



## Original article

Breast cancer treatment and work disability: Patient perspectives<sup>☆</sup>Corine Tiedtke<sup>a,\*</sup>, Bernadette Dierckx de Casterlé<sup>b</sup>, Angélique de Rijk<sup>c</sup>, Marie-Rose Christiaens<sup>d</sup>, Peter Donceel<sup>a</sup><sup>a</sup> Department of Occupational, Environmental and Insurance Medicine, Katholieke Universiteit Leuven, Kapucijnenvoer 35/5, B-3000 Leuven, Belgium<sup>b</sup> Centre for Health Services and Nursing Research, Katholieke Universiteit Leuven, Kapucijnenvoer 35/4, B-3000 Leuven, Belgium<sup>c</sup> Faculty of Health, Medicine and Life Sciences, Department of Social Medicine, Maastricht University, P.O.Box 616, 6200 MD Maastricht, The Netherlands<sup>d</sup> Multidisciplinary Breast Centre, Katholieke Universiteit Leuven and University Hospital Leuven, Herestraat 49, B-3000 Leuven, Belgium

## ARTICLE INFO

## Article history:

Received 11 March 2011

Accepted 7 June 2011

## Keywords:

Cancer  
Work  
Disability  
Experiences  
Patient perspectives  
Qualitative

## ABSTRACT

**Purpose:** Most female breast cancer patients are forced to interrupt their professional activities during treatment. Qualitative research was carried out to assess women's experiences of being work disabled because of breast cancer.**Patients and methods:** In-depth interviews were analyzed to understand patient's experiences and to gain more insight in their perspectives on living with breast cancer.**Results:** We identified a 'three-experience model': (1) *disruption*, with the feeling of irreparable loss, despair and no hope for the future; (2) *episode*, an unpleasant and inconvenient period, after which life continues as before; and/or (3) *meaningful period*, during which new life priorities are set.**Conclusion:** The different experiences will require different types of support, especially concerning communication around disability and returning to work. Our findings highlight the need of an individual approach of the management of work disability for breast cancer patients.

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## Introduction

Women perceive breast cancer as a challenge to their existence, their sense of self, their future goals and their values. Receiving a breast cancer diagnosis has a profound impact on women's daily life and implies short- and long-term decisions in many life domains. Dealing with many emotions, women go from feelings that things are beyond control to a position where they start to regain a sense of control.<sup>1</sup> Most women with a paid job are forced to interrupt their professional activities and have to deal with uncertainties about the future ability to work and possible job loss during treatment and after recovery.<sup>2</sup>

Breast cancer is no exception to the general finding that wide variety is found in the duration of work disability and the number of persons who return to work in a timely and healthy way. Women react individually and differently to treatment, so the impact on

returning to work may differ considerably.<sup>2</sup> A recent Swedish study showed that 59% of the women had returned to work by 10 months after primary breast cancer surgery, while the other 41% were still sick-listed part-time or full-time. Not only medical and treatment factors but also work demands play an important role in the ability to resume professional activities for women with breast cancer.<sup>3</sup>

Returning to work during or after breast cancer treatment is a complex process, during which women encounter many stakeholders with opinions and influence on the duration of work disability and the possibilities of returning to work: family, health care professionals, insurance instances, colleagues and the employer. Lack of communication<sup>4</sup> or even conflicting messages from different stakeholders can unnecessarily prolong work disability, whereas a supportive environment is an important facilitator for a successful return to work.<sup>2,4</sup>

Although breast cancer obviously has a profound impact on personal and professional life, empirical indications about the various needs of these women remain limited. Gathering knowledge about women's experiences during sickness absence could improve understanding of women's attitudes in living and working with breast cancer. These insights might be helpful for health professionals, employers and professionals from insurance agencies who have to understand women's care and support needs during the period of sick leave and in improving 'return-to-work' rates.

<sup>☆</sup> Parts of the results have been presented at the EUPHA congress 2010 (European Public Health Association).

\* Corresponding author. Tel.: +32 16 33 69 93; fax: +32 16 33 69 97.

