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Women Treated for Breast Cancer Experiences of Chemotherapy-Induced Pain

Memories, Any Present Pain, and Future Reflections

KEY WORDS

Adjuvant chemotherapy
Breast cancer survivor
Pain experiences

Background: Breast cancer survivors make up a growing population facing treatment that poses long-standing adverse effects including chemotherapy-related body function changes and/or pain. There is limited knowledge of patients' lived experiences of chemotherapy-induced pain (CHIP). **Objective:** The aim of this study was to explore CHIP and any long-standing pain experiences in the lifeworld of breast cancer survivors. **Methods:** Fifteen women participated in a follow-up interview a year after having experienced CHIP. They were interviewed from a lifeworld perspective; the interviews were analyzed through guided phenomenology reflection. **Results:** A past perspective: CHIP is often described in metaphors, leads to changes in a patient's lifeworld, and impacts lived time. The women become entirely dependent on others but at the same time feel isolated and alone. Existential pain was experienced as increased vulnerability. Present perspective: Pain engages same parts of the body, but at a lower intensity than during CHIP. The pain creates time awareness. Expected normality in relationships/daily life has not yet been achieved, and a painful existence emerges in-between health and illness. Future perspective: There are expectations of pain continuing, and there is insecurity regarding whom to turn to in such cases. A painful awareness emerges about one's own and others' fragile existence. **Conclusions:** Experiencing CHIP can impact the lifeworld of women with a history of breast cancer. After CHIP,

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there are continued experiences of pain that trigger insecurity about whether one is healthy. **Implications for Practice:** Cancer survivors would likely benefit from communication and information about and evaluation of CHIP.

The breast cancer survival has improved dramatically during the last decades because of improved treatment strategies, with a prevalence worldwide currently estimated to be 6.3 million.^{1,2} Cancer survivorship is an ongoing process, defined by the National Coalition for Cancer Survivorship as starting at the “time of diagnosis and for the balance of life.”³ Treatment options for localized breast cancer commonly include surgery followed by radiation, chemotherapy, and/or endocrine therapy, which may render long-standing adverse effects that present over time and may impact on the cancer survivor’s quality of life.⁴

Surgical procedures and breast cancer treatments may contribute to the development of pain with different characteristics.⁵ Chemotherapy predicts for decreased quality of life in breast cancer survivors,⁶ arising from decreased body functioning and pain.^{7–9} Chemotherapy-induced pain (CHIP)¹⁰ includes several severe pain conditions, such as an acute chemotherapy-released pain caused by taxane¹⁰ and chemotherapy-induced neuropathy.^{11–13} The mechanism behind CHIP is complex and only partly understood.^{14,15}

A common definition of pain is “...an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.”^{16(p217)} Pain experiences involve all dimensions of life: physical, psychosocial, and/or existential pain.¹⁷ It can cause or amplify other symptoms such as fatigue¹⁸ and can cause troublesome late sequelae even if the acute pain itself has faded.¹⁹ Even a short-term pain experience has the ability to create an indelible long-term pain memory, which can develop into a chronic pain condition.¹⁹ The healthy body is a silent body; when pain occurs, it makes one aware of the premise of being bodily present in the world.²⁰ The lived world as it constitutes itself is the lifeworld. Adopting a phenomenological approach means to explore the human experience of being, the physical, temporal, relational, and spatial presence in the world. Lifeworld research explores a phenomenon, as the phenomenon presents itself to human consciousness.²¹ The phenomenon in the present study is pain, which interrupts the lifeworld and impacts a human’s close relationships, social life, thoughts and language, and self.²⁰ The memory of a cancer-related pain experience can serve as a reminder of an individual’s vulnerability from simply existing in the world.¹⁹

