

Participation in Treatment Decision-making
The experiences of older women with breast cancer

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BACKGROUND

Worldwide, cancer is a leading cause of death. Of all cancers, breast cancer is the most common type in women (1), mainly diagnosed in older adults. In the rapidly ageing Dutch population, the prevalence of breast cancer in women over age 70 will double from 3,5% in 2000 to 7% in 2015 (2).

Different types of treatment interventions are available for breast cancer, including surgery, chemotherapy, and radiotherapy. There is no agreement on what is the best treatment in older women (3). Additionally, large individual variations in physical and mental conditions and personal preferences complicate individual treatment decisions in this group (2).

In the past three decades, the number of cancer patients who prefer participation in these difficult treatment decisions has increased (4). A recent review defines participation in treatment decision-making (TDM) as “making an autonomous decision in medical treatments or by sharing it with the physician.” Patients who delegate decisions to the physician do not participate, according to this definition (4).

With regard to participation in TDM, three models have been proposed. In the paternalistic model, the physician informs the patient and makes the decision. In the informed choice model, the physician informs the patient, and the patient takes part in the decision-making. In the third model, the so-called shared decision-making model, physician and patient share information and take steps to participate in the process of TDM (5). According to the above-mentioned review patients do not participate in the paternalistic model, but they do in the other two models (4).

Shared decision-making, which has no shared definition (6), is increasingly used in breast cancer patients (7). Many studies, mainly focused on young women, link shared decision-making with positive outcomes, such as improved quality of life (QOL) and patient satisfaction (8-10). Similar outcomes were seen in one of the rare qualitative studies aimed at older women with breast cancer (11). Two quantitative studies focussed on U.S. women explored women who participate in TDM also perceived greater self-efficacy in interacting with physicians (12) and less bodily pain (13).

In spite of these positive outcomes, 38% of all breast cancer patients prefer not to participate (14). They experienced a complex process of multiple options, time pressure, and they can be emotionally overwhelmed by TDM (15,16).

Little research has been carried out to determine if older women prefer to participate in TDM, and the existing studies give an ambiguous picture. One study indicates that older cancer patients preferred a more paternalistic style in TDM than younger patients (17). This corresponds to a previous study, which reported that older women feel comfortable leaving

decisions to physicians because they feel the physician is the expert (12). In contrast, two recent qualitative studies show that Canadian and U.S breast cancer patients do prefer to participate in the TDM by asking health care workers questions about treatment options (15,18). So, although some research is done, these were focussed on countries with health care systems different from the Dutch. In addition, various outcomes and the limited amount of the studies focussed on older women result in a lack of knowledge in how these women experience (non-)participating in TDM.

Oncology nurses play an important role in the care for older breast cancer patients. They give practical information and support these women in all aspects of care (19). Oncology nurses can support older breast cancer patients in participation in TDM by coaching them to engage in discussions about treatment options and the probability of success with their physician (20). When oncology nurses gain more insight in the experience of participation in TDM, they can improve their support and more effectively encourage patients to participate. And as studies suggest, oncology nurses may thus indirectly contribute to an increased QOL (8-10).

Problem statement

Although breast cancer is mainly diagnosed in women aged 70 years and older, experiences in participation in the decision-making process have rarely been investigated in this population. In studies in younger patients, participation in TDM is linked with positive outcomes such as improved QOL. In spite of these encouraging results, research shows that more than a third of all breast cancer patients prefer not to participate in TDM. Only four studies focus on older women, but all were carried out in U.S. and Canadian populations. Additionally, they give an ambiguous view of the TDM preferences among participants. Therefore, further research is needed in this area.

Aim

The aim of this research is to explore and describe the experience of participation in TDM for older woman with breast cancer. Understanding their experiences may improve the support provided by healthcare workers, such as oncology nurses, to enhance participation of these women in TDM.

Research question

How do women over 70 years of age who have been treated for breast cancer experience (non-)participation in the TDM process?

METHODS

Design

To answer the research question, a qualitative design with thematic analysis by Boeije (21) was used, which is influenced by the grounded theory approach. This design was applicable for this study because it intended to explore personal experiences of older women with breast cancer in their own words, in detailed understanding (21-23).