E-mail addresses: [corine.tiedtke@med.kuleuven.be](mailto:corine.tiedtke@med.kuleuven.be) (C. Tiedtke), [bernadette.dierckxdecasterle@med.kuleuven.be](mailto:bernadette.dierckxdecasterle@med.kuleuven.be) (B. Dierckx de Casterlé), [angeliq.derijk@maastrichtuniversity.nl](mailto:angeliq.derijk@maastrichtuniversity.nl) (A. de Rijk), [marie-rose.christiaens@uz.kuleuven.ac.be](mailto:marie-rose.christiaens@uz.kuleuven.ac.be) (M.-R. Christiaens), [peter.donceel@med.kuleuven.be](mailto:peter.donceel@med.kuleuven.be) (P. Donceel).

## Participants and methods

Our study aimed to explore women's experiences about being work disabled because of breast cancer. We performed qualitative research interviews and used a grounded theory approach for data analysis.<sup>5</sup>

A Belgian Sickness Fund contacted women in the Province of Limburg (Belgium) who had undergone breast cancer surgery in 2006 and who were employed at the time of diagnosis and not disabled for other reasons. Women working for the government and self-employed women were not included because of the different legal arrangements. Sixty-five women were contacted by letter including the purpose and the procedures and 24 women responded positively with written informed consent. After a telephone interview to collect demographical, medical, and working characteristics, 22 women wished to continue co-operation. In-depth interviews, with a mean duration of 70 min, were performed in the women's personal environment between May 2008 and August 2009. The topic list concentrated on experiences and interactions resulting from the breast cancer diagnosis in the private and medical environment and at work. The ages of the interviewed women at time of surgery ranged from 41 to 55 years; mean age 46 years. Most of the interviewed women were middle-class educated and working in service professions. Mastectomies and breast-saving operations were almost equally divided and all women underwent combined therapy. Three women suffered a relapse in 2006. Fifty percent of the women had returned to work at the moment of the interview.

All interviews were recorded and transcribed verbatim. Transcripts and narrative summaries were read and discussed by all authors. Relevant themes were identified and initially coded around the research question. Detailed coding was performed with the help of the QSR Nvivo8 program and emergent themes were clarified. An in-depth analysis took place in interactive dialog within the research team. After 15 interviews we discussed preliminary results with experts. All experts (breast cancer surgeon, social scientists, insurance physician) had a research background; two of these in qualitative research.

The study protocol was approved by the Ethical Review Board of the Katholieke Universiteit Leuven. Therapeutic support was available for the participants in case of emotional problems. This was used once.

## Findings

Women's experiences of being work disabled differ considerably and their experiences reflect a dynamical process of searching an equilibrium.

We identified a 'three-experience model'. The different experiences of being work disabled can be combined in a dynamical manner during the process. In the next sections we will describe the experience of being work disabled as (1) *a disruption*, with irreparable loss, despair and no hope for the future, (2) *an (unpleasant) episode*, after which life continues as before, and as (3) *a meaningful period*, during and after which new life priorities are set. As mentioned, these experiences related dynamically to each other. Some women were found to go through different experiences as time went by, in different patterns. For other women, the period of work disability was mostly characterized by one of these experiences.

### Work disability as a disruption

The experience labeled 'disruption' is dominated by feelings of loss and despair. As repeatedly expressed, women who experience disability as a disruption, cannot see a way round the difficulties they are going through. Regaining a 'normal' life is made impossible by their loss of identity, their physical appearance, and loss of work because of the breast cancer diagnosis and treatment. There is little hope for a better future, which includes a working life, adapted to the new situation.

As mentioned, the experience of being work disabled is strongly interwoven with the illness experience. Within the 'disruption' experience the pivotal wish to return to work is tied up with the intense experience of loss linked to the breast cancer itself, such as loss of a breast, loss of usual appearance, loss of perspective on life. (Table 1: quotation 1).

The 'disruption' experience is one of feeling incomplete, losing one's identity and no longer recognizing oneself as a woman or an employee. In addition, the over-all sense of loss causes an awful feeling of exclusion, which means no longer seeing oneself as a full and productive member of society. (Table 1: quotation 2).

