



Breast cancer patients' experiences on their individual care pathway: A qualitative study



E. Metsälä^{a,*}, S. Kivistik^b, K. Straume^c, L. Marmy^d, J.A.P. Jorge^d, B. Strom^e

^a Metropolia University of Applied Sciences, Myllypurontie 1, PO BOX 4000 00079, Finland

^b Tartu Healthcare College, Department of Radiography and Biomedical Laboratory Science, Nooruse 5, 50411, Tartu, Estonia

^c Avdeling for kreftbehandling og medisinsk fysikk, Haukeland Universitetssjukehus, Post Office Box 1400, N-5021 Bergen, Norway

^d School of Health Sciences (HESAV), HES-SO University of Applied Sciences and Arts Western Switzerland, Av. de Beaumont 21, 1011 Lausanne Switzerland

^e Western Norway University of Applied Sciences, Faculty of Health and Social Science, Inndalsveien 28, 5063 Bergen, Norway

ARTICLE INFO

Article history:

Received 1 December 2021

Received in revised form

7 May 2022

Accepted 3 June 2022

Keywords:

Breast cancer

Care pathway

Meaningful event

Patient experiences

Treatment

ABSTRACT

Introduction: Radiographers must be aware of the needs and expectations of women to be able to involve them in the decision making on their own care pathway. The purpose of the study is to describe experiences of women with breast cancer in their individual care pathway.

Methods: Data was collected with qualitative open-ended online questionnaires via national breast cancer patient organizations in four countries. The subjects were women who had completed their breast cancer treatments at a maximum of six months before responding. Data was analysed using thematic analysis.

Results: Women responding to the survey questionnaire (N = 14) reported 11 main meaningful events in their care pathways. According to respondents, being well informed about the treatment process, a smooth flow of the care process, being treated individually and having a properly organized follow-up were the most important aspects for the optimal breast cancer care pathway.

Conclusions: The subjects perceived their breast cancer care pathways somewhat differently from the way the pathways are usually described from the health care organizations' viewpoint. In different stages of their individual breast cancer care pathway, positive and less positive experiences of women were somewhat similar, yet contrasting.

Implications for practice: In addition to general forms of support, targeted interventions should be planned to improve the quality of breast cancer care specific to different stages of the treatment process. The findings can be used to promote education for radiographers and other cancer care staff, as well as to develop patient-centred breast cancer care.

© 2022 The Author(s). Published by Elsevier Ltd on behalf of The College of Radiographers. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Introduction

Radiographers must be aware of the needs and expectations of people with breast cancer to be able to involve them in the decision making of their own diagnostic and therapeutic practices.^{1,2} This is enabled by the daily interaction, which also allows to acknowledge patients' voice on what they expect from their individual care pathway.^{1,2} In the current study, the focus is on the entire patient care pathway from the definitive diagnosis of breast cancer to the

end of treatments in order to explore the holistic approach to the therapeutic stage.

The European Society of Breast Cancer Specialists (EUSOMA) working group divides breast cancer patient pathways into the following stages: diagnosis comprising physical, radiological and laboratory examinations, surgery and loco-regional treatment, radiation therapy and local control, systemic treatments comprising chemotherapy, hormonal and biological therapies, staging, counselling, follow-up and rehabilitation.³ In addition to the treatments, many diagnostic examinations like laboratory tests, nuclear medicine imaging, MRI, and mammograms are needed.³ Even if patients have similar clinical conditions, chosen treatment options may vary due to their personal situations, patient-clinician preferences and local clinical practices.^{4,5} Additionally, individualized care should

* Corresponding author.

