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The patient's perspective of the quality of breast cancer care

The development of an instrument to measure quality of care through focus groups and concept mapping with breast cancer patients

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ABSTRACT

Quality of care is often described by professionals. However, in this study breast cancer patients participated in developing an instrument that reflects quality of care from the patient's perspective.

Through focus groups and concept mapping patients' ideas on determinants of good quality of care were generated and categorised according to similarity and importance.

Information from eight focus group interviews with a total of 72 participants yielded 221 quality of care aspects. Following reduction, 81 aspects were used for categorisation during six concept mapping sessions with 67 participants. After analysis, 55 aspects remained grouped into six clusters.

This study was conducted with a large number of breast cancer patients, undergoing the full range of treatment modalities, in different hospitals, in different areas in the Netherlands. Therefore, this set of quality of care indicators can be considered valid and suitable for the evaluation of breast cancer care as experienced by patients.

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1. Introduction

Quality of care has become increasingly important in the evaluation of health care.[1–3] In addition, the patient's perspective in the assessment of quality of breast cancer care has been recognised.[4–7] To our knowledge, however, no publication has focussed on an instrument that corresponds with the needs, opinions, and wishes of breast cancer patients and provides reliable data on all aspects of breast cancer care. First, most existing questionnaires on quality of breast cancer care have been developed by managers, insurance companies, policy makers, and healthcare professionals.[8,9] As these groups often entertain views on quality of care that are different from those held by patients,[10] the validity of these questionnaires to measure quality of care from the patients' perspective is questionable. Second, overall (generic) quality of care is usually evaluated instead of disease or category specific aspects that may differ among specific patient groups.[11]

Satisfaction questionnaires have often been used to ask for patients' opinions. Existing patient satisfaction questionnaires often provide highly skewed scores (75–90% typically satisfied)[3] and produce results in absolute scores which do not give information about the reasons behind satisfaction or dissatisfaction.[12,13] Furthermore, satisfaction questionnaires have rarely been developed through systematic interviews with patients,[14] yielding direct insight into their opinions.

To deal with these disadvantages, Sixma et al.[15] published the theoretical concept for a questionnaire that takes into account patients' expectations and experiences and measures quality of health care services from their perspective. They used focus groups (FGs), in combination with concept mapping (CM) for the generation and structuring of data on quality of health care for specific patient groups.

Kleeberg et al.[12] constructed a questionnaire based on FGs with cancer patients. This oncology questionnaire was sent to women with breast cancer as well as to women with other types of cancer. The results of the questionnaire were compared between the two groups, yet the FGs were not organised with breast cancer patients specifically. Therefore, the results of the comparison do not provide breast cancer specific aspects on quality of care. Gray[16] published results from FG research with breast cancer patients derived from only one single FG with 11 patients. The external validity of his observations is therefore limited. Other publications concerning FGs with breast cancer patients described specific categories of patients, such as older breast cancer patients and their opinions about chemotherapy[17] or women who had received a risk assessment for familial breast cancer.[18]

The aim of the current study was to develop a questionnaire that is readily available, reliable and valid for assessment of quality of care by patients who have been operated on for breast cancer.[19]

2. Patients and methods

Data for analysis on quality of care for breast cancer patients were retrieved through a qualitative approach with FGs[15,20] and CM, a method that combines qualitative methods (brain-storming sessions) and quantitative methods.[21] Concept mapping aims to produce visual representations (concept maps) of relationships between ideas generated during the qualitative phase of the process.

2.1. *Ethical aspects*

The study was approved by the Committees for Ethics in the participating hospitals. From five hospitals all patients, aged 18 years or older, who had been operated on with curative intent in the previous 15 months because of any (pre)clinical form of breast cancer ($n = 387$) were invited to participate in the FGs during the period of August 2004 until June 2005. Lists with patients eligible for recruitment were obtained from the breast nurses in the participating hospitals.