It is important to identify cancer survivors who were treated with chemotherapy and are struggling with unwanted and lingering symptoms such as pain.²² Less is known about patient experiences following systemic chemotherapy; the lack of descriptions in the patient’s own words might lead to fragmented, difficult-to-interpret, and less clinically useful findings. When it comes to CHIP, there is a lack of knowledge about patient-experienced additional long-term effects and impact on daily life.²³ To our knowledge, this type of pain is underrecognized and undertreated.¹⁵ Furthermore, patient experiences of the impact of pain are rarely addressed in earlier research about CHIP in adjuvant breast cancer patients. These experiences are important

to capture in order to enable optimal and individualized care for breast cancer survivors. The purpose of this study was to explore memories of CHIP and any experienced long-standing treatment-related pain in the lifeworld of women with prior adjuvant chemotherapy for breast cancer.

■ Materials and Methods

Design

This study had an exploratory design with a qualitative phenomenological lifeworld approach.

Theoretical Framework

Fundamental for phenomenological research is the lifeworld. We, as humans, are bodily present in the lifeworld; thus, the body is fundamental for being.²⁴ In other words, the body is the point of departure of all dimensions of the world.²⁵ One can, like van Manen, operationalize “the lifeworld perspective” into 4 human existentials: first, the *lived body*, which is subjective, as we as humans are bodily present in the world^{21,24}; second, *lived time* incorporates a continuum and constitutes a person’s temporal way of being in the world; third, *lived other* is link made to others, creating the interpersonal space shared with other people²¹; fourth, *lived space* is the landscape that affects and surrounds us.²¹ In this study, the women’s memories of CHIP and any possible long-standing pain 1 year after treatment were explored, using an intentional thread linking to the woven structure of the memory of the past, present, and consciousness future²⁴ of these women.

Participants and Procedure

The Breast Cancer and Stress (BAS)²⁶ study was ongoing from May 2009 to August 2011. Patients participating in the BAS study during the period September 2010 to August 2011 were consecutively asked to participate in a substudy investigating CHIP during adjuvant treatment. Inclusion criteria for the substudy were treatment with chemotherapy in doses of 75 mg/m² or more of epirubicin and docetaxel, respectively, and scoring pain of 4 or greater on a visual analog scale (VAS). The women were asked to estimate pain on the VAS before each course and at day 10 between treatment courses. All invited women (n = 57) agreed to participate. Twenty-two of the women (38%) registered pain (VAS ≥4) between the courses, and 16 of 22 women were consecutively asked to participate in an initial first interview (data presented previously)¹⁰; hence, the data were considered as saturated. At the first interview, the interviewer requested permission to contact the participants again 1 year later. Informed consent was obtained from all individual participants included in the study.

One year later, during the period September 1, 2011, to August 31, 2012, the same women (n = 15) were contacted by telephone and asked to participate in a second interview. Meanwhile, 1 woman had died of breast cancer. The specific time point was chosen because earlier research has shown that women at this point in survivorship were still under stress, although their lives tended to have returned to normal.²⁷ All interviews took place in a hospital setting, except 2: one was conducted at the woman's home because of her immobility and the other at a private office because of the woman's full-time work schedule. The interviews lasted 30 to 90 minutes and were audio taped. The interviewer was a female nurse with extensive previous experience in oncology nursing but who had no part in the women's care.

The women (n = 15) described themselves prior to starting adjuvant treatment as socially active either in their careers or their spare time, or both. All of the women had participated in some form of physical activity. Seven of 15 women stated that they had previously experienced pain, but only 1 woman scored VAS more than 1 before starting the chemotherapy (Table 1).

Interviews

The women were individually interviewed using open-ended questions focusing on their body, mind, thoughts, feelings, and social life (Table 2). The interviewer reflected on the women's story with words such as "Can you tell me more...?" "Can you describe...?" "What do you think...?" "What do you feel...?" "Can you reflect...?" "What else is of importance?" The interview ended with an opportunity for the women to deal with and reflect on their answers and thoughts from the interview. This was to ensure that we captured how they perceived the content of the interview and that they felt comfortable with the situation.

