

# **Perceptions, needs and preferences for cardiac care, of women with breast cancer and cardiac damage, due to the cancer treatments.**

A qualitative study

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## **ABSTRACT**

### **Background:**

The most common type of cancer in women is breast cancer (BC). Survival has improved due to better treatment with surgery, chemotherapy, radiotherapy and/or immunotherapy. However, apart from surgery, these therapies can cause cardiac damage and increase the risk of cardiovascular disease. Research about the consequences of the cardiac damage on Quality of Life (QoL) for women with BC is lacking.

**Research question:** What are the perceptions, needs and preferences for cardiac care of women with BC and cardiac damage due to the cancer treatments?

**Methods:** A generic qualitative study using individual semi-structured interviews. A purposeful sampling technique was used to include 12 BC patients with treatment-induced cardiac damage. The content of the interview was based on the “Concept of Positive Health” and determinants to evaluate care of professionals. The interviews were analysed concurrently, by two researchers independently, using Thematic Analysis.

### **Results:**

Four overarching themes emerged; overwhelming burden, a lack of communication, acknowledgement and personalised care. The women perceived an overwhelming burden which was mounting and influencing quality of life and coping strategies, due to incomprehension of cardiovascular side effects associated with cancer treatments. A lack of communication was reported on a relative, nonrelative, professional, and interprofessional level. Acknowledgement of cardiac damage and cardiac care was inadequate, before-, during- and after breast cancer treatment. Most of the participants had experienced no personalised and holistic care.

### **Conclusion and implications of findings:**

Address financial, psychosocial, existential and sexual issues to cardiac follow-up care of women with BC. A personalised approach in cardiac surveillance is needed to fulfil participant needs and preferences in cardiac care.

**Key words:** Qualitative research[MeSh] , Breast Neoplasms[MeSh], Cardiotoxicity[MeSh], Cardiovascular Diseases[MeSh], Quality of Life[MeSh].

## BACKGROUND

The most common type of cancer in women is BC. The incidence worldwide is approximately 1.676.600 patients each year, accounting for 25% of all cancer patients<sup>1</sup>.

Due to improved BC screening and treatment, survival has increased. After 5 years, 89% of women diagnosed with early-stage BC are still alive. The survival is 83% after 10 years, and 78% after 15 years<sup>2</sup>.

BC treatment can be surgery, chemotherapy, radiotherapy, hormone therapy or immunotherapy. These treatments are often combined. However, all of these treatments, apart from surgery, can cause cardiac damage. Additionally, therapy-induced cardiotoxicity could be synergistic when therapies are combined<sup>3</sup>. For example, the incidence of left ventricular dysfunction due to Anthracycline-based chemotherapy is 0.9-11.4%, and the incidence of Trastuzumab-based immunotherapy in combination with Anthracyclines and Cyclophosphamide is 1.7-20.1%<sup>4,5,6</sup>.

Consequently, CVD is the second leading cause of morbidity and mortality in BC patients<sup>7</sup>. CVD can cause a variety of symptoms, for instance heart failure symptoms such as dyspnea, fatigue and insomnia. These symptoms affect the Quality of Life (QoL) of patients negatively<sup>8</sup>.

Since the increase of chronic diseases such as CVD, there has been more interest in a broader perception of health and QoL, than the existing ICF (International Classification of Functioning, Disability and Health) which doesn't perfectly fit with a chronic disease. Huber et al<sup>9</sup> developed a holistic vision of health, which they named the concept of "positive health", wherein lifestyle and self-management of the chronic disease is essential. with a social, physical, and emotional domain. To increase the survival and preservation of QoL, improving care with a holistic view for women with BC is needed.

Cardiotoxicity related to cancer therapies has been known for 40 years. Currently, oncology and cardiology are still separate fields and recommendations of international evidence-based guidelines for cardiovascular toxicity differ<sup>10,11,12</sup>. Gernaat et al<sup>13</sup> recommend "investigation in an individualised approach to balance between high BC tumour control and minimal cancer treatment-induced CVD risk." Evidence regarding current individualised cardiac healthcare for BC patients is limited and only evaluated in quantitative studies<sup>14</sup>. The consequences of BC on QoL are explored by Ferrell et al<sup>15</sup>, which reported "frustration in seeking attention for symptoms" wherein consequences were "minimized by health care providers and yet were of

great importance to their lives". Moreover, fear of death, balancing hope, the need to express emotions are described<sup>16</sup>. Furthermore, Berterö<sup>17</sup> investigated self-esteem and QoL in women with breast cancer and showed a negative impact of breast cancer and its treatment on QoL. In all studies the combination with BC and cardiac damage in QoL is lacking. We therefore assess this in a qualitative study. The research question of this study was:

What are the perceptions, needs and preferences in cardiac care of women with BC and cardiac damage due to the cancer treatments?

