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“It Is What It Is” – The Lived Experience of Women With Breast Cancer Undergoing Axillary Lymph Node Dissection

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Purpose	The lived experience of women undergoing axillary procedures as part of their breast cancer (BC) treatment remains unexplored. This lack of in-depth understanding could hamper implementation of person-centred care, which is concerning because BC is the most common form of cancer in women. The aim of this study was therefore to explore the lived experiences of women undergoing axillary lymph node dissection (ALND) due to BC.
Methods	Twelve women with a mean age of 59 years were interviewed about their lived experiences of axillary procedures as part of their BC treatment. The interviews were recorded, transcribed verbatim, and analysed using a phenomenological hermeneutical method. This narrative method enabled the researchers to reinterpret the worlds of the women with BC, as reflected in the data.
Results	The naïve understanding, ie, the meaning of the text as a whole, revealed that the participants were in a process of accepting and adapting to their life after ALND involving adjuvant chemotherapy and/or hormonal therapy. Thus, six main themes emerged in the thematic structural analysis illustrating the meaning of acceptance and adaptation when suffering from BC and undergoing a treatment trajectory, ie, establishing coherence, adjusting to treatment, safeguarding social belonging, re-defining oneself, feeling vulnerable, and accepting one's circumstances.
Conclusions	If healthcare professionals provided structure and consistency, the women's treatment and lived experiences made sense; the women experienced more certainty, freedom, and meaningful social interactions. Uncertainty occurred when the women became lost in their own sense-making process, leading to low self-efficacy. There is a need for a paradigm shift in surgical care from viewing women with BC as anatomical constructions in need of repair to deeply understanding that they are persons with an illness who require ongoing self-management support. (<i>J Patient Cent Res Rev.</i> 2024;11:222-230.)
Keywords	breast cancer; qualitative method; axillary procedures; cancer treatment

Patient-Friendly Recap

- Breast cancer (BC) is the most common type of cancer among women, but not much is known about the lived experience of women undergoing axillary procedures as part of their BC treatment (the axilla is the region under the shoulder joint).
- Twelve women that underwent axillary lymph node dissection (lymph nodes are glands that help immune function) were interviewed about their lived experiences from the cancer treatment.
- If healthcare professionals provided structure and consistency during treatment, the women's treatment and lived experiences made sense to them, and the women experienced more certainty, freedom, and meaningful social interactions.

The lived experience of women undergoing axillary procedures as part of their breast cancer (BC) treatment remains unexplored. This lack of in-depth understanding could hamper the implementation of person-centred care and precision nursing, which is concerning because BC is the most common form of cancer in women. Person-centred care means a shift away from a model in which the woman with BC is a passive target of medical interventions. Rather, person-centred care entails a contractual arrangement with her as an active partner in her care and the decision-making process. The starting point for this partnership occurs when healthcare

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professionals (HCPs) listen to the patient's narrative.¹ The world incidence of BC is 2.3 million, and in Sweden, where this study was performed, 9000 women receive a BC diagnosis every year.^{2,3} Every day, 20 women are diagnosed with BC in Sweden, and 85% survive for at least 10 years. Thus, a fairly large group of women live with BC as a chronic condition involving symptoms and possible complications caused by treatment.

The primary treatment for BC is breast surgery including axillary staging of the ipsilateral axilla to assess the extent of BC involvement, as BC often metastasizes (35%) to the axillary lymph nodes. There are two basic approaches to this: either sentinel node (SN), where one or two lymph nodes are removed, or a complete axillary lymph node dissection (ALND), where all lymph nodes in the axilla are removed.⁴ The latter causes well recognized symptoms.⁵ The status of lymph node involvement in the axilla is one of the most important BC prognostic factors. It is vital to know the status to plan further adjuvant treatment including chemotherapy, radiation, and endocrine therapy, all of which have co-morbidities.⁵⁻⁷ However, ALND is associated with relatively high morbidity, eg, swelling of the arm, and breast cancer-related lymphoedema (BCRL) with additional symptoms of heaviness/fullness, pain, and impaired limb function.⁸ A meta-analysis revealed that more than one of every five women who go through cancer treatment develops arm lymphoedema, which has a negative impact on their health-related quality of life (HRQoL)^{9,10} because it causes psychosocial distress and financial burden. To provide self-management support for these women, it is important to identify and diagnose BCRL at an early stage.¹¹ Furthermore, anxiety, depression, and disturbed body image must be evaluated to prevent suffering.¹⁰ For many women, the breast is strongly associated with their female identity, sexuality, and breastfeeding. Women in the older age group tend to have more perspective, pragmatism in decision-making, and competing sentiments in terms of balancing comorbidities.¹² In a newly published study, Boniface et al¹³ showed that patients with a limited spread to the axilla and no further ALND were not in worse condition compared to those with extensive axillary surgery, and safe treatment was not compromised when adjuvant treatment was added.

