



Patient Journey of Women with Breast Cancer During their Oncolytic Treatment in COVID Time: A Qualitative Study



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Submission: January 02, 2024; **Published:** January 11, 2024

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Purpose

Breast cancer can be treated effectively and is described in care paths of healthcare providers. To gain insight into the perspective of breast cancer patients, experiences of women in different curative stadia of ambulatory breast cancer treatment were summarized in a patient journey.

Methods

First, the schematic Breast Cancer Care Path from the Dutch Integrated Cancer Centrum (IKNL) was adapted to the situation at the Leiden University Medical Centre (LUMC). In a qualitative study women in a (neo-) adjuvant trajectory of breast cancer treatment were invited at the LUMC. Those who provided informed consent were interviewed twice and noted their daily experiences for five days. Interviews were audio recorded and analyzed with ATLAS.ti. Common themes were coded deductively using the Expanded Chronic Care Model to design a journey from the patients' perspective.

Results

The IKNL breast cancer care path was specified for the LUMC setting and extended for healthcare activities and providers involved. For the patient journey, ten women between 32 and 77 years were included. During diagnosis and treatment, additional steps and supportive elements were identified with patient emotions, activities and needs involved. Mainly the clinical nurse specialist was needed as a coordinator during treatment, daily life was an important part of patient's life during treatment, patients needed more time when receiving the diagnosis and improvement in amount, form and timing of information. Pharmaceutical care might be beneficial to optimize medication use during breast cancer treatment.

Conclusions

(Neo)- adjuvant breast cancer care can be improved with the insights from a patient journey.

Keywords: Breast cancer; Curative breast cancer treatment; Care path for breast cancer; Patient journey; Patient experienced care

Abbreviations: LUMC: Leiden University Medical Centre; ECCM: Expanded Chronic Care Model; PACIC: Patient Assessment of Chronic Illness Care; METC: Medical Ethical Assessment Committee

Introduction

Breast cancer comprises 18% of all cancer in women around the world, and is acknowledged to be the most common invasive cancer in females [1]. Due to effective treatment with surgery, radiotherapy, chemotherapy, hormonal and immune therapy, patients living with cancer are nowadays three times

as many as half a decade ago [2,3]. However, cancer care with surgery, radiotherapy, chemotherapy and effective management of pain, nausea and other adverse events is complex. It requires longitudinal relationships with healthcare providers in as well secondary as primary care [4]. Earlier research showed that to be

diagnosed with cancer is a life changing and traumatic event with physical, emotional and psychological challenges for patients and their social network [3-5]. Additional to treatment, social support, collaborative relationships with healthcare providers and patient empowerment were shown to improve patient's coping with the disease [6]. Traditionally healthcare systems are organized from the healthcare providers' perspective. Therefore, the treatment steps in the trajectory from diagnosis onward are described in care pathways that explain the organization of the healthcare system. These are meant to be further specified locally by protocols for the actual healthcare providers involved. Although this approach helps to describe and uniform the care desired for all patients, it also leads to fragmentation of the complex care trajectories, complicating efficient and goal-orientated organization. Furthermore, standardization does not match with the concept

of patient-centered care, adapted to individual patient's needs and stimulation of patient engagement. To match this concept, healthcare services need to be reviewed and innovated [7]. Moreover, to develop, provide and improve personalized care and patient participation in user-centered designs, it is important to understand patients' needs, concerns and experiences during the treatment trajectory [3,7-9].

The patient narrative was earlier shown as one of the most powerful forms to express and in depth understand personal suffering and experiences [5,10]. The term 'patient journey' has been used to describe the patients' passage through different disease stages focusing on the individual's perspective and to combine a comprehensible representation of a health service from the patient's perspective [3,7]. Other researchers used this approach to follow orthopedic patients from the patient's perspective in Italy during their hospital stay [11], in a meta-synthesis of breast cancer stories from 30 countries [5], in interviews of breast cancer patients during neo-adjuvant chemotherapy in the United Kingdom [8], to compare information seeking and diagnosis between different ethnical groups in Singapore [10] and in a meta-synthesis of qualitative studies to better understand the experiences of Australian women diagnosed with breast cancer [12]. A qualitative study with breast cancer patients in Spain defined seven stages during the patient journey for different medical processes during the curative trajectory from a patient perspective [3]. In their study, identification of key moments in patients' experiences helped to identify key moments to offer additional information and care in their setting [3]. However, no patient journey was developed for breast cancer patients specifically during (neo) adjuvant treatment trajectory to better understand their experience during treatment with related emotions, activities and needs. Consequently to better understand the perspective of breast cancer patients during medical treatment Netherlands, first the breast cancer care path from the healthcare system perspective was specified for steps of care provided with related healthcare providers; second experiences of women in

different curative stadia of ambulatory breast cancer treatment were summarized and mapped in a patient journey.

Methods

Study design

Breast cancer care was mapped from the healthcare system perspective for its application in the Leiden University Medical Centre (LUMC). The schematic Breast Cancer Care Path from the Integrated Cancer Centrum of the Netherlands (IKNL) [13] for the breast cancer trajectory was used and specified for the clinical practice of the LUMC by observations of one researcher (MM) during an internship at the hospital and outpatient pharmacy. Subsequently, a qualitative study was performed with interviews and diaries to explore the experiences of women with breast cancer during their oncolytic treatment, and to detect specific needs and wishes during their patient journey.