Analysis

The first author transcribed the interviews verbatim and conducted a first, tentative analysis of them. After this, a part of the interview material was jointly analyzed by 2 of the authors. Thereafter, the same part was analyzed by the other 2 authors to obtain congruence. Continuing, the interviews were read several times and categorized into 4 fundamental existentials lived: body, time, space, and other.²¹ Each existential was divided into past, present, and future perspectives. To achieve a main structure in the material, the themes in each perspective for all interviews were compared and combined. Thereafter, the results were analyzed through guided reflection as described by van Manen.^{21,28} The essential qualities of the theme aspects were identified and presented in a phenomenological description of CHIP as experienced in the women's lifeworld. The authors strived to actively bracket their preunderstanding of the phenomenon during the analysis²¹ and during the process had active discussion among them. The authors have different professional backgrounds: one has extensive experience of qualitative research methods (I.K.H.); one has extensive experience of clinical oncology and translational oncology research (M.-L.F.); 2 have extensive experience of psy-

 **Table 1 • Patient Characteristics (n = 15)**

Age, y	
30–39	2
40–49	3
50–59	5
60–69	4
70–79	1
Residential area	
Dalarna	5
Gävleborg	7
Uppsala	3
Marital status	
Living alone	1
Living together with a spouse/partner/children	14
Children	
At home	5
Grown-up children	10
Education	
Basic level	4
High school	10
University	1
Employment status	
Currently working	12
Retired	3
Primary surgical treatment	
Breast-conserving surgery	6
Mastectomy	9
Sentinel node	10
Lymph nodes	10
Adjuvant therapy	
Chemotherapy	15
Radiotherapy	13
Hormonal therapy	14
Previous pain experiences (before treatment start)	
Scoliosis	1
Osteoarthritis	2
Neck and back pain	7
Neuropathic pain	2
Muscle inflammation	1
Migraine	2

chosocial oncology (K.N., C.A.); and 3 have extensive experience in oncology care (C.A., M.-L.F., S.H.-B.).

The BAS project was reviewed by the ethics committee and approved on March 25, 2009, Dnr ma 2008/382, and the section with the interviews through an amendment to the study above, approved on May 28, 2010.

Findings

The Experience of Chemotherapy-Induced Pain

The findings are presented in past, present, and future experiences: (1) CHIP in the past, (2) present experienced pain, and (3) thoughts about pain experiences from a future perspective. The pain experiences are perceived in the women's bodies, impact their time perception, influence their relationships, and make them more aware of being in the world. (1) Past: bodily CHIP,

Table 2 • Interview Questions

- Can you tell me how you feel and think about life right now?
- Can you tell me about work and social life today?
- Can you describe how your body is right now?
- If you have pain, can you describe how the pain turns up in your mind, thoughts, and social life?
- Do you remember how your body reacted during the treatments? Can you describe these memories?
- Can you describe your reactions to the treatment at that time, and how your reactions affected your mind, thoughts, and social life?

The women spoke freely about their experiences and were encouraged to provide specific examples.

often described in metaphors, had led to dramatic changes in the women's lifeworld. Time was perceived as periodic, and they became entirely dependent on others. At the same time as they described an increased dependency, the pain made them withdrawn, increasingly isolated, and alone. Existential pain was described as a feeling of being completely vulnerable and alone with thoughts of annihilation. (2) Present: signals of bodily pain often incorporated the same parts of the body as during chemotherapy. The pain intensity was not as demanding as during chemotherapy, but made the women perceive time in a more conscious way. The pain increased the awareness of time and remainder of life, but this also increases the feeling of being present here and now. Expectations of returning to an unperceived normality complicated and impacted their social life, in both private and formal relationships. The women describe a painful existence in-between health and illness. (3) Future: The women expressed beliefs that some bodily pain would remain and continue to remind them of time and their insecure future. They were not fully aware of whom to turn to if they need to talk about their pain experiences. A painful and increased vulnerability arose, contributing to an awareness of their own fragile existence as well as that of other significant people in their lives. Finally, they experienced a fragile trust in being and a growing acceptance that this fragility is among life's premises (Figure).

