EXTERNAL BREAST PROSTHESES IN POST-MASTECTOMY CARE IN GERMANY – WOMEN’S EXPERIENCES: A QUALITATIVE STUDY

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Abstract

Aim: In Germany, external breast prostheses are recognized and funded as medical devices for adjustment and care following a mastectomy due to breast cancer. Nonetheless, there is a lack of awareness of the prostheses-fitting service in German breast centres and outpatient care. In this study breast cancer survivors give voice to their experiences. Design: The study employs qualitative research evaluation methods. Methods: Data was collected via semi-structured interviews. The analysis was carried out via open and axial coding. Results: Women’s experiences and requirements are presented in a two-phase model. Phase one describes their experiences of shock and crisis, and the subsequent initial prosthesis fitting in hospital. Phase two describes the women’s desire for normality, which they hope to achieve with the help of a breast prosthesis. Conclusion: The results confirm the consequences of losing a breast, the resulting distress, and the importance of a good-quality prosthesis for body image, femininity, and psychosocial well-being. The study confirms that a lack of information and choice in prosthesis fitting is a common problem. For the first time, the two-phase model demonstrates the differences between the initial hospital treatment and women’s long-term needs.

Keywords: breast cancer, external breast prostheses, mastectomy, supportive care, qualitative research.

Introduction

About 70,000 cases of breast cancer are detected in Germany every year, making it by far the most common type of cancer in women (Robert Koch-Institut und die Gesellschaft der epidemiologischen Krebsregister in Deutschland e. V., 2015). Around 80% of women initially diagnosed with breast cancer receive treatment in certified breast cancer centres (Rupprecht, Schulte, 2013; Deutsche Krebsgesellschaft, Deutsche Gesellschaft für Senologie, 2016). In post-mastectomy care, external breast prostheses have become a cosmetic substitute for a lost breast. There are, theoretically, various treatment options for women to choose from, and generally they opt for an epiphetical breast adjustment, which is a recognized medical appliance. The costs are covered by compulsory health insurance (AOK-Bundesverband, 2012; Frauentheilhilfe nach Krebs, 2014; Deutsche Krebshilfe, 2016). In Germany, only medical supply stores supply breast prostheses to individuals. These are licensed by health insurers and available on prescription. Initial care is provided in clinics by an external prosthesis fitter from the medical supply store. Every two years, a patient has the right to receive a new prosthesis. The prescription is issued by the respective gynaecologist; a medical supply company provides the prosthesis. Most information is provided by self-help groups on the internet, or by non-profit organizations (Frauentheilhilfe nach Krebs, 2013, 2014; Deutsche Krebshilfe, 2016). There is no valid data about the incidence of external prostheses fitting in Germany but experts estimate the prevalence to be between 120,000 and 150,000 external prostheses annually.

A review of the international literature (Wiedemann, Schnapp, 2016) reveals that breast cancer survivors predominantly regard their experiences of prostheses fitting as helpful (Livingston et al., 2003; Roberts et al., 2003; Livingston et al., 2005; Gallagher et al., 2009; Glaus, Carlson, 2009). Breast care nurses (BCN) and prosthesis fitters can have a strong influence in these situations, and their empathy, compassion, patience, sensitivity, and emotional and practical support are crucial for providing successful care to women (Roberts et al., 2003; Gallagher et al., 2009, 2010). The research literature emphasizes the
effect that a missing breast has on breast cancer survivors in terms of their perception of their own body, and the resulting distress (Roberts et al., 2003; Gallagher et al., 2010; Fitch et al., 2012), making access to a good-quality prosthesis and prosthetic care all the more important for women’s body image, femininity, and psychosocial well-being (Roberts et al., 2003; Gallagher et al., 2009). Special importance is placed by them on using the prosthesis when interacting with the outside world, i.e., during everyday social activities when out in public (Roberts et al., 2003; Gallagher et al., 2009). However, women are often dissatisfied with the range of choice they have between different types of prostheses (Livingston et al., 2003; Gallagher et al., 2010; Fitch et al., 2012) and the selection of prostheses and bras (Gallagher et al., 2009, 2010). International studies reveal problems due to a lack of, or inadequate, information, and the lack of options as a result (Livingston et al., 2003, 2005; Gallagher et al., 2009, 2010; Fitch et al., 2012). With regard to prosthesis characteristics, there is greater satisfaction with reduced-weight prostheses than with heavier models (Glaus, Carlson, 2009), and positive results with regard to self-adhesive breast prostheses, primarily because the latter are more readily considered part of the body than the alternatives (Münstedt et al., 1998; Thijs-Boer, Thijs, van de Wiel, 2001).