Participants

The general population consisted of women aged 70 years and older who had been treated for breast cancer during the last two years. Purpose sampling took place at breast cancer policlinics of two general hospitals in average-sized cities in the northern part of the Netherlands. Eligible women had to speak Dutch and had to be aged 70 years or older, at the time of breast cancer diagnosis. They had completed surgery, radiotherapy and/or chemotherapy as treatment for breast cancer within the last two years. Between February and April 2013, oncology nurses at the policlinics selected participants from patient records. Seventeen women were eligible. Studies that used the grounded theory approach reported that a range of ten participants could give data saturation (21,24). Therefore, it was decided that ten women would suffice. Although the researcher had no influence on this selection, a broad sampling (25,26) in variation of age, marital status and type of treatment was achieved and planned. Studies (15,17,19,27) showed that these variables could influence the TDM process.

Procedure

Recruitment:

The oncology nurses informed eligible participants by telephone about the study and asked if they wanted to be interviewed. Those who agreed were called by the researcher, who introduced herself, gave additional information, and asked again if they wanted to participate. The researcher then arranged an interview appointment with the women who agreed. Participants received the informed consent form and an information letter with date and time of appointment, description of the interview questions, and the aim of the study. Participants were aware they could withdraw from the study at any time they want.

Ethical approval was received from the Dutch Isala Clinics' Medical Ethical Review Committee (number 1209110). They concluded that a complete ethical review was not necessary. The risks of participation in the study were negligible and the burden minimal, as shown in previous studies (15,18).

Data collection: The current study was one of three studies conducted by the research group 'Innovation in care of older adults'. They combined data collection of all semi-structured face-to-face interviews by using the same interview protocol and topic list (22).

In consultation with supervisors BE and CS, researcher SS transformed the research question of the current study into topics (21,23) making use of previous studies (18,28). BE added and structured these topics to the topic list of the study in which current study was nested (21). SS checked the performance of the topic list during a pilot interview with a stand-in respondent (23). Experiences from completed interviews were processed in the topic list so that interviews conducted at the start of the study were not completely identical to later ones. (21).

SS and MH, who was also member of the research group, each conducted five interviews. They received interview training from two qualitative research experts. The interviews took place at the participants' homes, after participants had signed for informed consent, with only the participant and the interviewer present. For the opening question, example of interview questions, and topics, see table 1. Interviews took between 40 and 80 minutes, to minimize the burden on respondents. At the end of each interview, responses were verbally summarized to check for accuracy and to give the participant the opportunity to comment.

Observational and methodological memos were written to describe non-verbal signals by the participant and perceptions and reflections directly after the interview to contextualize the data (21,23). During analysis, methodological memos were written about new insights and methodological decisions (21).

Data Analysis

Because participation in TDM is a complex process (7), it was difficult to predict what data would be generated and what the frame of analysis would look like (21). Therefore, the flexible approach of analyses described by Boeije (2010) applied to this study (21).

Members of the research group analysed all interviews with a focus on their own research questions. This method of maximum data collection is the least burdensome for the older and sometimes vulnerable participant.

SS and AH recorded the conducted interviews and transcribed verbatim. They read and summarized all transcripts.

Open coding SS and AH re-read the first interview line by line. Together they determined the beginning, the end, and the in vivo codes of relevant fragments (21). The codes were discussed with CS and they came to an inter-rater agreement (21). SS and AH coded the next two interviews independently. They also discussed these codes and came to an

agreement. Codes that addressed the same topic were compared (21). The remaining 26 codes were introduced in computer-assisted qualitative data analysis. Fragments of all interviews were assigned to these codes. After analyzing each interview, SS, AH, and CS discussed the fragments and codes and came to an agreement. Adapted codes were tested in a subsequent interview. After ten interviews had been analysed, no new codes were assigned, indicating that saturation had been reached (21).

Axial coding: The entire list of 26 codes was checked by SS and AH to establish if they covered the data sufficiently and were clustered as main codes into a code tree (21), supported by CS. SS made choices in codes to extract the themes regarding the experiences in participation in TDM (see table 2). To identify the themes, SS made forward-backward movements between within-case and across-case analyses (29).

During analysis, SS invited researchers who were not members of the research group to ask questions about the methods, meanings, and interpretations of the study in peer debriefing sessions (22). The quality of data and analyses are presented in table 3.

RESULTS

Seventeen women were eligible and approached by the oncology nurses. Six women declined to participate; one initially agreed to participate but refused when the researcher called because she believed sharing her experiences would be too burdensome.

The average age of the remaining ten participants was 78.1 years. All lived independently. Of the three cohabiting women, two had spouses who needed care. For sociodemographic and clinical characteristics, see table 4.

In six women, the TDM concerned a choice between mastectomy and lumpectomy, in one woman between mastectomy and no surgery. Looking back all women were satisfied with the treatment choices that were made. They all had reasonable prospects; metastases were found in none of the patients.