Similar eligibility criteria were used for the recruitment of participants in the FGs and in the CM, except for the period in which patients had undergone their primary treatment. Because fewer participants were needed in the CM meetings than in the FGs, this period was reduced to 12 months. As analyses of the FGs took four months, CM sessions were held four months after the FGs had been conducted. Both time-related methodological aspects resulted in a (partly) new cohort of people. For the CM 296 breast cancer patients were invited.

An invitation letter (explaining the aim and content of the study) and an application form were sent by mail to the people who met the eligibility criteria for participation 2 weeks before the FGs and CM sessions. Patients could indicate on the application form whether they wished to stay informed about the results of the study and whether they wished to participate. The people who applied received a confirmation letter and an informed consent form by mail. Signed informed consent forms were obtained from all participants before the start of the FGs.

2.2. *Focus groups*

The diversity of breast cancer treatment regimens within and between hospitals is great. Potential local hospital-related opinions and experiences may raise different issues for different patients. To overcome differences between hospitals and to increase the external validity of the instrument, eight FGs consisting of six to a maximum of 12 patients each[22] (Appendix A) were planned. Grouping of the FGs was dependent on the location in the Netherlands. A flow chart describing the development process of the study is shown in Fig. 1.

A fixed scenario was used to chair the FGs.[23] The discussion was structured by the chair if needed but neither the chair nor the secretary played an active role in the discussion. An open-ended question was asked at the end of each meeting to identify areas of breast cancer care that had not been covered during the meetings. The FGs were tape-recorded and transcribed anonymously.

2.3. *Analysis of focus groups*

Nvivo (Version 2.0, QSR International Pty Ltd., Melbourne, Australia, 1999–2002) was used by two researchers for the coding of the texts. In case of discrepancy, consensus was

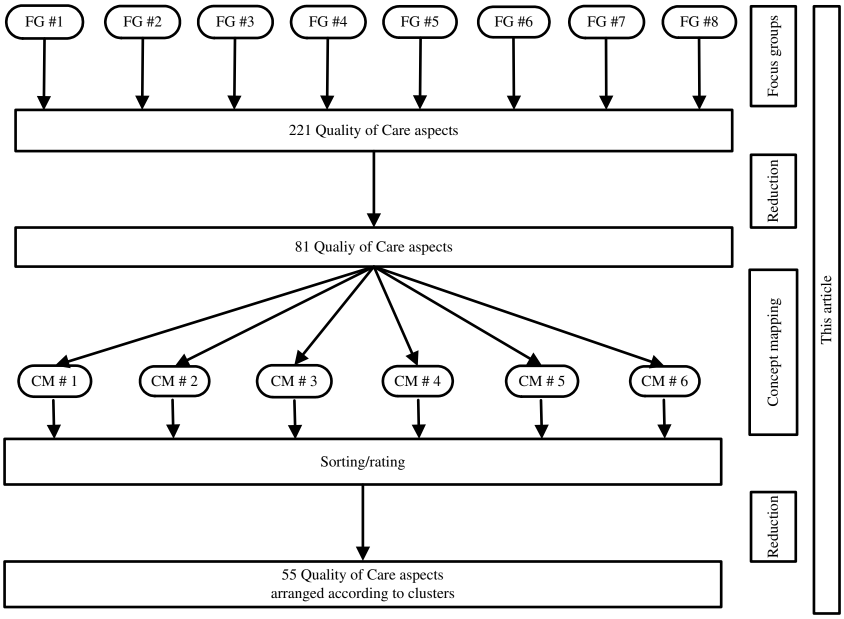

Fig. 1 – Flow chart showing the first part of the development process of the new instrument on quality of care for breast cancer.

reached through discussion. Parts of the texts were abstracted into aspects of quality of care. The number of aspects was reduced to a feasible number by using reduction criteria (Fig. 2A) that were predetermined by two of the authors (MdK, HS).