Unfortunately, no in-depth understanding of the women subjected to these treatments has been provided due to the quantitatively designed studies. To understand the inside perspective of the women involved, we need to adopt a qualitative approach to study their lived experiences of being a person subjected to advanced BC treatment. A systematic literature review revealed the depth of the patients' perspective, which differs from the outside

professionals' perspective.¹⁴ The BC diagnosis impacts all levels of life, that is, emotionally, socially, and physically. When HCPs understand the patients' lived experiences, it is possible to provide person-centred interventions with high precision and support useful coping strategies. Disease-related distress might be relieved and self-management support can therefore be delivered.¹⁴ All effective self-management and symptom management support starts with an in-depth understanding of the patient group and their challenges in everyday life related to their chronic condition. Living with a long-term condition such as BC is a self-management process that includes tasks and skills related to coping with the illness and growing as a person, as well as transitioning from a focus on the illness to integrating the illness into the context of the individual's life.¹⁵ Thus, the aim of this study was to explore the lived experiences of women undergoing ALND due to BC.

METHODS

Setting

After the multidisciplinary team round, the patient was invited to the surgical outpatient clinic, where she met the surgeon and the contact nurse. The clinic in which the study was performed had three senior surgeons, each with an individualized approach. The patient was examined by a surgeon. Then, the nurse performed a follow-up in a different room to ascertain how the information had been received. A great deal of information about the planned treatment was provided in a standardized manner and took approximately 45 minutes. If necessary, the medical social worker would be consulted. The patient then went home and returned the following week to prepare for surgery, including seeing the physiotherapist and a nurse.

Selection and Participants

The sampling strategy was purposeful, and we aimed for variation in patient characteristics (eg, age, time since surgery, and not being operated on by the researcher). Patients who had undergone BC surgery were recruited from a university hospital surgical clinic between spring 2021 and early summer 2022.

Inclusion criteria were: women treated with ALND due to BC 6 months to 6 years prior to the interview, with no regional/distant metastases, who were 18 years or older, who were able to understand the Swedish language, with no other treatment for a different ongoing cancer, and who were not treated by the researcher who performed the interviews. Those younger than 18 years and women with cognitive impairment or regional/distant metastases were excluded.

Procedure. Women who underwent ALND during the previous six years at one university clinic and were

not operated on by the first author who interviewed the participants were identified from the surgical register. From that cohort, women of different ages and time since surgery were invited to participate in the study (n=13). One woman declined the telephone interview due to a hearing impairment. All participants gave their written consent. The interviews were conducted both face to face and by phone due to the COVID-19 pandemic, in addition to the fact that patients were from different parts of southeast Sweden, some of whom lived far away from the surgical clinic. An interview guide that included open-ended questions was used and comprised the following four main questions: Can you please tell me about your experiences of ALND surgery and related symptoms? How is your everyday life affected by your symptoms? How have you experienced the care and support from the health care organization? Please describe the symptom management support that you received after surgery. The interview guide was pilot tested on two patients, and as no amendments were necessary, the data were included in the analysis.

Definitions. Lived experience is a depiction of a person’s experiences and decisions, as well as the knowledge gained from these experiences and choices as opposed to the knowledge a given person gains from a second-hand or mediated source.¹⁶ We use the term, lived experience, in a broad sense, since this is a qualitative study, and recognize that even specific events reported by patients are colored by their lens of being a) women, b) women with breast cancer, and c) women who have undergone ALND.