## **METHODS**

### **Study design**

A generic qualitative study was conducted. This design has been chosen because a qualitative design applies to exploring experiences.

### **Sample**

Twelve participants were purposefully recruited. Recruitment took place in cooperation with the outpatient clinic Cardiology of Radboudumc, an university hospital in the Netherlands. Inclusion criteria for participants were: women with BC and treatment-induced cardiac damage. Exclusion criteria were: inability to communicate in Dutch and cognitive impairment. This were reviewed by the treating cardiologist. By the use of maximum variation in age, cancer treatment and CVD diagnosis, a diverse sample was obtained in order to increase transferability<sup>18</sup>.

### **Data collection**

The data were collected through semi-structured interviews to get an insider's perspective of cardiac care for BC patients with cardiac damage<sup>18</sup>. An interview guide was developed using the "Concept of Positive Health" and the "TICD checklist". Both were used to obtain a comprehensive and holistic view on cardiac care<sup>9,19</sup>. To make sure that the participants recognised their own experiences the researcher regularly summarised answers during the interviews<sup>18</sup>.

Baseline demographic information of the participants was gathered out of the patient's file. The executive researcher (NvZ) is a female and was, during the time of the study, a nurse on an oncology ward in another hospital than the sample of this study. The participants and researcher had no prior relation. Patients were selected by a Cardiologist and approached by researcher (YK) to participate in the study by phone. After permission to participate, the executive researcher (NvZ) sent a patient information letter. An appointment for the interview was made by phone. The participant could decide if the interview took place at the participant's home or at the academic hospital.

During the interview probes and prompts were used to encourage outspokenness of the participant. Observational, methodological and theoretical observations were reported in memos and added to the audit trail<sup>18</sup>.

The interviews lasted 30-106 minutes and were tape-recorded. The fourth interview was a lot shorter than the rest, due to recall bias because QoL was improved by cardiac treatment. Not all interviews were recorded until the end of the interview due to audio recorder problems; in three of the interviews, a maximum of five minutes at the end was lacking. Hereby data is missing about the preferences of the participant. From one interview, approximately ten minutes is missing, which included their positive and negative experiences, motivation for the cardiac care and lifestyle education.

After consideration, the topic list was not adapted during the execution of the interviews because of no missing topics or redundant topics, wherein sexuality, didn't fit within the aim of the study.

### **Ethical issues**

Ethical approval to conduct the interviews was approved by the Medical Ethics Research Committee (Commissie Mensgebonden Onderzoek (CMO) in Dutch) of Radboudumc. The General Data Protection Regulation (GDPR, in Dutch AVG) and the principles of the Declaration of Helsinki version 9, October 2008 was followed when storing and transporting the data. Informed consent was obtained from all participants.

### **Data analysis**

All interviews were transcribed verbatim. The data analysis was conducted according a concurrent Thematic Analysis: familiarisation of the data, complete coding, searching for themes, reviewing themes, defining and naming themes and writing up<sup>28</sup>. The transcriptions of the interviews were coded by two novice researchers (NvZ and LD) for accuracy. To improve quality, the first four interviews were also coded by one postgraduate researcher (YK).

The analysis decisions of the regularly held analysis meetings were added to the audit trail, in order to enhance dependability and conformability. Discrepancies were discussed with a professor (HV). Data saturation was shown on all themes after ten interviews, and was confirmed in the last two interviews. The data management was supported by ATLAS.ti software, version eight (Scientific Software Development GmbH, Berlin, Germany)<sup>20</sup>.

### **Trustworthiness**

The interview techniques were tested by ways of a pilot interview and evaluated with an experienced researcher (YK)<sup>18,18</sup>, this interview was not added to the analysis because symptoms of cardiac damage suspicioned and not officially diagnosed.

To guarantee quality during the checklist for good TA from Braun and Clarke was used<sup>28</sup>.

Reporting the study explicit and comprehensive the COREQ checklist were complied<sup>21</sup>.

