# Professional views on elderly breast cancer patients

A qualitative research on the social and mental strengths and weaknesses of elderly breast cancer patients

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### Abstract

# <u>Title</u>

Professional views on elderly breast cancer patients

# Background

The number of elderly breast cancer patients who receive treatment and need care is increasing. Self-management is an approach to keep healthcare affordable and of high quality. The mental strength of patients is a predictor of self-management and the effectiveness of psychosocial care depends on the assessment of BCN on these strengths and weaknesses of the individual patient. Knowledge of views of BCN regarding these aspects is needed to monitor and develop the quality of psychosocial care.

# Aim and research question

To gain insight into views of BCN on mental and social strengths and weaknesses of elderly breast cancer patients and how BCN adapt psychosocial care to these aspects.

"What are the views of mamma care nurses on the mental and social strengths and weaknesses of elderly breast cancer patients and how do they adapt the psychosocial care they provide to these mental and social strengths and weaknesses?"

# Method

This study has a qualitative explorative design using semi-structured interviews.

### Results

Views of BCN resulted in several themes: diversity in mental and social aspects of elderly breast cancer patients, the mentally and socially strong patient, and the mentally and socially weak patient.

# Conclusion

MCVs perceive two types of patients: the mentally and socially strong patient, and the mentally and socially weak patient. They are also ambivalent concerning their views on mental and social strengths and weaknesses, which might result in psychosocial care tailored to individual views instead of the needs of patients.

# Recommendations

Further research needs to be done to explain differencing views, and their influence on the effectiveness of psychosocial care and self-management.

### Keywords (max. 5)

breast cancer, elderly, self-management, views, strengths and weaknesses

# Samenvatting

### Titel:

Visie van professionals op oudere borstkanker patienten

# Inleiding:

Het aantal oudere borstkankerpatiënten dat behandeling krijgt en zorg nodig heeft stijgt. Zelfmanagement is een methode om de gezondheidszorg betaalbaar en van hoogstaande kwaliteit te houden. Mentale kracht van patienten is een voorspeller voor de mate van zelfmanagement. De effectiviteit van psychosociale zorg is afhankelijk van de beoordeling van MCV van deze kracht en zwakheden van de patient. Kennis van de visie van MCV op deze aspecten is nodig om de effectiviteit van psychosociale zorg te monitoren en te ontwikkelen.

# Doel en onderzoeksvraag

Inzicht verkrijgen in de visie van MCV op de mentale en sociale kracht en zwakheden van oudere borstkanker patienten en hoe MCV psychosociale zorg aanpassen aan deze aspecten. "Wat is de visie van oncologieverpleegkundigen op de mentale en sociale kracht en zwakheden van oudere borstkankerpatiënten en hoe wordt de psychosociale zorg die zij verlenen aangepast aan deze sociale en mentale krachten en zwakheden?"

### Methode

Deze studie heeft een kwalitatief exploratief design met semigestructureerde interviews.

### Resultaten

De visies van MCV resulteerden in verschillende thema's: diversiteit in mentale en sociale aspecten van oudere borstkankerpatiënten, de mentaal en sociaal sterke patient en de mentaal en sociaal zwakke patient.

# Conclusie

MCV zien twee typen patienten: de mentaal en sociaal sterke patient en de mentaal en sociaal zwakke patient. Naast deze twee typen patienten zijn ze ook ambigu in hun visie op mentale en sociale kracht en zwakheden. Dit kan resulteren in psychosociale zorg die is afgestemd op de individuele visie van MCV en niet op de behoeftes van de patient

# <u>Aanbevelingen</u>

Verder onderzoek zal gedaan moeten worden om de verschillen in visies te kunnen verklaren en wat de invloed van deze verschillen is op de effectiviteit van psychosociale zorg en zelfmanagement.

# Trefwoorden (max. 5)

borstkanker, ouderen, zelfmanagement, visie, kracht en zwakheden

### Introduction

Cancer is related to ageing, and is a leading cause of death, with 8,2 million deaths in 2012.<sup>1</sup>
Among females, breast cancer is the most frequently diagnosed type of cancer, accounting for 23% of all cancer cases.<sup>2</sup> In the Netherlands, a quarter of all cancer diagnoses are categorized as being breast cancer. Further, a third of these patients are 65 years and older.<sup>3</sup> The number of older adults will increase for the Dutch population in the coming two decades.<sup>4</sup> This increasing number of older people and the link between ageing and cancer will result in more elderly cancer patients who need care in the coming decades. The Netherlands and most other western countries are faced with the challenge to keep the health care system affordable, and ensuring high quality care for cancer patients.<sup>5</sup>