The interruption of work because of breast cancer treatment also means missing out on the appreciation of and contact with colleagues. It is the experience of dearly wanting to contribute to society but not seeing how to achieve this, or no longer feeling

**Table 1**  
Quotations disruption.

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1. "...it's difficult to make an about-turn, I am waiting for the day that I'll be able to accept this, things will go better then...but now I feel, you know, look at me doing this like an old woman, but I believe that some day I can say: 'this is who I am!', things will go better...but now I still cannot accept that I can't do all these things anymore, it's difficult to explain, but nothing is the same anymore, many, many, many things have been taken away again, the first time I fought hard against the situation, but because of the second confrontation with breast cancer I feel completely trashed...I can't handle this, how I look, I have gained a good few pounds, due to medication they say, there's nothing I can do about it, all these things you have to accept..." [resp.4]
  2. "...I don't feel at ease at home, home is not my place, it's not where I belong, meanwhile I've adapted a bit, but when you have always worked fulltime, you are used to that hectic life, at home I feel guilty, I blame myself for not working, I want to contribute to society...financially you also lose, I didn't want all these things to happen, I want my life back, next week will be my birthday, to have my life back, would be a beautiful present...one week, give me one week, one week of working again, one week back to the walking and working woman I was, that would be the most beautiful present...but now, I feel put off from everything, everything has been taken away, no more work, no colleagues, no social contacts, no appearance anymore, it has an enormous impact, it's a rude awakening [lump in throat], and besides I have a lot of trouble with my arm, the lymph vessels have been removed, I have a very heavy arm, but I am not complaining...should that be all, please give me two such arms and give me back my life instead, and my former appearance and let me walk and run like before and, and, and... but things will never return..." [resp.4]
  3. "...I would like to have colleagues again, I would like to meet deadlines again (...) but I miss these things tremendously, I miss my work, the appreciation, yes the usual appreciation, at home there is appreciation too, when things go smoothly, but yes, 'work' was an extremely important part of my life, yes it always had been..." [resp.1]
  4. "...yes, and about work, yes and it's getting on my nerves when people say: I have to work two more days and then I'll have a day off, I am at home every day, I can't say I will have a day off, every day it's getting up in the morning and going to sleep at night and yes, you do as you like to, no one is saying: at this time we do this and at that time that, or in a few months it'll be my vacation or my day off, I don't have this because I am at home constantly, I miss all these things..." [resp.2]
  5. "...yes, I am out on my own, who I can share my trouble with, sometimes I think, is this my life [lump in throat], now I have my children and I strongly rely on them, but other than that [running eyes], yes, sometimes [raising her voice] I believe, I know I shouldn't think about it, but sometimes I think death is a release, simply that you [tears falling and silence]...but I should not think like that because of my children, my children do need me..." [resp.12]
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capable of keeping up with the hurried pace of work; sometimes even feeling unwelcome at work, and only being regarded by employers as a costly employee with limited productivity. Moreover, it is the experience of lacking the advantages of a structured life. (Table 1: quotations 3, 4).

Intense and alternating emotions and financial anxiety consume a lot of energy, sometimes leading to suffering in silence, a gloomy outlook on the future, feeling unable to accept the situation at hand, gradually feeling extremely frustrated because of the unbearable circumstances, and the feeling of coming up against a brick wall. Earning an additional income or attending a course could be risky in terms of women's eligibility for social security benefit. A few of these women mentioned feeling completely overwhelmed because of the lack of helpful advice and becoming tired of life. (Table 1: quotation 5).

It is obvious that the experience of work disability as a disruption is dominated by a sense of loss and feelings of despair. The daily routine is strenuous and tiresome and no plans for the future are made.

#### *Work disability as an episode*

The second experience of being work disabled is labeled 'episode', referring to a temporary and inconvenient period in life. The duration of the disablement does not seem to have a profound effect on those women who experience the breast cancer period as an episode. It is an experience of feeling thankful that one's life, including participation in paid work, appears to keep going after all, despite the bumpy road one has had to travel.