E-mail addresses: eija.metsala@metropolia.fi (E. Metsälä), siretkivistik@nooruse.ee (S. Kivistik), kjersti.straume@helse-bergen.no (K. Straume), laurent.marmy@hesav.ch (L. Marmy), jose.jorge@hesav.ch (J.A.P. Jorge), bst@hvl.no (B. Strom).

also consider non-clinical demands of the patient such as expectations, values, social and psychosocial state and environment, lifestyle factors and economic state.^{6,7}

Individualized patient centred care is associated with improved patient satisfaction and compliance, adherence, effective team performance, care coordination and quality of care.^{8–10} However, patients and their next of kin have reported dissatisfaction with the lack of involvement in treatment and health care decisions, the amount of information received, and a lack of information regarding the persons responsible for their care.^{11–13} Some women with breast cancer have received limited information, psychosocial support and individualized care, as well as inadequate choice of treatment or they have not received follow-up at the end of their treatment process.^{14–16} In regards to radiotherapy treatment, there have been extra concerns related to the embarrassment of nudity and associated feelings of disempowerment.¹⁷ Moreover, 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.¹⁸ Symptoms of distress-anxiety, depression, pain, fatigue, and insomnia are also often the symptoms reported by women involved in breast cancer treatment.¹⁸ For women who have already finished their treatment, the biggest concern has been reported to be a fear of the cancer returning.¹⁹

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, incorporating the importance of patient-staff interactions and patient involvement.²⁰ Patients are experts regarding their own individual treatment and care. They are also an important source of information, which can lead to improved diagnostic, care and treatment pathways.¹⁵ Patients may perceive the pathway differently compared to the understanding of health care staff or health care organizations, emphasizing other concerns as well. In addition, they may have the needs not recognized by health care staff or organizations.¹⁵ Thus, it is important that radiographers and other professionals, involved in breast cancer diagnostics and care, understand how women with breast cancer experience their care pathway, what is meaningful for them and how they wish to be supported in the care pathway. Meaningful events are described as perceived important circumstances, raising intense emotions and contemplations. Pleasant and positive events, as well as events having negative nature, are perceived more meaningful than emotionally less significant events.^{21,22}

The purpose of this study is to describe experiences of women with breast cancer in their individual care pathway. The research questions are:

1. What are the most meaningful events in the care pathway for women with breast cancer?
2. Which of these events did they perceive as positive and which ones as less positive?

Methods

Design, sampling and data collection

The methodological approach was informed by phenomenography, emphasizing how women with breast cancer construct their views on the breast cancer care pathway.^{23,24} Analysis is whole group orientated since all data is analysed together with the aim to identify possible conceptions of experience related to the phenomenon under investigation, rather than to study individual experiences.^{23,24} In phenomenography, the aim is to use open-ended

questions to allow the subjects describe their views as freely as possible. Interviews are the most commonly used method in phenomenographic studies, yet nowadays, multiple data collection approaches are allowed.²⁵

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 published the announcement calling for volunteers to respond to the study on their websites and in social media channels. In the announcement, there was a link to the survey and a patient information letter, including the data privacy notice. Four to six voluntary respondents from each country were recruited for the study, aged 18–70 years of age. The respondents had been diagnosed with carcinoma mammae in stage 1–3 and had been treated in the previous six months. The online questionnaire was simultaneously opened up in Estonia, Norway, Finland and Switzerland on 19.04.2021 and it was planned to be open for four weeks. However, since not enough responses were received during that time, the data collection period was extended until 30.05.2021. During the data collection, 14 responses were received: six from Finland, two from Estonia, two from Switzerland and four from Norway to identify common characteristics of the experiences of women with breast cancer in their care pathway.

The questionnaire comprised 13 open-ended questions concerning women's experiences during the period ranging from getting to know about their breast cancer diagnosis to the beginning of rehabilitation. In the first question, women were asked to list events meaningful to them and thereafter the questions were based on the steps described in the EUSOMA quality indicators of breast cancer care^{3,26} and some European research studies focusing on breast cancer care pathways.^{27,28} The original English version of the questionnaire was translated into the national languages (Estonian, Norwegian, Finnish and French), the translations were pilot-tested in each country by two women with breast cancer in order to check the clarity of the questions, the time needed for answering and the relevance of content. Filling in the questionnaire took about 30 min.