Past: Pain and Lived Body During Chemotherapy

Experiencing CHIP during treatment gave the women another awareness of their body as the foundation for their being; they are bodily present in the world. Their memory of physical pain is described in 2 different ways. The first entailed that pain memories could be related to other painful incidents earlier in life. With ordinary words used to describe their pain experience, this way of describing the pain belongs to a more manageable pain experience:

It was a nagging pain throughout my body (9).

The second way of describing the pain heritage is that it was hard to find words to describe the now experienced pain compared with earlier experiences of pain in life. Here, the women created pain descriptions with the help of metaphors. This metaphorical language belongs to stories in which the experienced pain is described as difficult and tumultuous:

The pain started under my feet and spread to my joints; I felt like I'd been run over by a steamroller (14).

I'll never forget that; it was something so terrible, and it was during the first course of the treatment. I thought that I would be torn to pieces... I felt like I was in a dryer, and I was thrown back and forth, like I was torn and ripped into pieces (3).

Present: Pain and Lived Body Now

The story of pain about a year after having completed treatment was partly separated from the story of pain during the treatment. Residual bodily pain often incorporated the same parts of the body as during the chemotherapy; nevertheless, the origin of the pain was difficult to identify. Questions arose as to whether the pain heritage was from earlier chemotherapy or other parts of the breast cancer treatment or was part of the natural aging process. The pain intensity did not have the same power as that during chemotherapy; therefore, the women used more everyday language to describe the pain experience. A common experience was that the body did not want to cooperate like before.

Yes, frustrated that I can't use the body as I wish to. When I want to peel something, I drop it. I become frustrated over the body, but it is manageable when I eat painkillers (8).

Pain and a built-in bodily sluggishness made the women reflect on their bodies as "altered." An embodied pain memory was described as activated and beyond the women's own control, and the pain could start at the mere sight of the hospital. There were also concerns about the interpretation of bodily pain signals causing a new uncertainty: am I healthy or not?

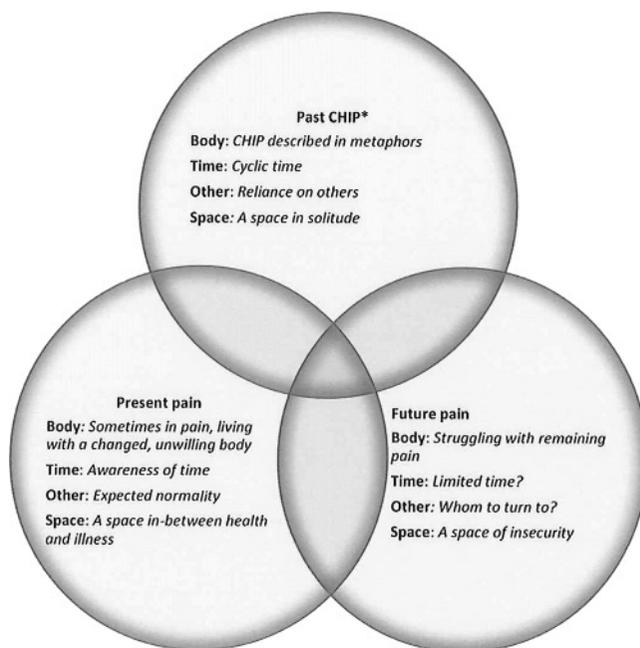


Figure ■ The 4 existentials and experienced pain from past, present, and future perspectives.

The pain triggers my thoughts, it makes me worried. You really listen to your body in a quite different way now. Every little thing you feel in your body could be signs of something abnormal, and you listen to your body and think: what was that, what a strange feeling (10).