2.4. *Concept mapping*

After application of the reduction criteria to the results of the FGs, participants in the CM grouped the aspects that were left, according to similarity. Each aspect was also ranked by the

A: From focus groups to concept mapping

1. Aspect is sensitive to change (van den Nieuwenhoff, 2001).
2. Aspect is an objective opinion.
3. The major part of the target population is able to judge the aspect.
4. In case of several specific aspects describing one subject, only the aspect that is applicable to most respondents, is preserved.
5. In case of several aspects describing in different words the same experience, only the aspect that describes the aspect most clearly, is preserved.
6. Aspects that are mentioned in several FGs have preference above aspects that are mentioned less frequently.

B: From concept mapping to final set

1. In case of several aspects describing a certain aspect of care, only the aspect that describes the aspect most specifically, is preserved.
2. Aspect is applicable to most respondents.
3. Aspect is not ambiguous.
4. An aspect that is rated relatively high on importance has preference above an aspect that is rated relatively low.

Fig. 2 – Reduction criteria used during the development process of the final set of aspects.

participants according to importance[24] on a scale from one (relatively unimportant) to five (extremely important).

2.5. *Analysis of concept mapping*

The software programme Ariadne (NcGv/Talcott, Utrecht, the Netherlands, 1995) based on multidimensional scaling and hierarchical cluster analysis, was used for analysis of the CM data. This resulted in visual displays ('concept maps') depicting relationships in clusters between the aspects that had been grouped by the participants. Furthermore, a list of aspects of care arranged according to importance on the basis of the participants' data was obtained.

Reduction of the number of aspects in both steps of the process was performed by two of the authors (MdK, HS), and was aimed at a set that covered the maximum scope of care with a minimum number of aspects. This set of aspects should be suitable for a questionnaire used to describe quality of care through the eyes of breast cancer patients. Reduction criteria B were used for determination of the appropriateness of inclusion in the final set of aspects (Fig. 2). Grouping aspects according to similarity resulted in general clusters of aspects that address a particular topic.

3. Results

The overall response rate for the FGs was 25% (95/387), which exceeded the planned maximum number of participants. Consequently, 23 over-recruited patients were randomly excluded from participation. A total of 72 participants (mean age ± SD; 56.7 ± 10.6) joined in one of the eight FGs. The number of participants (mean age ± SD; 54.4 ± 10.0) in the six CM meetings was 67 (response: 70/296 (=24%). Reasons for not participating despite application concerned transportation problems ($n = 1$), emotional problems ($n = 1$), and problems with the details of the exercises ($n = 1$). For both the FGs and the CM the response rate was comparable among hospitals. Both groups were representative of the Dutch breast cancer population.[25] All meetings lasted between 1.5 and 2 h. Characteristics of the participants in the FGs and CM are shown in Table 1.

Table 1 – Sociodemographic and illness characteristics of participants

Variable	Focus groups (N = 72)	Concept mapping (N = 67)
Gender		
Female	100 (100%)	100 (100%)
Civil status		
Married	54 (75%)	54 (81%)
Not married	8 (11%)	7 (10%)
Divorced	2 (3%)	2 (3%)
Widowed	8 (11%)	4 (6%)
Education		
Primary school	3 (4%)	2 (3%)
Secondary school	38 (53%)	42 (64%)
College	28 (39%)	16 (24%)
University	3 (4%)	6 (9%)
(Mod. Rad.) Mastectomy		
Yes	37 (51%)	36 (54%)
No	35 (49%)	31 (46%)
Lumpectomy		
Yes	48 (67%)	34 (51%)
No	24 (33%)	33 (49%)
Radiotherapy		
Yes	37 (51%)	38 (57%)
No	35 (49%)	29 (43%)
Chemotherapy		
Yes	27 (38%)	32 (48%)
No	45 (62%)	35 (52%)
Hormonal therapy		
Yes	8 (11%)	9 (13%)
No	64 (89%)	58 (87%)

3.1. *Focus groups*

The diversity in experiences between the participants gave rise to interactive meetings and lively discussions. Opinions differed on how care should be provided to breast cancer patients, on group level as well as on hospital level. Sharing experiences sometimes led to unexpected emotional reactions. Patients learned from each other and responded well to each other.

