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# We will be different forever: A qualitative study of changes of body image in women with breast cancer

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## Abstract

**Objective** This study explores the experience of body-image changes throughout the trajectory of breast cancer.

**Methods** We conducted qualitative in-depth interviews with 53 women ( $n=53$ ) representing diverse age groups, with a mean age of 48.61 years ( $SD=13.12$ ), from various regions across the Czech Republic. The interviews were audio/video recorded and divided into two phases. The initial phase consisted of a narrative part, followed by a semi-structured interview. Thematic analysis was employed to identify and explore the topics that held significant importance to the participants.

**Results** This research investigated how body image and emotional responses evolve in women with breast cancer during various stages of the illness. Throughout the breast cancer journey, women undergo diverse body image changes, with some of them being described as particularly traumatic, such as hair loss and preventive operations. The effects of breast cancer extend beyond physical scars, influencing femininity and womanhood in the long run. The experience of womanhood is marked by visible and non-visible effects that persist for years after treatment.

**Conclusion** Study has provided valuable insights into the emotional journey that women experience during breast cancer diagnosis, treatment, and survivorship. The illness trajectory framework has proven to be a valuable tool for understanding the complexities of body image concerns and the emotional implications faced by breast cancer patients. By acknowledging the significance of body image issues and providing targeted interventions, healthcare providers can improve the psychosocial well-being and overall quality of life for breast cancer survivors. Further research in this area is needed to develop and refine supportive interventions that address the unique challenges women face during their breast cancer journey. Ultimately, by fostering a sensitive and comprehensive approach to care, we can empower women to navigate their breast cancer journey with greater resilience and confidence.

**Keywords** Breast cancer, Experience, Body-image, Womanhood, Thematic analysis, Illness trajectory, Psychology

In the context of breast cancer (BC), women experience a multitude of changes in their lives, including significant alterations in body image. Brunet et al. [1] described how changes to the body negatively impact women's perception, feelings, and attitudes towards their own body image. Changes of body image profoundly influence their self-acceptance and perceived acceptance by their partners [2]. Moreover, women who encounter reduced feelings of attractiveness and femininity are at a higher risk of mental health issues [3], such as anxiety, depression,

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and post-traumatic stress disorder [4]. Emotions associated with body image emerge as the most influential predictor of life quality for these individuals [5]. Consequently, body image holds significant importance in the psychological adjustment of BC patients [6].

In general, body image is commonly understood as a multidimensional concept [7] and sociocultural model [8]. Womanhood is closely connected with societal ideals of femininity and womanhood [7]. Further, womanhood is exacerbated by media influence, affecting both healthy women [9] and women with BC, where appearance comparison serves as a mediator [10]. In the context of oncology patients, White [7] defined a cognitive-behavioral model of body image. According to this model, cancer can trigger appearance-related schemas, influencing individuals' investment in their appearance and self-evaluation. Subsequently, individuals may activate compensatory behaviors to enhance their appearance based on negative assumptions, thoughts, beliefs, and feelings related to their appearance [7].

Each medical intervention associated with the treatment of BC has a significant impact on the body image of women, experiencing alterations in their bodies [11]. As a result, their body image is threatened, as it no longer aligns with societal norms and expectations [1]. Women with BC often experience dissatisfaction with their appearance [12]. Women strived to look "normal" to others, or look like they used to, or natural [13]. Negative emotions are commonly associated with these altered bodies, including feelings of shame and guilt [14–16]. Alopecia ranked as the most distressing side effect of treatment, often causing traumatic disorder [17]. Additionally, body image concerns are associated with changes in body weight [18] and coping with the loss of a breast, which holds great significance for BC patients as it relates to femininity, beauty, and motherhood [19]. Moreover, women fear of others' reactions to their changed bodies [20, 21].

Body image is a complex concept that extends beyond physical appearance to include body functioning as well [2]. In other words, it is not solely about visible aspects but also encompasses aspects that are not visible to the outside world. Therefore, it is crucial to consider not only how patients appear but also what has been taken away from them. In a qualitative study, Barthakur et al. [22] identified that women expressed concerns about their identity, particularly in relation to womanhood, motherhood, and attractiveness. Women spoke about encountering uncomfortable situations and experiencing barriers when disclosing their diagnosis to sexual partners [22], which then affects their sexual health [23].

The importance of body image remains consistent regardless of age [24, 25] or the stage of the disease [26]. All women are concerned about their body image throughout the course of the disease. Older women may have an advantage in being post-menopausal, which could act as a protective factor against body image concerns [27, 28].

The impact of BC and its treatment is long-lasting, as reflected in the changes in body image experienced by women. For instance, some women reported still perceiving a changed body image even 31 years after treatment [1]. Similarly, Drageset et al. [29] observed that feelings of "being changed, being unprepared, and living in suspense (fear of recurrence)" persisted even 9 years after surgery.

While numerous strategies and interventions are available to help women with BC cope with body changes and improve their body image, adjusting to these changes demands considerable time and effort [30]. Providing informational support from medical personnel before surgery can significantly aid women with BC in adapting to the changes in their bodies after the procedure [21]. During BC treatment, women often undergo a transformative process of building a new body identity [31]. Some women adopt lifestyle changes, like alterations in diet and exercise, and develop strategies to rebuild a positive body image [1]. Additionally, women may come to appreciate and praise their bodies for their resilience in overcoming breast cancer, leading to a sense of self-worth that extends beyond mere appearance [28, 32]. Positive social support from family members, friends, or partners also plays a crucial role in facilitating individuals' adaptation to changes in their body image [28, 33, 34].