## RESULTS

Between January and May 2019, women with BC and cardiac damage were interviewed. None of the approached women refused to participate. Maximum variation was achieved for age (range 42-73 years, median 59), cancer treatment, CVD diagnosis. Participants characteristics are presented in Table 1.

Five overarching themes were defined: overwhelming burden, lack of communication, acknowledgement and personalised care.

### Overwhelming burden

All participants reported an overwhelming burden which was growing in duration, as well as symptoms or consequences. This was explained by the progressive character of heart failure adding to the burden of BC. The overwhelming burden resulted in limited activity and influenced the participant's overall vitality. Factors influencing this overwhelming burden were unpredictable fatigue, uncertainty and anxiety. The participants reported that each factor is accumulating.

Some participants perceived mental burdening worse than physical burdening, whereby negative thoughts arise more often when participants were not feeling well.

*P11 "Well, it is cumulative what I have been through, I can write a book about it."*

Furthermore, many participants reported less energy and thereby a decrease in working hours or ceasing work altogether. The women expressed concerns about income which lowered or stopped. Quitting work also had consequences in their social network. Moreover, some participants perceived sexual issues for example, a decrease in sexual desire due to no feelings in their breasts and decreased endurance.

*P1 "...and you want to, but you can't, and everywhere you are too late, your lacking behind in work, but at home too, in everything."*

The most described complaint of the participants was unpredictable fatigue, whereby they were limited in walking up the stairs, walking long distances and doing the household chores. The unpredictable fatigue was reported different to the fatigue during the oncologic treatment because of the unpredictable and exhausting character, which was unrelated to physical

activity. The participants had to include a brake into their daily lives and reduce their activities, they still had difficulties in balancing energy.

*P6 "I can do everything, as long as I take a rest in between, and I can also go on like a steam train, but then I'm broken for a day or two, or longer, it depends, I'm just broken, tired... like walking a marathon."*

Due to forgetfulness and reduced concentration, participants experienced uncertainty at work and about their life. Therefore, symptoms of depression were reported, as well as a concern for certainty about treatment possibilities of the CVD. Moreover, some participants were experiencing trouble doing study tasks or financial administration even when the participants received the right information.

*P5 "Yes, those first years I was really scared, and I didn't dare to go to sleep at night anymore ... so the mental damage was huge, at that moment certainly, it took a year before the confidence returned, that year my parents have always been with me at night ... I was so scared that my daughter would find me dead in bed."*

Anxiety was reported in three types: fear of death, fear of depression and fear of failure. All types of anxiety were related to stress, difficulties with falling asleep and nightmares. Some participants experienced a worsening of palpitations or dyspnoea in bed. Half of the participants were more worried about the BC. The other half were more scared of cardiac damage because of acute death.

*P9 "Eventually I think it's fear, because at a moment your heart is not functioning well, you don't get the immunotherapy, and when you don't get the immunotherapy, then you die."*

### **Lack of communication**

Incomprehension of cancer treatment associated cardiovascular side effects was reported on a relative, nonrelative-, social-, professional- and interprofessional level.

All participants reported that relatives and nonrelatives often had difficulties in communicating with them about the cardiac damage; such as feeling helpless, showing less empathy, having no interest or denial, which lead to a decrease in connection in their relationships.

Moreover, the participants often only discussed symptoms with their partner or close friends, rather and often pretended that everything is ok.

*P8 "If someone asks me, I'm always good, I don't show them so much of myself, I'd rather keep on going, but my partner does see it."*

Most of the participants reported that nonrelatives often didn't ask clarifying questions, but rather made their own conclusions about the consequences of cardiac damage due to misunderstanding. Besides, all participants reported that contact with some nonrelatives changed during their sickness.

*P5 "People find it hard to hear how I feel. On a certain moment, it all has to be over. But recovery, but, for me recovery takes, seems years or longer, I'm still not, you know."*

Participants experienced a lack of knowledge about cardiac damage, due to the difficulty in explaining their symptoms to a cardiologist who often only comforts the participant instead of suggesting treatment possibilities. All participants were shocked and upset, when the specialist told them the CVD diagnosis due to no previous information about the risk of cardiac damage.

*P9 "For me it was a huge eyeopener to hear that cardiac damage and cancer may have something to do with each other. I think there should really be more information there, eh. I never knew, and you hear it (cardiac damage) quite regularly."*

Interprofessional communication is reported as brief and with a lack of collaboration between oncology and cardiology. Moreover, all patients described that the coordination of care was not optimal and no continuity of care.