The perception seems to be dominated by the aim of 'recovering from the breast cancer' as soon as possible by doing what has to be done. Take care, get better and get back to work, is the motto. Former roles, as a woman, as an employee, are then restored. (Table 2: quotation 1).

Experiencing the disability as an episode means being fully aware of the interruption in life, but still having an enduring memory of the things one went through, and being capable of bringing the breast cancer period to an acceptable end. This involves women being reintegrated in work without insurmountable medical or (work) environment complications. (Table 2: quotation 2). Some feel an obligation to work, whereas others use work as a distraction from the illness. (Table 2: quotation 3).

In the 'episode' experience women come across as decisive, whilst also being aware of the bullet they have to bite, and still having positive ideas about the future, although fearing a relapse. It is not a distressing period in terms of reintegration possibilities, partially because of conceivably positive or cordial professional relationships. It is a recognized and for some a consciousness-raising period, after which the thread of life is taken up again.

#### *Work disability as a meaningful period*

The third experience of being work disabled is labeled 'meaningful period', characterized by the impression that when going through breast cancer diagnosis and treatment, life takes on a new meaning. Discovering that the period of being disabled can be integrated into a new meaningful life and declaring that a deeper meaning is found in the breast cancer diagnosis, allows for these women to change the course of their life. By giving a profound meaning to the breast cancer period, they seem not to be overwhelmed by the illness and disability. It is also the experience of spending a lot of time thinking, while attributing meaning to everything. During the illness it inevitably takes time to get better, to read up on the illness, to search and understand what's happening. This means trying to see the positive side of the period of being disabled and giving meaning to the illness, by reading helpful literature amongst other things. (Table 3: quotation 1).

Women who experience their work disability as a meaningful period, establish their position and want to live a life of total awareness, living from one day at a time, and focusing on their own priorities. As expressed, feeling chastened by adversity and seeing the purifying influence of having had breast cancer, makes them thankful. (Table 3: quotation 2).

Much as they would like to return to work, these women reported that work was no longer the only thing that counted in life. The 'meaningful period' experience is about seeking diversion, allowing oneself to enjoy life and, moreover, giving better expression to one's thoughts and feelings. It also can mean choosing a fulfilling (work) environment over financial gain. These women feel shaken-up and even enriched during the period of work disability. (Table 3: quotations 3, 4).

Giving a profound meaning to the illness period and being work disabled may start as early as the period in which the diagnosis of 'breast cancer' is received. This period is dominated by trying to get information from literature, searching for useful support by having intense meetings or conversations with others, and looking for the meaning of life, in the face of this diagnosis. Women's daily activities depend on their levels of energy, and a process of coping (with grief) might be part of the experience. The different outlook on life, with faith in the future, might in the end translate into a new attitude toward work.

#### **Discussion**

As our findings revealed, breast cancer women experience their work disability in broadly different ways. Based on the analysis of the varying experiences, we developed a 'three-experience model' with the different experiences linking differently to the past and to the future: (1) disruption, (2) episode, and (3) meaningful period. Within the *disruption* experience, all hope seems lost. These

**Table 2**  
Quotations episode.

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1. "...I just thought: I have this cancer, okay, it's happening to me, I just want to survive, and I want a reconstruction, and then, my troubles will gradually come to an end, I guess, yes, I've been very hard on myself, and down-to-earth (...) I don't worry too much, that doesn't make sense, it's no use thinking about: why me, how come...yes, it's hormonal, but I don't know why, or how, or what, no, that's not the point, it's like breaking your arm, you don't make a fuss about 'breaking your arm', I've got breast cancer, it's like a complicated broken arm, yes, and that's temporarily inconvenient..." [resp.16]
  2. "...still, we are people who take up the thread of life, in a different rhythm, but still we try to, but there may be people, for whom the world has stopped turning, who will never, and who will say, yes, I can't manage this [work] anymore, but whether that's better or not, but yeah, that it's over, let's close that file, come on, it's over, but it isn't, because it takes up an enormous space..." [resp.19]
  3. "...why are you coming to work with us...because I like to be among people, I said, and not feel locked up, because when I stay at home imprisoned, and everyday I am confronted with 'that', whereas working takes my mind off things, working helped me to strengthen myself so to speak, yes, there are days I feel really tired, but then I bite on the bullet and say to myself: just one more hour, well that's what I do, yes, but some days I'll say: I don't do anything now, and I'll sit down for a minute, but that's only when I'm really exhausted, sometimes, when I'm coming home exhausted, I'll sit down for an hour, but then I'll jump up and start to do things again..." [resp.3]
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**Table 3**  
Quotations meaningful period.