Understanding body image across the illness trajectory. While several previous studies have explored the concept of body image, they inadequately described the dynamics of its development. As highlighted by Brattheim et al. [35], psychological experiences of women with BC undergo changes in various psychosocial aspects throughout this trajectory. No one has examined the development of body image throughout the disease... Utilizing the illness trajectory framework proposed by Brattheim et al. [35], we will examine the disease across its five stages (initial signs, diagnosis, treatment, follow-up, and survivorship), enabling us to observe shifts in body image and emotional responses throughout the entire illness experience.

Although research on body image in BC patients has significantly increased in recent years [27, 36] there are still knowledge gaps due to common limitations in many studies. Notably, these studies often fail to acknowledge the complexity nature of body image and the illness trajectory itself.

Based on the previous research we have developed aim that will be addressed: To investigate how body image evolves in women with breast cancer across the entire illness trajectory.

Choosing a qualitative approach in addressing these aims, our study aims to enrich the understanding of the intricate interplay between breast cancer, body image, and emotional well-being. This approach allows for an exploration of participants' experiences, shedding light on the different aspects of their psychosocial needs. The study recognizes the socially constructed nature of reality and the subjective nature of human experiences. This methodological choice emphasizes capturing multiple perspectives and comprehensively understanding the contextual factors influencing the studied phenomenon. Through this qualitative lens, the research seeks to provide valuable insights that can contribute to supporting women's psychosocial needs and enhancing their overall quality of life throughout their breast cancer journey.

## Method

The methodological approach used was the DIPEX methodology, an applied science method focused on patients' experiences and aiming to further support patients and professionals [37]. This methodology involves rigorous analysis of narrative interviews of people with particular conditions, chosen to represent the widest range of experiences [38].

## Procedure

This study is part of the applied qualitative project focused on women's experience with BC. Participants were recruited through several channels, including social media, patient organisations, doctors' practices and recommendation from other participants. The information sheet was sent via email to all potential participants. After a period of 1–2 weeks, participants were contacted again by KAC for their agreement to participate in the study.

The main researcher, KAC, conducted in-depth interviews consisting of two parts. First, women were invited to tell their story about BC from the time when they noticed the first signs. Second, an interview guide was used to further explore and prompt participants, to gain detailed data about their experience. Interview guides were developed by the study team supported by an advisory panel, which is a multidisciplinary team supporting the researchers throughout the whole research process.

## Data collection

The recruitment of participants in the Czech Republic took place through various channels, including:

- Dissemination of leaflets and emails to patient organizations: Over 40 patient organizations affiliated with the Alliance of Women with Breast Cancer were approached for recruitment.
- Distribution of leaflets to general practitioners: Leaflets were distributed at regional meetings of the Society of General Practice of the Czech Medical Association across eight regions. Additionally, informational emails were sent to general practitioners in other regions.
- Distribution of leaflets and emails through a research project advisory panel.
- Utilization of social networks and websites of several organizations, such as the research institute, Alliance of Women with Breast Cancer, Amelie, patient organizations, regional patient groups, and closed patient groups.
- Snowball method: Recruitment was facilitated through referrals from other patients.

Individuals expressing interest in participating in the research reached out to the researcher via email or through the website's contact form. During the initial contact, potential participants received comprehensive information about the research objectives and the interview process. Following this introduction, applicants were sent an entry form and a study description.

A total of 87 initial contacts were established. Some of these contacts ( $n=4$ ) declined to be interviewed after the study introduction, while others ( $n=6$ ) opted out of the study due to changes in their health status.

After meeting the specified criteria (outlined below), interviews were conducted with 54 participants, comprising:

- 25 participants from patient organizations,
- 2 participants from general practitioners,
- 3 participants from the members of the advisory panel,
- 13 participants via social networks,
- 11 participants recommended by other patients.

Interviews were carried out between October 2016 and March 2018, led by a female researcher who had no pre-existing relationships with the participants. Trained as a psychologist, she received guidance and mentoring from experienced researchers throughout the entire process.

The data collection process comprised in-depth interviews, divided into two segments. The initial segment involved a narrative section ("*Please tell me about your illness since you noticed something might be wrong*"), where participants freely discussed their illness journey from the onset of symptoms. In the

subsequent part, the researcher delved into specific topics that surfaced during the narrative, conducting semi-structured interviews to explore additional pertinent subjects. Examples of questions are “How has breast cancer affected your perception of yourself as a woman? How did you feel about the possibility of having to undergo a mastectomy? How it impacted your relationships? How has it affected your sex life?”

The interview guide for this phase was collaboratively developed with input from a multidisciplinary advisory panel comprising twelve members, such as an oncogynaecologist, a general practitioner, a breast unit doctor, a breast unit nurse, an oncology nurse, a psychologist, representatives from patient organizations, a patient, and a family member of another breast cancer patient. This diverse team provided guidance from the inception of the research to the data analysis phase.

Interviews took place in various settings, including participants’ homes, hotel rooms, or patient organization offices. The duration of interviews varied, ranging from 45 min to 5 h, with an average length of approximately 2 h. Prior to each interview, participants were given a comprehensive explanation of the interview process, its objectives, and the overarching scope of the research.

The primary objective of the study was to achieve maximum variation in the sample [39]. Participants were at different stages of BC, leading to diverse treatment regimens. The study included individuals commencing treatment as well as those who had completed treatment. The interviews were conducted until data saturation, until no new code has been identified in three subsequent interviews (stopping criterion) [40].

