

ORIGINAL ARTICLE

## The impact of breast cancer on living an everyday life 4.5–5 years post-diagnosis – a qualitative prospective study of 39 women

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### Abstract

**Background.** The survival of women with breast cancer has improved. There are many studies available describing different aspects of how the illness and its treatment affect the women. Usually these studies are cross-sectional and focus on assessments of a sample of women at a single point in time during post-treatment. These studies are important but of limited value if we are interested in understanding more about breast cancer in a life context. The present study is a contribution. **Methods.** A consecutive sample of 39 women was followed up by means of repeated thematic interviews about how they lived their lives, from the end of radiation therapy to a point four years later, i.e. 4.5–5 years post diagnosis. **Results.** Four different groups of women emerged. Largely, the first group evaluated the cancer initiated transformation of their lives in a positive way. The breast cancer helped them depart from a career treadmill or to positive interpersonal experiences. In the second group the cancer and its treatment seemed to pass without marked traces. The cancer made a difference for the third group, but both in positive and negative ways. A different life perspective or improved relationships were weighted against troublesome side effects from treatment. Finally, in the fourth group a bodily decline due to side effects and other health problems was predominant and this obstructed their chances of living a good life. **Discussion.** The narratives showed that being diseased by breast cancer has different impacts depending on how the woman lives her life – it is very much a matter of transition in a life context. The results are furthermore discussed in relation to adaptation and coping theory.

Breast cancer is the most prevalent cancer in women [1]. Although early detection and advances in treatment have continuously improved survival rates, additional treatments also add bio-medical side effects to the psychological and social challenges connected to the cancer illness.

There are a great number of studies describing different aspects of how the illness and its treatment affect the women. We have learned from well-being studies that a psychological state of acute crisis with anxiety is not uncommon and that it may also be connected with a depressed mood – the prevalence of mood disorders varies within a range of 16–60% [2]. In addition to chemotherapy many women also receive adjuvant endocrine therapy often connected to menopausal problems, fatigue and musculoskeletal pain which may hamper an early return to everyday life [3]. From other studies we learn how women

make use of different coping strategies to deal with their situation [4]. At the long-term follow-up the overall psychosocial adjustment as assessed by quality of life instruments seems at the same time to improve and most of the women to do fairly well [5,6].

These descriptive and foremost cross-sectional studies typically assess a sample of women at a single point in time during post-treatment. They focus on structured pre-defined questionnaires about side effects, well-being, quality of life and coping strategies. These kinds of studies are undoubtedly important and a prerequisite for sound outcome-evaluation in clinical trials. However, if we are interested in the processes that occurred over time with the patient in her social and cultural context these studies do not necessarily provide us with sufficient information, and subsequently this calls for such qualitative prospective contributions [7]. First, quantitative

outcomes from studies based on separate variables are not easily transformed to the clinician's everyday life perspective. Second, this information is often based on mean values implying that patterns or subgroups are not easily detectable. Third, the outcome of well-being and quality of life in the questionnaires cannot be interpreted in an absolute sense. Irrespective of psychometric properties, the phenomena of response-shift implies that results must be interpreted with due caution – the utility of the outcome for comparing assessments at different points of time or with healthy people in the community is truly uncertain [2,8]. Repeated interviews in an everyday life perspective with reflections on previous-present-future are a way of dealing with these shortcomings.

Hence, the present study follows a consecutive sample of women with breast cancer from the end of radiotherapy to a point four years later by means of repeated thematic interviews which were based on the women's own descriptions of how they lived and valued their everyday life. From an explorative perspective the purpose of the study was to determine how life was *lived* and *valued* during and after treatment for breast cancer compared to pre-cancer life – which different transitions of everyday life could be detected?

## Method

### *Participants and interviews*

During 2005, 40 patients diagnosed with primary breast cancer were consecutively included (71% of those asked) in a project that investigated different aspects of how women with breast cancer accustom themselves to new forms of everyday life. The project was approved by the local ethics committee.