1. "...going on according to this book, you actually think: falling ill probably wasn't pleasant at the time, but it made me see, look, my life had been accomplished at that point, I had to set a new course, and those things in one's life, apparently make you realize you have to set a new course, because otherwise I wouldn't have quit with my colleague, you just go on then, even if you don't like your work as much as you used to, but, yes, may be I may not say so, but I have the feeling, I had to be ill, to fall ill, to realize, I had to start doing something different..." [resp.17]
2. "...certainly not, but still I'm glad I had it, also towards other people, I believe, how shall I say, I don't ever keep away from suffering, when people are suffering or in distress, I'll never walk away from it, but you'll always have the feeling, you don't understand them, I still can't, but now I've been through a lot myself, I am grateful for that, now I've had some distress, but facing the suffering of others, it's not much, compared to the death of a partner or a child, or, or, I believe you can't compare those things, but putting it that way, sometimes I'm glad for also having suffered a little, yes it may sound strange, but what shall I say (...) I think, yet it was a precious time, I wouldn't have missed it, if I had to choose, I wouldn't choose it, but now I've been through it, I won't ban that part of my life, no, you might find that hard to believe (...) the slowness, the slowing down, was fine by me, and also the feelings of friendship I met, I wasn't aware of people's affections..." [resp.11]
3. "...even if I earn less money, I don't care, besides I don't want to work fulltime anymore, not now, no, I want to do things here at home, having time for my daughter, yes, I've really been shaken up..." [resp.13]
4. "...actually, the whole world should get cancer once, the world would be a better place I believe, people would change their ways of life, and think differently, now I stand up for myself more and more, I used to say: oh, my work, oh my work, oh my work, work, work, work, yes I did, I still do my work well, but so far, so good..." [resp.19]

women feel that they have few possibilities to find (new) work suitable for their situation. Life has changed completely for them. Women who experience their disability as an *episode* are fortunately able to continue their former (working) life, after a really inconvenient period. Women who give *meaning* to the breast cancer period plan to live a life of total awareness and in a way they feel enriched as a human being by their experience of falling ill. Some women's experiences change as time goes by.

Our aim was to contribute to a better understanding of patient experiences and not to judge the three experiences in terms of better ways to deal with the period of being work disabled.

Kennedy identified a lack of communication between patients and stakeholders.<sup>4</sup> Practitioners tend to assume that patients could decide for themselves how treatment and recovery might affect their work.<sup>2,4</sup> During sickness absence women might prepare their return to work mentally or physically, because this is a step toward regaining their normal life. Some are actively seeking information, testing their abilities and making concrete plans to return to work. Seeing returning to work also as a (mental) process,<sup>6</sup> practitioners should be aware of the way patients experience their illness and disability. A woman, who experiences her disability as an episode, might need less support than a woman who experiences her disability as a disruption, with irreparable loss and feelings of despair.

The three identified experiences are equivalent to the story-line types Thomas-Maclean<sup>7</sup> used to enhance understanding of breast cancer narratives, following Frank's<sup>8</sup> well-known narratives of illness. The *chaos* story-line imagines that life never gets better, which is comparable to the disruption experience. These women suffer from the over-all loss and feelings of despair by losing their grip on life and by losing their job permanently. The *restitution narrative* story-line refers to moving through three themes: health, sickness and returning to health, which is consistent with the episode experience. 'Episode' women feel the practical or social need to return to work as soon as possible, either as a distraction from their illness or because of the (former) employer/employee bond.