Aim

To our knowledge, there are no studies about prosthesis fitting in Germany in relation to the German healthcare system. The aim of this study is to evaluate fittings with external breast prostheses that take place during both in-patient and out-patient care. While a PhD study from the Universität Witten/Herdecke focuses on this issue, this article illustrates the women’s perspective.

Methods

Design

We used qualitative methods to study the experience of women with breast cancer. In order to contrast, link, and compare the women’s experiences and points of view with the other stakeholders in prostheses fitting, we employed qualitative research evaluation. Qualitative research evaluation aims at analysing processes that influence outcomes, exposing participants’ subjective perspectives, thus making it more transparent and comprehensible (von Kardorff, 2012).

Sample

The study participants were recruited through four certified breast centres in Germany (Deutsche Krebsgesellschaft, Deutsche Gesellschaft für Senologie, 2016). They are located across Germany and differ in size from 150 to 700 cases per year. 20 breast cancer survivors formed a convenience sample (see Table 1). Using the breast centres’ tumour documentation systems, the author identified all women aged > 18 years who had undergone a mastectomy without reconstructive breast surgery whose diagnosis dated back more than one year. Additional inclusion criteria were then verified: i.e., no cognitive limitations, and a sufficient command of German; women in palliative care were excluded.

Table 1 Recruitment of Study Participants

<table>
<thead>
<tr>
<th>Letters sent</th>
<th>Returned</th>
<th>Rejected</th>
<th>Accepted participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>total n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>73</td>
<td>100</td>
<td>37</td>
<td>50.7</td>
</tr>
</tbody>
</table>

a – two approvals could not be included because the women received primarily reconstructive care

The average age of the study participants was 63 years (48–76 years), and about half the women were married (see demographic characteristics in Table 2). The average time elapsed since breast cancer diagnosis was 1.8 years (10 months; 4.6 years).

Most women wore a breast prosthesis only on one side, five of them on both sides. Two of these five women suffered a relapse, developing breast cancer again after more than 20 years. One participant did not wear a breast prosthesis post-mastectomy, 15 from the remaining 19 wore light-weight prostheses, and two wore adhesive prostheses. Five women indicated that they had been planning breast reconstruction since the beginning of the diagnosis, and at the time of the interviews, two reconstructive surgeries had been performed. Two other women decided on breast reconstruction during the interviews and one was being performed at the time.

Data collection

Data was collected via individual semi-structured interviews. Question themes were derived from the literature review (Wiedemann, Schneppe, 2016), the six main topics were (1) impact of the loss of a breast, (2) information/knowledge, (3) supplying
prostheses/fitting prostheses, (4) satisfaction with the prostheses, (5) types of prostheses, and (6) the psychosocial influence a prosthesis has on a patient’s life. Most of the interviews took place at the interviewee’s home. However, five of them took place on the premises of the respective breast centres, and three were conducted in a café. Before each interview, the author explained the research again and obtained the participants’ written consent. All of the interviews were recorded. On average, each interview lasted 42 minutes (17:17 min. – 1:29:45 hours).