The women had varying experiences in (non-)participation in TDM. Seven women indicated they experienced participation at certain moments in TDM but also moments of nonparticipation. Three women indicated there had been no participation at all. The women could not answer the question how they would prefer to participate.

Themes

Major findings of this study are reported as themes. Each theme represents older women's experiences of (non-)participation in TDM. These themes are: "This is the best, and it's what we'll do." and "Choice? I had no choice", which represented nonparticipation.

The themes “Making my own decision” and “I could choose” with subtheme ‘information’ represented participation in TDM.

“This Is The Best And It’s What We’ll Do”

Most women had great faith in their physicians. They accepted the TDM made by the physician because they felt he was the expert, “You’re in good hands, they know more than I do, so go ahead.” Women went along if a paternalistic style in TDM was used, “The doctor said, this is best for you and it’s what we’ll do. Then you resign yourself to it and you say, if that’s the best, then we’ll do it”. Lumpectomy seemed easily accepted; for one woman lumpectomy meant she didn’t need chemotherapy, “The doctor immediately said breast-saving, I heard some women could choose but he didn’t ask me. I was happy that it was breast-saving.”

“Choice? I Had No Choice”

One woman experienced nonparticipation in TDM and indicated she would have liked to have the opportunity to participate. She was really upset,

“Mastectomy, the doctor said. I thought, no choice, this is it. Afterwards you think, why didn’t they do lumpectomy? Why didn’t they ask? If I could have had a choice, they had to present it to me. But they didn’t.”

Other women experienced they had no choice because they felt their backs were against the wall. One woman refused mastectomy initially,

“I said, I won’t do it! I was angry and rebellious, why do I get it now, you don’t ask for it. The doctor said: I can’t force you, you have to decide it for yourself. He said: it’s causing a lot of trouble because it’s growing fast. So, when I came home I thought, what are you doing? Anyway, you have no choice.”

Another woman said, “When you have a lump in your breast, you’re willing, you have no choice”. Another recalled, “One doctor said, there is no choice. And if I don’t do it, then things won’t go well.” One woman felt she had no choice because she was afraid to be found cocky if she questioned the physician's opinion. Another woman was afraid to die if she chose lumpectomy because she had heard about other women's experiences.

“Making My Own Decision”

Although nine women had children and three had spouses, women generally made the TDM without them, “They can’t decide for you. When I say, I won’t do it they can’t say, Mom, you should do it.” One woman had discussed her choice in TDM with her children but they said that she had to decide it for herself. One son encouraged an autonomous decision. He told his mother to be unconcerned about people’s different views and advised her to make her own decisions.

“I Could Choose”

Some women had the opportunity to choose between lumpectomy and mastectomy. The effects of chemotherapy or radiation therapy were considerations in TDM. Two women based their choice on the risk of body damage.

“I could choose. I liked that, yes, I thought that was a good idea. The doctor said, remove that little lump and then radiation or the whole breast, and after that chemotherapy. At first, I said: Take it all off! What’s gone can’t be sick. But after a few days, I thought, I shouldn’t let them take it away completely. Otherwise I’m so damaged”.

Some women based their choice on the experiences of others, “The doctor asked, what do you want? I said, well, if it’s possible, breast-saving. A friend of mine never had problems with it. You still have the idea that something remains”. One woman had the feeling she had a choice in TDM because of the information she received from health care workers, “They explained everything well. It makes you feel more confident.”

Information Women received verbal information from physicians, oncology nurses, and other healthcare workers to make an informed choice in treatments, but they couldn’t remember what information exactly was given. They could ask questions at any time, also by phone, but made little to no use of this. If they did, they mainly asked oncology nurses who spoke plain language, and expected clear and honest answers. They had less knowledge of breast cancer and treatments before diagnosis. None of the women actively sought information, but sometimes their children did. The women received information leaflets, which they read sometimes. Information leaflets were targeted younger women, but overall, older patients considered the information to be sufficient. During the TDM process, none of the women actively contacted fellow sufferers.

