding to the survey in this study (N=14) reported 11 main meaningful events during their treatment pathways. With preparation prior to treatment, it is important that women are well informed about the treatment process. During the treatment, the flow of the process, being treated individually and a seamless process were all mentioned by respondents. In addition, having a properly organized follow-up was cited as the most important thing at the end of the treatment process.**Conclusions:** Women who had completed the breast cancer treatment process perceived meaningful events of the care pathway somewhat differently, to how the care pathways had been described from the point of view of the health care organization. Targeted interventions to improve the quality of breast cancer care specific to different sub-stages of the treatment process should be planned in addition to general forms of support.**Keywords:** Breast cancer, Care pathway, Meaningful event, Patient experiences, Treatment.**Introduction**

The European Society of Breast Cancer Specialists (EUSOMA) working group divides breast cancer patients' pathways into the following stages: diagnosis, surgery and loco-regional treatment, radiation therapy and local control, surgery, systemic treatments comprising chemotherapy, hormonal and biological therapies, staging, counselling, follow up and reha-

bilitation [1]. In addition to the treatments, many diagnostic examinations like laboratory tests, nuclear medicine imaging, MRI, and mammograms are needed.

The sentence: "There is no such thing as the breast cancer patient" neatly summarizes why we need to focus on individual care pathways in breast

cancer care. Even if two patients' clinical conditions are similar, the treatment options chosen can be different due to the patient's overall life situations, the patient-clinician preferences, and the type of hospital or the local clinical practices [2,3]. In addition to the clinical condition of the patient, individualized care should also take into account non-clinical patient demands associated with patients' expectations, values, social and psychosocial state and environment, lifestyle factors and economic state [4,5].

Individualized patient-centered care has been associated with better patient satisfaction and compliance, adherence, effective team performance, care coordination and quality of care [6,7,8]. However, patients and their next of kin have reported dissatisfaction with the lack of involvement in treatment and healthcare decisions, the amount of information received, and a lack of knowledge regarding responsible persons for their care [9,10]. Studies have reported women who have had breast cancer having too little of the right kind of information, lack of psychosocial support, lack of individualized care and choice of treatment, as well as a lack of follow-up during their treatment process [11-13]. In regards to radiotherapy treatment, there have been extra worries related to the embarrassment of being naked and associated feelings of disempowerment [15]. However, patients undergoing chemotherapy and adjuvant hormonal therapies have been reported to experience several side-effects as well as negative impacts on women's quality of life. Symptoms of distress-anxiety, depression, pain, fatigue, and insomnia are also often symptoms reported by women involved in breast cancer treatment. For women who have already finished their treatment, the biggest concern has been reported to be fear of the cancer returning [15,16].

Though quality control of breast cancer care is established in most health care organizations treating breast cancer patients, there is a lack of quality guidelines, which also take into account the importance of patient-staff interactions [17]. Patients are experts regarding their own individual treatment and care, and they are also an important source of valuable information which can lead to an improved care pathway. Patients may see the pathway differently than health care staff, putting emphasis on different concerns than staff or health care organizations, or have unmet needs not recognized by health care staff or organizations [12]. That is why it is important to understand, how breast cancer patients experience their care pathway and how they wish to be supported during it.

The purpose of this study is to breast cancer patients' experiences on their individual care pathway. The research questions were:

1. What do women who have had breast cancer consider the most meaningful events on their breast cancer care pathway?
2. Which of these events did they perceive as positive and which ones as less positive?
3. What other kinds of support than the ones they received would these women have anticipated from different healthcare professionals?

Methods

Design, sampling and data collection

Methodological approach chosen was phenomenography where the emphasis is on how people construct their views from the world. Analysis is whole group orientated since all data is analyzed together with the aim of identifying possible conceptions of experience related to the phenomenon under investigation, rather than individual experiences [18,19]. The project group used a critical incident approach aimed at finding critical points (positive and less positive experiences) of the breast cancer patient's individual care pathway from the patient's viewpoint [20].