Future: Residual Pain and Lived Body

From a future perspective, the women expect their body to be a continuous reminder of what they have been through during treatment. Bodily pain will remain, and this seems hard to cope with. Pain acts as an echo into the future:

Sometimes when I wake up I think, “Will the pain be like this every day, always, always—that’s hard to manage sometimes (15).

Past: Lived Time During Chemotherapy

During chemotherapy treatment, time is perceived as cyclical, and pain is experienced as time consuming, especially during the first course of taxotere. The women described how they lived in 3-week periods, concentrating on the pain fading away. Thanks to corticosteroids directly after the course, the pain was held back for a number of days, but around day 3 after the course, the pain started growing stronger. It then persisted for 3 to 17 days, before gradually fading away. When life began to normalize, it was time for the next course of treatment. When the pain was at its worst, lived time was occupied by pain:

For 3 days, I lay in bed concentrating on my breathing; it was the only thing I could concentrate on (7).

Some women found strategies to cope with the pain, for example, planning their time, taking painkillers, trying to find comfortable resting positions, or moving their body in a specific way in order to manage the pain. Uncertainty as to the source of the pain influenced the quality of their lived time. If they achieved effective pain release, their quality of lived time was improved. Lived time and less successful pain treatment became an experience of suffering:

Before the second course, it was hell... you thought about what lay ahead of you, that you weren’t going to get any rest, you wouldn’t be able to sleep, and that there was no body position that was bearable (12).

Present: Pain and Lived Time Now

The women described how previous treatment and the continuing pain experience resulted in a more conscious perception of time. Residual pain conditions, that is, ongoing pain or pain that occurred now and then, interrupted their lived time. For example, it took time to start up their daily activities in the morning because of a stiff, failing, painful body. It also took time to slow down in the evening.

If I sit down in the evening, my body starts to twitch, then I have to get up and around again. Just like in the morning, I have to sit for a while... so it’s good that I’ve gotten painkillers (8).

Time had become significantly more finite; the women described a painful awareness of restricted time. At the same time, though, this awareness had the power to influence their choices in everyday life in a positive manner. Even though the pain was interrupting their time, ordinary things such as going to work, cleaning the house, and cooking were described as new sources of joy.

Future: Residual Pain and Lived Time

There was an acceptance from a distant perspective that traces of pain and other symptoms could affect future time. The expectation and hope for the future were to stay free from breast cancer. Imagining facing a future reality with a new breast cancer disease and time-consuming treatment sessions with treatment-induced pain seemed unbearable. The women’s relationship to lasting time changed, whereby the perception could be that their time was severely limited, whereas others around them had a more infinite amount of time:

I was so angry for a while. I didn’t even dare to drive, because I came close to hitting someone. It felt like everyone was driving too slowly, and I didn’t have the time to sit there and wait... I felt like “you have all the time in the world, but my time’s running out” (11).

Past: Pain and Lived Other During Chemotherapy

To be able to deal with the pain during chemotherapy, the women depended on relatives, close friends, or healthcare providers (HCPs). It felt supportive to get practical help, such as personal care and supplies during daily life activities. However, simultaneous with this increased dependence, the pain made them withdraw. Some women with less severe pain were able to devise their own strategies for taking care of themselves or remain involved in daily life with the family. This was achieved by rationing their energy, resting, or by recharging through short physical activity.

The space I had when they were in school and at leisure time, when I was able to be at home and rest, gave me energy to take of when they arrived back home again (13).

Others with more severe pain chose to retreat and keep the pain experiences to themselves. The pain affected their temper and patience with their family:

I remember that I was irritated by the pain. I couldn’t cope with the kids as much as I would have liked to (6).

The women described various help and support from the HCPs for dealing with the pain management, such as advice, analgesic drugs, prolonged cortisone treatment, and decreased dosage.

Present: Pain and Lived Other Now

In a social context, the women as well as their family members and employers expect that they will return to everyday life. However, the women did not always perceive that they were back to normal:

They said in a year you'll be back to your regular everyday life, and I'm not. It's a disappointment, and I also see that my family demands more of me now, which I'm not always able to live up to (13).