DISCUSSION

This study showed that women over 70 years of age who are treated for breast cancer have diverse experiences with (non-)participation in the TDM process. Four themes were found. Women who experienced nonparticipation because they “delegate the decision to the physician” (4) were best captured by the first theme: “This is the best and it’s what we’ll do.” One might assume that this theme derives from the paternalistic model that was common for many years in these older women’s lives. The second theme described women who experienced nonparticipation because they felt their backs were against the wall. To the best of the researcher’s knowledge, this has not been previously described. These women felt that making the wrong decision might be fatal, so perhaps they felt safe to let the physician choose the treatment, as in the paternalistic model. Participation in TDM defined as “making an autonomous decision” (4) appeared in the third theme, “Making my own decision.” This theme was also found in a previous study (15) that indicated older women with breast cancer wanted to be independent and self-reliant in the TDM, but gave no insight in the motivation of these women. The current study showed that these women did not want to be a burden on their social environment. Most of them lived alone or their spouses were fragile; their children often had jobs, and so the women were used to making independent decisions. The informed choice model (5) and participation in TDM defined as “sharing the decision with the physician” (4) were seen in the last theme “I could choose.” Steps to be taken in participation in the shared decision-making model, such as sharing information (5) were not clearly seen in the results. Possible reasons were a lack of time and/or training for the physician (5) to apply this model. Additionally, women were not active information seekers, in contrast to subjects in a recent qualitative study (15). All women lived in small villages in the northern part of the Netherlands, with a population known for its attitude of accepting life as it is. This cultural aspect might explain their decision not to seek additional information. Although oncology nurses provided information and answered questions, their role in the TDM was unclear. They seemed not to support women’s participation in TDM. Maybe oncology nurses do not know how to support and involve women in this process, and need training on how to coach women to engage in discussions (20). Perhaps when trained oncology nurses support these women to participate in TDM, when different treatment options are offered, as in the shared decision-making model, and when women get involved in treatment discussions, they will experience participation in TDM, and feel less like they have their backs against the wall.

Limitations

This study provides unique, in-depth information about experiences of older women, but it does have several limitations. Sometimes depth in data was lacking because this study was

a part of a greater research project. Although TDM occurred recently, it is reasonable to assume that women did forget some of their experiences. So a longitudinal study should be done on how women experience participation in TDM. An additional quantitative study might reveal how women would prefer to participate in TDM. The sample represents a small population derived from one region in the Netherlands. Study in a broader breast cancer population in different parts of the country would allow generalisation. The role of oncology nurses in the TDM process was unclear. An observational study would be able to provide clarity.

CONCLUSIONS

Older women have varying experiences of (non-)participation in TDM. This study yielded four main themes that give insight into this process. A new finding is that women experienced nonparticipation because they feel they have their backs against the wall. They accept nonparticipation because they feel the physician is the expert. Women make choices in treatments based on experiences of other women. Some women make autonomous decisions. They are not active information seekers. Perhaps with more insight in the role of oncology nurses, women could get more support in the TDM process so they no longer feel they have their backs against the wall.

RECOMMENDATIONS

Further research is needed to explore the experienced participation in TDM in older women with breast cancer. Different study designs in a broader population and study of the role of oncology nurses are needed to advance knowledge of the experiences of participation in TDM. With these results oncology nurses can improve participation so that older women feel they have a choice in TDM.

DUTCH SUMMARY

Titel Participatie in de behandelingsbesluitvorming; de ervaringen van oudere vrouwen met borstkanker

Inleiding Participeren in de behandelingsbesluitvorming is nauwelijks onderzocht bij vrouwen ouder dan 70 jaar, terwijl borstkanker juist bij deze groep vrouwen het meest voorkomt. Op dit moment is onduidelijk hoe participatie in de behandelingsbesluitvorming bij oudere vrouwen met borstkanker eruit ziet.

Doel en onderzoeksvraag Het doel van deze studie is om inzicht te krijgen in hoe oudere vrouwen met borstkanker de participatie rondom de behandelingsbesluitvorming ervaren. Het begrijpen van deze ervaringen kan gezondheidszorgmedewerkers, zoals oncologieverpleegkundigen, ondersteunen om de participatie van deze vrouwen te verbeteren.

De onderzoeksvraag is: Hoe ervaren vrouwen van 70 jaar en ouder met borstkanker (non-)participatie in de behandelingsbesluitvorming?

Methode De studieopzet is een kwalitatief onderzoek, gebruikmakend van een thematische analyse. Deelnemers waren tien vrouwen met een gemiddelde leeftijd van 78,1 jaar, die werden behandeld voor borstkanker in de afgelopen twee jaar. Face-to-face semi-gestructureerde interviews werden afgenomen. De gegevens werden verzameld en afwisselend geanalyseerd met behulp van een flexibele aanpak. Na codering werden hoofdthema's rond de ervaringen in de behandelingsbesluitvorming geëxtraheerd.