All the women were face-to-face interviewed by the first author in his office at the end of radiotherapy. These interviews were thematically structured and were intended to gain knowledge about how the woman looked upon her life *before* she got breast cancer, how the illness and the treatment affected her *present* situation and her expectations about the *future*. In addition to sociodemographics, the major interview focused on different venues: work, leisure time, family, friends and sexuality [9]. Finally a series of questions were posed concerning how she experienced health care, impact of treatments and possible rehabilitation efforts, physical and mental well-being; and not the least what she thought about when she compared her post-cancer living with her pre-cancer life. The face-to-face interview constituted a platform that was complemented with repeated follow-up telephone interviews that scrutinized the same themes at intervals of about 6, 12, 18 and 48 months

thereafter. Each telephone-interview was deliberately connected to the previous interview, evaluated the posed expectations by examining her view on her present living in order to enable a process perspective on the transitions of her everyday life. Overall the interviewer felt welcome, sometimes even asked for, and the connection to the previous interviews sort of contributed to a co-created biographical red thread to reflect on. At the end of the last interview many women actually expressed thankfulness for being part of the study.

One woman was excluded due to a short follow-up; she withdrew from the study due to trauma in the family. Of the remaining 39 women, two were only interviewed two and three times respectively. They declined further interviews as they were getting on with their lives and felt they had nothing more to say. Another two women were interviewed four times, one could not be found for the last interview and one had died. In all, 35 of the 39 included women (Table I) were thus prospectively interviewed five times, from end of radiation therapy to four years later, i.e. 4.5–5 years post diagnosis. In total 188 interviews were conducted.

### *Analysis*

All interviews were conducted by the first author. Notes were taken during the interviews that were transcribed immediately after the interview. Each interview was read through and condensed into a shorter case narrative that aimed at reflecting the essentials for how each woman in the different interviews told about her breast cancer and its impact on her everyday life [10]. The temporal dimension implied that the case narrative reflected a process. The first author then categorized the 39 case narratives by means of the similarities-differences methodology in grounded theory, i.e. characterizing codes were assigned to each narrative which facilitated their grouping (similar/different) into categories representing different trajectories [11]. To test the confirmability of the categorization, authors three and four were then independently given the categories (groups) and the case narratives with the task of assigning the cases to the preliminary categories (groups). Three researchers thus categorized the cases. By means of Cohen's Kappa [12] the agreements between the three rater pairs were calculated (Kappa = 0.76, 0.49, 0.52; all  $p < 0.0000$ ).

The case narratives were then reallocated in accordance with the outcome of the confirmability test. Finally, the second author assigned the case narratives to the categories and the agreement with the reallocated categorization was calculated. The Kappa now turned out to be 0.64 ( $p < 0.0000$ ), which is

Table I. Age, work and treatment characteristics of the studied women at inclusion.

Ms.	Age	Work	Treatment
1. Helped me to a better life			
1	54	Nurse	M + C + R + E
2	42	Assistant nurse	M + C + R + E
3	55	Personal assistant	L + C + R
4	50	Manager	L + R + (E)
5	50	Teacher	L + R + (E)
6	49	Estate Agent	L + R
7	52	Gardener	L + R
8	51	Assistant nurse	L + R
2. Passed without leaving marked visible traces			
9	52	Own business	L + C + R + E
10	59	Head of department	M + C + R + E
11	56	Nurse	M + C + R + E
12	43	Assistant nurse	L + C + R
13	54	Clerk	L + R + E
14	49	Consultant	L + R + E
15	51	Nurse	L + R + E
16	48	Hairdresser/early retirement	L + R
17	51	Preschool teacher	L + R
18	49	Assistant nurse	L + R
19	47	Cook/clerk	L + R
20	52	Teacher	L + R
3. Made a difference both in a negative and positive sense			
21	54	Various worker	M + C + R + E
22	43	Laboratory assistant	M + C + R + E
23	54	Receptionist	M + C + R + E
24	52	Marketing manager	L + C + R + E
25	58	Receptionist/early retirement	L + C + R
26	55	Engineer	L + R
4. Definitely changed my life to the worse			
27	35	Secretary	M + C + R + E
28	39	Assistant nurse	M + C + R + E
29	42	Cleaner	M + C + R + E
30	50	Inspector	L + C + R + E
31	53	Receptionist	L + C + R + E
32	48	Clerk	L + C + R + E
33	55	Physiotherapist	L + C + R + E
34	46	Unskilled worker	L + C + R + (E)
35	50	Information officer	M + C + R
36	54	Economist	M + C + R
37	40	Preschool teacher	L + C + R
38	55	Physician	L + R + E
39	47	Clerk	L + R

M = Mastectomy; L = Lumpectomy; R = Radiation therapy; E = Endocrine treatment; (E) = Endocrine treatment terminated prematurely.

slightly better than the mean of previous agreements. No further reallocations were made.