Table 2 Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Number of participants</th>
<th>n = 20</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Ø 63 years</td>
</tr>
<tr>
<td>less than 50 years</td>
<td>3</td>
</tr>
<tr>
<td>50 to 59 years</td>
<td>2</td>
</tr>
<tr>
<td>60 to 69 years</td>
<td>9</td>
</tr>
<tr>
<td>70 and above</td>
<td>6</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>married</td>
<td>11</td>
</tr>
<tr>
<td>separated/divorced</td>
<td>1</td>
</tr>
<tr>
<td>widowed</td>
<td>4</td>
</tr>
<tr>
<td>never married</td>
<td>4</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
</tr>
<tr>
<td>no child</td>
<td>9</td>
</tr>
<tr>
<td>1 child</td>
<td>4</td>
</tr>
<tr>
<td>2 children</td>
<td>7</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
</tr>
<tr>
<td>full-time/part-time employment</td>
<td>4</td>
</tr>
<tr>
<td>jobless (unemployed) due to breast cancer</td>
<td>1</td>
</tr>
<tr>
<td>homemaker</td>
<td>1</td>
</tr>
<tr>
<td>early retirement due to breast cancer</td>
<td>3</td>
</tr>
<tr>
<td>retired, earlier partly homemaker</td>
<td>11</td>
</tr>
</tbody>
</table>

Data analysis

All of the interviews were transcribed verbatim, according to the extended transcription rules by Dresing and Pehl (2013) – Breaks in conversation have been indicated by ellipsis according to length, and are marked with brackets, ( . ) indicating one second. Words or utterances that were given particular emphasis have been identified using CAPITALS. Explanations by the author have been placed within square brackets [ ].

For systematic analysis, the data was entered into the qualitative data analysis software MAXQDA 11, and subsequently edited (Kuckartz, 2010). In general, qualitative research evaluation allows any qualitative research methods to be used. In this study, interviews were open-coded, line by line, inductively, and supplemented by questions generated in memo form. In the second phase of the interpretation, categories were worked out from the codes (Reichertz, 2012).

On this basis, a two-phase model was developed. The PhD study advisor provided supervision, and, according to the peer-to-peer principle (Ruppel, Mey, 2012), the NetzWerkstatt research group provided subjective validation, with joint text analysis.

Results

Surprisingly, prostheses-fitting post breast cancer diagnosis and mastectomy has various shortcomings. The study presents women’s experiences in two phases over time. Phase one concerns the diagnosis and the resulting loss of a breast; Phase two focuses on living with breast cancer after losing a breast. Phase one illustrates women’s needs after a mastectomy, and establishes the resulting requirements for initial care in terms of information about prostheses fitting. Phase two describes the psychosocial influence of prostheses on women’s lives, revealing how important it is to retain a sense of control in social situations and a sense of one’s own external normality. In this phase, the process of prostheses fitting becomes more important than before.

Phase one – Experiencing shock and crisis

A vacuum exists concerning knowledge and experience of initial prosthetic care. The shock of breast cancer diagnosis is clearly in the foreground, as is the resulting existential crisis. Women have to grapple with the diagnosis, and with breast removal. They do not possess any experiential knowledge, and do not know what possible courses of action are open to them, leading to a feeling of helplessness on one hand and gratitude for any direction offered by the breast centre on the other. While their first care needs may be fulfilled, they do not have any expectations and are noncritical in their evaluation at the same time. (See Figure 1)

Breast cancer diagnosis as a shock

Still in shock when they deal with their first reaction to being diagnosed with breast cancer, the initial information about a breast prosthesis is meaningless to women, as it is often not clear at this point whether the breast will have to be removed or not. The diagnosis of having a malignant kind of cancer means an existential threat to them, and, consequentially, a crisis. In this situation, women do not think about how to carry on or which surgical procedure will be right for them: “No, no. [Nobody spoke about removing the breast] We, well, on the 9th, we first just talked about the result, then I had to let it sink in.” Processing the diagnosis is the priority in this phase.
On hearing the diagnosis, the situation is characterized by an excess of factual information that the women and their family members often cannot comprehend. For many women, having to make many decisions under the pressure of time, immediately after the diagnosis, is a stressful experience.