Data analysis

Project group members translated responses from their native languages into English. Data comprised 13 pages of translated text written in Times New Roman, font size 12 and spacing one. Data was analysed using both inductive (data for research question 1) and deductive thematic analysis (data for research question 2). In deductive analysis, the steps of breast cancer care pathway included in the questions of the data collection instrument were used as the theoretical framework of analysis.^{29,30} Firstly, the researcher EM familiarized with the data to identify units of analysis, which then were formed into condensed meaning units and finally coded. Out of these codes, themes with potential sub-themes were created. The first author EM performed the preliminary coding, followed by checking the coding consistency by authors BS and SK. No major discrepancies were found in the coding.

Research ethics

All the patient organizations participating in the study were asked for research permits. An ethical board permit was requested from the Norwegian centre for research data since the Western Norway University of Applied Sciences (HVL) was coordinating the data collection of this study. However, the Norwegian centre for

research data responded that the ethical board permit was unnecessary since no medical or personal data was collected. Data was collected only about patients' opinions and viewpoints regarding 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". In addition, a research collaboration agreement was signed between the partners, regulating their responsibilities for data processing according to every country's national legislation and Article 26 of the General Data Protection regulation.

The software used for data collection was Cisco AnyConnect Secure Mobility Client governed by the HVL. Only nominated persons from the project group processed and analysed the data, which was stored in the closed cloud drive and protected from third party data access. When presenting the results, all such information where the respondent or the health care setting could possibly be identified has been anonymized in the text.

Results

Meaningful events of the care pathway

Respondents of this study (N = 14) reported 11 main meaningful events of the care pathway based on their experiences. As a starting point of the entire care pathway was seen the search for first stage examinations of breast cancer. Many patients 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 as a continuum for getting the diagnosis. Operation, reoperation and breast reconstruction were associated with a variety of feelings and connected with different follow-ups. Almost all respondents considered meetings with the health care staff as meaningful. Chemotherapy, hormonal therapy and other medical therapies were often reported as meaningful, yet unpleasant. A majority of respondents mentioned radiotherapy as a meaningful event and had 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 treatment seemed to be a predominant stage for women (Table 1).

Table 1
Meaningful events in the 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. Somehow, 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 for women in their individual care pathway

In the following chapters, the positive and less positive experiences are reported more in detail, organized according to the steps of the breast cancer care pathway found in literature.^{3,24–26}

Positive and less positive experiences associated with preparation prior to treatment

Women's positive experiences associated with preparation for breast cancer treatment were divided into four themes. Two of them were associated with being well informed about the upcoming treatments and about the forms of support available (Table 2). Being informed helped patients to prepare for what was 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 reckoned with their next of kin. They appreciated honest and empathetic encounters with the members of staff.

"They (staff) asked how the family has taken the situation, resources and networks." (A Finnish woman)

Less positive experiences in preparation for treatment could also be divided into four themes (Table 2). Women reported being confused by the large number of different appointments before the beginning of actual treatment. Furthermore, changes to the treatment plans, including treatment methods and their length also caused confusion. Most patients commented on the lack of information at the beginning of the process. They 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 health care professional.

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

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

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

The fluent flow of surgical, radiotherapy, laboratory and mammography services was important for the patients. The feeling of being heard, taken care of and treated as an individual in surgical and radiotherapy services was also important for them. 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 so uncomfortable as they had expected, they did not experience any complications or side effects and the treatment really seemed to work for them. In almost all the steps of their treatment, respondents had most positive experiences regarding competent and friendly staff that helped them to survive through the process (Table 3).

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

“Nice technician.” (An Estonian woman)

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

“Physiotherapy, flower therapy, acupuncture, reflexology. I also find it great to offer makeup classes to patients, although I personally did not feel the need to follow them.” (A Swiss woman)

Less positive experiences meant the lack of aforementioned positive experiences. Haste and not giving enough or timely information

regarding the 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)

Less positive experiences related to the health care staff were mentioned in association with surgical, radiotherapy and mammography services, including staff insensitivity towards the patient's feelings and their life situation, frequent staff turnover during the treatment period, impersonal treatment and dissatisfaction with staff behaviour (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)

Considering all treatments, the less positive experiences were related to side effects, particularly in regards to chemotherapy, which caused nausea, for instance. However, according to patient opinion, treating side effects should have been taken more seriously than it actually was. Patients also reported about some less positive experiences related to the organization of both breast cancer treatments and diagnostic services. There was a lack of clarity in the execution of services, appointment times were not followed or they were hard to organize in a patient-friendly way. Patients also reported some unnecessary examinations or tests being carried out. Furthermore, some patients felt that laboratory examinations or mammograms were painful or inconvenient. Regarding other potential services, a couple of comments were made regarding the lack additional services (Table 3).