Resultaten Vier thema's zijn voortgekomen uit de data-analyse: "Dit is het beste, en zo doen wij het", "Ik maak mijn eigen beslissing", "Ik kon kiezen" en "Keuze? Ik had geen keus." Citaten illustreren de ervaringen van de vrouwen.

Conclusie Vrouwen hebben verschillende ervaringen in (non-)participatie in de behandelingsbesluitvorming. Ze ervaren non-participatie omdat ze het gevoel hebben met de rug tegen de muur te staan en accepteren het omdat de arts de expert is. Sommige vrouwen maken autonome beslissingen. Vrouwen baseren hun keuzes op ervaringen van andere vrouwen. Informatie wordt niet actief gezocht.

Aanbevelingen Verder onderzoek is nodig in een bredere populatie van oudere borstkankerpatiënten. De rol van oncologieverpleegkundigen moet nader worden onderzocht om meer inzicht te krijgen in participatie in de behandelingsbesluitvorming.

Trefwoorden Oudere vrouwen, Borstkanker, Participatie, Behandelingsbesluitvorming, Ervaringen

ENGLISH ABSTRACT

Title Participation in Treatment Decision-making; The experience of older women with breast cancer.

Background Despite the fact that breast cancer is most common in women over 70 year of age, there is limited concerning their experience with the decision-making process. Participation in treatment decision-making in older breast cancer patients is unclear.

Aim and research question The aim of this research was to explore and describe the experience of participation in treatment decision-making for older woman with breast cancer. Understanding their experience may enable healthcare workers, such as oncology nurses, to improve the support they provide to older women and their participation in TDM.

Research question is: How do women over 70 years of age who are treated for breast cancer experience (non-)participation in the TDM process?

Method The study has a qualitative design using thematic analyses. Participants were ten women with a mean age of 78,1 years, who were treated for breast cancer within the last two years. Face-to-face semi-structured interviews were conducted. Data were collected and analyzed alternately using the flexible analysis approach. After coding, main themes were extracted.

Results Ten women were interviewed. Four themes emerged from the data: "This is the best and it's what we'll do", "Making my own decision", "I could choose" and "Choice? I had no choice". Quotes from the women illustrate their experiences.

Conclusions Women have varying experiences how they (non-)participate in treatment decision-making. They experience nonparticipation because they feel their backs are against the wall and accept it because the physician is the expert. Some women make autonomous decisions. Women made choices based on experiences of other women, some made autonomous decisions. They are not active information seekers.

Recommendations Further research is needed in a broader population of older breast cancer patients; the role of oncology nurses should be studied to explore experiences with participation in treatment decision-making in older women with breast cancer.

KEYWORDS Older women; Breast cancer; Participation; Treatment decision making; Experiences

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Table 1. First question, example of interview questions and topics

Questions:	Topics:
First question: can you tell what happened from the moment you thought something was not right?	
Can you tell how the decisions were taken?	(Need to) decide (what time)
To what extent did you feel you had a choice in treatments that you would get?	Who / what provided support in decisions
What factors played a role in taking decisions?	Personal considerations
Have you discussed what you thought would be important in decision-making, and if so, with whom?	Enough time for decisions Satisfied with decisions

Table 2. Code tree with main codes and sub codes

Decision making	- Process TDM - Consideration TDM
Information	- Information
Health care workers	- Trust in health care workers - Communication health care workers
Support	- Experience support - Don't want to burden environment
Treatment	- Experience chemotherapy
Care program	- Experience provided care
Breast surgery	- Dealing with body image

Table 3. Quality of data and analysis (21,25,26)

Criteria	Application
Credibility	The use of memo's and field notes Peer debriefing sessions
Transferability	Broad sampling variation A detailed thick description of the study Respondents check by summarizing interview Purposeful sampling
Dependability	Describing researcher own perceptions and reflections on the

Dependability	Describing researcher own perceptions and reflections on the interview Inter-rate agreement
Trustworthiness	The use of an interview protocol and a structured topic list Recording interviews Computer assisted data analyse
Reliability	Interview training Coding done by two researchers
Source for criteria	Data collection until saturation was reached

Table 4. Sociodemographic and Clinical Characteristics (N=10)

Characteristics	n
Marital status	
Married	3
Never married	1
Divorced	1
Widowed	5
Living situation	
In house or apartment with spouse	3
In house or apartment without spouse	5
Sheltered housing without spouse	2
Hospital of treatment	
A	5
B	5
Type of treatment	
Lumpectomy	5
Mastectomy	7
Radiation therapy	5
Chemotherapy	2
Hormonal therapy	3