Data was collected via national breast cancer patient organizations KAEV in Estonia, Europa Donna in Finland, Brystkreftforeningen in Norway and the Swiss patient association Mairaines du Sein. The national contact person in each patient organization put the announcement calling for volunteers to respond to the study on their websites and social media channels. In the announcement, there was a link to the survey as well as a patient in-

formation letter, which also contained the study's data privacy notice. Four to six voluntary respondents from each country, aged 18 to 70 years of age, who had been diagnosed with cancer mammae in stage 1-3 and had been treated in the previous six months were recruited for the study. This was expected to be sufficient to complete the qualitative data research. A web-based questionnaire was simultaneously opened up in Estonia, Norway, Finland and Switzerland from 19.4.2021 and the initial idea was that it would be open for four weeks. However, since not enough responses were received during that time, the data collection period was extended until 30.5.2021. During the data collection 14 responses were received: six from Finland, two from Estonia, two from Switzerland and four from Norway.

The questionnaire comprised 13 open-ended questions concerning women's experiences during the time period between getting a breast cancer diagnosis and starting rehabilitation. The questions were based on steps described in EUSOMA's quality indicators of breast cancer care and some European research studies focusing on breast cancer care pathways [1,21-23]. Furthermore, the websites of a number of hospitals that treat breast cancer which described breast cancer care pathways were reviewed. Translation of the original English questionnaire was made for each of the national languages (Estonian, Norwegian, Finnish and French) and were pilot-tested in each country by two women who had breast cancer, in order to check the clarity of the questions, the time needed for answering and the relevancy of the content. Filling in the questionnaire took respondents about 30 minutes.

Data analysis

Responses were translated from their original language into English by 'Breast Cancer Patients' Experiences on Their Individual Care Pathway: A Qualitative Phenomenographical Study' project group members, after which they were ready for analysis. Data covering the three questions of the data collection instrument reported in this article comprised 14 pages of translated text (from national languages to English) written in Times New Roman font size 12 and spacing one. It was analyzed using both inductive (questions 1 and 13) and deductive thematic analysis (questions 2 to 12). In deductive analysis, steps of the breast cancer care pathway present in the questions were used as a theoretical frame of analysis [24,25]. Firstly, the researcher EM familiarized with the data to identify units of analysis, which then were formed into condensed meaning units, and finally coded. The first author EM performed the preliminary coding, followed by checking the coding consistency by authors BS and SK. No major discrepancies in the coding were found.

Ethical issues

All the patient organizations participating in the study were asked for research permits. An ethical board permit was requested from the Norwegian center for research data since Western Norway University of Applied Sciences (HVL) was coordinating the data collection of this study. However, the Norwegian center for research data responded that the ethical board permit was not necessary since no medical or personal data was collected. Data collected only comprised patients' opinions and viewpoints on their care and treatment process. The subjects were asked for informed consent in the data collection form. If they agreed to participate in the study, they ticked the box "I agree to participate in this study". No personal data was collected from the respondents, ensuring anonymity of the data and participants. In addition, a research collaboration agreement between the partners regulating the research partners' responsibilities for processing data according to every country's national legislation and General Data Protection regulation Article 26 was made.

The software used for data collection was Cisco AnyConnect Secure Mobility Client governed by Western Norway University of Applied Sciences (HVL). Only nominated persons from the 'Breast Cancer Patients' Experiences on Their Individual Care Pathway: A Qualitative Phenomenographical Study' project group processed and analyzed the data, which was stored in the closed cloud drive and protected from third party data access.

When we present the results, all such information where the respondent or her site of treatment could possibly be identified has been anonymized in the text.

Results

Meaningful events during the care pathway

Out of meanings units condensed meanings were created and then they were coded. Out of these codes these themes with no sub-themes were created. Female respondents to the survey in this study (N=14) reported 11 main meaningful events from their own experiences.

Searching for first stage examinations of breast cancer was seen as a starting point on the entire care pathway. Patients often felt that they already knew they had breast cancer before the diagnosis was confirmed by the pathologist's report. Examinations performed after the diagnosis was confirmed were viewed by some as a continuum from getting the diagnosis. Operation, reoperation and breast reconstruction were associated with a variety of feelings and follow-ups. Meetings with a doctor and breast cancer nurse were mentioned as meaningful by almost all of the respondents. Chemotherapy, hormonal therapy and other medical therapies were often reported as meaningful but not very pleasant. A majority of respondents mentioned radiotherapy as a meaningful event and had pretty neutral opinions about it. Managing side effects was seen as important in relation to all types of treatments. There were contrasting experiences related to the follow up of treatments as well as in regards of psychosocial support or lack of it. The end of the treatment seemed to be a very important stage for women. (Table 1).