Positive and less positive experiences associated with aftercare and counselling

Women's positive experiences of aftercare and counselling were related to a proper follow-up plan and the information on contact options after the end of treatment, as well as receiving enough information and feeling supported. These aspects 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 completion of 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 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
<p>Surgery and reconstruction of the breast</p> <ul style="list-style-type: none"> • Non-radical surgery went smoothly • Being happy with the outcome of the 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 • Impersonal treatment • Frequent changes among the treatment staff • Feeling anxious, alone and fearful • Problems in the treatment process • Side effects of radiotherapy • Lack of information of the therapies • Problems in the treatment process • Side effects of therapies • Side effects of therapies were not treated properly • Difficulties in sample taking causing inconvenience to the patient • Challenges in organizing appointment times • Experiencing mammography as unpleasant, painful examination • Dissatisfaction with behaviour of mammography staff and doubts regarding their competence • Lack of other services
<p>Radiotherapy</p> <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 easy going treatment 	
<p>Chemotherapy, endocrine and biological therapies</p> <ul style="list-style-type: none"> • Having peer support • Nice and competent staff • The relief of smooth treatment 	
<p>Laboratory services</p> <ul style="list-style-type: none"> • Competent laboratory staff • Laboratory services were fast, efficient and seamless 	
<p>Mammography</p> <ul style="list-style-type: none"> • Arranging the appointment quickly • Mammography not being painful • Nice and competent staff 	
<p>Other services</p> <ul style="list-style-type: none"> • Satisfaction with other services related to psychosocial support, physiotherapy and other different types of non-medical therapies 	

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 the end of treatment • Difficulties in contacting staff and being heard

Discussion

Women's experiences of meaningful events in their care pathway

Radiographers and other professionals involved in breast cancer diagnostics and care often inspect patient pathways from the organizational viewpoint. The pathway of breast cancer patients is often divided into diagnostic, therapeutic and rehabilitation or follow-up stages.^{3,27} However, it seemed that women themselves considered the care process to begin with the step of seeking first stage examinations for breast cancer. Not all the women reported the stages in the same order and different respondents emphasized the stages variously. Furthermore, some stages of the care pathway were seen as limited and/or combined. It is also noteworthy that the women experienced the confirmation of final diagnosis in a different way compared to the health care professionals, for whom the final diagnosis of breast cancer means the pathologist's report. In our study, some women seemed to understand the diagnosis as a final one, when the health care professional told them about the possibility of having cancer. The EFRS Statement on Patient Engagement and Inclusion in Radiotherapy² highly recommends

that patients should be involved in the redesigning of the radiotherapy process. In addition to that, they should be involved in the redesigning of their entire care pathways. Considering the patient viewpoint might help to conceptualize and understand them better.³¹

Women's experiences associated with preparation prior to treatment

Having limited timely information still seems to be a problem for women with breast cancer.^{12–14} Having enough information is one of the most important aspects helping women to prepare for the upcoming breast cancer treatment.² Knowing beforehand the different stages of the process, the support available, the timetable for different examinations and treatments, as well as their strenuousness, helps patients and their next of kin to plan their lives both psychologically and practically.¹⁵ 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 with transportation, housing and the economic situation of patients since they do not know how to organize their life. Occasionally, not giving enough information may be interpreted by patients as staff incompetence.