## Results and reflections

Background data of the 39 women in the four groups is displayed in Table I. The groups reflect different impacts that the breast cancer had on their everyday life. In the first group the women expressed that they, when years had passed, were grateful because being

affected by breast cancer implied a transformation to a better way of living. In the second group, they did not find that the illness had had any obvious impact on their lives, while the women in the third group felt that it really had left negative and positive traces, and in the fourth group, they found the negative impact to be quite overwhelming.

### 1. My life is better now

All but one of the eight women in this group (Ms. One–Ms. Eight; 21%) told how they were dissatisfied with their lives at the time of being diseased, and their dissatisfaction mainly concerned how their work interfered with their well being. Each of them described more or less troublesome side effects of the treatments, but these side effects were successively overshadowed by the experience that being diseased implied a break that helped them to live a better life than they had had before. In retrospect the most prominent cause to a better life was that the illness took her off the *treadmill* of working life. As an accepted cause the breast cancer helped Ms. Six to get sick-leave and a healthy distance to her way of living:

Ms. Six was quite devastated when she got her diagnosis. She was filled with anxiety, but soon expressed content with being on sick-leave. She felt that the disease had rescued her from the “lion’s den”, as she called her work place as an estate agent. For a while the rather bored relationship with her husband improved, but then he suddenly left her. Left alone and with treatment induced rheumatic problems she tried to resume her work part-time. She did resume but as she was unable to perform satisfactorily she was made redundant when the company cut back on staff. Filled with bitterness she started taking antidepressants and went into psychotherapy. She soon got another job as receptionist which she managed and at the last interview she concluded that after a long and “revolutionary trip” her present life was quite different and ‘better, even though it hardly seems that way at first glance’.

For Ms. Six being diseased by breast cancer initiated a process of dramatic transformation of the way she lived her life. There is an obvious *existential* dimension in this and other narratives that focuses on the treadmill. It’s not just a matter of quantity, i.e. of overload, but also of quality, i.e. what is important. Ms. One for instance initially at time of radiotherapy expressed that she was not satisfied with her life situation, she was bored. After the breast cancer she did not change her way of living, but the cancer helped

her to vitalize her outlook on her own life – she expressed that ‘it gave me a bit of excitement’.

Another origin for a better life was experiences of being *cared for* as a person in a way she had not been before:

Ms. Seven with a history of depression lived a rather quiet life by herself. For her getting cancer was almost unnoticed. She experienced minor side effects and wanted to resume her work as soon as possible. When she summarized her experiences in retrospect, she concluded that ‘I’ve had positive experiences from the good medical services. I’m grateful for the care I was given. Without being diseased I guess I would have lived as today, except for not having that experience and the experience of meeting others who have been worse off. It’s nice to feel cared for.’

It was strengthening for Ms. Seven to feel cared for – that others focused on her well-being and seeing others worse off contributed to a better well-being. In a similar way the cancer made Ms. Three felt *acknowledged* in a new way by her workplace as well as her friends:

Ms. Three worked as a personal assistant to a mentally disabled man. She cared for him but felt she got nothing back – there was a lack of mutuality. The family situation was characterized by her husband’s pain syndrome. When she got her cancer she just couldn’t manage her work any longer. She turned to her boss who acknowledged her dissatisfaction and, to her surprise, without hesitation supported her desires for a change. Rehabilitative efforts did however not succeed and she received temporary disability pension. She was relieved. In addition, she then experienced that she got a new position among relatives and friends. Previously, her husband was in the forefront. Now, their positions changed – now she felt more interesting and acknowledged. They related to her instead of discussing his back pain! She summarized by saying that ‘previously I was wife, mother and assistant – now I’m Eve. I’m being looked upon as the person I am.’

When the women in this group got their cancer they described a dissatisfying life context, characterized by problems at work or just discontent in their everyday life. In retrospect, despite the fact that most treatments had side effects, these women evaluated being diseased by breast cancer positively because it either helped them leave a working situation where they were on their way towards losing control, i.e. the experience pushed them back to a

reasonable everyday life; or being diseased implied experiencing encounters with psychological benefits. Crucial for their evaluation was the contrast between their discontent with pre-cancer life or just that the cancer experience *en passant* added something encouraging – their lives had been transformed in different ways.