Table 1. Meaningful events during breast cancer care pathway reported by women.

Meaningful event	Authentic citation
1. Searching for first stage examinations of breast cancer (14 codes)	"Got an appointment with the GP the following week. During the doctor's appointment, he confirmed my assumptions and wanted me to be examined in the hospital. He registered me on the pathway. One week later I got an appointment for mammography, ultrasound and biopsy." (A Norwegian woman)
2. Getting the breast cancer diagnosis (9 codes)	"Cancer diagnosis confirmation announcement by the gynecologist who followed my case." (A Swiss woman)
3. Examinations after getting the diagnosis (5 codes)	"Many tests after the diagnosis." (A Finnish woman)
4. Operation, reoperation and breast reconstruction (15 codes)	"Fear of the surgery" (An Estonian woman)
5. Appointments with a doctor and breast cancer nurse (9 codes)	"Of course also meaningful was the visit to the doctor after the operation, when it became totally clear what was to come. The doctor told me about chemotherapy and radiation therapy and hormonal medication. Some how I feel that there came quite a lot of information during one visit." (A Finnish woman)
6. Chemotherapy, hormonal therapy and other medical therapies (12 codes)	"Chemos from deep down there." (A Finnish woman)
7. Radiotherapy (8 codes)	"Radiotherapy 25 sessions." (A Swiss woman)
8. Managing side effects (2 codes)	"Now I have started with 5-10 years of Tamoxifen treatment and the side effects are very noticeable." (A Norwegian woman)

9. Follow up or lack of it (3 codes)	"When my radiation therapy period was finished, they informed to me that there is no after care in this area, if the treatments have been effective, no until in august 2021 the first control." (A Finnish woman)
10. Psychosocial support or lack of it (3 codes)	"Having been very scared and feeling enormous loneliness throughout the whole pathway, despite the fact that I have family and friends around me." (A Norwegian woman)
11. The end of the treatment (6 codes)	"When it was finally over, I felt great." (An Estonian woman)

Positive and less positive meaningful events during women's individual care pathway

Positive and less positive experiences during the breast cancer care pathway are presented in three sub-chapters divided according to the substages of the breast cancer care pathway: 1. Preparation prior to treatment, 2. Treatment comprising a) surgery and reconstruction of the breast, b) radiotherapy, c) chemotherapy, endocrine and biological therapies, d) laboratory services and e) mammography f) other treatments and 3. Aftercare and Counselling following treatment.

Positive and less positive experiences associated with preparation prior to treatment

Women's positive experiences associated with preparing for breast cancer treatment were divided into four themes. Two of them were associated with being well informed about upcoming treatments and about the forms of support available. (Table 2) Respondents reported that being informed helped them to prepare for what was about to follow.

"Received decent information with regard to all practical things that should happen." (A Norwegian woman).

"In many steps I was reminded about different forms of support and they made sure that I had all the contact information." (A Finnish woman)

Women were happy to get good psychosocial support, which took into account their next of kin. They also appreciated honest and empathetic encounters with members of staff.

Less positive experiences in preparing for treatment could also be divided into four themes. (Table 2) Women reported being confused by the large number of different appointments before the actual treatment started. Furthermore, changes to treatment plans including treatment methods and their length also caused confusion. Most of the comments regarding less positive experiences were about the lack of information at the beginning of the process. These patients felt that they were expected to seek information for their care process on their own, or they were only given information when they asked for it from a healthcare professional.

"I was sent for a radiotherapy treatment planning scan so that I had no idea where I was going. I wish I had more information about this." (An Estonian woman).

"If I had not read about things beforehand, I would have been totally outside of everything, like a snowman" (A Finnish woman citing a Finnish proverb).