## Participants

A total of 53 women from various regions of the Czech Republic participated in the interviews (see Fig. 1: Geographical distribution of the participants), with one participant later withdrawing her consent, resulting in the exclusion of her data. The participants’ ages at the time of diagnosis ranged from 25 to 72 years, while their ages at the time of the interview ranged from 28 to 76 years, with a mean age of 48.61 (SD=13.12). Further details about the participants’ characteristics are presented in Table 1.

## Inclusion criteria

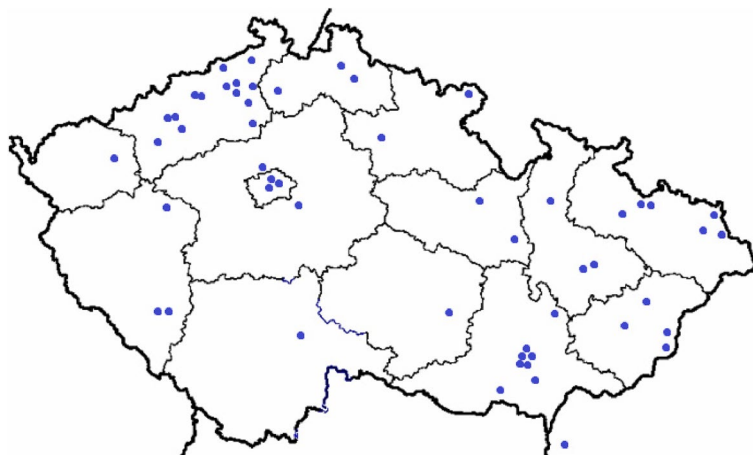
Participants were selected based on the following criteria: (1) diagnosed with breast cancer (2), at any stage of their treatment or post-treatment journey (3), aged 18 years or older at the time of diagnosis, and (4) willing to share their personal experiences through in-depth interviews. This approach allowed for capturing a wide range of experiences and insights from women at various points in their illness trajectory, from initial diagnosis to long-term survivorship.

## Analysis

The interviews were audio/video recorded. All recordings were transcribed verbatim and verified for transcription adequacy (KAC, MP). Data management was carried out using NVivo 10 software. Thematic analysis, following the method proposed by Braun & Clarke [41], was employed to analyse the transcripts.

## Methods to ensure Rigour

The coding process involved three researchers. The first three transcripts were independently coded by each researcher to develop a coding framework. This framework was subsequently discussed and refined within the



**Fig. 1** Geographical distribution of the participants. Note. Each dot represents one participant

**Table 1** Sociodemographic and illness-related characteristics of the participants

| Sociodemographic Characteristics of Participants | n  |
|--|----|
| Age at diagnosis (years)                         |    |
| 18–30  | 4  |
| 31–40  | 27 |
| 41–50  | 11 |
| 51–60  | 9  |
| 61–70  | 1  |
| 71+  | 1  |
| Age at interview (years)                         |    |
| 18–30  | 1  |
| 31–40  | 16 |
| 41–50  | 17 |
| 51–60  | 5  |
| 61–70  | 10 |
| 71+  | 4  |
| Period since the diagnosis                       |    |
| Up to 6 months                                   | 6  |
| 6 months – 1 year                                | 16 |
| 1–2 years  | 3  |
| 2–5 years  | 11 |
| 5+ years   | 17 |
| Recurrence                                       |    |
| Once   | 4  |
| Multiple times                                   | 1  |
| Education  |    |
| Vocational School                                | 5  |
| High School                                      | 24 |
| University                                       | 24 |
| Marital Status                                   |    |
| Single   | 7  |
| Divorced   | 10 |
| Separated  | 1  |
| Married  | 29 |
| Widowed  | 6  |

Participants were on average 48.61 years old (*SD* = 13.12)

*N* = 53

research team based on received feedback. After establishing the final coding framework, the remaining transcripts were coded accordingly. The initial independent coding served as a form of inductive exploration, allowing the researchers to immerse themselves in the raw data without preconceived notions. The subsequent development of the coding framework emerged organically from the coded content, contributing to the inductive nature of the analysis. In the case of any new topics or themes emerging during the coding process, they were addressed and incorporated into the framework through regular team meetings. With reflexivity aiding in

credibility, a detailed coding diary maintained by the main author recorded all changes made and the entire coding procedure.

To ensure the credibility and validity of the research procedure, investigator triangulation was employed, wherein each interview was first coded independently by one researcher and subsequently cross-checked by a second researcher. This approach was adopted to enhance the overall authenticity and confirmability of the study.

All researchers involved in the study hold degree in psychology and have received training in qualitative research. Importantly, none of the researchers had personal experience with BC. LKK provided supervision throughout the entire research process.

**Translation process**

Quotes from the participants were originally in Czech language and were then translated into English using a combination of machine translation tools, including a general translator and DeepL, which is known for its language processing capabilities. Following the translation process, the English versions of the quotes were further reviewed and verified by a native English speaker. This step was taken to ensure accuracy and clarity in conveying the participants’ perspectives while avoiding any potential misinterpretations that can arise from automated translations. The involvement of a native speaker helped to refine the English interpretation and ensure that the intended meaning of the quotes remained intact.

**Results**

For our study, we utilized the illness trajectory framework, which has been successfully employed in previous research on breast cancer patients [35, 42]. This framework offers a valuable approach to examining the changes in body image over time, encompassing the entire course of the illness, including the post-treatment period. By adopting this framework, we are able to gain unique insights into how body image evolves and is experienced by women at different stages of their breast cancer journey.