## 2. *My life is almost as before*

In the long run, being diseased by cancer neither significantly changed everyday living nor put a new perspective on life for the 12 women in this group (Ms. Nine–Ms. Twenty; 31%). Even if the period of diagnosis and initial treatment for some of them was a period of despair, they soon regained their guiding theme in life. Some of these women just did not seem to let the illness affect them in a distinct way and to others the impact of the breast cancer seemed to be eased by other strains in their lives:

Ms. Eighteen was already troubled in life when she got breast cancer. It was characterized by own severe arthrosis and endocrine disorders, an emotionally chilly marriage, worries about a disabled daughter and caring for old parents. She couldn’t be sure whether the cancer treatment added insult to injury. Her relationship to the labor market had not changed; she worked occasionally part-time as before. Later she both entered a choir and the red ribbon campaign and got new friends whom she appreciated very much. She would not have engaged in these activities if she had not had the breast cancer, but the disease on the other hand was a cause for concern during the follow-up and ‘when things happened among friends’. She concluded that she now lived almost as she did before, but that she now did not want to postpone things, which, she added, ‘on the other hand eventually might be related to that I’m getting older’.

The context of their pre-cancer life might also in another sense contribute to the possibility of regarding the cancer experience as a parenthesis. To Ms. Twenty being diseased by cancer was an additional burden, but it on the other hand helped her to gain a new perspective about what previously burdened her:

Ms. Twenty had worked as a teacher for many years, but was on sick leave due to being bullied by some students and due to being exhausted by her caring of her sick mother. She felt stressed and suffered from anxiety and insomnia. When she got breast cancer, another problem was added, but she also got another kind of distance

to her work and her mother: 'It became more justified to focus on myself – on the whole I stopped thinking of them'. She entered psychotherapy which focused on her way of straining herself, partly due to guilt, by taking responsibility for others. She was soon transferred to another job and concluded that: 'life has its ups and downs as before'.

In contrast to these women Ms. Ten was not burdened in her life before the cancer, and she did not let the cancer come to the forefront:

Ms. Ten worked as a head of a department. The kids had left home and the situation in the family was quite stable. Her work was important for her and despite that she received all treatment modalities and described severe adverse effects of chemotherapy, she declined the sick leave recommendations and was only on sick leave for a total of 28 days. This was made possible because of her flexible work and the fact that her problems with lymph oedema, joint stiffness and fatigue smoothly faded away. She described her relationship to her husband initially as vitalized, but this vitalization also faded away. At the last interview she summarized that 'life is as before, I guess there is no difference'. However, just minutes before she told that when she got the appointment for the mammography screening she still reacted with anxiety.

Ms. Ten was devoted to her work and she did not let the cancer experience intrude on the essentials of her life. To others in this group the work mattered less and they gladly accepted the proposed sick leave – even if they did not find it necessary they looked upon it as a chance to rest and to catch up with everyday life at home.

After the period of diagnosis and initial treatment the breast cancer was in this group more or less regarded as a parenthesis. These women evaluated the impact of the illness in a broader context that dealt with their work or life stressors; and this contextualization seemed to reduce its impact. They had difficulties identifying differences between their present life compared to the pre-cancer time and vague expressions were common: 'I guess my work has become less interesting'; 'I think we indulge in consuming more'; 'I think I might have become more open as a person' or 'I've nearly forgotten, it's just at time of follow-up I think about it'.

### 3. My life is different, but hardly worse

The six women in this group (Ms. 21–Ms. 26; 15%) did not look upon the experience as a limited

parenthesis. The illness had really affected them, there were no contexts that eased its impact, but in addition to negative consequences, positive consequences were also put forward. These women were the same age as the previous groups.

The negative dimensions were described in terms of treatment *side effects* and the positive dimensions in either a *different perspective* on their life or in terms of *better relationships*. The overall evaluation seemed to reflect a seesaw in reasonable balance.