Some women felt that at the beginning of the treatment they were offered either too little or no psychosocial support or genetic counselling. In their opinion, these would have been very helpful to be able to prepare for the upcoming treatment process. (Table 2).

Table 2. Positive and less positive experiences associated with preparation prior to treatment.

Organising theme: Women's experiences associated with preparation prior to breast cancer treatment	
Positive experiences - themes	Less positive experiences - themes
<ul style="list-style-type: none"> • Being well informed about treatment • Being well informed about support available • Good psychosocial support • Receiving genetic counselling 	<ul style="list-style-type: none"> • Confusion associated with organising the treatments • Lack of different kinds of information • Lack of psychosocial support • Lack of genetic counselling

Positive and less positive experiences associated with breast cancer treatments and examinations

Among the positive and less positive experiences associated with different breast cancer treatments and examinations as reported by respondents, we can find several similar sources of satisfaction and dissatisfaction. The fluent flow of services was mentioned in the case of surgical, radiotherapy, laboratory and mammography services. The feeling of being heard, taken care of and treated as an individual were all mentioned in relation to surgery and radiotherapy services. In addition, women were happy about smooth chemotherapy, endocrine and biological therapy as well as radiotherapy treatment. They were happy that these procedures were not as difficult as they had expected, they did not experience any complications or side-effects and that the treatment really seemed to work for them. Respondents had most positive experiences through almost all the steps of their treatment regarding competent and friendly staff that helped them to survive through the process.

"Top staff. I had a good experience of the surgery. I appreciated the calm and relaxed manner of the nursing staff, especially the anesthetists, while feeling they were attentive and competent." (A Swiss woman)

"Nice technician." (An Estonian woman)

With regard to other services patients had, they simply reported being happy having them. Women reported positive experiences with extra psychosocial support, physiotherapy services and non-medical services like acupuncture, flower therapy and even make-up sessions and said they were helpful and supportive. (Table 3).

Most of the less positive experiences reflected the lack of positive experiences reported previously. Haste and not giving enough or timely information regarding surgery and radiotherapy treatments made patients feel unprepared and unsafe. Some patients did not get enough psychosocial support in regards to these procedures. (Table 3)

"Wish I knew more about what I was going to experience." (A Norwegian woman).

Negative experiences related to health care staff were mentioned in relation to surgical, radiotherapy and mammography services. These were associated with staff insensitivity towards patient's feelings and their life situation, frequent staff turnover during the treatment of the patient, impersonal treatment and dissatisfaction with staff behavior. (Table 3).

"Going to surgery everything was strange and new including the place, so a slightly busy and grumpy encounter did not feel good. In that situation one is quite sensitive." (A Finnish woman)

In regard to all treatment, less positive experiences regarding side-effects were reported. For example with chemotherapy, respondents reported side-effects, such as nausea management, and that the treating of side-effects was not taken as seriously as they should have been, according to the patients' own opinions. Patients also reported less positive experiences related to the organisation of both breast cancer treatments and diagnostic services. There was a lack of clarity in the execution of services,

appointment times were not kept or they were hard to organise in a patient-friendly way. Patients reported that some unnecessary examinations or tests were carried out. Furthermore, some patients felt laboratory examinations or mammographies were painful or inconvenient. Regarding other potential services, a couple of comments related to not receiving any other services. (Table 3).

Table 3. Positive and less positive experiences associated with breast cancer treatments.