**Experiencing the surgical procedures**

The routes to a decision for a mastectomy are various. It is usually the culmination of several operations. For many of the study participants, it is not clear at the time of diagnosis whether the breast will have to be removed or not. In many cases, breast-preserving surgery is initially the chosen procedure. During the course of the illness, however, it becomes apparent that the tumour has not been completely removed, and that more surgery is necessary. This diagnosis is another heavy blow to women. Their hopes are repeatedly crushed. Shock follows shock: “I had breast-preserving surgery on the first day, so, on 14 March, and then they said, within a week, that it wasn’t enough, that they had to remove it. (...) YEAH so I was shocked at first because till then (...) everything had been fine.”

Fearing more surgery, some women decide not to have further breast-preserving surgery after the first procedure. By electing to have the whole breast removed, they themselves initiate an end to the surgical process, and maintain some control. In some cases, direct removal of the breast is necessary, e.g., when the proportion of breast volume and tumour size is unfavourable or when multifocality occurs.

**Experiencing the loss of the breast**

The kind of influence that experiencing breast removal has on the situation of an initial prostheses fitting became very clear during the interviews. It is not possible for the women to imagine their body without a breast, as there is no negative imagination. A missing breast is inconceivable. After surgery there is a moment in which breast removal is consciously grasped: when the scar is seen for the first time. Visualizing the scar means confronting the situation; now they realize what it means to have lost a breast. This can only be experienced through sensory perception, i.e., by seeing and feeling. “But STILL when you see that, you don’t imagine it like this, [it] looks terrible, you can really say that.” In this situation, the previously suppressed emotions often come to the surface, and they break down in tears: “and, yeah, so, then after the surgery I, I started to CRY bitterly when I saw [how] the breast looked.” Women commonly describe feeling “lopsided”. The fact that something is missing is dramatic: “That was the FIRST time that I was confronted with something like that. [...] when one side is MISSING then that (...) is VERY odd in the beginning, I got a shock there first when I looked down at myself.”

**Getting a prosthesis: primary care needs**

All interviewees described how little significance is given to prostheses fitting provided by professionals at the hospital. Only a few women were shown an external breast prosthesis by breast care nurses before surgery. Subsequently, the role of care falls to
the prosthesis fitter. Women sense the topic to be medically “irrelevant” from the very beginning. In addition, it is difficult for them to verbalize their experience of their bodies, and so they feel unable to ask questions.

Women describe the process of receiving a primary prosthesis fitting as happening almost as an aside, as unspectacular. They are grateful that something like a prosthesis exists, and grateful that the arrangements by the breast centre are made immediately during their inpatient stay, so that they do not have to take care of it themselves. For the time being, they are glad to have been taken care of, as their immediate need for an adjustment is fulfilled. In this situation, they have no expectations of the prosthesis, or of the adjustment process, and, in the beginning, are content with whatever they are given: “Yes, so, right, something simple somehow. That’s what I got [...] she came up with the prosthesis, fitted it, I was content, DONE. OK. All right.”

The prosthesis fitters appear and either offer women a primary care prosthesis, or start directly with a silicone prosthesis; the decision is the homecare dealer’s to make. As the women do not have any kind of experience, they barely question anything about the care process or the external prosthesis at this point. They usually recount that little information was given to them during the prostheses fitting. They see themselves as completely inexperienced in this situation and could not evaluate the care or the consultation: “Yes, they didn’t show me anything here. Um, I got this and that was it for me. I was totally inexperienced, right?” At this point in time, the women are still preoccupied with themselves and their cancer diagnosis; they have not given any thought to the breast prosthesis, it is not important to them: “No, no. That, to have that, one doesn’t have time for that, no. One’s head is so full (...) and that was actually secondary, right.”