A frequently used term to achieve this high quality of care, as well as greater efficiency, is 'self-management'. In other words: "activities that individuals perform and decisions they make, with the people in their network, including their partner, friends, family and caregivers, to deal with their disease and to minimize progression and consequences of this disease".<sup>5</sup>

Self-management is based on the individual patient's possibilities to manage their treatment, symptoms, physical and psychosocial consequences, which are inherent when living with a disease. Patient-related factors like self-efficacy, knowledge about their disease, and psychological and social factors, like mental and social strengths, influence the self-management of patients. According to research from Dingley et al., mental strength is a strong predictor of self-management in women with cancer 8.

Breast cancer nurses (BCN) are specialized in breast cancer, they inform curative patients who will undergo a breast amputation or breast sparing operation. <sup>9</sup> They have an important role in giving psychosocial care during the one to two year-period of care after surgery, which includes encouraging self-management. <sup>10, 11</sup> The effectiveness of psychosocial care depends on the assessment of mental and social strengths and weaknesses of patients by the individual BCN. <sup>12</sup> Currently, the individual views of BCN on these mental and social strengths and weaknesses of elderly breast cancer patients and how they adapt their psychosocial care are unknown.

This research explores the individual views of BCN on the mental and social strengths and weaknesses of elderly breast cancer patients, and how they adapt their psychosocial care to these strengths and weaknesses.

### **Problem statement**

In breast cancer care, BCN have an important role in increasing self-management by adapting psychosocial care to the strengths and weaknesses of their patients. <sup>10, 11</sup> It is proven that this psychosocial care depends on the individual views of BCN on patients' mental and social strengths and weaknesses and mental strength is a predictor for self-management. <sup>8 12</sup> Knowing mental strength is a predictor of self-management, and the effectiveness of psychosocial care depends on the assessment of BCN regarding these strengths and weaknesses. Knowledge of the views of BCN concerning these aspects is needed to monitor and develop the quality of psychosocial care.

### Aim

The aim of this study is to gain insight into the views of BCN on the mental and social strengths and weaknesses of breast cancer patients aged 70 years and older, and how BCN adapt the psychosocial care they provide to these mental and social strengths and weaknesses.

Moreover, the results of this study contribute to knowledge about the individual views of BCN to monitor the effectiveness of this psychosocial care and therefore, the efficiency of encouraging self-management.

# Research question

The research question of this study is:

"What are the views of breast cancer nurses on the mental and social strengths and weaknesses of elderly breast cancer patients and how do they adapt the psychosocial care they provide to these mental and social strengths and weaknesses?"

### Method

### Design

An explorative qualitative approach, using semi-structured interviews, was used to gain insight into the views of BCN and how they adapt their care concerning these aspects. This design was most appropriate to give participants the opportunity to provide their own perspective on the strengths and weaknesses of elderly breast cancer patients.<sup>13</sup> Twelve semi-structured interviews were held among BCN while this number of interviews resulted in a high level of data-saturation<sup>14</sup>

# Population, sample and procedure

The studied population consisted of BCN with at least a year of work experience, and a completed and additional education for specialized oncology nursing or breast cancer nursing.<sup>15</sup> The sample was a purposive sample, as the participants were selected based on their knowledge about elderly breast cancer patients<sup>16</sup>. The different participants were selected depending on the region of their hospital, their age, and their work experience. By maximizing the differences at the start of this study, the likelihood that the results exhibit different views increased.<sup>17</sup>

The researcher contacted participants by sending an email to outpatient mamma care clinics, which contained information on the research and a consent letter. After three days, the researcher phoned BCN, provided them with additional information, and asked for their participation. After BCN agreed, an interview appointment was scheduled. Prior to the interview, the researcher repeated the procedure, and participant signed an informed consent form.

As no patients were involved, a WMO declaration was unrequired.<sup>18</sup>

### <u>Participants</u>

Fourteen mamma care clinics were approached. The BCN, all females, were invited to participate in this study. One BCN refused participation though she had recently participated in another study. Another BCN did not respond to the invitation. The final sample consisted of twelve MCVs, who work for eight different hospitals. While seven BCN came from an urban region five were from a rural region. The age of participants was between 30 and 64 years (table 1).