One FG needed more guidance than the other, and in some groups there was time for joking (e.g. showing each other wigs and mentioning anecdotes on forgetting the prosthesis). The patient approach and the wish to be treated less as a number and more as an individual person, was a core theme throughout all FGs.

Data from the FGs were abstracted into 221 aspects on quality of care and arranged into 19 general dimensions of care. The dimensions most commonly addressed were patient education (37 aspects, e.g. 'breast nurse provides me with information on reconstructive surgery'), involvement in decision making (26 aspects, e.g. 'in case of a trainee I am asked for permission regarding his/her presence'), skills of caregivers (22 aspects, e.g. 'physician reads my file before he enters the room') and a patient centred approach (20 aspects, e.g. 'on the day of surgery I am given a choice between going home or staying overnight'). Aspects of involvement in decisions and patient approach were mentioned in most sessions (mean: 3.0 and 2.9 times per aspect respectively). All transcripts of the eight FGs contained conversations on education, involvement in decision making, skills of caregivers, continuity of care, psychological aspects and waiting times.

When patients were asked which aspects of care they would improve if they could, aspects relating to waiting times as well as the wish for a postoperative visit by the breast nurse were most frequently mentioned. Other areas for improvement concerned communication between clinicians and general practitioners and more flexible scheduling at the department of radiotherapy. Few patients felt that the quality of breast cancer care was optimal.

Application of reduction criteria to the 221 aspects derived from the FGs resulted in 81 aspects to be included in the CM sessions. The largest part of the reduction was performed on the basis of the criteria 'content similarity of aspects' and ‘frequency with which aspects were mentioned’[26] (Fig. 2A: criteria 5 and 6 respectively).

3.2. Concept mapping

Patients reported to have more problems with the similarity assignment than with the importance assignment. Some meetings lasted the maximum 2 h that were planned.

The rating of aspects according to importance on a scale from one (relatively unimportant) to five (extremely important) led to mean scores that ranged from 1.4 (‘my physician provides me with information about the existence of patient support groups’) to 4.7 (‘direct referral by the GP to the hospital when a suspicious lesion is found’).

Following the grouping according to similarity, two researchers reviewed the different cluster solutions. Over six clusters, the division of aspects into the different clusters became inconsistent with the interpretations obtained from the FG transcripts and the cluster labels that were given by the participants. Under six clusters, aspects clung together into very broad non-specific groups. Therefore, it was decided that a six-cluster solution fitted best (Fig. 3). In this figure, the distance between the aspects illustrates the degree of similarity between the aspects; those aspects that were arranged together by more participants appear closer to each other than other aspects. For example, aspect 22 (‘on the day of surgery I am operated on within 3 h after my operation was scheduled’) and aspect 49 (‘within 2 h after surgery the surgeon comes to see me’) were considered related by participants, whereas aspect 71 (‘results of diagnostic tests are given by the surgeon that I have seen before’) and aspect 3 (‘during diagnostic tests caregivers tell me what they do and see’) were felt by the participants to be less related to one another.

Consensus was achieved about adding aspects 11 (‘nurses give practical advice for the home situation on wound care and exercises’) and 15 (‘nurses give clear instructions about what I can and cannot do after surgery’) to the cluster ‘continuity of care’ (cluster 2 in Fig. 3). The researchers also agreed that aspect number 5 (‘caregivers ensure that all results are available when I have an appointment with them for that reason’) and aspect number 71 (‘results of diagnostic tests are given by the surgeon that I have seen before’) were added to the cluster ‘focus on the patient’ (cluster 6 in Fig. 3), instead of the cluster ‘continuity of care’ (cluster 2 in Fig. 3). Moreover, cluster Y was split into two separate clusters: ‘period of admission’ (top part of cluster 5 until aspect number 60) and ‘time schedule’ (bottom part of cluster 5 below aspect number 60). In a seven -cluster solution this division would have been included with a different cut-off point.