The illness trajectory framework is particularly suitable for our study as it allows us to investigate body image changes and emotional responses across various phases of BC. By incorporating the trajectory from diagnosis to survivorship, we can examine the continuum of experiences that women go through, starting from the initial impact of the diagnosis, navigating the challenges of treatment, and addressing the long-term effects after completing treatment. This longitudinal perspective enables us to understand the complexities of body image and its emotional implications over an extended period, providing a comprehensive view of women’s psychosocial

needs throughout their breast cancer journey. Additionally, the framework allows us to identify patterns, trends, and unique factors that contribute to the persistence or resolution of body image concerns, which can inform targeted interventions and support strategies to enhance the overall well-being and quality of life of breast cancer survivors.

### Pre-diagnosis

At this time, women were primarily focused on receiving a prompt diagnosis. They expressed a strong need for information about the stage and type of cancer and the treatment process. Fear was a prevalent emotion, linked to the potentially life-threatening diagnosis and the potential change of body. During this period, many women found themselves under the care of the medical system, and for some, it was their first serious encounter with healthcare. They recognized that being diagnosed with BC is a sensitive topic, touching not only on their health but also on their womanhood, and medical personnel did not always handle that with the necessary sensitivity. Some of the women felt like mere numbers in the medical system, with concerns that their emotional well-being and their female bodies were not adequately considered.

*“Actually, the doctor was happy that she found something and I was offended by it, as a woman. You have this feeling that you’re a piece for analysis, it’s very wrong, I didn’t like the approach at all and I thought for a long time that I would call the doctor afterwards. I did not like that approach, I was offended, if she does it with other women, it was very unpleasant for me.” (P02, age 59, survivorship).*

### Diagnosis

In this phase, thematic analysis revealed several individual themes that emerged across the study, as well as several deviant cases. We categorize these themes into the areas of Emotions, Uncertainty, and Coping Strategies.

### Emotions

After being diagnosed with BC, women confronted the harsh reality of a potentially life-threatening disease. However, the lack of sufficient information and support to address their concerns intensified feelings of fear. Many women expressed the fear of stepping into the unknown regarding their bodies. As one woman put it, *“Well, anyway, it’s terrible for the woman if you don’t know what you’re getting into” (P11, age 74, treatment).* The fear further extended to concerns about the potential impact of treatment on their physical appearance, particularly concerning scarring and the extent of the

required operation. For instance, P21 (age 34, treatment) was deeply worried about the possibility of her body being deformed due to the treatment.

*“I’m just gonna be, deformed. I’m not gonna have a nice neckline anymore, I’m just gonna have to throw out all my shirts. I couldn’t even imagine. I knew that there were bras with that insert, with that epithesis, right, but I couldn’t imagine how it worked, how it was done. A piece of you, a piece of you is missing, right.” (P21, age 34, treatment).*

The need for surgery, including mastectomy, came as a shocking revelation for some women, leading to initial resistance to undergo the operation due to the potential loss of a breast. P12 (age 42) expressed her reluctance towards the procedure. On the contrary, receiving information that their breast could be preserved brought relief to some women, and they more easily complied with the need for operation.

*“I was actually, I was glad that I didn’t lose, the breast. Even though, I guess I wouldn’t have minded it. The woman is always relieved when she finds out that they’re just going to operate on it in a way that the breast is going to be saved, that maybe only small part of it is going to be taken out, that you won’t even be able to tell.” (P03, age 49, post-treatment).*

During this phase, women struggled with ambivalence, facing a challenging choice between keeping their breast with the potential risk of disease recurrence or opting for mastectomy and accepting the loss of part of their womanhood. This decision was fraught with emotional turmoil, as it touched upon deeply ingrained aspects of their identity, body image, and femininity. The internal struggle was evident in P21 (age 34, treatment) statement *“So I kept going over it in my head, but then I decided that I’d rather just get it all out, just to be sure. And that’s what I was like in my head that I wanted that security, but on the other hand, you don’t want to lose a breast, right?” (P21, age 34, treatment).* This highlights the intense conflict between the desire for physical security and the fear of losing a fundamental part of one’s body and sense of self.

### Uncertainties

In addition to fear, women also struggled with uncertainties during the diagnosis phase. The extent of the operation remained uncertain and weighed heavily on their minds. This uncertainty extended beyond the immediate medical implications. P02 (age 59, survivorship) emphasized the importance of having clear and comprehensive information about the procedure:

*“A woman needs to have everything in order; she*

*needs to know if something is there, what it looks like, if they take half a breast, a quarter of a breast, the whole thing, what it's actually going to be like. You live with it as a woman, and every woman wants it to be done as best as possible, the smallest part to be taken away, so that it's almost not visible."* (P02, age 59, survivorship).

This statement highlights a critical need for detailed and transparent communication from healthcare providers. The lack of specific information can exacerbate anxiety, as women try to mentally prepare for an unknown future. Knowing the extent of the surgery helps them to set realistic expectations and mentally prepare for the changes to their bodies. These uncertainties encompassed practical aspects of daily life. For instance, P19 (age 37, diagnosis) expressed concerns about how the surgery would influence her ability to engage in everyday activities and maintain her self-image *"Well, how am I going to handle it all, especially if I'll be able to handle it mentally? Will I be able to look at myself then, after the surgery? How will I go swimming? How am I going to go to the pool, because we're used to going to the pool with the kid? How is it going to be, or how is the body actually going to look? Will it be symmetrical or asymmetrical? What if my back won't hurt? I kind of thought about it in practical life. Also, how will my husband look at me, and how will I look at myself? I know the kids will take it in easily. Mostly, for me, I guess it's about how I'm going to feel."* (P19, age 37, diagnosis).