Organising theme: Women's experiences associated with breast cancer treatments	
Positive experiences - themes	Less positive experiences - themes
Surgery and reconstruction of the breast	
<ul style="list-style-type: none"> • Non-radical surgery went smoothly • Being happy with the outcome of surgery process • Being well informed and feeling heard • Feeling of being well cared for 	<ul style="list-style-type: none"> • Haste in the process • Lack of psychosocial support • Insensitive behaviour of hospital staff • Side-effects of the operation • Fear and shock
Radiotherapy	
<ul style="list-style-type: none"> • Appointments were organized in a patient-friendly way • Being well-informed and feeling taken care of as an individual • Nice and competent staff • The relief of easygoing treatment 	<ul style="list-style-type: none"> • Impersonal treatment • Frequent changes among the treatment staff • Feeling anxious, alone and fearful • Problems in the treatment process • Side-effects of radiotherapy
Chemotherapy, endocrine and biological therapies	
<ul style="list-style-type: none"> • Having peer support • Nice and competent staff • The relief of smooth treatment 	<ul style="list-style-type: none"> • Lack of information of the therapies • Problems in the treatment process • Side-effects of therapies • Side-effects of therapies were not treated properly
Laboratory services	
<ul style="list-style-type: none"> • Competent laboratory staff • Laboratory services were fast, efficient and seamless 	<ul style="list-style-type: none"> • Difficulties in sample taking causing inconvenience to the patient • Challenges in organizing appointment times
Mammography	
<ul style="list-style-type: none"> • Arranging the appointment quickly • Mammography not being painful • Nice and competent staff 	<ul style="list-style-type: none"> • Experiencing mammography as unpleasant, painful examination • Dissatisfaction with behaviour of mammography staff and doubts regarding their competence
Other services	
<ul style="list-style-type: none"> • Satisfaction with other services related to psychosocial support, physiotherapy and other different types of non-medical therapies 	<ul style="list-style-type: none"> • Lack of other services

Positive and less positive experiences associated with aftercare and counselling following treatment

Women's positive experiences related to aftercare and counselling were for the most part associated with the same things as in other stages of the process. They were related to having a proper follow up plan and some place to contact after the end of the treatment, as well as receiving enough information and feeling supported. These things supported their feeling of being safe and having a positive attitude towards the future. (Table 4)

"During the last radiation treatment, a radiation therapist said that everything looked fine and that I would be summoned for an annual follow-up for the next 10 years. Otherwise, she wished me luck." (A Norwegian woman)

Less positive experiences reflected the lack of follow-up or the follow-up being too far from the conclusion of the treatment. Some women felt they were left totally without any aftercare and follow-up or there were major difficulties when they did receive them. (Table 4)

"After radiation therapy I fell on nothing, when at first the pathway was so clear. Immediate return to work. A bit of a feeling of abandonment, when the mind just started dealing with all that had happened." (A Finnish woman)

"Have not received any follow-up and I have missed that. This is another element of uncertainty, in the crisis one already has been through." (A Norwegian woman)

Table 4. Positive and less positive experiences associated with aftercare and counselling following treatments.

Organising theme: Women's experiences associated with aftercare and counselling following treatments	
Positive experiences - themes	Less positive experiences - themes
<ul style="list-style-type: none"> • Having a plan and contact for aftercare and follow-up • Getting enough information • Being supported by health care staff 	<ul style="list-style-type: none"> • Lack of aftercare and counselling • Too little follow-up and follow-up time being too far from end of treatment • Difficulties in contacting staff and being heard

Extra support required during the treatment period

During their breast cancer care pathway, women reported experiencing many kinds of support, which will be further reported in other articles related to this study. However, they were also asked what kind of extra support they would have wished for, that they did not receive during their care and treatment. These extra forms of support could be categorized into three organizing themes without sub-themes: Psychosocial support; More intense follow up and Timely and accurate content information. Some women said that their psychosocial needs were not met at all or the support was not sufficient.

"I am still on 100% sick leave and have a body full of fear and anxiety. Would really like more support and that there was some sort of follow-up after radiation." (A Norwegian woman)
More intense follow up was also wished for.

"I stayed 'on nothing' after the treatment ended. Next was the annual control" (A Finnish woman)
As already reported in the previous chapters, women would have also liked timely and accurate content information.

"I would have liked to have more information about hormone preventive medication and its side-effects." (A Finnish woman)

Discussion Meaningful events and women's' experiences of them during their care pathway

Health care professionals often inspect patient pathways from an organizational viewpoint. A breast cancer patients' pathway is often divided into diagnostic, therapeutic and rehabilitation or follow-up stages [1,22]. This issue also came up in the questionnaire created for this study: women were asked to reflect upon the time period between getting the breast cancer diagnosis and beginning rehabilitation. However, it seemed that they considered the care process to begin from the step of seeking first stage examinations for breast cancer. Not all the women reported the stages in the same order and different individuals put a different kind of emphasis on different stages. This aptly demonstrates that every patient should be approached and considered as an individual [4,7,26]. Furthermore, some stages of the care pathway were seen as limited and/or combined. This came up in almost all the subjects' responses. Also noteworthy in the results was the finding that patients did not necessarily experience getting the final diagnosis in a similar way as health care professionals, for whom having the final diagnosis of breast cancer means the pathologist's report. In our study, some patients took the diagnosis as granted when a health care professional told them about the possibility of having cancer. This is something health care professionals should take into account when they are communicating with patients about their stage of the disease.