In the following reduction process (Fig. 2B), the majority of reduction was performed on the basis of the criteria ‘content specificity of aspects’ and ‘mean importance scores of aspects’ (Fig. 2B: criteria 1 and 4 respectively). ‘The hospital Professionals take into account my agenda when planning appointments’ is an example of an aspect that was rated relatively low as compared to other aspects. Most aspects that were not included in the final list addressed quality aspects in the cluster ‘Focus on the Patient’. A final list of 55 aspects was established, divided into six general clusters. Fig. 4 shows these aspects with their mean item importance scores in the third column. For example, direct referral by the general practitioner (Cluster ‘Time Schedule’) was considered the most important aspect whereas a waiting time of less than 15 min (Cluster ‘Focus on the Patient’) was perceived less important by the participants when they assessed quality of breast cancer care. The cluster ‘Time Schedule’ contained the highest mean cluster score (3.89) as opposed to ‘Period of Admission’ (2.70), the cluster with the lowest mean cluster importance score (Fig. 4: fourth column).

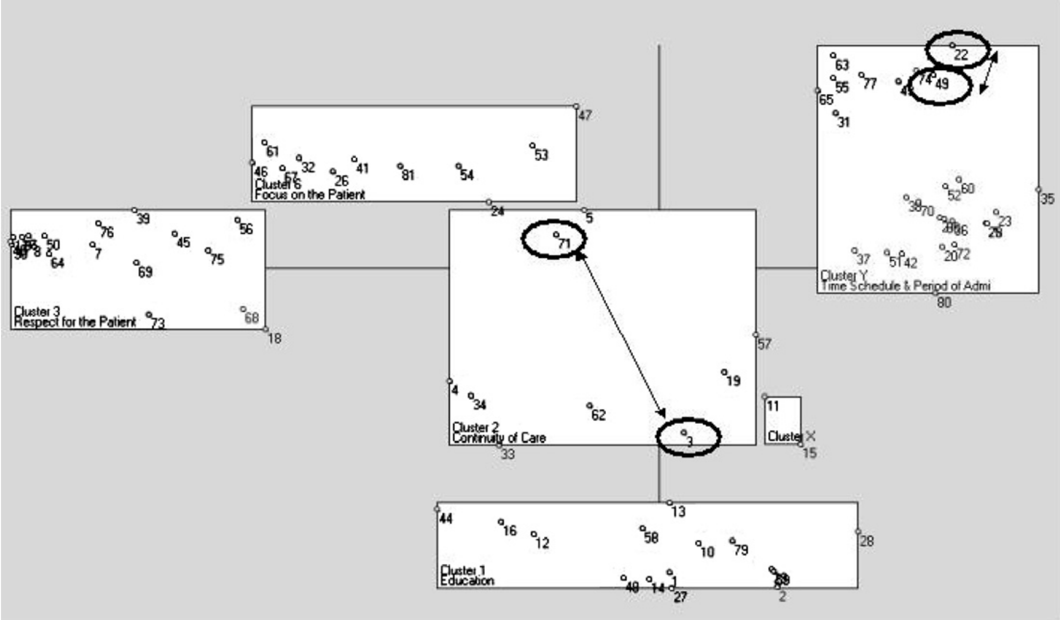

Fig. 3 – The distance between the aspects (shown as dots with numbers), not the exact location of the aspects on the map, illustrates the degree of similarity among the aspects within a cluster and between clusters.