This illustrates the wide-ranging impact of surgical uncertainty. Women worry not only about the physical appearance of their bodies but also about their ability to participate in family activities, such as swimming, and how these changes will affect their mental health and relationships. The prospect of asymmetry or physical discomfort adds another layer of concern. Furthermore, the anticipation of how their partners and children will react to the changes can lead to additional stress and anxiety.

### **Coping mechanism and strategies**

At the time of diagnosis, women employed various coping mechanisms and strategies to navigate their emotions and uncertainties surrounding potential breast loss. Some women found comfort in *the process of making peace* with the possibility of losing their breast. For example, P19 (age 37, diagnosis) shared her perspective of wanting to maintain an attractive appearance post treatment, as she planned to return to work and desired to dress elegantly. For these women, focusing on survival and completing treatment took precedence, with concerns about changes in body image taking a backseat.

On the contrary, some women, like P01 (age 48, survivorship), demonstrated a resilient attitude towards breast loss. Despite the doctor's assurance that the surgical scars would be discreetly located, P01 expressed minimal concern about the physical changes: *"Then he drew on me with this marker, where he was going to cut it, and he said, 'It's going to be below the swimsuit line,' and I was like, 'That's nice of you, but I just, I don't care about this, yeah, whether I have a scar below the swimsuit line or above the swimsuit line, it's really like a marginal thing for me."* (P01, age 48, survivorship), prioritizing her health and successfully navigating through treatment overshadowed worries about cosmetic outcomes.

During the diagnosis phase, receiving clear and comprehensive information from healthcare providers about the scope of the operation played a pivotal role for women. It served as a crucial moment for them to mentally and emotionally prepare for the impending changes in their body image and carefully weigh their treatment options. Knowing what to expect helped alleviate some of the uncertainties and empowered women to make informed decisions about their healthcare.

### **Treatment**

During the treatment period, the topic of body image emerged in connection with treatment and its side effects especially mastectomy, hair loss, body weight and hormonal changes. These topics emerged when a woman experienced them during the course of treatment or perceived them as risks. Some women who underwent breast-conserving surgery expressed feelings of relief: *"operation was so small it is not visible"* (P03, age 49, post-treatment), and gratitude that they did not lose their breast entirely. For them, preserving their breast symbolized completeness and femininity.

*"...She saved my breast, which was important for me from a woman's point of view, because I couldn't imagine that I would somehow be partial or incomplete...."*

*... when I woke up afterwards [operation] and found out that I actually had part of my breast left and the rest was reconstructed, I was so happy. I knew I could handle everything that I wouldn't have to worry about being attractive to my partner anymore."* (P52, age 43, treatment).

Conversely, women who underwent mastectomy often experienced profound feelings of loss and trauma. P11 (age 74, treatment) described the emotional devastation of losing her entire breast, highlighting the psychological impact of such a significant change to her body image and identity. *"Unfortunately, they took my whole breast,*

*it wasn't like today; they only take part of it. They took my whole breast. I was really depressed. Of course, for a woman to have her breast taken, is the end of being whole. Such psychological trauma, it has terrible effect on a person." (P11, age 74, treatment).*

The visible asymmetry and scarring post-operation were particularly distressing for many, such as P39 (age 43, survivorship), who likened her scars to a *shark bite*, emphasizing the shock and discomfort associated with the physical alterations.

*"Actually, I came out of the hospital saying, I mean, I didn't have the breast, but it was in such a state, the wound was nasty. Well, just, like, creased the skin prepared for reconstruction." (P49, age 41, post-treatment).*

For many women, hair loss due to chemotherapy was a particularly distressing aspect of treatment. This physical change often symbolized illness to both themselves and others, impacting their self-esteem and sense of identity. P50 (age 55, treatment) described hair loss as catastrophic, leading to feelings of shock and a sense of disfigurement.

*"And so what really bothered me was not that I had surgery or anything, that I was going through chemo, but when my hair fell out. That was catastrophic for me. That was such a shock. I just couldn't take it. I mean, even though I had a wig at home, I couldn't look at the mirror, absolutely not. Without a wig. No way. It was just disastrous for me. I didn't really accept that I was sick with some disease that could end up in death or something. Like, when my hair looked like that." (P50, 55, treatment).*

For some it was an immediate reminder or sign of the disease that everyone can see. They also mentioned that it took a long time for their hair to grow back. Some women resorted to wearing wigs or scarves to cope with these changes, even at home, to avoid feeling exposed or humiliated.

*"At the beginning of the treatment, I wore definitely a wig or a scarf or something like that because you really look completely, completely different. Even before my son, I was embarrassed, that I looked so bad. So I tried to adjust; he never saw me with a bald head because it's humiliating. It's just a terribly uncomfortable feeling, you feel like you're disfigured, kind of like excluded from society, yeah. I don't know how to put it, although my son never... I've never let him see me without a scarf, yeah, I've even slept with a scarf on because I've been embarrassed. Except when I've been*

*alone, I've taken it off because it's quite uncomfortable." (P05, age 61, post-treatment).*

Weight gain during chemotherapy also affected women's self-esteem and body image. P38 (age 42, treatment) noted how sudden weight gain altered her clothing choices and made her feel less confident in her appearance, further complicating her emotional well-being during treatment. *"Yeah, and I gained weight during the chemo. But of course it affects you, suddenly you don't wear what you want or what you bought." (P38, age 42, treatment).*