Ms. Twenty-six was busy as an engineer and quite unsatisfied with her work when she got breast cancer. She was relieved by her sick leave, her friends supported her and she described herself as 'nearly euphoric'. She successively resumed work, but developed an oedema which bothered her as a stigma, she withdrew from her fellows at work and isolated herself socially. She felt that after the operation she could not stand stress and she went on sick leave again because of 'depression due to exhaustion' and was referred to a four-month rehabilitation course. This made her feel better. Back at work she realized that she could no longer work full-time – she no longer had that mental capacity. She instead increased her activity in a voluntary organization that she felt was quite meaningful; it provided her with another social circle.

The breast cancer initiated a transformation of Ms. Twenty-six's life and four years after diagnosis she lived differently. Although she felt that her mental capacity had diminished, she felt she had gained a more meaningful leisure time. Ms. Twenty-two experienced more extensive side effects but nevertheless felt that the new perspective on life counterbalanced:

When she got her breast cancer, Ms. Twenty-two's husband was on sick leave due to both physical and mental exhaustion. She commented that this in fact might have been helpful since they were in a sense prepared and now shared a 'platform'. She experienced the typical intensive problems with being forced into menopause and she also developed cardiac insufficiency, probably due to the chemotherapy treatment. However, changed endocrine medication and cardiac rehabilitation successively made her feel better and four years after terminating the radiation treatment she generally felt more 'filled with lust' and after a breast reconstruction she was back in full-time employment. At the last interview she commented that she was back in everyday life, a life that might even be better due to increased vigilance.

Most women in this group were to a great extent affected by treatment side effects. However, in due time, these effects at least to some extent declined and when looking in retrospect they valued their new everyday life as similar to their prior life and even suggested a benefit in terms of a changed perspective. It may be suggested that this changed perspective is a reflection of the contrast between faring poorly due to side effects and hope for a prosperous future.

#### 4. My life has definitively changed to the worse

All women so far, despite the side effects, in different ways found a similar or a new satisfactory everyday life. In contrast, the 13 women in the fourth group (Ms. 27–Ms. 39; 33%) were not content with their lives.

The very dominant cause of these women's dissatisfaction was the negative *side effects* of chemotherapy and endocrine treatment; however other *stressors* in their life context and *worrying* for the future contributed as well.

Ms. Thirty-eight lived by herself and was devoted to her work as a physician, both in a professional and social sense. Her cancer was regarded as uncomplicated. She had however always been disgusted with her sweating and the endocrine treatment caused her great problems. She could not work more than part-time, lost her sexuality and she separated from her live-apart partner. The endocrine treatment was terminated in advance and she started taking antidepressants. Successively she felt better, resumed work close to full-time, but things nevertheless had changed – she felt that the menopause had had a negative effect on her womanliness.

Ms. Thirty-eight represents those women who experienced devastating side effects of being forced into menopause. As a result of gaining weight, dry mucous membranes, oedema in arms, painful feet, etc., others expressed that they were 'fed up with the stiff body' or 'being like 90 years old'. The cancer might also trigger a sense of hopelessness when it was added to other life stressors, as for Ms. Thirty-three – it just became too much:

Ms. Thirty-three worked part-time due to years with different health problems, primarily arthritis. The cancer treatment worsened her joint stiffness and pain, as well as her insomnia, and it added sweating, blushing and exhaustion. She became more sensitive, easily emotional and did not manage her family. Complications emerged. She wanted to work and do so much, but felt

she managed nothing. Different complementary treatments were tried without success. In her mind the cancer treatment catalyzed a bodily decay: 'It's not the cancer that bothers – it is that I can't stand that the body doesn't function properly'. Five years after diagnosis she was in line for a disability pension.

For others, as for Ms. Thirty-nine, worries about a relapse were the main burden:

Ms. Thirty-nine's cancer was regarded as very modest with a good prognosis. She didn't experience any biomedical side effects, but that did not help her from worrying. As soon as she felt something abnormal she got anxious. She was a worrier and this was enhanced by the cancer diagnosis. Her husband was rational and a bit distanced, and she looked for support by seeing professionals, first of all a psychologist. In her mind life had become more vulnerable. She worried for herself and for her family, especially her children.

Ms. Twenty-nine's life became more worrisome after her diagnosis.