4. Discussion

In this study a set of breast cancer specific indicators was developed that reflects quality of care from the patient's perspective, using a combination of FGs and CM meetings. A recognised difficulty in planning FGs is the number of participants to recruit and the number of sessions to hold.[22] Exploring quality of care and collecting brief opinions on this complex topic was more important to us than collecting long stories from participants. Therefore, we planned FGs with large numbers of participants. The FGs resulted in a wealth of data, concerning many aspects of breast cancer care, ranging from the breast screening programme to home care nursing after surgery. After six or seven FGs it became more difficult to gather new information and we observed the point of 'theoretical saturation'; more FGs would not yield new

# Aspects / Cluster		Mean Item Importance Score	Mean Cluster Importance Score
	Cluster #1 Education		
1.	Clear information about the risks of the treatment I have chosen.	4.2	3.63
2.	Adequate information about possible side effects of the treatment I have chosen.	4.0	
3.	Clear information about different treatment options.	4.0	
4.	physician gives clear information about diagnostic tests .	3.9	
5.	The caregiver explains exactly about the content of the treatment that I have chosen.	3.8	
6.	Openness about my current status at each moment that I ask for it.	3.4	
7.	Clear information on the period of admission.	2.9	
8.	Good information about a possible drain and/or prosthesis.	2.8	
	Cluster #2 Continuity of Care		
1.	Mutual communication on relevant information about me by the different caregivers.	3.7	3.14
2.	Openness by the physician about the length of the waiting times (for outpatient clinic, results, surgery)	3.6	
3.	During diagnostic tests a caregiver tells me what he/she sees and does.	3.5	
4.	The caregivers give me tips on what to do with the consequences of the adjuvant treatment (e.g. tiredness, baldness, swollen arm).	3.5	
5.	Clear instructions about what I may and may not do after surgery.	3.3	
6.	Follow-up by the physician/breast nurse after hospital treatment.	3.2	
7.	Clarity about which person to turn to with questions during my treatment.	3.0	
8.	A breast nurse that is always available for questions.	2.6	
9.	Caregivers give me instruction about exercises and wound care for the period after surgery.	2.5	
10.	Caregivers provide me with practical information on wound care for the home situation.	2.5	
	Cluster #3 Respect for the Patient		
1.	During treatment nurses and physicians listen with close attention to me.	3.5	3.13
2.	Caregivers work accurately.	3.5	
3.	During treatment caregivers take enough time for me.	3.4	
4.	Caregivers know about my general health status.	3.3	
5.	Caregivers take me seriously.	3.3	
6.	Caregivers are prepared for a consultation and do not prepare during my consultation.	3.2	
7.	The physician pays attention to the fear that waiting (for surgery and the results) encompasses.	3.2	
8.	There is room to give my opinion.	3.0	
9.	Carefulness with personal data.	2.9	
10.	The physician can always be reached for questions, either in person or by phone.	2.8	
11.	During treatment caregivers approach me in a respectful manner.	2.8	
12.	Caregivers approach me equally.	2.7	
	Cluster #4 Time Schedule		
1.	Direct referral by the GP to the hospital when a suspicious lesion has been found.	4.7	3.89
2.	Caregivers offer me a follow-up consultation six months after surgery.	4.3	
3.	The result of the core biopsy is known within a week.	4.3	
4.	The results of X-ray, ultrasound and fine-needle aspiration are known within a day.	4.2	
5.	Within a week after referral from my GP I have a first consultation at the Breast Unit.	4.2	
6.	Within two weeks after the results I am operated on.	4.1	
7.	All diagnostic tests take place at the same day.	4.0	
8.	In case of worries on my side I am able to come to the Breast Unit within a day.	3.6	
9.	Within three weeks after surgery I receive an announcement for adjuvant treatment.	3.3	
10.	Caregivers engage home care nursing before discharge if needed.	2.2	
	Cluster #5 Period of Admission		
1.	On the day of surgery I am operated on within three hours after I was told.	3.2	2.72
2.	Within two hours after surgery the surgeon comes to see me.	3.2	
3.	As soon as I am awake, the department nurse comes to see me.	2.9	
4.	There is a possibility to stay in the hospital until I feel well enough to go home.	2.6	
5.	Caregivers leave the choice up to me whether I go home on the day of surgery or not.	2.2	
6.	At discharge caregivers take into account my situation at home .	2.2	
	Cluster #6 Focus on the Patient		
1.	Caregivers take care that all results are available when I come to the hospital to hear them.	4.4	3.36
2.	During treatment I see the same physician every time.	4.1	
3.	The surgeon leaves the choice up to me whether I undergo breast conserving surgery or a breast amputation.	3.9	
4.	I can take part in the decision about my treatment.	3.6	
5.	My attending physician operates on me.	3.5	
6.	My attending physician provides me with the results of diagnostic tests.	3.3	
7.	Caregivers take into account my preference for a certain physician.	2.8	
8.	Within two hours after surgery the breast nurse comes to see me.	2.5	
9.	The caregivers do not let me wait in the waiting room for more than 15 minutes.	2.1	
Total # of aspects 55			