### **Psychological impact and identity**

With all the changes, women mentioned a feeling of estrangement or a change of their appearance. The combination of physical changes like hair loss, weight gain, and surgical scars contributed to a sense of being disconnected from their pre-diagnosis selves. Some women felt shame for their appearance and being deformed and excluded from society. P36 (age 32, post-treatment) expressed how looking in the mirror felt like confronting a stranger, describing the psychological toll of feeling swollen and physically altered.: *"When I stood in front of the mirror after my chemo, when my eyelashes were falling out, my eyebrows were falling out, I didn't have a breast, I didn't have hair, and I stood in front of the mirror, it was someone else. It just wasn't me. It was someone just completely foreign, standing there at that moment. Swollen, fat and just completely, it was horrible, it was so hard on the mind."*

Some treatments, such as hysterectomy leading to premature menopause, intensified feelings of loss of womanhood. Despite not desiring more children, women like P41 (age 45, treatment) felt a deep sense of loss associated with the removal of reproductive organs, viewing it as a loss of what society traditionally associates with femininity: *"Well, it was tough. Somebody might say, 'Oh, it's reproductive organs, you won't need them again.' Because I wouldn't want another baby, of course. But it was hard. I felt like I was giving off some kind of feminine thing. What a woman is supposed to have."*

### **Adaptive coping and self-care**

Despite these challenges, women employed various adaptive strategies to maintain a sense of femininity and self-care. P32 (age 36, treatment) described how wearing scarves and colorful earrings helped her feel more feminine and uplifted during treatment, illustrating the importance of self-expression and personal style as coping mechanisms.



### Post-treatment

Some women experienced relief during the post-treatment phase as their wounds healed and they could assess the appearance of their scars. This healing process often brought a sense of closure and acceptance of their changed physical appearance.

Conversely, others felt handicapped by the loss of part of their body. The absence of breasts or the removal of ovaries through hysterectomy was particularly challenging. This loss contributed to feelings of diminished femininity and a sense of being incomplete. Women, such as P25 (age 42, survivorship), described difficulty in situations like changing clothes at public places, feeling uncomfortable due to the visible changes and the need for privacy.

### Psychological impact of body image changes

For many women, the removal of breasts or ovaries symbolized a loss of femininity. This sentiment was compounded by the societal norms and personal perceptions associated with these body parts. P25 expressed discomfort in public settings like swimming pools or saunas, where the visibility of breast substitutes or scars might draw unwanted attention and affect their sense of self-esteem.

*"I'm not as feminine anymore, I lost my breasts, I lost my ovaries. At that moment, it seems like it's nothing, but there are situations when it bothers you.*

*R: In what situations does it bother you?*

*P: When you want to change clothes at the pool, you can't. Girls usually change clothes easily, so I have to go somewhere in private, because not everyone finds it pleasant, neither do I find it pleasant. Well, not that it's not pleasant for me, rather, I don't need everyone to know that I have this problem. Those who need to know, like my friends, my family knows, but not everyone on the street needs to know that this woman has such issues, I don't think it's appropriate. (P25, 42, survivorship).*

The changes in physical appearance also influenced women's intimacy and social interactions. P28 (age 61, survivorship) mentioned feeling self-conscious about how these changes might be perceived by others in social settings, affecting her comfort and confidence in such environments:

### Adoption of breast substitutes

Some women found solace in wearing breast substitutes to regain a sense of normalcy and femininity. Despite

the practical and emotional challenges associated with them, these substitutes played a significant role in helping women feel more comfortable and accepted in public settings. P28 highlighted the emotional weight attached to wearing breast substitutes, indicating their importance in maintaining a sense of identity and appearance.

*"A lot, because actually it's such a feminine symbol, you know, the breast. So it influenced me a lot. Even though it's not visible outwardly, but in life, you have a bit of a problem, you know, totally. In terms of intimacy and so on. Also, when you go somewhere to swim, you have to go to the changing room, you have a little bit of a problem, you know, aesthetically. Even though there are women there too, but it doesn't make you feel as good anymore, you know. You're already thinking a bit differently." (P28, 61, survivorship).*

In contrast, others like P32 (age 36, treatment) resisted using breast substitutes as a form of personal defiance against the disease. Choosing to wear tight-fitting shirts was a way for her to assert control over her appearance and demonstrate resilience in the face of her condition. This approach reflected her inner struggle and determination to confront the challenges brought about by breast cancer on her own terms. *"So, no, I just didn't wear any wigs, no prosthetics, or silicone substitutes. I just didn't wear them. On the contrary, I always chose tight-fitting shirts. It was my kind of defiance, not against society, but against the disease. Just that it doesn't bother me. It's my inner struggle." (P32, 36, treatment).*

### Survivorship

While in the post-treatment phase, some women typically retained concerns and negative feelings from previous periods, the transition to survivorship was marked by a noticeable reframing of their perception of body image for many of them.

Some women, like P15 (age 35, post-treatment): *"You just don't have a boob. It's just not the most important thing in the world to me. I see my priorities as something else entirely,"* shifted their life values after treatment, prioritizing survival and overall health over physical appearance. The loss of a breast was seen as a secondary concern compared to the importance of being alive and healthy. This perspective highlights a profound shift in priorities brought about by the experience of facing breast cancer. Others, such as P06 (age 55, treatment-recurrence): *"A woman looks good, and that it is not so visible. And I don't have it on my face. At that moment, somehow, I don't want to say that it soothed my soul, but I suddenly realized it wasn't so devastating," (P06, age 55, treatment-recurrence).*

Expressed a realization that the loss of a breast, while significant, did not define their worth or identity. They found solace in the fact that the absence of a breast was not immediately visible like a facial feature, which helped mitigate the emotional impact to some extent.