We undertook this study using a qualitative research process known as the “phenomenological hermeneutic approach.”¹⁷ This approach has been used when researchers feel it is important to obtain knowledge regarding the meaning of the lived experiences of their study participants.¹⁸ The method is designed to improve the researchers’ understandings of specific phenomena, in our case, our patients’ lived experiences. The process involves analysis and interpretation of the text of participants’ narratives in three steps: a “naïve reading,” a structural analysis, and an interpreted whole. In the naïve reading, the text was read several times to grasp its meaning as a whole. It should be noted that during interview, it is imperative, when following the phenomenological hermeneutic approach, that the researchers/interviewers try to follow the participants’ narratives and let them finish talking. This prioritizes the participants’ lived experiences and helps minimize the potential overlay of the researchers’ preconceptions. During the analysis, the researchers strive to ensure that interpretations are rooted in the participants’ perceptions of their experiences.

Lastly, sense-making means understanding cause and effect and how and why one’s health condition is affected,¹⁹ while meaning-making means nurturing aspects that one finds interesting and meaningful by using one’s inner drive to move forward.¹⁹

Data Collection

Data were collected from twelve women with a mean age of 59 years (SD 13.99 years) by means of in-depth interviews that were recorded and transcribed verbatim. Medical information and demographics are presented in Table 1.

Data Analysis

We chose the phenomenological hermeneutic approach to explore the meaning of having to adapt to BC treatment involving ALND. We wished to reveal the patients’ lived experiences and to interpret and understand the meaning of being a person subjected to and dealing with the everyday consequences of ALND. We followed three analytical steps in accordance with the phenomenological hermeneutic approach based on the philosophy of Ricoeur²⁰ and the methodology developed by Lindseth and Norberg.¹⁷

In the first step, the naïve reading, all authors read the interviews several times to grasp their meaning. During the naïve reading, we tried to switch from a natural attitude to a phenomenological attitude. The naïve understanding was viewed as a first conjecture and was then validated or invalidated by the subsequent structural analysis. Thus, the naïve understanding guided the structural analysis.

Table 1. Characteristics of the Twelve Participants

Mean age (range)	59 years (34-74 years)
Mean time from axillary surgery to interview (range)	4 years (0, 5-6 years)
Vocational status (n):	
Working	6
Retired	6
Marital status (n):	
Married/cohabitating	9
Single	3
Anti-hormone therapy (n):	
Yes	11
No	1

In the second step, the structural analysis, primarily performed by EVP and AF, the text was divided into meaning units. It was then condensed, brought together, and sorted into subthemes and themes to capture the meaning of the process of acceptance and adaptation after ALND.

In the third and final step, the comprehensive understanding, all authors read the interview text again as a whole and reflected on it together with the naïve reading. All authors validated the themes in relation to the research question and the context of the study by checking yet again that each theme was grounded in the data and illustrated by quotations.¹⁷ Any disagreement among the authors was settled by returning to the data again. After repeatedly going back to the data, any remaining ties/disagreements were settled through further discussions until consensus was reached. The fourth author (AF) had the ultimate authority in the matter due to her extensive experience with qualitative research and this particular method. The interpretations of the findings were filtered through the researchers' pre-understandings as surgical team members. The pre-understandings involved what it means to have BC, what it means being subjected to cancer treatment, and the pros and cons of how the current surgical care is organized. To mitigate bias, we discussed our pre-understandings and scrutinized them, when

necessary, in relation to the study and our interpretations. For example, as all authors are women, we discussed assumptions about breast cancer based on our gender.

Ethical Considerations

Approval was granted by the Swedish Ethics Review Authority (Dnr 2021-01571), and the ethical requirements outlined in the Declaration of Helsinki were fulfilled. The participants were informed about the purpose of the study, assured anonymity, promised confidentiality, and guaranteed that they could withdraw at any time prior to submission of the paper. They gave their informed consent both verbally and in writing.

RESULTS

Naïve Understanding

The naïve understanding revealed that the participants were in a process of accepting and adapting to their life after ALND involving adjuvant chemotherapy and/or hormonal therapy. Therefore, the thematic structural analysis (Table 2) consisted of six main themes illustrating the meaning of acceptance and adaptation when suffering from BC and going through a treatment trajectory involving ALND. Twelve quotations are presented in Box 1 based on the participants' lived experiences to further support the findings.