Patient inclusion to map the patient journey

We aimed to include at least 8 women with breast cancer, treated at the LUMC and continue until data saturation. Earlier studies on patients' experiences had included eight [11,14] or nine (9) patients. Women with preferably varying social and cultural backgrounds were included from different stadia of a curative, adjuvant or neo-adjuvant trajectory. In an adjuvant trajectory, treatment is given in addition to curative treatment to reduce the risk of recurrence. Neo-adjuvant treatment is given in advance of surgery to reduce the tumor size. Women within these curative trajectories were included at above 18 years of age, being able to speak and write the Dutch language and having provided written informed consent. Patients from a palliative trajectory were excluded, as the treatment goal at the end of life differs from curative trajectories [15]. Eligible patients were invited by two oncologists from the LUMC and informed about the study by information letters. Women who were interested in participating, were contacted by the research team by mail. If they were willing to participate, they were asked to provide written informed consent to use the anonymized transcriptions of the interviews and the diaries for this study.

Data collection with interviews and diaries

Semi-structured interviews were conducted twice with each participant by two female researchers (MM or MT). MM is 25 year old medical student trained in patient consultations, MT is a 59 year old pharmacist and epidemiologist with experience in qualitative research. For both interviews, topic guides were developed (RG and MT), discussed within the research group and updated accordingly. Semi-structured interviews provide the possibility to address specific topics and to probe further questions based on patients' responses during the interviews. In this manner, information can be collected that provides in depth insights into patients' experiences, needs and wishes [16]. The topic guide for the first interview was based on the Expanded

Chronic Care Model (ECCM) [17]. This model was used before in developing interview guides for cancer management [4]. The ECCM maps both components of the community as well as the embedded health system, for productive interactions and relationships between patients and healthcare providers to achieve the functional and clinical outcomes desired [17,18]. Correspondingly, the patients were questioned about their experiences during the diagnosis and treatment trajectory related to their interaction with the healthcare system, social support and personal coping. In previous research, these ECCM topics had been expanded with questions from the Patient Assessment of Chronic Illness Care (PACIC) model to assess patient-centeredness [19]. Following this example, the following topics were added to the interview guide: availability of a treatment plan, the decision support experienced, types of patient activation, personal goal setting and contextual problem solving.

After the first semi-structured interview, patients noted their daily experiences in a diary to be filled in during five days with one page per day. These days did not have to be consecutive, but were between the first and the second interview within one month. Information on daily activities had been part of creating patient journeys before [3]. This diary was sent to the participants per mail and could be filled as well online or as on paper after printing. For each day rows showed the time in hours between 6 am and 11 pm. In three columns, information could be added for daily activities (as sleeping, meals, working), contacts (as social contacts and contact with healthcare providers) and medication use (as intake, experienced effects and adverse reactions). The filled-in diaries were sent back before the second interview, during which the diary notes were discussed. The topic guide of the second interview was based on the content of the diary columns. This interview served as an in depth interview, in which actual experiences during a certain disease stage were explored. Based on the participants' preferences, interviews could be conducted either online via the platform Microsoft Teams (version 1.4, Microsoft, Redmond (WA), USA), physically at the LUMC or at the patients' home. Each interview lasted for approximately one hour. All interviews were audio-recorded and only accessible to the researchers. The audio data was transcribed with the aid of program Trint (Trint Limited, London, UK) and anonymised and reviewed by a member of the research team (MM, MT). After transcription, all audio records were deleted.

Data analysis

Transcripts underwent qualitative, deductive content analysis using the items from the topic guide based on the ECCM and PACIC [17,18]. After the first interview, three members of the research team (MM, MT and RG) separately coded the interview. After coding, a consensus meeting was held. This was followed by

the development of a coding tree, based on the ECCM and PACIC topics and with additional codes yielded from the first interview. Afterwards, the first interview was recoded accordingly and a final consensus meeting took place. All further interviews were coded using this final coding tree (MM, MT). Codes were categorized for differences and similarities and themes were defined for underlying meanings. Coding and arrangement of codes was done with the program Atlas.ti (version 9, Atlas.ti Scientific Software Development GmbH, Berlin, Germany).

Ethical considerations

The content and scientific validity was evaluated by the scientific committee of the department of Clinical Pharmacy and Toxicology and the department of Oncology at the Leiden University Medical Center (LUMC). In addition, the Medical Ethical Assessment Committee (METC) of the LUMC declared this study as not subjected to the Medical Research Involving Human Subjects Act (WMO) (METC number: N21.088).