#### **Importance of physical appearance and social perception**

For many women, the societal and personal significance attached to breasts posed a significant emotional challenge. P29 (age 41, survivorship) described the difficulty of coping with the visible absence of a breast, which affected her self-image and sense of femininity. The perceived judgment from others about their changed appearance compounded their emotional distress, leading to a desire to conceal their condition. *“That was terribly hard for me. I definitely wouldn’t have gone like that for the first five years. I would have just tried to at least not be seen or anything and I didn’t want to present it anywhere....”*

*...Because for a woman breasts are so important. It just is. First of all, it’s obvious to see. You look and you see that it’s [breast] actually not there. On the other hand, it’s mental, because you’re suddenly not the same as all other women.” (P29, age 41, survivorship).*

#### **Intimate relationships and self-image**

The impact on intimate relationships was profound for some women, as seen in P16 (age 42, survivorship): *“I haven’t taken off my shirt for 10 years. It influenced me a lot. Even though my husband says it doesn’t bother him, he really doesn’t mind. But I still, I still don’t like my breasts, I still, I haven’t found a way to accept them. I don’t know if I’ll ever find it.” (P16, age 42, survivorship)*, who struggled with allowing her husband to see her without a shirt even years after treatment. This reluctance stemmed from feelings of shame and insecurity about her changed body, highlighting the ongoing emotional burden of breast cancer survivorship on personal relationships.

#### **Permanent reminders and body image issues**

Many women viewed their surgical scars as permanent reminders of their battle with breast cancer. The asymmetry and feeling of being handicapped by the physical changes led some, like P14 (age 35, survivorship): *“Because this is something you’ll live with for the rest of your life. Even if I don’t look like it [sick] now, and it doesn’t concern me now. So it’s something that happened to you and its part of you for the rest of your life, that’s what you experienced.” (P14, age 35, survivorship)*, to opt for breast reconstruction later on in an attempt to regain a sense of normalcy and symmetry. This decision

underscores the enduring psychological impact of breast cancer treatment on body image and self-esteem. .

#### **Self-esteem and acceptance**

The stigma and shame associated with not having a breast contributed to feelings of being less feminine and acceptable to society. Women often compensated by putting extra effort into makeup and accessorizing, attempting to enhance their appearance and feel more comfortable in their own skin. Despite these efforts, the lingering feeling of not belonging among other women persisted for many years post-treatment *“we will always look different” (P49, age 41, post-treatment)* and *“we are the torso of an attractive woman” (P39, age 43, survivorship)*, reflecting the deep-seated emotional scars left by breast cancer.

#### **Discussion**

Breast cancer significantly impacts women’s body image and their sense of womanhood, as highlighted in this study. Through a qualitative analysis, the research delves into the complex and multifaceted ways breast cancer influences women’s self-perception, emotional responses, and interpersonal relationships. While aligning with existing literature on the psychological challenges faced by breast cancer patients, this study offers a nuanced exploration of how body image concerns evolve throughout the different stages of the illness. By employing the illness trajectory framework [35], the study sheds light on the ongoing struggles women face as they navigate changes to their bodies and the corresponding emotional responses, from diagnosis through post-treatment. In the discussion, we focus particularly on the pervasive nature of body image concerns, starting from the initial diagnosis and extending through post-treatment, emphasizing the need for comprehensive psychological support and the development of targeted interventions to address these issues. Our findings suggest that early psychological intervention and the integration of specialized rehabilitation programs into the standard care pathway could significantly improve long-term outcomes for breast cancer survivors.

#### **Body image concerns**

Body image issues are present from the initial signs and first contact with the medical system through the post-treatment period. Consistent with previous research, women are often concerned about body changes due to surgery [11] and the expected asymmetry [12], frequently using vivid analogies to describe their post-operative scarring [20]. In this extreme situation, women strive to maintain a sense of normalcy and womanhood, often opting for immediate breast reconstruction, as previously mentioned by Grogan & Mechan [31] and Denford

et al. [13]. For some women, it becomes more of a struggle against societal norms of perfection and symmetry, leading them to reject the option of breast reconstruction with a mindset that emphasizes this disease is not a reason to feel ashamed of their bodies, as also observed by Grogan et al. [32].

Certain bodily changes were particularly challenging for women throughout the illness trajectory, with some responding traumatically. This was especially true in situations where body changes were immediately visible, significantly affecting their self-esteem and sense of femininity, as mentioned by Dua et al. [17], with hair loss being one of the most impactful changes. These visible changes also served as a constant reminder of the illness, making it ever-present and almost tangible, as discussed by Paraskeva et al. [20].

Body image concerns were not limited to visible changes alone. Consistent with findings by Brederecke et al. [2], women were also worried about body functionality. This concern is linked to the feeling of being whole as women whose bodies are hormonally functional. This feeling tends to be less intense in older women, with age acting as a protective factor.

### **Comprehensive psychological support**

Addressing body image issues from diagnosis through post-treatment requires a comprehensive approach to psychological support services. A key component of the healthcare system is clear communication and emotional support, which should be present in all phases of breast cancer (BC). Body image concerns are often linked to emotional responses, beginning with the fear and uncertainty about the severity of the disease and the extent of the surgical procedure. These findings align with Herring et al. [20], who highlight the benefits of meeting informational needs and providing support. Additionally, accurate information can prevent women from seeking distressing images online [28]. While emotions may shift to feelings of relief and gratitude, they can easily turn into feelings of desperation, depression, and anxiety due to the challenging process of illness recovery.