Table 2. Structural Analysis of the Twelve Women With Breast Cancer Who Displayed Acceptance and Adaptation After Undergoing Axillary Surgical Procedures

Main themes	Sub themes
Establishing coherence	Making sense. Making meaning. Mastering uncertainty.
Adjusting to treatment	Dealing with side-effects of the hormonal treatment. Dealing with symptoms and complications after surgery.
Safeguarding social belonging	Protecting significant others from grief. Assisting friends/relatives in how to approach participants.
Re-defining oneself	Comparing with previous health status. Comparing with others. Changing self-perception.
Feeling vulnerable	Mastering one's anxiety. Feeling abandoned by professional caregivers.
Accepting one's circumstances	Feeling embraced and cared for by professional caregivers. Feeling embraced and cared for by significant others. Feeling safe despite being far away.

Box 1. Quotations From the Participants Illustrating the Meaning of the Different Themes in the Structural Analysis

Q1. *“You simply have to be cool in this situation. On one hand it is shit [the cancer], and on the other hand great that it hadn’t spread to the axillary nodes. If there is no other way to find out, you simply have to accept it”* (Patient 1).

Q2. *“The first operation was one thing, and then when you had barely recovered you were down again [the second operation] and then up again only to have six rounds of chemo. It wears you and your body out. And then it is easy for me and the people around me to think that now I am well again. Now she is back on track and her usual self. But you don’t feel like yourself because of the mood swings. I’m not talking about my physical strength but the mental condition”* (Patient 1).

Q3. *“You are sort of in a state of shock because of the things that are happening in your life. Not so easy to grasp the information you get”* (Patient 11).

Q4. *“First, I get moody and sad, crying for a while and having difficulties falling asleep. I spend the evenings pondering. After a while I decide to stop overthinking.... I talked to the surgeon on the phone. And she said I shouldn’t spend time worrying so much about these things. In my head everything is so big”* (Patient 3).

Q5. *“When you are invited to stay overnight at some friend’s place and there are five people using one bathroom, I can’t spend the whole evening washing compression socks and massaging my arm. It takes time, and sometimes the hats need washing too. And they need to be dry by the morning, and you need somewhere to dry them. So, it’s a lot of fuss and, as I told you, all the stuff you need to bring. A small tin for the prosthetic breast, and the prosthetic, as well as an extra prosthetic, in case the first one gets broken when you are away. We have travelled to Africa a lot, and each time you need an extra bag when you are away for three weeks. And how do you wash the compression socks when access to water is limited?”* (Patient 5).

Q6. *“I asked my husband if he wanted a wife with one breast or one with a reconstructed breast. It doesn’t matter what he said. So, I don’t know if my close relationships are affected that much. I don’t think my kids are bothered. The only thing is that they don’t understand my frustration. You can’t expect people to understand what you’re going through. My best friends respect me and ask questions about my treatment. And I am not in a context where it matters to my friends whether I have one breast or two”* (Patient 1).

Q7. *“I can’t walk around identifying myself as ‘a breast cancer patient.’ I am so much more than that”* (Patient 11).

Q8. *“Breast cancer has not reduced my value as a person/woman. I am as valuable as anyone else”* (Patient 1).

Q9. *“Seroma, yes, that was tricky. The drainage was difficult, and it was painful when I tried to fall asleep. You had to rest on your back, the bag was in the way, but it was still in my head. I was thinking that this won’t last, and it will heal. However, I was anxious when I had pain and there was a lot of fluid. So, I visited the contact nurse. She measured the fluid, and it was a lot. Then she talked to the surgeon, and I had to keep the drainage tube for a few more days. And that was enough to give me distressing thoughts. You are vulnerable. I felt abnormal”* (Patient 3).

Q10. *“There are no professionals talking to each other. That has been a huge struggle. No spot where you can turn to talk about things that are happening. Because I have had side effects from the hormones and all the stuff that I take. But the breast nurse deals with that. I have never met the same doctor twice. There has been no continuity during these two years. So, it has been a real struggle. You get tired of reconnecting when you never meet the same professional”* (Patient 5).

Q11. *“When you have a question, one of the four contact nurses is always available”* (Patient 2).

Q12. *“The answer to your question about how I cope is that I have a great husband. We are doing great together. The animals and the children and grandchildren. That’s my life. And it’s enough for me. There is a large circle of support. I can be alone if I choose to be, but I am never alone”* (Patient 4).