Results

The generic IKNL care path for breast cancer starts with patient's referral to hospital, followed by diagnostic and prognostic testing and treatment and follow-up. It ends with palliative care, which was not subject of this study [13]. It was expanded with information on detailed treatment steps and healthcare providers involved for the current situation at the LUMC. Figure 1 shows the breast cancer care path for breast cancer patients during (neo) adjuvant treatment from the perspective of the LUMC healthcare organization. For the patient journey, ten women between 32 and 77 years of age were included and data saturation was reached (Table 1). Most of them were Dutch and half of them had a Christian background. The majority had additional morbidities beside breast cancer. Three participants were in the neo-adjuvant trajectory, seven in the adjuvant trajectory and one had chemotherapy followed by hormonal therapy. One patient was interviewed at home, one patient at hospital and the other patients were interviewed online. The first interview took 27 and 71 minutes (average 58 minutes), the second interviews between 22 and 61 minutes (average 34 minutes). All women described journey steps starting with their diagnosis and subsequently during their treatment up to their actual situation. Figure 2 shows women's emotions, needs and activities for patient relevant journey steps during diagnosis (first signs, referral, receiving and sharing the diagnosis) and treatment (decision making for treatment including information, treatment experiences and daily life with contact to healthcare providers and to other breast cancer patients and environmental support). In the following the patient journey steps are described more in detail including quotes from the interviews.

Table 1: Demographic and clinical characteristics of participants.

Patient	Age	Culture	Religious	Comorbidities	Breast Cancer Family	Treatment Trajectory	Current Treatment
P1	59	Dutch Indies	no	Psoriasis, Pancreatic cyst, high cholesterol	no	Adjuvant	Surgery, radiotherapy, chemotherapy, waiting for hormonal therapy
P2	32	Dutch Indies	yes	no	yes	Neo-adjuvant	Surgery, chemotherapy
P3	55	Dutch	yes	no	no	Adjuvant	Hormonal therapy, surgery, waiting for radiotherapy
P4	64	German	yes	no	yes	Adjuvant	Radiotherapy, hormonal therapy
P5	41	Dutch	no	Thyroid cancer	no	Adjuvant	Chemotherapy surgery
P6	77	Dutch	no	Multiple sclerosis, lung cancer, cardiac arrhythmia	no	Adjuvant	Chemotherapy surgery
P7	71	Dutch	no	Rheumatoid arthritis	yes	Neo-adjuvant	Chemotherapy
P8	60	Dutch	yes	High blood pressure, diabetes mellitus, bipolar disorder	no	Adjuvant	Surgery, chemotherapy
P9	47	Dutch	no	no	no	Neo-adjuvant	Chemotherapy surgery
P10	62	Dutch	no	no	no	Neo-adjuvant	Chemotherapy

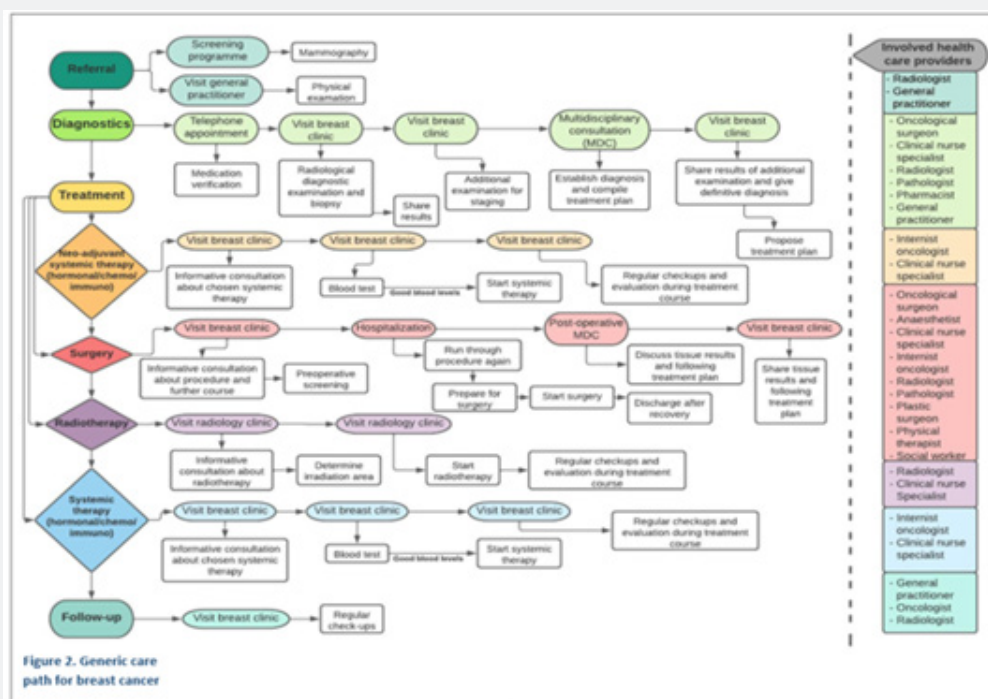


Figure 1: Shows the breast cancer care path for breast cancer patients during (neo) adjuvant treatment from the perspective of the LUMC healthcare organization.