Women's experiences associated with breast cancer treatment and examinations

Women with breast cancer reported about the less positive experiences related to the organization of both breast cancer treatments and diagnostic services. Changes in the planned schedules and confusion regarding the organization of services may cause the patient to feel that nobody really knows what is happening in her care. To avoid fragmentation of services different types of coordinated care models have been proposed for breast cancer treatment.^{16,26} This is one of the reasons why

multiprofessional collaboration in breast cancer diagnostics and care is extremely important.^{3,32}

Women in our study reported feeling happy about smooth chemotherapy, endocrine and biological, radiotherapy treatments. They also reported about the less positive experiences regarding the side effects and treatment. Having few side effects of the treatment or being treated in an optimal way helped women to live as normal a life as possible during the treatment period, resulting in a better quality of life.¹⁸

Women had positive and less positive experiences associated with being or not being heard, taken care of and being treated as an individual. Haste and not giving enough or timely information regarding surgery and radiotherapy treatments made women with breast cancer feel unprepared and unsafe, results that were also found in the study by Probst et al.¹⁷ Some patients did not get enough psychosocial support during these processes. However, women reported many positive experiences throughout almost all of the steps of their treatment in relation to competent and friendly staff that helped them to survive the process. As Sandager et al.¹³ suggest, these results should be interpreted with caution. Expectations, patient characteristics, survey timing, loyalty to health care professionals, backing up their own choices, and questionnaire and item design have been identified as the factors potentially influencing the association between delivered care and patient reported experience.¹³

Women's experiences associated with aftercare and counselling following treatment

Women's positive experiences of aftercare and counselling were related to a proper follow-up plan and the information on the contact options after the end of 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. The results by Edib et al.¹⁴ were mainly similar to the results of our study. However, all the health care organizations treating women with breast cancer 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.

Trustworthiness and limitations

The data was collected from women with breast cancer in four different countries. Though the number of subjects was limited ($n = 14$) as it often is in qualitative studies, the fact that women's experiences in their care pathway were similar regardless of the country support the transferability of the findings. Back and forth translations from English to national languages (Estonian, Finnish, Norwegian and French) were made for the data collection instrument. 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 and the data.

In this study, dependability of the analysis was ensured by peer coding. The codes and categories were discussed and negotiated between the authors. The authors also discussed the 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 thematization we made out of the data.³³ Also, 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.¹⁸ Also, in interpreting the findings, it must be considered 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 had finished their breast cancer treatment process, perceived meaningful events of the care pathway a bit differently compared to the care pathways which are usually described from the health care organizations' viewpoints. Health care staff, including radiographers, should be aware of this fact in planning breast cancer care and treatment pathways in a patient-centred manner. In different stages of their individual breast cancer care pathway, women's positive and less positive experiences were somewhat similar, yet contrasting. Undergoing treatments, the seamlessness of the process and individual approach, including proper care of the side effects, seem to be the most significant factors of the optimal breast cancer care pathway. After the completion of treatment, properly and timely organized follow-up care was highlighted.

Practice implications

When women are preparing for breast cancer treatments it is important that health care staff inform them well about the treatment process so that they are able to arrange their daily life and prepare psychologically. While notified for the first time about the possibility of having breast cancer, women should also be told whether the diagnosis is definitive to avoid unnecessary confusion, fear and anxiety. Targeted interventions to improve the quality of breast cancer care specific to different stages of the treatment process should be planned in addition to general forms of support. Radiographers and other professionals involved in breast cancer diagnostics and care should know each other's roles and responsibilities to be able to offer seamless and patient centred services, ensuring the provision of coordinated care, as well as safe and competent services to women with breast cancer. It seems that although a lot has been done, not all the breast centres are still able to provide optimal psychosocial support and aftercare. No woman with breast cancer should be left without clinical and psychosocial support at the end of treatment. The findings can be used to promote staff education and the patient-centred approach in breast cancer care.

CRedit authorship contribution statement

Eija Metsälä: Conceptualisation, Methodology, Validation, Data collection, 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.

Funding

This work was supported by European Commission Erasmus+ Strategic partnership programme grant number 2020-1-EE01-KA203-077941. For the Swiss associate Partner this work was supported by the Swiss national agency MOVETIA. The European Commission support for the production of this publication does not constitute an endorsement of the contents which reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

Declaration of competing interest

None.