Continued treatment-related pain sometimes in combination with other pain experiences created barriers in the social interaction with family and friends. For those with younger children, their thoughts often were affected by the memory of their reactions, influenced by pain during the treatment. If their children had been affected by their illness and treatment, various interpretations were made; some were comfortable with how they had handled the situation, whereas others expressed a more uncertain attitude:

It was really tough, when you were back to your old self you thought, "Oh, God, you shouldn't be so grumpy and upset about such simple things"; I hope it doesn't have any lasting effects (6).

The women mostly described their family interactions in a positive manner. Their descriptions were stories of experiences of greater intimacy, better transparency, and understanding within the family. However, continuing pain caused worries about being a burden to one's family. During supportive talks within the family, the women sometimes experienced a very present pain, as the communication made them relive their CHIP. Meanwhile, communication and relived experience were ultimately described as communication that soothed and helped:

When you think about what you've been through, it's like the pain doesn't only exist in my arm, but in my whole body. When we talk about it in the family, it's like the pain fades away, and you can move on (3).

Future: Residual Pain and Lived Other

The women did not express thoughts about the future impact of pain on their close relationships. However, they did express insecurity concerning whom to turn to in the future regarding the arbitrary body signaling symptoms:

This year when I was in therapy, there was such a focus on my getting through the therapy; you're so privileged and looked after. The problems start after that; whom do you turn to when you have pain in your hip like I do? (4).

Symptoms constantly reminded them of their own or close relatives'/friends' vulnerability from being in the world. This was also highlighted by close relatives' and others' life events, such as accidents and outcomes of other severe illnesses.

Past: Pain and Lived Space During Chemotherapy

During CHIP, another painful experience arose, going beyond physical pain and instead involving existential experiences of being: an experience of being totally exposed and vulnerable, with no option to do anything about it but to simply be there. An existential loneliness emerged, described as a painful loneliness of not being connected to one's fellowman but being totally alone with oneself—a pain caused by the fundamental loneliness of the

being as a human. The women described it as going into solitude; they wanted to be alone with themselves or with a silent companion, such as a horse or another animal:

A few months into treatment, I felt disappointed in life, like I was abandoned and totally alone. Not abandoned by my fellowman but abandoned by life... I spent a lot of time alone but I had to, to get through it (1).

Present: Pain and Lived Space Now

The women described finishing the chemotherapy treatment as something they had very much been looking forward to. Now a new existential pain of loneliness arose: not having regular treatment appointments was more difficult than they had expected. It was hard to suddenly trust yourself and interpret pain signals on your own. They described that they did not know if the signals were normal, or if they could really trust that they would stay healthy. They found that their perceived experiences had left permanent painful signs in their lifeworld, which could never be restored to how it had been before they received a diagnosis of breast cancer:

Now I've finished my treatment but am stuck in a period where I sit and think, "Am I healthy or am I not?" It's like something in-between? (10).

Future: Residual Pain and Lived Space

With a higher awareness of what it means to be bodily present in the world and a part of human existence, some women expressed a more cautious approach to the future and any remaining pain. Their bodies had been invaded by a silent, severe disease that did not knock on the door itself but was most often discovered through mammography. They described having to live with insecurity regarding the future and trust whatever was yet to come:

I couldn't even imagine that it was like this to have such a disease (silence). A disease you don't know anything about, a disease that has the power to live its own life in your body. At last I've found acceptance. I can't step out of myself. I can just fold my hands and hope for the best (1).

■ Discussion

This study highlights several important issues: first, experienced CHIP and the role of memory, language, and interpretation; second, how the memory of CHIP influenced the women's perception of time; and third, CHIP and its influence on relations and space.