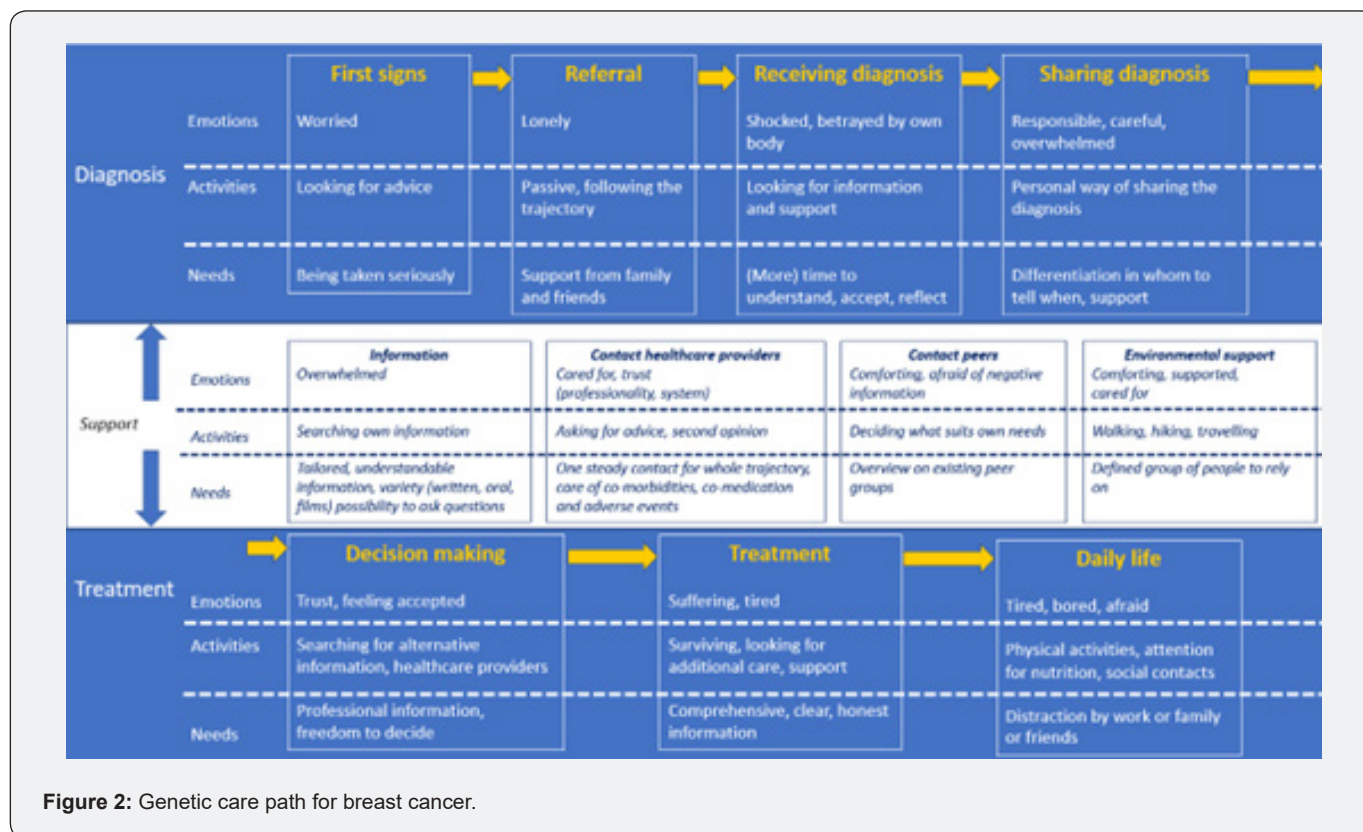


Figure 2: Genetic care path for breast cancer.

First Signs

The patient journey started with first signs of breast cancer. Some women got these from the population screening whereas others got suspicious themselves: "I felt that I had a nodule in the breast and I did nothing with it in first instance. I normally rely on my own immune system, but it grew nevertheless. And then I thought at some point: on Monday I see the GP". (P4) There were reasons to postpone further diagnosis: "The mammogram was painful, my entire cleavage was red. I can imagine that other women might not do it". (P1) Some women experienced difficulties to get a referral from the General Practitioner (GP): "In July 2020 I went to the GP because my nipple was inverted. When I got there, she examined it and she could not find anything.. But I am a person that goes once, and if I am not taken seriously, then I will not return. And then it was months later and I thought 'I do not trust this'. And then I thought I go again to the doctor and I will not have myself rejected again." (P2) First signs were detected by self-diagnosis or population screening. Referral may be postponed due to too vague signs from self-diagnosis or due to pain experienced at population screening.

Referral to hospital

Patients with suspicious first signs were referred to hospital for further examination and diagnosis. During the corona pandemic, patients had to undergo examinations at hospital alone.

"I immediately went for an ultrasound, puncture and everything else. And because of Covid, I had to go inside and undergo the examination alone, while my brother was waiting outside. That was hard, a bit extra difficult." (P2) At hospital diagnostics were performed quickly, and women preferred to have someone with them during this step.