Acceptance was illustrated by the participants' extraordinary ability to accept their circumstances despite the remaining complications from ALND and profound side effects of the hormone treatment, as illustrated in quotation 1. Adaptation was an ongoing process throughout the whole treatment trajectory, where ALND was but one part of a bigger puzzle, as shown by quotation 2.

Structural Analysis

Establishing coherence. Suffering from BC and being subjected to burdensome treatment led to a need for coherence. The women tried to make sense of everything that had happened to them since the diagnosis and entered a state of meaning-making to gain a sense of coherence. This pursuit was not easy due to the shock and grief caused by being a person with cancer (quotation 3).

The core of sense-making involved an effort to make sense of how the cancer occurred and find reasons for the experienced lack of energy. Some participants explained it as being due to their age, the isolation during the COVID-19 pandemic, the hormone treatment, and the fact that they were slightly inactive. Various personal explanation models were developed where, depending on the content of the sense-making, some were consoling yet others caused grief and distress. When unable to discuss their explanations with healthcare professionals, the participants received no feedback on their thoughts, resulting in uncertainty and a sense of loneliness, which they had to cope with alone (quotation 4).

Adjusting to treatment. The women mainly adjusted by coping with the side effects of the hormonal treatment, adjuvant chemotherapy, or radiation therapy, as well as the symptoms and complications after surgery. There were distressing mood swings caused by the hormones and a constant sense of feeling low and not yourself. The surgery led to persistent pain problems and nerve damage. Many participants had a numb feeling in their arm, which was swollen, and they dreaded having the compression glove and sock on it. Going through the initial surgery, recovering, and then undergoing the ALND was considered a struggle, as was reaching a state of acceptance that there were no other options, which led to a sense of one's freedom being violated, as expressed in quotation 5.

Safeguarding social belonging. The participants protected their family and significant others from grief by not showing their distress and never crying in front of others, particularly their children. They were also forgiving to friends who did not know how to act or approach a person with cancer. Instead, they tried to

assist people around them in terms of how to act because they were eager to safeguard their friendships and social network (quotation 6).

Re-defining oneself. Due to the cancer and its treatment, the participants were in a process of re-defining themselves. This process involved comparisons with their previous health status. Before the surgery and treatment, they had a great deal of energy, could exercise, and worked full time. Then, they had to cope with fatigue, changed physical appearance, physical restraints, and mood swings. Another strategy was to compare themselves with other women who had BC. The participants rarely participated in patient groups, as they did not want to identify themselves as a "breast cancer woman." When they saw others identifying themselves with their cancer, they became frustrated and wanted a different identity, as presented in quotation 7.

Self-perception was changed due to their new physical appearance. Because parts of or a whole breast had been removed, they pondered on their value as women and as persons. If they had a partner, they asked him/her about and measured their value in relation to friends and significant others (quotation 8).

Feeling vulnerable. Undergoing cancer treatment meant feeling vulnerable, not knowing the outcome, or not knowing how complications and side effects would affect one's everyday life. Even having achieved acceptance and finding strategies to master their anxiety, very little was needed to "rock the boat," causing low self-efficacy and doubts about how things would turn out (quotation 9). A sense of vulnerability also occurred when feeling abandoned by professional caregivers. It meant that one had to deal with symptom management on one's own. Several participants described a lack of continuity due to always meeting new nurses and physicians/surgeons. The different professionals did not cooperate or coordinate their interventions. The participants were lost in a sort of no-man's land, which made the treatment journey difficult and lonely (quotation 10).

Accepting one's circumstances. Those participants who experienced continuity via stable and caring relationships felt embraced and cared for by professional caregivers. This enabled acceptance and increased self-efficacy. Even if not the same contact nurse, a team of nurses was always available to deal with patients' concerns, as described in quotation 11.

Another factor enabling acceptance was feeling embraced and cared for by significant others. Family and friends were instrumental in overcoming the cancer treatment

and achieving acceptance. Being able to spend time with close friends provided a sense of security and comfort, which, in combination with the opportunity to reach the contact nurses whenever necessary, made the participants feel safe, thus facilitating acceptance (quotation 12).