*P2 "I think it is both in my body (oncology, cardiology), but are you ever in one room together."*

### **Acknowledgement**

All participants reported a lack of acknowledgement of cardiac damage before, during and after treatment for BC. Some of the participants reported comforting instead of taking action by the professional and all perceived a lack of knowledge in BC treatment related CVD.

Moreover, many participants weren't able to differentiate between symptoms of the BC and



symptoms of the cardiac damage, whereby they do not know which specialist they have to inform about it. Furthermore, the cardiac symptoms were often not immediately recognised by the patient, (non)relative and professional due to other symptoms as women as opposed to men.

*P5 "It is not funny, dragging yourself and that, that those doctors do not take seriously that heart failure or heart problems run differently within a woman or a man, it's still embedded, and because they don't see it in the classical symptoms and therefore is not determined, so then it doesn't exist."*

Due to late acknowledgement, participants reported feelings as unfairness, anger, denial and frustration. For participants, disease insight played an important role, for example in asking help of relatives and acceptance.

Participants described confrontations during the conversations or examinations with the professional, which can lead to a reality check of the consequences and contribute to acceptance.

One participant felt that the CVD could have been prevented, if an intervention had been performed earlier. Some participants missed apologies of the professional, because of the late diagnosis of CVD.

*P5 "But if you forget it then, because you're not familiar with it, or it's not yet a protocol, then I think it's possible, especially 20 years ago, or eh, 15 years ago. But when it does happen, why don't you say sorry, because I need to deal with it for the rest of my life, they don't have my heart, that doesn't, that's not functioning fully."*

### **Personalised care**

Most of the participants had experienced no holistic and personalised care somewhere during their oncologic or cardiac treatment. Moreover, some missed shared decision making with partners about cardiac treatment. Whereby, the women wanted to discuss the experienced side effects of medicines in combination with the benefits.

*P6 "I had no more energy at all, and ... (cardiologist) said at the last pill, it was such a low dose, I wouldn't be able to notice, ... but I'm not going to wind myself up all the time, rather than no pill, and die earlier."*

Often participants viewed female caregivers as more sensitive, with more collaboration between symptoms and medical fields. Furthermore, life style factors as food, sleep and balance between exercise and relaxation were hardly mentioned by the cardiologist.

The participants reported less attention of the cardiologist to oncologic background during consults, the focus of the consult were the cardiologic problems, but the participant experienced both important and not apart from each other.

*P9 "That's also an issue between two expertise's, to connect those to each other is also very hard for a patient, because uhm, uhm, an oncologist has an opinion and a cardiologist has an opinion, and they both say about each other, eh, uhm, yes, but that's not my area, ... as a patient you need something from both expertise's."*

## DISCUSSION

This is the first qualitative study which explored the perceptions, needs and preferences in cardiac care of women with BC and cardiac damage, due to the cancer treatments. The study revealed that the women perceived an overwhelming burden which were influencing QoL. The factors unpredictable fatigue, uncertainty and anxiety were reported as contributing to the overwhelming burden. The participants perceived a lack of communication on a relative-, nonrelative-, professional- and interprofessional level, which lead to less connectedness in relationships and inadequate acknowledgement of the cardiac damage. The participants needs and preferences were more personalised and holistic care focussing on the burdening issues.

The negative influence of BC on QoL **quality of life**, has been reported in several studies, wherein fatigue is an well-known factor.<sup>22</sup> Our study reveals similar to a qualitative review of patients with heart failure, an unpredictable and exhausting fatigue which is not related to activity. In contrast to the fatigue during the oncologic treatment, whereby balancing energy is difficult. Consequently, women with BC and cardiac damage could use some lifestyle support in the follow-up care.

The women in our study had experienced symptoms of anxiety and depression which had a negative impact on the QoL, which was related to the burden of the BC and CVD. According to Gold et al<sup>23</sup>, almost 50% percent of the women with BC experience anxiety and depression, which were also associated with increased fears of recurrence, and a decrease in life satisfaction. This is also seen in another study, whereby Hamer et al<sup>24</sup>, recommend individualised interventions. Thus, individualised psychosocial follow-up care of women with BC should be developed, to treat and prevent the prevalence of anxiety and depression.

Moreover, the financial burden of breast cancer is noted. This is in line with the study of Ferrell<sup>15</sup> et al and our study and suggest that financial issues and education should also be a part of the BC follow-up care.