**Phase two – Striving for normality**

In Phase two, striving for normality becomes apparent. Unlike the strict division suggested in the model, the phases are closely intertwined; they are manifold and individual. (See Figure 2)

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**Figure 2 Phase two – Striving for normality**

### Long-term mastectomy experience

- being lopsided
- not being whole
- not being normal
- shabby exterior
- being naked = shame

(partial) acceptance

### Needs

- normality
- in the public sphere
- in the private sphere as well
- being equal in relation to the other breast

### The prosthesis as a way toward normality

- in the public sphere
- in the private sphere as well
- gives a feeling of security
- because it is not seen
- temporary = means to an end
- not necessary (any more)

### Breast prosthesis fitting

- formal knowledge has no meaning
- positive body experience through breast prosthesis and choices = satisfied with own breast prosthesis fitting

limited, negative body experience through prosthesis, no choice = dissatisfied with own breast prosthesis fitting

importance of the prosthesis takes a back seat

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### Long-term mastectomy experience

The personal definition of what it means “to be a woman” and of gender identity is the key for assessing the loss of a breast. For most of the study participants, normality, as a woman, means having two breasts: “Yes, when you have two breasts (...) you are again, a real woman.” Only two women questioned this notion. For them, even after more than a year and a half of post-surgery treatment, breast removal as a result of breast cancer is still of great importance. This shows the change in body image in many ways. Experiencing being “lopsided”, disproportionate, or, rather asymmetrical, is still a central issue: “it’s not looking similar, so this (...) this symmetry is not there so to speak, that (...) you look disfigured somehow.” The desire for symmetry.
goes so far in some cases that some women say it would be better if both breasts had been removed, making the whole situation less obvious.

To describe the change and the accompanying emotions is often hard for the women. Some describe it as an unpleasant feeling of “not being whole” – something is missing, they are not themselves. They do not feel feminine any more: “Like when I am standing now under the shower and look down at myself. I am just NOT WHOLE.”

The women experience breast removal as particularly stressful when there are situations in which they are naked, i.e., they experience a feeling of shame. These situations occur repeatedly: when performing rehabilitation exercises, or when swimming, or in the sauna. They experience a sensation of being “inspected” like an object, of feeling helpless, and without control. They experience other people’s pity as an affront that hurts them deeply. This leads to their not wanting to show themselves naked any more, to hide “it”, or rather, themselves, and to avoid these situations: “it is EXTREMELY embarrassing because I am not used to [showing] myself in public or with other women in the shower, to be inspected NAKED, and it is EXTREMELY uncomfortable for me. […] I LOOK and they look and then I have to run out, because I feel ASHAMED.”

Over the years, this can change and lead to a degree of acceptance. This becomes clear when the women describe the feelings with which they regard the scar and the surrounding area: “But it’s not like I SUFFER every day. Well, there are better days and worse days. Sometimes I have there, I call them then ‘flat days’ when I look into the mirror and think ‘oh shit, how does that look’ […] so when I feel SOOOO extremely flat.”

The prosthesis as a way toward normality

In view of the physical and emotional damage to their own identity, the need for normality in everyday life is of the utmost importance. Especially important is the restoration of symmetry, “being balanced” in relation to the other breast. A missing breast should not be noticeable from the outside, i.e., in public. For all women, using a prosthesis means a feeling of security when in the public sphere, and thus a feeling of control in certain situations because “it” is not visible: “Yes, so, when I’m outside with it, I feel comfortable with it. And then I think nobody sees it, nobody can see it because it does not stand out, the size is the same as my other breast and that’s when I feel CONFIDENT with it, right, when I’m out.” However, “public” can be defined in different ways. For most of the women, it is equivalent to “being outside”. A vital issue is the presence of other people. These women do not wear the prosthesis in the private sphere. They do not need the prosthesis “for themselves”. The prosthesis and especially the bra, into which it is inserted, are often perceived as constricting and uncomfortable, and are thus removed. Few women wear the prosthesis at all times, i.e., in the private sphere as well as in public. These women wear the prosthesis from morning to evening when they go to bed.