Receiving the diagnosis

For patients with no earlier signs the diagnosis from population screening was totally unexpected. "... this came really as a shock... I did not panic but felt sadness... that your own body betrays you like this." (P7) Even patients who experienced symptoms or knew they were at high risk had not expected the diagnosis breast cancer: "At the end of the year I discovered a bubble..... and during the week I immediately called the hospital. Since my 25th I am there under control as it is in the family..... Luckily I could come the following day. And there it was, a bit unexpected....." (P2) Patients needed time to reflect on the news before being able to think of further steps. "... I was phoned by the doctor's assistant and that they had detected.... And she immediately started over hospitals. And I thought 'Well, I first want to tell my husband', the hospitals can come later.... It was an enormous shock." (P10) Receiving the diagnosis for breast cancer felt as a shock for all women, even when they were at high risk or experienced symptoms. They first needed time to accept and share this news before being able to listen to any other information.

Sharing the diagnosis

The way patients shared their diagnosis with family, friends and at work differed: some just told it, others made choices in whom and when to tell. This depended on their way to communicate and their culture to talk about illness. 'I am a bit clumsy to introduce things... I just told it.' (P 2) "You well select whom you tell what." (P1) 'For me it's difficult to share these kind of things. My husband and my two daughters knew about it of course, but besides that... We did not discuss illness when I grew up, maybe that is where the difficulty comes from' (P4) However sharing also gave immediate though unexpected support. "Everybody was shocked...I immediately received lots of flowers from alle the colleagues. But I thought 'Nothing yet has happened.' (P1) The way of sharing the diagnosis depended on woman's character and habits. The spontaneous reactions from the social environment were not expected but felt as a support.

Treatment decision making

After the diagnosis was made, for every patient an individual treatment plan was compiled by the healthcare providers at hospital. This was communicated by the clinical nurse specialist or by the oncologist. "It (the treatment plan) was told to me immediately by the oncologist." (P5) Patients were comprehensively informed on the whole trajectory. "I was immediately told that first I would get a chemo treatment to make the tumor as small as possible, than an operation, and then perhaps - depending on the type of operation - radiotherapy. (P9) Some patients appreciated that they could make their own decision: "They constantly told me 'It's your own choice...' and when I had decided they again asked 'so this is what you want?' That was really nice." (P1) Patients got information to weigh decisions and could take time to make up their minds. ".... and then the professor really extensively explained over what (to do) depending on age and fitness ... there are data models to this... and she showed them to me ... and she looked how big the chance was that I would survive the next 10 years ... And now it is the question whether we can add another little bit with a chemotherapy. And then I could think about this." (P1) Patients felt well assessed and approved for the treatment to take when their whole situation was taken into account: "Well, she thought me fit enough. ... They expected I could deal with this." (P7) Patients were free to consult additional healthcare providers: "I was always free to make my own choices. I thought only chemotherapy to look whether the bubble shrinks, that's not what I want, as of course I knew of the side effects.... Thus I thought I just go to have a second opinion. And that also was no problem." (P4) .

However making personal decisions could feel lonely: "What had a lot of impact on me, loneliness is perhaps the good word, is that I was facing it alone to make a good decision with sparse information. Of course you get some flyers and a number of things, but you want to make the best decision for your own situation and in this I did not feel supported." (P5) Other patients trusted the

expertise of the treating doctor and the healthcare system: "For every type of breast cancer, there is a certain protocol regarding treatment plan. And I followed that plan without hesitation, I am not a doctor." (P9) The oncologist or the clinical nurse specialist comprehensively informed patients on the whole treatment trajectory and gave women enough time for shared decision making. Women could follow the doctor's advice They were also free to ask for additional advise and to make their own decisions; this could feel lonely.

Treatment

Patients experienced the healthcare providers engaged in the treatment as professional and friendly, also when things eventually went wrong. "It was very well cared for and people were very friendly." (P4) "....I was operated. ... And I was hospitalized with high fever and I was very ill. Then it didn't go well at the LUMC, because they placed me over to another hospital ... and they later apologized for that...." (P8) Chemotherapy was experienced as very hard. Personal attention from the clinical nurse felt as a great support. ".... The first chemotherapy treatment hit me really hard. It was right after my diagnosis, suddenly your whole life is upside down, so yeah... the first session was the hardest." (P7). "The clinical nurse said... 'Monday is your bad day, isn't it?'... And then on Monday they would send me an app or she called me to ask 'how are you?....or 'It is nearly Tuesday'." (P1) Hormonal therapy often was estimated as less intensive then chemotherapy before the start but was later on experienced as unexpectedly intense. "I thought: 'the only thing I have to do is to swallow a pill, that can't be too hard. ...I did not expect, no...that I would suffer so much from the side effects, I had not expected that." (P3) Also the impact of surgery was bigger and lasted longer than expected. "The surgery was very intense. I was a bit naïve looking back. They told me I could go home after two or three days.... But it took me a whole week to be able to return home. Recovery was doable, but during surgery some complications arose with which I am still struggling. I still cannot use my arm properly and the skin on my arms still feels affected." (P2) One patient had to arrange follow-up surgery herself after complications. "After my surgery with direct reconstruction I got complications. When I insisted on getting it checked by the plastic surgeon it showed that the expander wasn't in place and leaked. My GP referred me to a plastic surgeon in another hospital, but he could not fix the problem. At that point I was totally done and I looked for another plastic surgeon myself. It took him quite a time but luckily he did it perfectly." (P6) Radiotherapy also had notable side effects. "After three weeks of radiotherapy I was really tired. Then you realize that radiotherapy did something, it even burned my skin."(P1) All treatment trajectories were experienced as intense with side effects, and mainly hormonal therapy was underestimated for its impact. Regular and personal attention from the clinical nurse was highly appreciated. In case of complications patients had to take their own measures for recovery.