Womens' experiences associated with preparation prior to treatment

Having too little timely information still seems to be a problem for women with breast cancer [10,11]. As cited in the responses to this study, having enough information is one of the most important things helping women to prepare for upcoming breast cancer treatment. Knowing beforehand the different stages of the process, the support available, the timetable for different examinations and treatments, and how they might strain the patient and her next of kin helps them to plan their lives both psychologically and from a practical viewpoint. Not being informed well enough causes feelings of anxiety, insecurity and fear. Not knowing about counselling and other support services leads to their underuse or dissatisfaction with not having them. Not knowing what is to come can cause difficulties in transportation, housing and patients' economic situation since one does not know how one should organize one's life. Occasionally, not giving enough information may be interpreted by patients as staff incompetence.

Getting a clear idea of the course of the care pathway helps the patient to orient and plan for the future. Changes in the planned schedules and confusion regarding the organization of the services may cause the patient to feel that nobody really knows what is happening in her care. This is one of the reasons why multiprofessional cooperation in breast cancer care is extremely important [1,27]. When health care staff know each other's roles and responsibilities, they are able to provide seamless and patient-centered services that give the patient the feeling of coordinated care and safe and competent services.

Womens' experiences associated with breast cancer treatment and examinations

Seamless services or cut-offs in the service chain were mentioned in patient's both positive and less positive experiences during this study. Patients reported less positive experiences related to the organization of both breast cancer treatments and diagnostic services. To avoid fragmentation of services, in addition to breast cancer nurses coordinating the care, different types of models of coordinated care have been proposed for breast cancer treatment [13,21].

Women in our study reported feeling happy about smooth chemotherapy, endocrine and biological, radiotherapy treatments. However, they also reported less positive experiences regarding side-effects and their treatment.

In cases where there were not many side-effects from the treatment or they are treated in an optimal way, this helps women to live as normal a life as possible during the treatment period. However, if there are a lot of side-effects and they are not treated properly this may lead to a deterioration in quality of life [15].

Women had positive and negative experiences associated with feeling that they were being heard, taken care of and treated as an individual. Haste and not giving enough or timely information regarding surgery and radiotherapy treatments made patients feel unprepared and unsafe, results that were also found in the study by Probst et al., (2021) [14]. Some patients did not get enough psychosocial support with regard to these processes. Edib et al., (2016) suggest that giving timely and appropriate psychological and physical rehabilitation programs in healthcare settings ought to be the highest priority to support them in the long-term adjustment process and ensure a better quality of life [11]. In the light of the results of our study, we agree with this recommendation.

Women reported a lot of positive experiences throughout almost all of the steps of their treatment with relation to competent and friendly staff that helped them to survive the process. However, as Sandager et al., (2016) suggest in their study, these results should be interpreted with caution. Expectations, patient characteristics, survey timing, loyalty to healthcare professionals, backing up their own choices and questionnaire and item design have been identified as factors potentially influencing the association between delivered care and patient reported experience [28].

Women's experiences associated with aftercare and counselling following treatment

Women's positive experiences related to aftercare and counselling were mostly pretty much the same as regarding the other parts of the process. They were related to having a proper follow-up plan and some place to contact after the end of the treatment, as well as getting enough information and feeling supported. In some of the comments the agony of being "kicked out of the system" and left without any kind of psychosocial support could clearly be heard. In the study by Edib et al., (2016) the most prevalent unmet psychological needs of the breast cancer patients were uncertainty about the future, fears about the cancer spreading, feelings of sadness, feelings about death and dying, concerns about those close to the patient, worry that the results of treatment were beyond their control, and feeling down or depressed were broadly the same as reported by the women participating in our study. Being left alone with these kinds of burdens seems to be something no patient should experience. All the health care organizations treating breast cancer patients should put as much emphasis on taking care of their patients' psychosocial needs and give as good care in that respect as they obviously do on the clinical side.