# **Data collection**

Twelve interviews, taking approximately one hour each, among BCN were held between 20 February and 29 April 2014. The interviews were led by a topic list developed at Windesheim University by the research group "Innovation in elderly care" (table 2). In consultation with research colleagues, the topic list was expanded with topics on the views of BCN on the strengths and weaknesses of elderly breast cancer patients.

The interviews were held at the outpatient clinic where participants work. Two interviews were incomplete due other work-activities resulted in limited time for the interviews. The interviews were recorded, transcribed verbatim, and used anonymously by the researcher. During data collection and data analysis processes, personal notes were made that contain relevant impressions, evaluations and thoughts. <sup>19</sup> The notes were used during the data analysis. Data was gathered in a simultaneous process of data collection and data analysis. <sup>20</sup>

### Data analysis

The data was analyzed using the Qualitative Analysis Guide of Leuven (QUAGOL). This method consisted of two parts: the preparation of the coding process and the actual coding process.<sup>21</sup> During preparation of the coding process, data was re-read and interpreted to develop a useful framework with meaningful concepts.<sup>21</sup>

Next, the actual coding process was performed.<sup>21</sup> Concepts were analyzed, which resulted in the description of the data.<sup>21</sup> For this process, the QRS NVivo 10 software was used to manage, shape and analyze the qualitative data.<sup>17</sup> The data analysis was an iterative process for which the researcher moved back and forth from data collection and data analysis.<sup>16</sup> In order to optimize the methodological quality of the study, several strategies were performed by the research team of Windesheim University. These strategies included peer debriefing, investigator triangulation with research colleagues and audit trails.<sup>16</sup> Reflexivity by the researcher was done during the data collection, analysis, interpretation, and writing.<sup>16</sup>

### Results

This qualitative research among BCN indicated the following themes: diversity in mental and social aspects of elderly breast cancer patients, the mentally and socially strong patient, and the mentally and socially weak patient.

The study showed BCN treated every elderly breast cancer patient as an individual and not as a homogenous group. Besides this diversity in individuals, they identified two types of patients: the majority of the patients are considered as mentally and socially strong, and a minority is seen as mentally and socially weak.

While most views of BCN were similar, there was ambiguity between views of BCN on strengths and weaknesses. Several BCN considered certain aspects to be a strength of a healthy elderly patient, yet other BCN considered these aspects to be weaknesses.

### Diversity in individual elderly breast cancer patients

A great diversity in types of elderly breast cancer patients is seen by BCN in their daily practice. They mainly described diversity in the mental and social aspects of elderly breast cancer patients. BCN recognized their patients as individuals with needs and problems, which resulted in tailored care:

"One 70-year-old is not the same as another." (P1A, P7E)

# The mentally and socially strong patient

BCN saw most patients as being strong and several aspects were mentioned as being typical for these strong patients. Some aspects seemed to be weak but BCN found this unsurprising, and did not consider them as weak aspects. In these cases, no or a minimum of extra psychosocial care is needed.

BCN saw elderly breast cancer patients as strong women who accept and understand their illness. The patients showed fighting spirit, trust in their treatment and, according to BCN, had no questions about their chance of survival:

"Patients state that this could be part of life in which you become ill and it turns out to be breast cancer." (P4A)

"I think it is amazing how powerful these women are." (P3A, P12G)

BCN explained this trust and resignation as a result of ageing, life experience or former loss giving the diagnosis less impact:

"It is a generation of women the diagnosis has an impact on, but less impact in comparison to younger women." (P4A)

BCN also witnessed grief and shock, which is not considered to be a mentally weak response, but rather a regular reaction for every patient who is diagnosed with breast cancer: "These women are also very shocked they have breast cancer." (P5A)

BCN said most patients reacted with certain ease at the loss of a breast. Patients said they did not need the breast anymore; it would have been much worse if they were younger: "I am not 42 anymore; take it off" (P1A, P11G))

Other BCN said they elicited the same reaction, but when questions began, their patients became emotional about the loss of the breast. These BCN stated that the patients wanted a good prosthesis, or in some cases a reconstruction. This information and care was provided by these BCN, and they did not state this as a weak aspect, though as an understandable reaction.

BCN frequently mentioned that patients effaced themselves. Patients were more concerned about other people, like their partner or children, instead of themselves: "Some women are more concerned about their husbands than themselves." (P2A)

Asking their family or BCN for support was difficult for this elderly generation, according to BCN: "This generation is used to doing everything themselves. Support is not very obvious." (P9A) Although effacing and the difficulty of asking for help could be seen as weak aspects, BCN frequently saw these aspects in elderly patients, which they believed, did not belong to the weak patient.