Acknowledgements

The authors would like to acknowledge patient's that shared their experience with us as well as national breast cancer patient organisations KAEV in Estonia, Europa Donna Finland, Brystkreftforeningen in Norway and patient association Mairaines du Sein in Switzerland.

References

- European Federation of Radiographer Societies. *Statement on the importance of patient engagement and the patient voice within the radiographic practice*. <https://api.ehrs.eu/api/assets/posts/165>; 2021.
- European Federation of Radiographer Societies. *EFRS statement on patient engagement and inclusion in radiotherapy*. <https://api.ehrs.eu/api/assets/posts/255>; 2021.
- Biganzoli L, Marotti L, Hart C, Cataliotti L, Cutuli B, Kühn T, et al. Quality indicators in breast cancer care: an update from the EUSOMA working group. *EJC (Eur J Cancer)* 2017;**86**:59–81. <https://doi.org/10.1016/j.ejca.2017.08.017>.
- Spronk P, van Bommel A, Siesling S, Wouters M, Vrancken Peeters M, Smorenburg C. Variation in use of neoadjuvant chemotherapy in patients with stage III breast cancer: results of the Dutch national breast cancer audit. *Breast* 2017;**36**:34–8. <https://doi.org/10.1016/j.breast.2017.08.011>.
- Verhoeven D, Allemanni C, Kaufman C, Siesling S, Joore M, Brain E, et al. New frontiers for fairer breast cancer care in a globalized world. *Eur J Breast Health* 2021;**17**:86–94. <https://doi.org/10.4274/ejbh.galenos.2021.2021-1-1>.
- Kogan A, Wilber K, Mosqueda L. Person-centered care for older adults with chronic conditions and functional impairment: a systematic literature review. *J Am Geriatr Soc* 2015;**64**:e1–7. <https://doi.org/10.1111/jgs.13873>.
- Waelli M, Minvielle E, Acero M, Ba K, Lalloué B. What matters to patients? A mixed method study of the importance and consideration of oncology patient demands. *BMC Health Serv Res* 2021;**21**. <https://doi.org/10.1186/s12913-021-06247-0>.
- Ponte P, Conlin G, Conway J, Grant S, Medeiros C, Nies J, et al. Making patient-centered care come alive. *J Nurs Adm: J Nurs Adm* 2003;**33**:82–90. <https://doi.org/10.1097/00005110-200302000-00004>.
- Robinson J, Callister L, Berry J, Dearing K. Patient-centered care and adherence: definitions and applications to improve outcomes. *J Am Acad Nurse Pract* 2008;**20**:600–7. <https://doi.org/10.1111/j.1745-7599.2008.00360.x>.
- Lawless M, Marshall A, Mittinty M, Harvey G. What does integrated care mean from an older person's perspective? A scoping review. *BMJ Open* 2020;**10**:e035157. <https://doi.org/10.1136/bmjopen-2019-035157>.
- Mallinger J, Griggs J, Shields C. Patient-centered care and breast cancer survivors' satisfaction with information. *Patient Educ Counsel* 2005;**57**:342–9. <https://doi.org/10.1016/j.pec.2004.09.009>.
- Sandager M, Sperling C, Jensen H, Vinter M, Knudsen J. Danish cancer patients' perspective on health care: results from a national survey. *Cognit Technol Work* 2014;**17**:35–44. <https://doi.org/10.1007/s10111-014-0301-3>.
- Sandager M, Freil M, Knudsen J. Please tick the appropriate box: perspectives on patient reported experience. *J Patient Exp* 2016;**3**:63–79.
- Edib Z, Kumarasamy V, binti Abdullah N, Rizal A, Al-Dubai S. Most prevalent unmet supportive care needs and quality of life of breast cancer patients in a tertiary hospital in Malaysia. *Health Qual Life Outcome* 2016;**14**. <https://doi.org/10.1186/s12955-016-0428-4>.