The revived previous pain experiences are enhanced or diminished by the women's memories. For those who experienced more severe CHIP during treatment, their memories of pain are described in the same manner as the they did during the first interviews (data published earlier).¹⁰ They often use a similar metaphorical language, sometimes even identical to that describing their previously experienced CHIP,¹⁰ as if the metaphor has

become a part of their lifeworld. Women who experienced less severe CHIP are vaguer in their descriptions, as if their memory of the pain is not as sharp. It seems that the memory of CHIP gives the women access to experiences of pain in different ways. Their metaphorical language plays an important part in their communication about their pain experiences. Biro²⁹ argues that pain is a black hole in which language seems to disappear and that we cannot understand or communicate pain without using metaphors. Pain is portrayed and interpreted in the form of metaphors. Sometimes, the interpretation itself can help dealing with the pain as the pain has now been defined.²⁹ In this study, the women with more severe CHIP used metaphors for their pain and sometimes perceived that the HCP did not recognize or acknowledge their experiences. Could it be that the present knowledge regarding pain and presumed defined pain definitions among³⁰ HCP affect their ability to communicate about pain experiences with patients? Or could it be a question of insecurity in the HCPs when they should interpret metaphorical narratives told by their patients? The International Association for the Study of Pain Subcommittee on Classification (IASP) definition of pain includes and encompasses the opportunity for many different types of pain, but stresses the occurrence of actual or potential tissue damage.¹⁶ However, a view of CHIP is not fully covered in the IASP definition, a psychological pain,³¹ pain that might be brought on by loss, such as that of a limb or of the innocence of being in the world. The women in the study used metaphors to describe an embodied memory of CHIP that is beyond their own control. If their entire CHIP experience is to be included in a single pain definition, the broadly used pain definition by IASP needs to be expanded or replaced with one that includes a more phenomenological experience of pain. Biro³² advocates a broader definition of pain: "Pain is an aversive internal experience that threatens to destroy everything except itself and can only be described metaphorically." The metaphor has a task in the communication of pain and has the ability to make use of physical, social, psychological, and existential experiences and sharpen the perception of these experiences.³³ Metaphors provide an expanded, better opportunity to more fully communicate with patients about their pain experiences, which should be highlighted.

Memory and perceived time had an impact on the women's interpretations of CHIP. Frequent thoughts expressed by phenomenological philosophers such as Heidegger³⁴ and Merleau-Ponty²⁴ concern how pain and illness affect the human perception of time. Gergel³⁵ writes that the phenomenological time perception is about our relationship to the world and is always aimed to be in the future while taking shape with its starting point in our present and past. The women described how their memory of experienced CHIP and remaining pain made them more aware of their own presence in the world. Through memories of CHIP, this had the capacity to affect their everyday life in a positive way through a more conscious awareness of time and being and a distant threat in the future experienced as an embodied pain awoke when new pain sensations turned up or residual pain became prominent. These experiences raised a tangible painful awareness of what it means to be mortal.^{10,36} This is not unique to women with breast cancer in the context of CHIP; it is rather a

general experience shared by cancer patients in their trajectory of cancer.³⁶⁻³⁸ Little and Sayers³⁶ describe this as "the mortal extreme experience". This embodied painful consciousness challenges one's hope.³⁶ Every single new pain or experienced sensation in the body challenged the women's hope of being in the world. Hope is described by Fromm³⁹ in this way and is connected to a generalized form of hope linked to time. In the present study, hope is about time and pain relief or, if pain relief is not available, being able to live well despite the pain. Hope is also about staying healthy without recurrent cancer and new treatment-related CHIP and raising one's awareness of what may come in the future.