Some women use the prosthesis as a temporary “means to an end”, i.e., as a stop-gap solution until reconstructive surgery. For these women, normality means having two breasts again in the long run. Frequently, this attitude is fixed already at the time of diagnosis, and does not change over time – regardless of how well the prosthesis fits. These women cannot integrate the external breast prosthesis into their body image: “For me it is just a, well,(.) I don’t know how to explain it(.) but it is, it does not BELONG TO my body. It is a crutch after all, right. It’s a temporary solution and I’m glad when it’s time for the surgery that I’m RID of it again.” Other women decide only after a short time in favour of reconstructive surgery, even when they are coping well with the prosthesis. For these women, it is about closure, about finally ending the chapter of breast cancer, and not getting into situations again in which they are asked about it. Two of the women do not wear a prosthesis at all; it is not necessary (anymore); both have accepted their altered body.

Breast prosthesis fitting

For women it is not evident that there are different manufacturers with which the respective homecare dealer cooperates. Similarly, they do not know how many breast prostheses the provider has available to choose from in their portfolio, and how ordering and delivery work. Prosthesis fitters convey only oral information about legal claims as part of prostheses fitting, concerning the resulting costs and the means of settlement. Generally, Statutory Health Insurance assumes the expenses of the prosthesis, as it is a recognized device, and women pay the prescription price. However, some women reported that for an “especially good prosthesis” they had to pay a premium of 20 euros or more – up to 320 euros – for a prosthesis on prescription. The pro-rata cost absorption for the bra depends on the SHI provider; generally, about 40 euros is covered. Women frequently describe problems with out-of-pocket payments, non-transparent costs for different bra models, and very little choice in this area as well. The entire settlement process is not transparent for them at the time of care; there is no written cost itemization, and an invoice only at a later point.

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in time. It is not clear how much their own contribution will be. Thus, it is not possible to make an informed decision as a responsible patient.

For the majority of women, neither manufacturer nor the characteristics of their prosthesis matter; they do not have any “formal knowledge” about them, and neither is a priority for them. At the same time, this shows how little knowledge most women have about their care and how little information was given to them. Answering a researcher’s question regarding which prosthesis she was wearing, one woman replied: “Yeah. (...) [takes the prosthesis out of the bra] it is THIS piece.” This is also true for women who are basically happy with their prosthesis.

The information deficit is even more obvious when it comes to the different characteristics of breast prostheses. None of the women knew the difference between normal weight and lightweight prostheses, despite the fact that, as became clear during the interviews, 15 of the 19 women were wearing a lightweight prosthesis. Coincidentally, almost all women perceived their prosthesis as being (too) heavy.

**Satisfaction and positive body experiences**

Prostheses fitting is successful when women receive information about different prostheses, their respective materials, and various models and types, and they are shown alternatives that they can choose from to finally integrate the prosthesis into their body image: “She looked at the breast and said ‘yes, that’s this and THIS shape. And we would need this and this, um structure. Like there are different shapes’. And accordingly, she then picked out three for me and showed them to me. And, yeah, explained to me the pros and cons of each prosthesis.” A successful selection that leads to a subsequent feeling of comfort occurs through looking, touching, trying out and trying on, i.e., the decision is made based on physical experience: “Yeah, actually, the different shapes of the prostheses and the I just, yeah, actually more through looking and checking, I picked this one and then also by trying it on. I just felt most comfortable with THAT one, let’s say, right.”

During the prostheses fitting process, the atmosphere and the way one is treated by the prosthesis fitters is important to women. Once they have found a homecare dealer that they are happy with, they continue to go there.