Extra support required during the care pathway

We wanted to study patient's unmet needs since it is common knowledge and there is also research evidence that patients' unmet needs are not being recognised by health care staff or organizations [12]. According to Kogan et al., (2015) and Waelli et al., (2021) individualized care should also take into account non-clinical patient demands associated with patients' expectations, values, social and psychosocial state and environment, lifestyle factors and economic state. That was also the case in this study [4,5]. The extra support they would have wished for, but felt did not get enough of, was accurate about non-medical aspects of their welfare like psychosocial support and getting enough information about procedures.

Trustworthiness and limitations

The study used convenience sampling of women recruited via breast cancer patient organizations in four countries with the objective of having a more generic viewpoint as to women's experiences than from just one country. We also wanted to see if women's experiences coming from four

culturally different countries might be largely different, which did not seem to be the case based on the responses received. The data collection instrument was tested in each participating country (Estonia, Finland, Norway and Switzerland) with a couple of individuals who had breast cancer but did not respond to the final data collection of this study. Back and forth translations were made for the data collection instrument from English to national languages (Estonian, Finnish, Norwegian and French). However, the translators were not all English language professionals but researchers possessing good English competences and native speakers in the languages the instruments were translated into. These persons also translated the responses back to the English language. This may have caused some bias to the data collection instruments in the native languages and translations from the native languages back into English. Limitations associated with patient-reported data apply to this study. Patient reported experience data should be interpreted with caution, as reported positive experiences might neither reflect high quality care nor satisfied patients [28].

In this study dependability of the analysis was ensured by peer coding. The codes and categories were discussed and negotiated between the authors SK, BL and EM. These authors also discussed codes and categories both for trustworthiness reasons but also to guarantee methodological expertise throughout the whole analysis to ensure conformability. An effort to increase the credibility of the research is to use authentic citations in the text to validate the thematisation we made out of the data. The data was collected from women who have had breast cancer in four different countries. Though the amount of subjects was limited (n=14) as it often is in qualitative studies, the fact that women's experiences about meaningful events during their care pathway and positive and less positive experiences during their care pathway were similar regardless of the country were quite equal regardless of the country support the transferability of the findings [29]. However, in interpreting the findings, it must be taken into account that there exist differences in health care systems and organization of care in these four countries that may have had an impact on women's experiences regarding their breast cancer care pathway.

Conclusions

Women who have finished the breast cancer treatment process perceive meaningful events of the care pathway a bit differently than how care pathways are described from health care organizations' viewpoints. When women are preparing for breast cancer treatment it is important to be well informed, about the treatment process in order to plan one's life practically and prepare psychologically for the upcoming breast cancer treatment. In treatments, the flow of the process, being treated individually and a smooth treatment process including proper care of treatment side effects seem to be core issues. Having properly organized follow-up, which is arranged soon enough after the end of the treatment is the most important thing at the end of the treatment process. No breast cancer patient should be left without clinical and psychosocial support at the end of the treatment. Targeted interventions to improve the quality of breast cancer care specific to different sub-stages of the treatment process should be planned in addition to general forms of support.

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CRedit authorship contribution statement

Eija Metsälä: Conceptualisation, Methodology, Validation, Data collec-

tion, Data analysis, Writing original draft, Writing Review & Editing, Visualisation, Supervision, Project administration, Funding acquisition.

Siret Kivistik: Conceptualisation, Data collection, Data Analysis, Editing the manuscript, Project administration, Funding acquisition.

Kjersti Straume: Data collection, Data analysis, Writing Review & Editing. José Pires Jorge: Data collection, Data analysis, Writing Review & Editing. Laurent Marmy: Data collection, Data analysis, Writing Review & Editing. Bergliot Strom: Conceptualisation, Methodology, Validation, Data collection, Data analysis, Writing original draft, Writing Review & Editing, Supervision.

Declaration of competing interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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