Comprehensive Understanding

The structural analysis revealed that women with BC who have experienced ALND develop a state of acceptance that enables adaptation to their present condition and ongoing cancer treatment. The journey to acceptance involves both a state of motion, by means of sense- and meaning-making, and a state of being, where a sense of coherence is achieved. The state of motion comprises a struggle to understand what has happened, what is about to happen, and the consequences of the ongoing hormone and adjuvant chemo- or radiation therapy in everyday life. Not knowing the outcome of the treatment and what to expect also implies a need to master the uncertainty about different side effects of the treatment.

The women adopted active approaches, choices, and actions, ie, adjusting to treatment, safeguarding their relationships with significant others, re-defining themselves, and dealing with an ever-present vulnerability. The sense of coherence and acceptance was enhanced when the women felt that they were taken seriously by both significant others and healthcare professionals, which made them feel safe despite the distance from hospital care. They accepted their “battle scars” and gave their body a new purpose without too much grief or concern. When their treatment and experiences made sense and the healthcare professionals provided structure, the women could feel certainty, act in accordance with their own free will, and enjoy participating in meaningful social interactions. Uncertainty occurred when they became lost in their own sense-making processes, leading to low self-efficacy. Uncertainty could occur when changing medications due to severe side effects, developing a complication (eg, seroma), or lack of continuity of care. A sense of deviating from the norms of patient care occurred when a complication arose. The fear of tumour recurrence was ever present, as reflected in the meaning of quotations like “it is my fault if I can’t stand the side effects and the change in treatment leads to a poor outcome.” Several participants also pondered the psychosocial reasons for developing cancer.

Two specific factors that enabled coping with uncertainty and a reasonable sense of coherence were feeling embraced by significant others and by healthcare professionals who provided continuity of care. Stable and caring relationships with contact nurses or physiotherapists acting as credible authorities were essential. Thus, it is vital that healthcare

professionals are invited to share in both the sense-making and meaning-making processes or, if not invited, they should take the initiative and show an interest in the patients’ personal understanding of their illness. If ignored, patients become isolated in their vulnerability and quickly exhibit low self-efficacy when set-backs, side effects, and complications occur. The participants shifted from feeling capable, embraced, hopeful, and satisfied with their own efforts to experiencing a lack of self-trust brought about by uncertainty and self-blame for being unable to endure the side effects of the treatment. As there is a high risk of getting lost in one’s own sense-making, resulting in uncertainty, loneliness, and lack of self-efficacy, BC professionals must adopt a person-centred approach and focus on the personal explanation and meaning-making models that might possibly act as a barrier to self-management and a sense of coherence.

DISCUSSION

This study provides an in-depth understanding of lived experiences of women undergoing ALND as part of their overall BC treatment, including breast surgery and neoadjuvant/adjuvant chemotherapy/hormonal therapy or radiotherapy. The findings corroborate a recent study on how persons with a chronic condition strive for social belonging and adopt a social process of coherence, acceptance, adjustment, and balance.²¹ Furthermore, Nolvi et al¹⁹ described the process of meaning-making and sense-making as important parts of achieving a sense of coherence, a pattern that was clearly present among the women with BC in our study. A challenge is that HCPs seldom pay any attention to this process, leading to a risk that the individual meaning-making and sense-making will cause psychological distress and uncertainty.²² The standard information provided is seldom relevant or adjusted to fit the individual patient.²³ Subsequently, patients may feel that the information about the disease or treatment is not timely or that it is insufficient.²⁴ The meta-synthesis by Cappiello et al²⁵ revealed that HCPs cannot adequately meet patients’ needs or do not understand patients’ sense-making because they do not seriously listen to what patients are saying.

The healthcare system is dominated by an objectified and biological view of human beings. Women with BC might be viewed from a purely medical perspective based on physiology and personalized medicine of the body. These therapies are based on the genetic content of other molecular or cellular mechanisms of each patient.¹ We are eager to establish correct diagnoses and inform patients about their tumours, tumour characteristics, and evidence-based treatment plans. The things HCPs say seldom make sense to each woman concerned, as the “one size fits all”