Women are not only deciding on the preservation of their health but also on their sense of femininity, as previously reported by Herring et al. [20]. Providing support and accurate information can significantly aid in the decision-making process. The information offered should be not only medically accurate but also comprehensive, addressing practical aspects of life such as choosing appropriate underwear, swimming attire, and more.

Healthcare providers should implement targeted counseling sessions and support groups for women at similar stages of their breast cancer journey to foster discussion and resilience. Educating patients and their

families about the physical and psychological changes resulting from breast cancer treatments can empower them to manage these challenges. This includes providing detailed information about the entire process of BC diagnosis through the post-treatment period, including treatment impacts, coping strategies, reconstructive options, and more. These interventions would help guide women through their breast cancer journey. Moreover, we propose that integrating these support systems into routine care could facilitate better long-term outcomes by addressing the multifaceted impacts of breast cancer on body image and self-perception.

### **Longitudinal support systems**

The need to feel feminine and preserve womanhood leads women to employ different strategies. Consistent with the research of Brunet et al. [1], women employed various strategies to reconstruct their body image following breast cancer treatment, fostering a positive attitude toward their altered bodies. In some cases, body image concerns were outweighed by the priority of health, with some women choosing not to undergo additional surgeries. Others viewed body changes as a sign that the treatment was effective and used cosmetic treatments or beauty products to enhance their femininity. Thornton & Lewis-Smith [28] also noted that women exhibited self-care behaviors, demonstrating heightened awareness of their physical and psychological needs.

The body changes resulting from breast cancer treatment are not as immediately visible as those from facial surgery or limb loss, as mentioned by women in this study. For instance, P06 expressed relief that her scarring was not on her face or involved limb loss, which might be noticeable at first glance. However, breast cancer still leaves a lasting mark of traumatic experiences on their bodies, both during treatment and afterward. This impact goes beyond visible physical changes, affecting non-visible aspects of their sense of womanhood. Women in the study expressed feelings of not belonging among other women who are considered “complete.” Despite understanding that these changes result from their battle against a life-threatening disease, they often experience shame and a sense of being different or handicapped by their altered appearance. These feelings persisted for several years after completing treatment, highlighting the profound and enduring psychosocial effects of breast cancer on women’s self-perception and identity. Brunet et al. [1] also support the notion that body image changes following breast cancer treatment can have long-lasting effects, extending beyond physical scars and affecting feelings of femininity and womanhood during long-term survivorship.

Longitudinal support systems should be developed and integrated into the healthcare system or any supportive care for these women. Developing specialized rehabilitation programs focused on body image restoration could be beneficial. These programs should include physical rehabilitation, cosmetic and reconstructive options, and psychosocial support aimed at helping women rebuild their body image and confidence. Additionally, we recommend further research to explore the long-term effectiveness of these interventions, as well as the development of best practices for integrating body image restoration into comprehensive survivorship care plans.

## Conclusion

This study underscores the profound and multifaceted impact of breast cancer on women's body image and sense of womanhood. Our qualitative analysis reveals that body image concerns begin from the initial diagnosis and persist through the post-treatment period. These concerns are deeply intertwined with emotional responses, including fear, uncertainty, and the ongoing struggle to maintain a sense of normalcy and femininity. Our findings align with existing literature on the psychological challenges faced by breast cancer patients but also provide a nuanced understanding of how body image issues evolve throughout the illness trajectory. Specifically, we observed that visible bodily changes, such as scarring and hair loss, significantly affect women's self-esteem and sense of femininity, while concerns about body functionality also play a crucial role in their overall experience.

To address these issues effectively, a comprehensive approach to psychological support is essential. Clear communication and emotional support should be integral to all phases of breast cancer care. Accurate and comprehensive information, addressing both medical and practical aspects of life, is critical in helping women navigate the challenges associated with body image changes. Our study highlights the importance of developing and integrating longitudinal support systems into routine care. Specialized rehabilitation programs focusing on body image restoration should be established, including components for physical rehabilitation, cosmetic and reconstructive options, and psychosocial support. These programs should aim to empower women to rebuild their body image and confidence, addressing both visible and non-visible aspects of their sense of womanhood.

## Limitations

Despite the valuable insights provided by this study, several limitations should be acknowledged. Firstly, the sample consists solely of women from the Czech Republic, which may limit the generalizability of the findings to

other cultural contexts. Secondly, the participants were at different stages of their breast cancer journey, ranging from initial diagnosis to long-term survivorship. This variability in the stages of illness and treatment could lead to differences in their experiences and perceptions of body image, potentially affecting the consistency of the findings. Additionally, the retrospective nature of the interviews may have introduced recall bias, as participants might have had difficulty accurately remembering past experiences and feelings. Future research could focus on more homogenous groups of patients at specific stages of their treatment and recovery to better understand stage-specific impacts on body image.

## Authors' contributions

Kristyna Anna Cernikova - data collection, data analysis, authored the main manuscript. Lucie Kluzova Kracmarova - supervision of data collection, data analysis, participated in the manuscript review process. Marketa Pesoutova - data analysis, participated in the manuscript review process. Peter Tavel - participated in the manuscript review process.

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## Availability of data and materials

The data that support the findings of this study are available from the corresponding author, KAC, upon reasonable request.

## Declarations

### Ethics approval and consent to participate

Ethical approval was obtained from the Palacky University Ethics Committee (reference number: 2017/03). All participants signed informed consent prior to the interview. They chose their own pseudonym, by which they were identified.

### Consent for publication

Not Applicable.

### Competing interests

The authors declare no competing interests.

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