Daily life

Most patients experienced fatigue during the treatment. "I have less energy. Before I was able to do everything I wanted to do, Now I'm constantly tired." (P2) As a consequence, patients could not work and daily duties were transferred to their family. "Well I don't work at all right now. I'm on medical leave." (P3) "I'm easily tired, therefore my husband is taking over the householding duties. I try to help when my body allows it." (P7) Beside the physical burden there also was the mental impact. "My trajectory was emotionally very difficult. Besides that, I have a huge fear for recurrence of the cancer." (P5) "Hospital visits are hard. The confrontation of being sick and being a patient is always hard." (P9) For some patients working or spending time with family and friends were beneficial. "I didn't stop working until the surgery. For me work is a distraction." (P1) "I have a nice day when my kids are having fun, when I see them play and laugh a lot. That's always what makes my day good." (P2) For many participants taking control on their lifestyle was a good way to cope with their disease. Lifestyle concerned physical activity, social contact and nutrition. "Look, working out is not my hobby, but I can feel that I need it. After physical activity I just feel better." (P1) "I make sure that I go outside for one hour at least to get fresh air and for physical activity. Besides that I follow a healthy diet." (P4) "I started taking yoga classes and I noticed that certain breathing exercises were very relaxing. That worked really fine for me." (P6) "Every day is the same, all boring... But on that Saturday I and my husband went visiting friends, and well that makes my day. You can see it in the diary, I scored that day with an 8 (of 10)." (P3) Due to the physical and mental consequences of the acute treatment, women were tired and could not work or meet family and friends. When they were able to, work, social contact, physical activities or caring for nutrition helped them to cope with their disease.

Information on the treatment

Though patients were informed, some wanted more information to be better prepared for the treatment to come. "Well, they were best able to clearly explain everything to me, also the side effects and how everything exactly works. But I realized especially at the beginning that there might have been a bit more information." (P2) "I would have preferred to have known more things before. More clearly..." (P3) Additionally, patients had to deal with a lot of unknown terms: "I have to use a dictionary. ... She said 'oh you have a cyst' All these words... you really need a translation." (P1) Videos about how things looked like gave more confidence. "With the chemo... I know it's via an infusion, but how does this look like? There were videos that people had taken themselves and shared (online), and there I could see oh that is how it looks like. That was comforting." (P2) For some patients the amount of written information was too much to deal with: "... you get a lot of written information, a whole binder. With the best intentions, and I think a lot of time and energy was spent to make this as good as possible.... But when you know that you have breast

cancer and you get the whole trajectory, you have to organize lots of things at home... and then you also get all these papers you have to read as well..... you read it, but do not ask me how much I can remember." (P6)

For some participants the contact moments with healthcare professionals were too short to pose all their questions. "... You wait 20 to 30 minutes and then we went inside, and 2 minutes later we were outside again.... And when you get information then you later think 'oh yes, but...?' (P3).

Some patients did not receive the information they asked for. "They didn't want to tell me how big the piece was that they would take out of my breast, because I wanted a breast sparing operation. ... And then finally on the operation table with the surgeon bending over me and when I asked 'how much are you going to take out?' the surgeon very paternally said 'you do not want to know'. To which I replied 'well actually I do'" (P6) It differed per participant whether they searched themselves for additional information or chose not to do so. "Yes, I read what I got and could get on the internet until I got fed up with it." (P4) "I did not google or so. No. I decided not to do so to prevent myself from losing my mind." (P8) Personal needs on treatment information differed for the amount (flyers, a whole binder), the understandability of medical terms, and the way of getting it (written, by video, oral or searching the internet). Treatment information needs better adaptation to individual knowledge and needs.

Contact with healthcare providers

During a complex trajectory, patients have to deal with a lot of healthcare providers. "When you get an operation, the surgeon is in charge and when you go to the oncologist, this is the main practitioner then and when you get radiotherapy it's the radiotherapist." (P6) During the whole trajectory most participants considered the clinical nurse specialist as their main contact person. "The one that is the spin in the web is the clinical nurse specialist. If something is not okay then it is her that I always can contact." (P7) "It is so nice to have somebody,.... And F. (husband) had questions as well of course. And... you mailed and you get an answer." (P10) Two participants, however, did not experience a central person in their whole trajectory with many different healthcare providers involved. "I think that the care system should dispose on a clear trajectory, that you know from each other what you do with the patient. Or determine someone who has the total overview.... This (person) was really missed." (P6) "There wasn't one point of contact. When I had a question, I always had to contact a different person". (P8) Cooperation between different healthcare professionals was even more important for two participants who were also treated for other diseases. "Beside my breast cancer treatment, I need to undergo surgery for removal of a pancreas cyst. I noticed that the cooperation between the breast cancer department and the gastro-enterology department wasn't very good. They didn't cooperate, but for me both treatments belong together" (P1)