approach results in poor precision compared to the “my size fits me” approach. A key value in all healthcare is shared decision-making and shared consent.²³ However, we rarely promote these core values in their proper sense, as they require a person-centred approach where we start by listening to each patient’s understanding of her situation. A starting point in person-centred care involves the narrative wherein HPCs are supposed to listen to the patient.²⁶ A simple question – “Can you please tell me how you understand your situation?” – may enable the HPCs to gain access to the patient’s personal explanation of illness models. We must assume that the patient is not familiar with the new health situation or the words or expressions that we use. Thus, we must change the way we approach our patients, viewing them as a human being and helping them make sense of their new situation. Indeed, the starting point should be the patient’s need for information and what she manages to comprehend in that particular moment. While that requires a presence, it will not necessarily take more time. Practicing shared consent in its true sense means inviting the woman with BC to a therapeutic alliance in line with Ricour’s philosophy about Homo Capax,²⁷ or the capable human being. Empowering the women to take control of the situation and be a part of the decision making facilitates a sense of self-efficacy and self-management. Focusing on capabilities associated with being treated as a person, including the ability to reason, feel, and respond to emotions, emphasizes that the person, ie, the woman with BC, intends and initiates actions, as well as has self-awareness and self-directing abilities.²⁸ Narrowing the team to a handful of contact nurses, a physician/surgeon, and a physiotherapist will ensure continuity in the provision of care and make more sense to the patient, thus enabling a successful process of adaptation and sense of coherence.¹⁹

Methodological Considerations and Study Limitations

A strength of this study is that the interviews were performed by the same researcher. The same interview guide was used, and follow-up questions were added, eg, “could you please tell me more?” As a result, the findings provide an in-depth understanding of the meaning of acceptance and adaptation among women with BC. The analysis was mainly conducted by two of the authors, one of whom was not involved in the BC treatment and thereby not biased due to pre-understanding.

The study was performed during the COVID-19 pandemic. During this period, the number of digital encounters increased. Only healthy patients were allowed to visit the clinic in person, but without relatives. The increased number of digital encounters was viewed as an advantage by patients who would otherwise have had to

travel a great distance. The perceived lack of healthcare support is likely an illustration of the follow-up tradition after BC in general rather than the effect of the pandemic restrictions.

The main limitation was that the sample only included native Swedish-speaking women with BC and thus fails to reflect the ethnic diversity that is increasing in Swedish healthcare. This also limits transferability to a solely western perspective. In addition, there is always a risk of recall bias in a retrospective study. A final limitation is that this was a single-centre study. Although the findings only reflect a specific clinical institution, we argue that they are nonetheless transferrable to other settings both in our country and beyond. The need to be taken seriously and supported in one’s sense-making and meaning-making is highly generic and present in many different groups of persons with a chronic condition. The follow-up procedure at this single institution reflects the nationwide tradition of follow up after BC and how care is organized in Sweden, as well as the inherent approach to patients as understood chiefly from a medical and natural science model. As argued by Ekman:

The concept of person is crucial in legal matters and used to give somebody responsibility vis-à-vis a situation which concerns him or her. Person-centred care therefore more clearly than the concept of patient-centred care emphasizes the need for a shift away from a model in which the patient is the passive target of medical intervention to another model where a more contractual arrangement is made involving the patient as an active partner in his or her care and the decision-making process. Person-centred care is about building this ethics as a springboard.²⁹

The requirement for person-centred care is not linked specifically to ALND but to being a woman subjected to cancer and advanced treatment. Early in the interviews, it was obvious that even if ALND was in focus, the narratives were about life, coping with cancer, and being subjected to numerous advanced and demanding treatments of which ALND was one. From a surgical perspective, ALND was the treatment with the greatest impact on the women’s lives, even more so than adjuvant chemotherapy and radiotherapy, which was the reason for this study.

CONCLUSIONS

There is a need for a paradigm shift in surgical care from viewing women with BC as anatomical constructions requiring repair to deeply understanding that these women are persons with an illness in need of ongoing self-

management support. A more person-centred care approach is essential. The team that meets the patient should be able to work together for a longer period, thus ensuring continuity. The contact nurses should support patients throughout the whole cancer treatment and rehabilitation journey. They should be well educated in the principles of person-centred care. Finally, the whole team must acknowledge that BC treatment is about supporting a Homo Capax, a capable human being, who happens to be their patient for a while.

Author Contributions

Study design: Drott, Wennerholm. Data acquisition or analysis: All. Manuscript drafting: Patil, Forsberg. Critical revision: All.

Conflicts of Interest

We, the authors, declare that we received financial contributions from Moa-Lina, a local branch of the Swedish Breast Cancer Association. We have no other relevant financial or non-financial interests to disclose.

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