While this effacing and difficulty of asking for help is evident, BCN simultaneously stated that most patients manage their illness well and needed little support. Though, in the ensuing period a validated questionnaire was used to investigate problems, BCN stated that most patients were without problems.

Usually, the social support system of elderly patients is smaller in comparison to younger patients, but remains efficient. BCN related social support to the increased mental strength of elderly breast cancer patients.

Patient support was largely from healthy husbands, and their children. Furthermore, they also received support from neighbors, friends and people from the church, especially the current patient category aged between 70 and 80 years.

One BCN from the east of the country said the church provided far-reaching support. The role of BCN for religious patients in that region was purely informational:

"Religious patients come to me for practical questions. They go to the reverend and people from the church for mental, social and religious aspects, which are very important to them and which gives them much power and support." (P7E)

BCN noted that patients accustomed living alone, and doing many activities in the middle of their lives. were able to take care of themselves during illness, and after their treatment. Extra care from BCN or other disciplines was unrequired, but they received support from friends, family, children or neighbours:

"Some time ago I saw a women who was all alone. I find her a strong woman because she arranged her whole life by herself." (P8A)

While extra care was not required by these strong patients, BCN instructed the general practitioner of many elderly patients to keep an eye on them after admission, mainly caused by a short admission between one or two days. BCN thought this was more important for elderly patients than for younger patients:

"I am also asking if they are in good contact with their general practitioner; he keeps an eye on her as well." (P2A)

# Mentally and socially weak patients

Several aspects were mentioned as weak and BCN often saw a combination of these aspects, which resulted in a mentally and socially weak patient. With cases of weak patients, psychosocial care is tailored to the needs of the individual patient by BCN.

BCN stated that patients aged 80 and older were considered to be really old and therefore more vulnerable:

"I consider women aged from 80-85 and up to be really old." (P8A)

According to BCN, patients from this generation have difficulties talking about their disease and emotions. Moreover, MCV stated, co-morbidity, former loss of relatives, or grieving about complex family situations could cause mental weaknesses in some elderly patients.

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In these cases, extra psychological care was offered. However, most elderly patients did not accept this, as they said they did not need the care:

"Patients say: 'I am not crazy." (P10G)

Some patients (mainly 85 years and over), had loss of memory according to BCN, they needed to receive the information in phases, and repetition was necessary. BCN recognized this, and made an extra appointment to provide the patients with information again. Furthermore, BCN asked the family of the patient to repeat this information.

If a patient was healthy but had a vulnerable husband and she was his caregiver, BCN saw the patients efface themselves completely, as the husband was their primary concern. These patients neglected their illness. Respectively, BCN asked them if their children could be more supportive; in some cases, the general practitioner was informed to arrange a temporary admission for the vulnerable husband.

"The vulnerable husband is their greatest concern." (P5A)

BCN saw patients as being socially weak if they lived alone and were widowed, childless, without contact with their children or lacking further social support. Because of the little practical support, and lack of mental support from relatives, these patients were considered to be mentally weak by BCN. They saw a connection between these social and mental aspects: "A women who is older, and who is alone, has less mental flexibility because the group of people around her is smaller." (P6A)

Concurrently, BCN said that social support partly depends on the character of the patient and how they live their life. Introverted patients who remained at home had less social support, according to BCN:

"If they are very introvert women who remain at home, then yes, they are alone." (P5A)

With exceptional cases when patients had no support at all and were completely alone, BCN arranged an extra night at the hospital, and had the possibility to arrange home care or visits from an oncology nurse if necessary.

Volunteers were another option to care for patients with no social support. BCN from the west of the country mentioned an organization that employs volunteers who accompany patients on hospital visits and gives them both social and mental support. Respondents from the east of the country did not mention this possibility regarding adapted care.

Even though BCN stated that most of the support came from children, in some cases, the support was inefficient or limited, because children lived far away or were busy with their own lives.

One BCN saw cases in which the children accompanied the patient when they did not trust that their mother could manage alone. In her view, when the patient and husband collaborated, this proved that they had a certain strength and independence:

"When patients come alone, or together with their husband, it proves that the family trusts that the patient can manage the hospital visit on her own." (P8A)

BCN stated extra care was needed and arranged for social and mental weak elderly breast cancer patients. They were very caring for patients and expected little or no self-management. One BCN said she adapted her care upon the personal strength of patients. This respondent asked patients about their positive activities and encouraged them to undertake these: "What do you like to do? And patients say 'I like to do this and I do not do that anymore'. And why not? So I try to find the personal power of the patient." (P6A)

She used the strength of patients, where most BCN became more focused on the mental weaknesses of patients; adapting their care to these weaknesses.