"Then you see that there are also disadvantages with a specialized hospital, because my GP very clearly had written in the transfer letter that I also had multiple sclerosis, but they constantly ignored this. Thus constantly wrong treatment choices were made and nobody listened to me." (P6)

However the other participants had good experiences for cooperation between healthcare professionals. I found it very nice to know that the psychologist, the oncologist and the nurse specialist contact each other, that they really form a team."(P5) One participant experienced a well-structured cooperation of different healthcare providers around the clinical nurse as a central point. "Yes, it is a sort of team, the clinical nurse and there around her circle the oncologists, the surgeon and all the other people who take blood, and... they all circle around her." (P10) Some patients also had physiotherapy or psychological support or consulted a dietician. 'I had heard from starting with physiotherapy and sports under supervision.... Thus that is what I do.' "(P1) "I also had a trajectory with a psychologist because of the fear that the cancer would return, which I couldn't get rid of...."(P5) And also the social worker can play a role. "The social worker who comes at home. Who talks to everybody. She helps with supportive tasks, doing things together". (P2) "Yes, I see a dietician. And she advises me. And eh I eat less. I have to lose weight because I have diabetes." (P8) The role that was considered for the GP care differed. "My GP calls me every month and asks how everything is going so far. I really appreciate that." (P7) "I don't have a lot of contact with my GP. I spoke to her on the telephone once, when I got my diagnosis, and that was it. She is just very busy."(P8)

Some patients had good experiences with the services of the ambulatory pharmacy and trusted their competence. "The pharmacist here (at the hospital) I really have a good feeling about. When you start with the hormonal inhibitors you want in fact as little as possible adverse effects, and she gave me the advice that it works for about 12 hours and that then I would have the most side effects. And when I asked whether I could take them during the night, that was a good option. I found this a smart advice, that nobody earlier had told me." (P6) There are more chances for pharmacists to contribute as some patients had difficulties to get appropriate medication to treat the adverse effects of their therapy. "I had to swallow so much paracetamol ... and I took it and it went out immediately. It was a bit of a shame she did not offer me a suppository." (P1) Some patients got the protective medication too late. "When I took the gastroprotection and already three hours later I already felt better. Such a shame. I was so sick so many days and afterwards that could have been avoided...." (P3) Sometimes things went wrong in the prescribing process. "The first chemo I was very sick. Then there was an error with the prescription (from the clinical nurse specialist) and I did not get what I needed to cure the sickness." (P7) For some patients a medication review was wanted. "Only I would like to use minder medication. I use quite a lot and sometimes I think 'is

that good?'" (P8) Depending on patients' needs various different healthcare providers were involved. Coordination was needed, especially with different comorbidities involved, and the clinical nurse as coordinator and central contact person was appreciated. More involvement of primary healthcare providers as GPs and pharmacists could be beneficial for the right medication form, comedication to avoid side effects b or medication review..

Contact with other breast cancer patients

For some participants contact with fellow breast cancer patients was comforting. "I became a member of the breast cancer association.... And you look for other things: what people do for their make-up." (P1) I really liked talking with fellow patients. I went some times to a meeting." (P9) It needed searching for the group that fitted best. 'I... joined the breast cancer patient group, but that was not where I belonged.. In the ... (local cancer patient) walk-in house you sit with a number of persons with the same goal, how can you better be active for a solution. There also came doctors and nurses for advice, that was more productive...." (P6) Others didn't chose for contact with fellows. "I am a very positive person. ... All what happened, you of course have to deal with it. And then the surgery and other things are coming. But I mean, talking with others over this... then I think, well then it might become even more difficult for me." (P10) Needs for contact with other breast cancer patients and for additional information wanted differed.

Environmental Support

The supportive environment was very important and comforting during the treatment trajectory. "Everyone is willing to help. Even neighbors offered to do the groceries and to give me a ride to the hospital and back when I had an appointment." (P1) My mom often suggests to go for a walk together or she offers to iron the laundry for example.' (P3). "I'm very satisfied with the support from my environment. Especially my husband and also my two daughters were important to me during this trajectory." (P4) "When I have a little break down and all I can do is crying, I just go to my husband and I hug and talk to him. Then I'm okay again." (P7) For some participants their religion was important. "My religion is very important to me. That is what gave me guidance and hope."(P2) 'We walked the Jakob's path, the Santiago de Compostela. This is a pilgrims path..."(P4) Others sought an escape from being a patient by travelling. "After finishing radiotherapy, I went to Spain for an international horse competition..... I just didn't want to be a breast cancer patient for once, I just wanted to do what I like and not focusing on my disease." (P6) Social support from family, friends and neighbors was very helpful for women, and also walking, hiking or travelling could help recovery.

Discussion

In this qualitative study, we specified the LUMC breast cancer care pathway from the healthcare system perspective.