## Discussion

### Summary

This consecutive explorative study of 39 women displays different outcomes of the trajectories after being diseased by breast cancer. Four different groups emerged. The first group of women evaluated their illness experience from a context of dissatisfactions or shortcomings in their former everyday life. The breast cancer mattered in the sense that life was transformed, something that helped them depart from a career treadmill or, through new interpersonal experiences they felt psychologically strengthened. In the second group the impact of the disease seemed to be eased by a context of other burdens which mattered in life; and everyday life was therefore not experienced as disrupted. In the third group, the cancer really made a difference, but the process encompassed a seesaw of disadvantages and advantages. A different life perspective or improved relationships were weighted against troublesome side effects from treatments. Finally, in the fourth group the bodily decline became predominant and the cancer experience was generally evaluated negatively. Side effects mattered a great deal, especially when added to other health problems. For others, being diseased by cancer implied the burden of continuously being preoccupied by worries about the future, due to the risk of relapse.

Concerning the distribution of treatment modalities, it can be suggested that the “better”-group (group 1) and the “almost the same”-group (group 2) were less burdened. As regards age, the ‘worse’-group (group 4) was slightly younger than the other three groups.

#### *On method*

The strength of this qualitative study is that it includes a large number of participants in a consecutive and prospective design with quite an acceptable compliance. With a few exceptions the women were thematically interviewed by the same researcher five times during a period of about four years. It was therefore possible to apply a process perspective, how life changed from pre-diagnosis to the present. When contacting the participants, the researcher felt expected and welcome. On the whole it is therefore reasonable to believe that the findings are valid.

A weakness of the study is the condensation of data by the construction of short case narratives, as this was solely made by the first author. Collaboration with another author during this stage would have strengthened the study; however, that option was not implemented because of the extensive amount of data and the consumption of time that would have required. Nevertheless, the confirmability test made of the categorization of the narratives showed a high rate of accordance.

#### *On results*

About one third of the women evaluated that the cancer experience definitively changed their lives to the worse (group 4). Despite a bit different transformations the others (groups 1–3) valued their everyday life 4–4.5 years after diagnosis overall as being as good as or even better than before.

These findings are complementary to previous prospective findings that focused on quality of life assessments. Although post-treatment adaptation seems to go well for women with breast cancer, they also suffered from specific problems related to treatment [13]. These assessments are usually based on large samples and the outcome presented in terms of means implying that we cannot follow individuals and groups of individuals. Furthermore, as primarily expressed in groups one and three, and also *en passant* in group two, many women found benefits of different magnitude from the illness experience. This is well-known from previous studies [14,15]. In particular, women describe changed priorities such as putting more emphasis on relationships, on appreciation of life and less on different trivial concerns. It seems that the cancer illness, in contrast to benign

illnesses, for some is a transitional event that alters the individual’s life perspective and that this change may be of long-lasting nature [16]. This is very much our impression – the women could all express positive aspects or benefits with being ill, but they differed in how this was stressed and weighted against the negative aspects, i.e. foremost biomedical side effects of treatment.

The extent of these positive benefits may come as a surprise if not seen from an adaptational perspective. A suggestion is that the function of these benefits is twofold. First, it expresses a cognitive act of creating order. People want to maintain the fundamentally positive assumptions held about the world and their place in it [17]. The found benefits help to avoid cognitive dissonance and potential chaos [18]. Second, it is part of the “meaning-making” process, i.e. people attribute meaning to avoid meaninglessness [19]. It is hard to bear that we are just victimized by such unmitigated evil. It is easier to bear the situation if we can find the evil at least cracked, and thereby also define ourselves as not being victims, but creators of our lives. When making use of this adaptational perspective, we should however also be cautious not to make interpretations that would take the sting out of the women’s narrated experiences as real experiences.

When comparing the different trajectories and applying an adaptational perspective it may be appropriate to suggest that, due to what we learned from the first three groups, that adaptation may be facilitated by some contextual factors. From group one we learned that a dissatisfied and closed life situation may become a sounding board for regarding the cancer as a saviour, from group two that an already burdened life may (paradoxically) dilute the psychological impact of cancer and from group three that a decrease in biomedical side effects may facilitate adaptation. These different contexts may have been springboards for downgrading the impact of being diseased and thus for a positive adaptation.