The third *quest* story-line is equivalent to our meaningful experience of being work disabled, where illness becomes a 'motivator' for social action or change, and in which illness might be expanded to reveal fate or destiny. The women, who experience a 'meaningful' period, feel enriched by the process of reflection and they express the wish to change the course of their lives, by giving way to new priorities. That women feel enriched coincides with the idea that cancer survivors may experience positive effects from their cancer experience.<sup>9</sup>

The 'disruption' experience also relates to some domains Schmid-Büchi et al<sup>10</sup> found in women with breast cancer: living in fear with an unpredictable future and hopelessness, where all

energy is needed to maintain control over life and simply go on living, with no choice but to go through the situation, by motivating themselves.<sup>10</sup> If they become disabled pensioners, these vulnerable women may need special assistance.<sup>9</sup>

The participants in our study seek to find a balance in experiencing a variety of emotional reactions after receiving the diagnosis and they manage the situation in their own way. To some extent this seems influenced by medical and environmental factors. The disruption experience more often referred to several diagnoses of breast cancer, more invasive treatments and less understanding employers. Even though, the interaction between medical treatment and social environment requires further study. Findings from similar studies support this view, while emphasizing the need for social and medical support.<sup>9–13</sup> While patients receive a lot of support close to the diagnosis period, helpful support drops off significantly within the first year.<sup>14</sup> Low levels of support seem to predict maladaptive coping.<sup>9</sup>

A possible limitation of our investigation is that we had no information about the characteristics and the motivation of the women who did not wish to participate (selection bias). Moreover, this study was performed in the specific social security context of Belgium, which may limit the generalizability of our findings. However, we believe that the focus on the informants' personal experiences makes our results relevant for other Western countries.

Strengths of the study are the richness of experiences from 22 interviews and the heterogeneity of the sample: age, education and profession, kind of surgery, and treatment. We believe this heterogeneity will make our findings applicable to a larger population. The multidisciplinary composition of the research group is a second strength. Future studies on breast cancer disability and returning to work should include significant stakeholders, to complete views and perspectives' regarding a woman's working life after breast cancer.

In this study we gained more insight into understanding women's experiences of being work disabled because of breast cancer. Little current research has studied how women act and feel during work disability. Our findings might be of value for medical as well as insurance practitioners, company doctors and employers. The 'three-experience model' developed here, seems to require quite different types of support to meet the women's needs. This calls for flexibility of professionals involved. Also other research underlined the importance of health care services being based on requirements defined by the women with breast cancer.<sup>12</sup>

Particularly practitioners, who are involved in supporting return-to-work, need to be aware of those differences as they affect the patient's perspective on the future. There is some evidence showing that supportive care can make an important difference in how patients deal with the breast cancer over time,<sup>15</sup> suggesting

that professionals can make a difference, but more research is needed to study patient–provider interactions in breast cancer care.

### Conflict of interest statement

The author(s) indicated no potential conflicts of interest.

### Author's contribution

Conception and design: Peter Donceel, Corine Tiedtke, Bernadette Dierckx de Casterlé, Angélique de Rijk, Marie-Rose Christiaens.

Financial support: Peter Donceel

Provision of study materials or patients: Peter Donceel

Collection and assembly of data: Corine Tiedtke

Data analysis and interpretation: Corine Tiedtke, Bernadette Dierckx de Casterlé, Angélique de Rijk, Marie-Rose Christiaens, Peter Donceel.

Manuscript writing: Corine Tiedtke, Bernadette Dierckx de Casterlé, Angélique de Rijk, Marie-Rose Christiaens, Peter Donceel.

Final approval of manuscript: Corine Tiedtke, Bernadette Dierckx de Casterlé, Angélique de Rijk, Marie-Rose Christiaens, Peter Donceel.

### Ethical approval

The study protocol was approved by the Ethical Review Board of the Katholieke Universiteit Leuven.

### Acknowledgments

This research was supported by grants from the Flemish Cancer League, Flanders, Belgium.

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