Additionally we mapped the patient journey as experienced from ten breast cancer patients during diagnosis and treatment with their related feelings, activities and needs. Compared to the cancer care pathway, the patient journey showed that patients experienced additional steps: during the diagnosis phase patients went through the uncertainty of first signs, referral to hospital, receiving the diagnosis and sharing it with their environment. The treatment phase included treatment decision making, treatment with related information and daily life with contact to health care providers and peers and environmental support. This extension is in agreement with other studies identifying different emotional stages for an emotional journey of women during the diagnosis [10, 20], treatment phase and beyond [3, 5, 12]. Some patient journeys earlier mentioned 'life after breast cancer [12] or a 'post treatment period' [5]. However, our study showed that during treatment patients have to deal with 'daily live' as far as possible. Though the other patient steps are mainly in accordance with steps taken in the care path way, daily patient life at home is totally ignored. Better understanding of patients' needs in combining treatment and daily life could help to improve patient care. Additionally our study findings showed that after receiving the diagnosis, healthcare providers should give women more time to deal with their emotions and thoughts before they can be confronted with information of their further treatment. Even for women who were under regular control for hereditary breast cancer in their families, the definite diagnosis was a shock and needed reflection.

All patients interviewed felt involved in the decision making for their treatment and felt free to make their own choices. Their decisions varied from following the trajectory suggested up to obtaining a second opinion and follow a different treatment path. Patient involvement, instead of doctor's decision-making, was shown before to foster patient activation, being beneficial for many patients [14] It should be noted, however, that the patients' ability for self-management differed; some patients mentioned they felt overburdened when asked to make their own decisions [20,21]. Country-specific studies showed that shared decision-making was not common in the UK, Spain and Germany [3,14,21] Consequently, this topic may be a cultural as well as a more recent issue in healthcare systems. However in our setting shared decision making fitted well to patients' needs. Patients' needs to search for additional information on their disease and treatment differed, which also is in agreement with earlier findings [8,14,20-22] With the wish of one of our participants for information videos to really see what a chemo infusion looks like, more attention could be paid to supply information as well as written, online, oral or by video sources. Furthermore patients wanted to be better prepared on the treatment they had to undergo and how to deal with side effects. Though information was provided from the healthcare professionals, it was mostly written, overwhelming in quantity and with medical terms not easily understood. These findings are in agreement with the results from Beaver et al. for breast cancer

patients in the United Kingdom (UK) who valued the relationship with the specialist oncology nurse and felt unprepared for the immediacy of side effects with need for tailored information during the trajectory [8] Our patients sometimes consulted other primary healthcare professionals, such as the physical therapist, psychologist, GP or pharmacists. Our results also showed that additional pharmaceutical care was beneficial to optimize drug formulation, to prevent side effects of the oncologic treatment by adding preventive co-medication or for medication reviews during oncologic treatment.

Another important finding in our study was that for patients beside treatment there was a daily life. For this social support from mainly family members and friends was essential. This helped to deal with essential needs for meals and housekeeping but also to be distracted from being ill, as was reported for other countries before [8,12,20] For some patients, peer groups with breast cancer patients were important to get more information and support. In agreement with earlier findings, a variety of activities in focusing on a healthy lifestyle including food and exercise but also walking, hiking and travelling gave the women more control on their daily life and helped to cope with the disease [20]. In this study we focused on breast cancer patients in a neo-adjuvant or adjuvant trajectory in one academic hospital the Netherlands, which limits extrapolation of our findings to other cancer forms, trajectories or countries. However, as breast cancer care is in principle equally organized in medical centers in the Netherlands, we believe that our care path from the health care system perspective is also applicable to other centers in the Netherlands and abroad. With the strict inclusion criteria, our research population was homogeneous in terms of treatment plan, and thus suitable to better interpret and analyze collected information. Important to note is that personal characteristics of the study participants differed for age, treatment stage, comorbidities and culture. We collected in depth information during different phases of the treatment trajectory and reached data saturation with two interviews per patient and information from a diary. As participation in our study was voluntarily, there may have been selection bias for women being more capable for self-management. Consequently our results might overestimate patient activity, but are less likely to be biased for emotions and needs. As the interviews were held by a medical student at internship in the LUMC at that time and a research employee of the LUMC, patients might have been too positive in their answers relating to the healthcare system. However in the interviews also processes going wrong or negative experiences were shared, so we did not experience reserves in sharing negative experiences. Furthermore involvement of different expertise and experience in our research team for developing code trees, interviewing, coding and analyzing contributed to investigator triangulation. Overall the methods applied followed the quality criteria in qualitative research [23].

Conclusion

In conclusion, our study showed provided an extended breast cancer care path from healthcare providers' perspective and the breast cancer patient journey for (neo)adjuvant breast cancer patients. The patient journey added additional steps during diagnosis and treatment phase that patients experience with additional supportive elements, all with different related emotions, activities and needs. Importantly daily life during treatment is a main part of the patient journey but totally ignored in the care pathway. Suggestions for improvement of the care path from these insights are: reserve (more) time for patients to accept and share their diagnosis, provide one person is needed to coordinate the complex treatment with eventual comorbidities and to be accessible for questions, improve patient information supply in amount, timing and format. Finally additional pharmaceutical care for suitable drug intake, preventive comedication and medication reviews might contribute to optimal medication use and reduction of adverse events.

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DOI: [10.19080/JPCR.2023.09.555775](https://doi.org/10.19080/JPCR.2023.09.555775)

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