Being regarded as "healthy" and on the way out of the health-care system they had previously been dependent on made the women face a new painful experience. They wanted to end the treatment and be rid of the CHIP, but felt unprepared for the emotions that arose when the treatment ended. They felt that they had been thrown into an existence they believed would bring delight at being free of disease and treatment, but instead discovered that they had become very lonely. When pain arrived, it triggered thoughts of something "undefined" in the body. They found, as other cancer patients before them,⁴⁰ it is difficult to target information and find the right HCP to answer questions that might define the undefined. Feelings of increased vulnerability, depressive thoughts, and pronounced loneliness are described in other studies after completion of cancer treatment,^{38,41} feelings that might affect the quality of life in the future.⁴¹ Approximately a year after experiences of CHIP, the women described that life was gradually moving toward some sort of normality, but was not like before. The body now hurt and was perceived as unwilling and altered. These experiences collided with not only the women's own expectations of how it should be, but most of all with those of relatives and employers. This has been previously described by, among others, Little and Sayers³⁶ and Rosedale and Fu.⁴² One distinction between the results of Little and Sayers³⁶ and Rosedale and Fu⁴² is that in the present study the women describe improved communication between family members. So, despite increased expectations of normality from relatives, a much better, deeper, and more sincere communication balances the different expectations within the family. It is as if the experience of CHIP might have helped the women and their relatives develop their efforts to communicate with each other. Hence, perceived CHIP might contribute to better communication within the family. As a part of a symptom sequel after chemotherapy, pain might also act as an important trigger of other symptoms. Neglected pain and insufficient pain control can be other reasons for more adverse effects.⁴³

Method Discussion

This study was conducted with a group of women who had experienced CHIP during breast cancer treatment. They might also have experienced additional treatment-related pain. They had been treated at 3 different oncology day care units and represent both rural and urban areas. They represent young, middle-aged, and elderly women with different family constellations and education levels. All this reflects a wide range of different social

backgrounds, contributing to trustworthiness. Another effort to attain trustworthiness throughout this study entails its systematic methodical approach. Quality criteria were considered, following the Consolidated Criteria for Reporting Qualitative Research (COREQ)⁴⁴ (credibility, dependability, confirmability, and transferability). The first criterion, credibility, was supported by the research process as presented above and strengthened by author I.K.H.'s contribution to the process. Dependability is a strength, as the process can be followed and repeated elsewhere. Confirmability of the data was strengthened and confirmed by the women's stated pain experience. All interviews were conducted by the same interviewer and using open-ended questions and an interview guide that had previously been tested. The women had also answered the same questions about a year earlier, which strengthened the dependability. Concerning transferability, whether the storylines can be adapted to the reader's context is left to each reader to judge.

Limitations

This qualitative study includes a small sample of Swedish women; thus, the findings cannot be generalized. However, as stated above, they may be transferable to similar contexts and patient groups.

Conclusion

For the 15 interviewed women, CHIP and the memory of CHIP have a central impact on the past, present, and future perspectives in the lifeworld. Chemotherapy-induced pain affects the 4 existentials lived: body, time, other, and space. Breast cancer survivors continued to experience long-standing pain after previously experienced CHIP. They described that CHIP was not explicitly addressed during the information they received before chemotherapy, and that HCPs sometimes seemed surprised by the women's pain stories. After completed chemotherapy, some pain still remained, creating insecurity as to whether they were healthy. A painful loneliness emerged, and it was unclear whom to turn to when the arbitrary body signaled undefined pain.

Implications for Practice

The findings of this study highlight opportunities for nurses and other HCPs to improve the care of patients at risk of developing CHIP, through (1) communicating and informing about CHIP and adopting a generally applicable definition of pain including phenomenological pain experiences, (2) identifying each patient's individual experience of pain during their cancer trajectory from diagnosis through treatment and throughout rehabilitation and providing pain treatment and an ongoing communication about the experience of pain, and (3) clearly informing the patient which HCP to turn to after completed adjuvant treatment, who are prepared to address cancer survivors' emerging issues.

Implications for Further Research

Patient-centered pain interventions should be performed and tested, aiming to improve HCP ability to capture, diagnose, and

remedy pain. This could be achieved through communication, assessment, and evaluation and an aim to decrease less severe pain among cancer patients with adjuvant or palliative chemotherapy treatment.

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