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The quality of radiation care: The results of focus group interviews and concept mapping to explore the patient's perspective

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ABSTRACT

Background and purpose

In this study, we explore the quality aspects of radiation care from the patient's perspective in order to develop a draft Consumer Quality Index (CQI) Radiation Care instrument.

Materials and methods

Four focus group discussions with (former) cancer patients were held to explore the aspects determining the quality of radiation care. The list of aspects generated was categorised based on similarity and importance in a concept mapping procedure.

Results

Four focus group discussions revealed seven main themes related to the quality of radiation care: information provision, a patient-centred approach, professional competence, planning and waiting times, accessibility, cooperation and communication, and follow-up care. Results of concept mapping procedures revealed which items the patients considered to be most important. A radiation oncologist who is up to date about the patient's file is of paramount importance for cancer patients receiving radiotherapy.

Conclusions

The quality aspects found through focus group discussions provided useful insight into how patients experience radiation care. Furthermore, concept mapping made these results more solid. To evaluate the quality of radiation care from the patient's perspective, these quality aspects will be guiding in the development of a CQI Radiation Care.

By making many healthcare systems more demand-driven and encouraging competition between healthcare services and providers, hospitals and governments are aiming for quality improvements and more patient-centred care [1], [2] and [3]. To reach goals such as more competition and more patient centredness, the performance of healthcare organisations needs to be transparent. This transparency can be achieved not only by measuring and publishing healthcare indicators such as cost-effectiveness and safety, but also by looking at quality aspects related to the patients' perspective. Here, patients' experiences can be used as an additional source for quality assessment. Insight into patients' experiences allows caregivers to compare the quality of their performance to that of other healthcare providers, which may act

as a stimulus for improvement in the quality of care. However, the wishes and requirements of the patient must be clear if this is to be achieved [4].

As the prevalence of cancer will continue to rise over the next 20 years, it may be anticipated that patients will be looking more and more for high quality of cancer care. As cancer treatment nowadays often consists of a combination of either surgery, chemotherapy or radiotherapy, treatment has become more complex. Treatment with radiotherapy is characterised by a complex schedule of appointments planned within a relatively short period of time, in which many different healthcare providers are involved. Radiation care in the Netherlands has always been allocated to a number of hospitals. There are 21 specialist radiotherapy centres located at departments of academic (7) or general hospitals (7), independent radiotherapy institutes (6), or hospital specialising in cancer care (1). Because cancer already creates many physical and emotional problems, it is essential that patients experience the quality of radiation care as positively as possible.

Patients' opinions on quality of care are often measured using generic satisfaction questionnaires. However, these instruments may not be measuring true values and experiences of health consumers, as highly skewed scores (75–90% are satisfied) illustrate [5]. A shift has recently been seen towards questionnaires that focus more on the frequency and importance of experienced events. Examples of standardised surveys using these report-type questions are the QUOTE (i.e. QUality Of care Through the patients' Eyes) designed in the Netherlands to measure patients' experiences and the importance of quality of care aspects, or the widely used Consumer Assessment of Healthcare Providers and Systems (CAHPS) assessing the frequency of experienced events mainly in the USA [6], [7], [8] and [9]. The Consumer Quality Index, a new family of surveys in the Netherlands, comprises the best of both QUOTE and CAHPS as it not only questions patients' experiences on widely used scales, but also on the importance patients' award to the quality aspects of care [10]. This new generation of quality measures should result in information that is more useful for quality assessment and quality improvement than the 'old-fashioned' satisfaction measures [11]. Studies show that the patients' judgement of the quality of the care received is almost always based on aspects such as accessibility, communication, information services, organisation, professional competence, autonomy, facilities, follow-up care and the attitude of healthcare professionals or a patient-centred approach [12], [13] and [14].

Qualitative methods are commonly used to explore the patients' perspective of quality of care. Qualitative research aims to obtain a more in-depth understanding of people's opinions and behaviour [15]. The best way to identify the patients' ideas and preferences about radiation care is to let them discuss pre-defined topics in a semi-structured setting (better known as focus group interviews or focus group discussions) [16]. Concept mapping is a useful tool in public health research in addition to focus groups [17]. Using qualitative discussion data, concept mapping provides a way to quantify these data to discover similarities of ideas and produce quantifiable information that is used to enhance qualitative interpretations [17]. To our knowledge, both methods have previously only been used in an earlier study to gain insights into quality of care aspects for breast cancer patients [18].

Aim of this study is to explore the different quality aspects of radiation care through focus group discussions and determine their importance based on patients' input by using the concept mapping method. This study describes the first explorative phase of quality aspects of the development of a new instrument measuring quality of care from the perspective of radiation therapy patients: the Consumer Quality Index (CQI) Radiation Care.