**Dissatisfaction and limited, negative body experiences**

A lack of information and choices leads to a situation in which women are dissatisfied with the consultation, and, frequently, also with their prosthesis. In this study, more than half of the women were either unhappy with their breast prosthesis, or it had no importance to them as they had other priorities in life. It is hard for women to verbalize their discomfort. Furthermore, they have only had experience of the one or two prostheses fitted for them. Only a few women had received any information regarding other aspects, such as adhesive prostheses, different shapes, and thermo-regulated properties. Repeatedly the answer was: “I’ve NEVER heard that.” Some of the women who were unhappy with their care, and who had had negative experiences started actively looking for information elsewhere to improve their care themselves. By visiting other prosthesis fitters, they wanted to find out about prostheses by other companies and different types. They found fashion shows for external prostheses, and lingerie and swimwear for women with mastectomies helpful. However, they rarely used the Internet when looking for information, as they did not find it helpful.

The importance of the prosthesis takes a backseat

Despite poor prostheses fitting, some women were not unhappy, as they had adjusted to the prosthesis, and it did not have much importance in their lives anymore. The reasons are usually formative experiences in their lives. One woman talks about her genetic disposition and her fear of having passed on the risk to her children. Given this possible scenario, her own problems take a backseat: “And I was VERY lucky, both of them did NOT inherit it. [...] I had to cry right away when we left there, I was so happy... That was, that was SUCH a relief for me.”

**Discussion**

The study findings confirm the central results of previous studies (Roberts et al., 2003; Gallagher et al., 2010; Fitch et al., 2012), illustrating the effect that losing a breast has on breast cancer survivors in terms of changing body experiences, and their resulting distress. The results in this study substantiate the importance of good-quality prostheses and prosthesis care for women in terms of body image, femininity, and psychosocial well-being after a mastectomy (Roberts et al., 2003; Gallagher et al., 2009), as well as wearing the prosthesis in public. The problem – a lack of information or inadequate information – described in previous studies (Livingston et al., 2003, 2005; Gallagher et al., 2009, 2010; Fitch et al., 2012) presents itself in this study as well, and frequently leads to a situation with few, if any, options. Unlike previous assumptions, it becomes clear here that a cognitive transfer of knowledge alone is not
sufficient to reach the women, i.e., factual information alone does not help, as understanding and accepting an external breast prosthesis occurs as a physical experience and physical realization. Usually, women are both unsure of their ability to choose between different prostheses (Livingston et al., 2003; Gallagher et al., 2010; Fitch et al., 2012), and the selection of prostheses and bras (Gallahger et al., 2009, 2010). In this study, half of the women were initially unhappy with their prosthesis; some of them then actively started looking for better care. A quarter of the women were content despite inadequate care, as it was not important to them. There are also differences in the care provided by professionals. While empathy, sympathy, patience, sensitivity, and emotional and practical support from prosthesis fitters are important indicators for successful care (Robert et al., 2003; Gallagher et al., 2009, 2010), in Germany breast care nurses – other than those in international settings – do not take on any duties concerned directly with prostheses fitting. Their function is limited to contacting prosthesis fitters and writing prescriptions. Women do not perceive the caregivers as experts or contact persons for prostheses fitting. A positive experience is the emotional support from caregivers who attend to the women, which is in accordance with the international literature.

Conclusion

The results illustrate the complexity of the cancer diagnosis, which the women experience as an existential threat. The experience of breast loss and prostheses fitting should be given more space and importance so that women are better able to deal with these situations. Women use their personal experience when judging a breast prosthesis. The experts should take into consideration the fact that the prosthesis has to be the same as the remaining breast, and that symmetry should be maintained. In this way, a prosthesis can help ensure that everything appears normal to outsiders. The results clearly demonstrate the importance of information and consultation, in order to inform women of their choices and to support their autonomy.

Ethical aspects and conflict of interest

The study was carried out in accordance with the Helsinki Declaration. An approval by the ethical review committee of the University Witten/Herdecke is available (81/2013). The authors have no funding or conflicts of interest to disclose.

Acknowledgement

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Author contribution

Concept and design (RW, WS), data collection (RW), analysis and interpretation of data (RW, WS), the drafting of the manuscript (RW), a critical revision of the manuscript (RW, WS), the final completion of the article (RW, WS).

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