Fig. 4 – Final list of aspects after concept mapping and analysis. Participants ranked the aspects according to importance on a scale form one (relatively unimportant) to five (extremely important).

information.[27] We believe that concerning this complex subject the number of eight FGs was appropriate and that the greater part of the subject was covered.

Several aspects play a role in the external validity of the data. The study was undertaken in five hospitals throughout the Netherlands and the age range of the participants corresponded well to that of the Dutch breast cancer population in 2003. The study population was therefore a representative sample of the Dutch breast cancer population. Furthermore, as not all participants had experienced the same therapies, the variety of treatment regimens enhanced the brainstorming process and led to few dimensions of breast cancer treatment remaining untouched. On the other hand, a homogeneous sample of participants was achieved by inviting only people who had experienced breast cancer treatment. As a result, comparison between the different groups was facilitated.[28] The final aspect that contributed to the external validity was the large number of participants in both the FGs and the CM.

In our opinion, CM provides an elegant tool to differentiate between aspects on the basis of importance scores and similarity scores and making qualitative data quantifiable. In reaching the optimum set of aspects, we made some adjustments to the concept map solutions as provided by Ariadne. These adjustments addressed aspects that either led to more specific clusters or were on the periphery of the original clusters, indicating that they did not play an important role within the original clusters.

Kleeberg et al.[29] presented data suggesting that breast cancer patients showed a need for more information on, for example, effects of treatment on sexual life and therapy-related side effects. Although the latter aspect was addressed in both the FGs as well as the CM part of our study, the former aspect was not mentioned in any of our eight FGs. This may be explained by the fact that Kleeberg conducted FGs with patients with different types of cancer and applied the results to breast cancer patients illustrating that his study was not breast cancer specific.

In seven out of eight FGs the importance of patients' support groups was mentioned, consistent with other research.[30] The support groups were included in an aspect during CM. However, CM analysis showed that the aspect had been given a relatively low importance score (1.4 on a scale from one to five) compared to other aspects. Therefore, it was not included in the final list of items (Fig. 4), in which items are shown that best describe quality of care according to breast cancer patients. This difference supports our idea that a combination of several FGs and CM sessions increases the validity of the results.

According to the response to the open-ended questions, content validity of the data have would have improved if the role of the partner had been more extensively discussed. This suggestion will be included in the following steps of development of the questionnaire.

The next step is to pilot these aspects and develop a final questionnaire that could be validated internationally.

Conflict of interest statement

The authors declare no potential conflicts of interest.

Role of the funding sources

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Appendix A. Supplementary data

Fixed scenario used for the focus groups. All 'heading topics' are discussed and start with a question by the chairman on what quality of care on the concerning topic is, according to the participants. The subjects indicated by bullet points serve as a guideline for the chairman to lead the discussion on the topic as mentioned in the heading, rather than discussing all subjects in a chronological order. Whether or not the subjects indicated by bullet points are all discussed depends on the amount of information that participants have to share with each other. At the end of the discussion of each topic, participants are asked which information they would like to add to complete the information about quality of care concerning that topic. Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.ejca.2007.03.012.

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