### **Discussion**

In this study, views of BCN on mental and social strengths and weaknesses of elderly breast cancer patients were investigated. The findings revealed diversity in the individual breast cancer patients; the mentally and socially strong, and the weak elderly breast cancer patient, according to BCN.

This study shows similar, but also ambiguous views among BCN on mental and social strengths and weaknesses of elderly breast cancer patients. While some BCN stated that single patients are mentally and socially weak patients, others stated that single patients are mental strong. Ambiguous views result in differences in psychosocial care, which is mainly adapted to mental and social weaknesses. BCN who declare patients as weak, give them more psychosocial care in comparison to BCN, who witness patients being in the same situation as strong patients. In these cases, care is dependent upon the views of BCN contrary to the needs of the individual patient. This corresponds with a study by Watts et al. where the perspectives of nurses on provided care to cancer patients was studied. <sup>12</sup>

BCN considered the majority of the elderly breast cancer patients in their practice as strong patients with enough support, and who found it difficult to ask for help. These views seem contradictory, as BCN state that patients receive enough support and, simultaneously, they display struggle with asking for help. Yet BCN conclude that patients have enough support, although BCN also identified patients' difficulty asking for support. No literature is found to confirm this result.

The majority of BCN were caring and adapted their care to the weaknesses of the patients. One BCN said she used personal strengths of patients to give psychosocial care. Utilizing the strengths of patients is an important factor when increasing self-management <sup>8</sup> However, this study shows that it is uncommon for BCN to use the strengths of the patient in their psychosocial care. This compares with a study from LeRoy, 2013, which shows that using patients' strengths is not a dominant approach in care by health providers, which includes BCN.<sup>22</sup>

# **Practical implications**

Results of this study show similar and ambiguous views of BCN on several mental and social strengths and weaknesses. Firstly, BCN should be aware of their views and the influence they might have on the effectiveness of psychosocial care. Secondly, they should realize that they may be adapting their care without concentrating on patients' needs, but on their own views. When adapting patient care, BCN should focus more on strengths of patients instead of their weaknesses.

# Strengths and limitations

Two interviews were incomplete due limited time. This might result in missing data on the topics and total results; this is a limitation of the study.

Participants came from different regions in the Netherlands, with work-experience varying from one to sixteen years, and they are in the age category between 30 and 64. These aspects result in relevant themes for BCN in the Netherlands, and can be considered as a strength of the study.

### Conclusion

The principle findings of this study were that BCN perceive two types of patients: the mentally and socially strong patient, and the mentally and socially weak patient. Yet BCN were ambiguous on their views on mental and social strengths and weaknesses that result in psychosocial care tailored to views of individual BCN rather than the needs of patients. Most BCN are mainly focused on the weaknesses of patients, while a minority use patients' strengths when providing care.

### Recommendations

Further research needs to be conducted to explain the differences in views, how this influences elderly breast cancer patients, and the effectiveness of psychosocial care and self-management. This knowledge is important to give effective tailored psychosocial care, which does not depend on the individual views of BCN, but on the needs of elderly breast cancer patients.

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# **Tables**

Table 1. Characteristics of participants

Participant	Age	Working experience	Function	Mamma care related education	Region Netherlands
1	44	5 years	RN and MCV	Mamma care education	Urban region
2	30	6 years	RN and MCV	Oncology education	Urban region
3	55	11 years	RN and MCV	Mamma care education	Urban region
4	38	7 years	RN and MCV	Mamma care education	Urban region
5	53	16 years	RN and MCV	Oncology education	Urban region
6	51	1 year	RN and MCV	Oncology education	Urban region
7	62	16 years	RN and MCV	Mamma care education	Rural region
8	44	5 years	RN and MCV	Oncology education	Rural region
9	64	12 years	RN and MCV	Oncology education	Urban region
10	57	5 years	RN and MCV	Oncology education	Rural region
11	51	2 years	RN	None	Rural region
12	53	6 years	RN and MCV	Oncology education	Rural region

Table 2. Main topics of interview guide

Introduction
How do you see elderly breast cancer patients?

Topics
Social strength
Social weaknesses
Mental strength
Mental weaknesses
Adaption of care