- Zöylner I, Lomborg K, Christiansen P, Kirkegaard P. Surgical breast cancer patient pathway: experiences of patients and relatives and their unmet needs. *Health Expect* 2019;**22**:262–72. <https://doi.org/10.1111/hex.12869>.
- Shakeel S, Tung J, Rahal R, Finley C. Evaluation of factors associated with unmet needs in adult cancer survivors in Canada. *JAMA Netw Open* 2020;**3**:e200506. <https://doi.org/10.1001/jamanetworkopen.2020.0506>.
- Probst H, Rosbottom K, Crank H, Stanton A, Reed H. The patient experience of radiotherapy for breast cancer: a qualitative investigation as part of the SuP-PORT 4 All study. *Radiography* 2021;**27**:352–9. <https://doi.org/10.1016/j.radi.2020.09.011>.
- Paraskevi T. Quality of life outcomes in patients with breast cancer. *Onco Rev* 2012;**e2**. <https://doi.org/10.4081/oncol.2012.e2>.
- Fiszer C, Dolbeault S, Sultan S, Brédart A. Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. *Psycho Oncol* 2013;**23**:361–74. <https://doi.org/10.1002/pon.3432>.
- Prakash A, Sardar M, Shaikh N, Inkollu S, Dansih M, Sharon D, et al. The perspective of a breast cancer patient: a survey study assessing needs and expectations. *Cureus* 2020;**12**:e9171. <https://doi.org/10.7759/cureus.9171>.
- Drew N. Expanding self-awareness through exploration of meaningful experience. *J Holist Nurs* 1997;**15**(4):406–24.
- Murphy S, Bastian B. Emotionally extreme life experiences are more meaningful. *J Posit Psychol* 2019;**15**(4):531–42.
- Yates C, Partridge H, Bruce C. Exploring information experiences through phenomenography. *Libr Inf Res* 2012;**36**:96–119. <https://doi.org/10.29173/lirg496>.
- Akerlind G. Variation and commonality in phenomenographic research methods. *High Educ Res Dev* 2005;**24**:321–34. <https://doi.org/10.1080/07294360.2011.642845>.
- Han F, Ellis R. Using phenomenography to tackle key challenges in science education. *Front Psychol* 2019;**10**. <https://doi.org/10.3389/fpsyg.2019.01414>.
- Biganzoli L, Cardoso F, Beishon M, Cameron D, Cataliotti L, Coles C, et al. The requirements of a specialist breast centre. *Breast* 2020;**51**:65–84. <https://doi.org/10.1016/j.breast.2020.02.003>.
- Baffert S, Hoang H, Brédart A, Asselain B, Alran S, Berseneff H, et al. The patient-breast cancer care pathway: how could it be optimized? *BMC Cancer* 2015;**15**. <https://doi.org/10.1186/s12885-015-1417-4>.
- Héquet D, Huchon C, Baffert S, Alran S, Reyat F, Nguyen T, et al. Preoperative clinical pathway of breast cancer patients: determinants of compliance with EUSOMA quality indicators. *Br J Cancer* 2017;**116**:1394–401. <https://doi.org/10.1038/bjc.2017.114>.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**:77–101. <https://doi.org/10.1191/1478088706qp0630a>.
- Nowell L, Norris J, White D, Moules N. Thematic Analysis: Striving to meet the trustworthiness criteria. *Int J Qual Methods* 2017;**16**. <https://doi.org/10.1177/1609406917733847>.
- Langford AT, Kang SK, Braithwaite RS. When does nonadherence indicate a deviation from patient-centered care? *Am J Manag Care* 2021;**27**:e141–4. <https://doi.org/10.37765/ajmc.2021.88635>.
- Strøm B, Pires Jorge J, Meystre N, Kukkes T, Metsälä E, Hafslund B. Interprofessional work in early detection of breast cancer: an integrative review. *Radiography* 2019;**25**:170–7. <https://doi.org/10.1016/j.radi.2018.11.005>.
- Leung L. Validity, reliability, and generalizability in qualitative research. *J Fam Med Prim Care* 2015;**4**:324–7. <https://doi.org/10.4103/2249-4863.161306>.