The finding of a lack of communication was an important finding to the participants of our study. Relatives and nonrelatives felt helpless, showed less empathy and no interest or denial, which lead to less connectedness in relationships. Furthermore, the lack of communication on professional and interprofessional level, perceived by the participants, state that communication should be improved, in order to explain symptoms and differentiate between oncologic and cardiac symptoms. Whereby, knowledge was lacking about symptoms cardiac damage and the different onset of symptoms between men and women. Thus, there is in line with a study by Taylor et al<sup>25</sup>, a need for more awareness of symptoms of heart failure with attention to gender differences<sup>26</sup>.

Last of all, similar to Fenlon et al<sup>27</sup>, the participants, were convinced that holistic and personalised issues regarding BC and cardiac damage should be addressed in follow-up care.

### Strengths

Trustworthiness was enhanced using memo's, an audit trail, triangulation of researchers during the analysis, and the use of the checklist of Braun and Clarke. The checklist ensured correct application of the phases of TA<sup>28</sup>. The consolidated criteria of reporting qualitative studies (COREQ), strengthened the quality of execution and reporting the study<sup>21</sup>.

Although twelve women were included, maximum variation in age, cancer treatment and CVD diagnosis are used to get diverse perceptions, needs and preferences of cardiac care in women with BC and cardiac damage to expand transferability. Besides, transferability is also improved by achieving data saturation on all themes after ten interviews.

### Limitations

The study has a couple of limitations. Due to missing data at the end of some audio recordings, the transcriptions of these interviews were incomplete, thus the data about preferences of cardiac care was missing. The participants were on beforehand informed that the duration of the interview would be approximately 45-60 minutes. However, the maximum length of the interviews was 106 minutes. The participants didn't take in account this amount of time on beforehand and could shorten their answers by realising.

### Implications

The results of this study can serve as knowledge about the impact of BC and cardiac damage on their QoL. Changes in follow-up care of BC patients are required to improve knowledge in participant, (non)relatives and professionals, about symptoms of cardiac

damage. Hereby, interprofessional collaboration is important to connect symptoms and interventions in diverse medical specialties. Regarding personalised and holistic follow-up care, financial, psychosocial, spiritual and sexual issues should be monitored. In future research the content of sexual issues should be more explored.

## **CONCLUSION**

Cardiac damage for women with BC has a great impact on the quality of daily life. However, participants in this study perceived less attention to contributing factors of QoL in follow-up care. The findings suggest the importance of personalised and holistic care. Several limitations of BC follow-up care were identified, having implications for future care.

**Table 1 Characteristics of participating women with BC and cardiac damage**

<b>Participant</b>	<b>Age</b>	<b>Year of breast cancer diagnosis</b>	<b>Year and type of cardiac damage or CVD diagnosis</b>	<b>Therapies*</b>	<b>Lowest measured LVEF**</b>
1	63	2006	2007 LVEF	Chemotherapy Hormone therapy Radiotherapy	31%
2	73	2014	2009 sick sinus syndrome with bradycardia, AF	Immunotherapy	46%
3	70	2015	2015 STEMI 2015 AF 2017 MI	Chemotherapy	26%
4	55	2010	HFmrEF	Chemotherapy Immunotherapy Radiotherapy	48%
5	50	1999	2004 STEMI	Chemotherapy Radiotherapy	45%
6	42	2011	2014 aortic valve insufficiency	Chemotherapy Radiotherapy	39%
7	66	2016	2017 LEVF	Chemotherapy Immunotherapy Radiotherapy	35%
8	46	2010	2017 LEVF	Chemotherapy Radiotherapy	40%
9	47	2015	2018 LEVF	Chemotherapy Immunotherapy	27%
10	59	1999	2014 AF	Chemotherapy Immunotherapy Hormone therapy Radiotherapy	63%
11	58	1998	2009 LEVF 2014 MI	Chemotherapy Immunotherapy Hormone therapy Radiotherapy	40%
12	62	2010	2017 LEVF	Chemotherapy Radiotherapy	26%

\* Chemotherapy can include Anthracyclines

Abbreviations: Heart failure based on left ventricular ejection fraction (LVEF)

preserved ejection fraction (HFpEF) LVEF  $\geq$ 50%

mid-range fraction (HFmrEF) LVEF 40-49%

reduced ejection (HFrEF) LVEF <40%

AF: Atrial Fibrillation

Mitral Insufficiency: MI

Aortic Insufficiency: AI

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