The findings in this study shed light on some limitations of coping theory. Coping theory is a widely referred theory dealing with how people respond to a crisis, mostly in a perspective of personal control and self-efficacy [20]. The research typically focuses on how different ‘coping-strategies/styles’ relate to levels of distress and a more or less reified instrumental approach is not uncommon, i.e. ‘which coping responses relate to better outcomes for this treatment and the long-term adjustment to breast cancer’ [4,21]. The present finding however displays another perspective: the women did not express different intentional strategies/styles, but demonstrated a *transition* in a life context [20]. The narratives showed that being diseased by breast cancer has different impacts

depending on how the woman lives her life – it is a matter of circumstances. To understand this idiosyncrasy of breast cancer in context it is thus not sufficient to dwell on personal coping characteristics, since we must also consider her life situation.

As displayed in the findings section, the relationship to their work was of crucial importance to many women, especially for those who greeted the breast cancer as a godsend (group 1). As an example, Ms. Six had lost control of her career and although she lost her job, her husband and a healthy body she looked upon the cancer as a benefit. Transferred to coping theory this reflects that she *used* a certain coping strategy ('positive reappraisal?'). To us it makes more sense to say that the breast cancer changed her life circumstances, something which implied a transition in her view of her life. Ms. Seven also evaluated her cancer experience positively, but due to her feeling that she was cared for. Experiencing good caring was her lasting impression of getting cancer. This is interesting as 'good caring' thus meant more than absence of malpractice – experiences in health care can create internal relationships that promote better well-being. Ms. Seven's narrative may be seen as supporting the application of attachment theory to the patient-health care relationship [22]. Ms. Three also seemed to have benefited psychologically, but in her case it was a matter of altered relationships in their circle of friends – being diseased helped her to become an individual and she gained self-esteem.

Even if the women in the "almost as before"-group (group 2) received less systemic therapy than those in the "better"-group (group 1) and in that sense were better off concerning side effects, some of them nevertheless received all treatment modalities. Although the majority of the women in the "different"-group (group 3) received all modalities and they typically described severe long-lasting side effects, as time went by, these problems decreased and things became better. Quite a few of them were really worse off, bordering on hopelessness; and when the side effects decreased it was a dramatic relief, which it may be hypothesized, as a contrast enabled them to find positive aspects of what had happened [23]. Being severely affected by the treatment gave them a reference that enabled them to find a positive appreciative attitude to their life.

The women in the "worse"-group (group 4) were a bit younger than the other women and they did not experience any brighter sky during the studied period. To them the side effects contributed to a successive biomedical decline and their everyday life changed to the worse. All but one of the women in this group received at least one systemic treatment. Ms. Thirtynine did not and she was the one whose life changed

to the worse due to fear of recurrence. It is worth noticing that the women were not generally to a severe extent preoccupied with this fear so often connected with the cancer experience. A suggestion is that the side effects of contemporary systemic treatments, such as arthritis and musculoskeletal pain, sleep disturbances, hot flushes, vaginal dryness and other menopausal symptoms stood in the forefront and overshadowed other potential problems. In short: their problem was that they focused on a body that did not work in the present and not on what might happen in the future. This requests us to be attentive with the concepts 'anxiety' and 'depression'. As an example, it is more than probable that patients with these severe side effects score higher on 'anxiety' (and 'depression') in the frequently used instrument HADS [24]. These women are burdened by their somatic complaints (e.g. score 'definitely' on "worrying thoughts go through my mind") and may pass cut off for 'anxiety' caseness, but may nevertheless not qualify for what clinicians mean with 'anxiety' as a concept of psychological distress.

Studies show that younger breast cancer survivors' health and quality of life improves years after diagnosis and that it is generally rated as "good" [13,25]. This is comforting but, as scrutinized by Buijs et al., [4] individual reports show large variation and studies restricted to mean values and standard deviations may cover sub-groups of patients with different health and quality of life trajectories. In addition the women may underreport the impact of side effects as these are regarded as a reasonable price for staying healthy, i.e. a kind of response shift [8].

When the women in the present study were asked to narrate aspects of their everyday life it turned out that the impact of side effects was paramount to their living. The next step is to turn this the other way around, i.e. how did the side effects change their living in their everyday life venues: work, leisure time, relationships and sexuality. "How" is important as these individual reports can contribute to a guiding knowledge that can facilitate the patient-physician consultations where decisions about treatment initiation and termination are to be made. Endocrine treatment undoubtedly improves disease free survival for women with receptor positive breast cancer, but living with severe adverse effects for five years is obviously regarded as more than a transient inconvenience for quite a few of these women.

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