MATERIALS AND METHODS

Focus group interviews

Four focus group interviews were organised with (former) cancer patients who had recently received radiotherapy. Three radiotherapy centres agreed to participate in the study; one hospital specialising in cancer located in the capital city Amsterdam (region A), and two located in the more Eastern area (region B) of which one is an independent radiotherapy centre and one a radiotherapy department of an academic hospital. A letter of invitation signed by a radiation oncologist was sent to eligible patients. The completion of radiotherapy treatment 6–10 weeks earlier was used as the main inclusion criterion, in addition to being at least 18 years of age and being in a sufficiently good state of health. Therefore, as well as for ethical reasons, patients who received radiotherapy as palliative treatment were excluded. After approval, participants were given further information by one of our researchers.

According to the literature, the ideal size for focus group discussions is 8–12 participants, in order to allow enough opportunities for discussing the topic. Anticipating a 10% response rate, 281 patients were invited (138 patients in region A and 143 in region B).

The focus group interviews were conducted in June 2010. During the two-hour meetings, participants were encouraged to exchange experiences, feelings and ideas about the radiation care they had received. The group discussions, which were moderated by two researchers, started with the question; 'State three positive and three negative aspects of the radiotherapy treatment received'. To structure the meetings, a list of quality aspects of care based on the literature was used as a topic list by the moderators including general dimensions of care such as organisation, expertise and attitude of health care professionals, patient education, rooms and facilities, time schedule, autonomy, psychosocial care, aftercare and continuity of care [3] and [4]. Discussions were audio-taped (with the participants' informed consent) and complete transcripts were produced. Two researchers made a descriptive thematic analysis of the quality aspects independently. Parts of the texts were abstracted into aspects of quality of care. Where there were discrepancies, consensus between the researchers was reached through discussion.

Concept mapping

Concept mapping is a qualitative and quantitative method for conceptualisation of a specific subject [19], [20] and [17], in this case the quality of radiation care received. Two concept mapping meetings were organised. Apart from the participants of the focus group discussions who were invited a second time, an additional 193 patients were invited; 75 in region A and 118 in region B.

First, the quality of care aspects derived from the focus groups needed to be reduced to a suitable number. Aspects that were not applicable to radiation care were therefore removed. Ones that were ambiguous, subjective or not relevant for all participants were eliminated next. The recommended maximum number is 98; the minimum is 40 [21]. Aspects that were mentioned in more than one focus group discussion were preferred. In the end, we choose 70 quality of care aspects, because the number needed to be divisible by five. Statements of these quality aspects were printed on a set of cards and provided to all participants.

During the concept mapping meeting, participants were asked to: 1) rate all cards on a scale from one (relatively unimportant) to five (extremely important) and spread them equally over these groups, and 2) sort the statements into clusters based on one's own opinion of similarity. Five equal groups needed to be created in order to prevent participants from judging all statements as just as important [19]. For the second assignment there was no limit on the amount of cards distributed per cluster. However, all 70 cards needed to be classified in no more than one cluster.

The rating and sorting data from all participants were analysed using the software package Ariadne which is based on multidimensional scaling and cluster analysis. First, Ariadne was used to calculate mean importance scores for all statements and mean scores for the similarity designations. As a result, the imaginary distances between statements can be calculated. This results in a two-dimensional concept map with an XY matrix, as proposed by Trochim [20]. Mean similarity is presented as general categories or clusters of aspects addressing a particular topic on the concept map. The imaginary distance between the aspects will illustrate how often these were sorted into the same cluster. Starting with 70 clusters and categorising until the content of the clusters no longer made sense conceptually, we decided to use a nine-cluster solution. Differences in importance scores between subgroups were tested by calculating Spearman rank correlation coefficients.

RESULTS

Respondents

A total of 35 patients were willing to participate in the four focus group discussions (response 12.5%) resulting in 3–14 participants per group. A total of 28 patients (response 14.5%) took part in the concept mapping meetings; 17 in region A and 11 in region B.

The patient demographics are displayed in Table 1. Most participants were male, between 70 and 79 years, and had received higher education. Furthermore, most men received radiotherapy treatment for prostate cancer, whereas most of the women had been treated for breast cancer. Two partners participated in the concept mapping session.

[TABLE 1]

Overall, the group meetings proceeded in an open and pleasant atmosphere. Patients were both motivated and dedicated, pleased to be involved in improving patient care, and found sharing experiences with peers to be very valuable. A majority of the participants completed both concept mapping tasks within 1.5–2.5 h.

Results from the focus group interviews

Differences in experiences of the radiation care received led to four interactive focus group discussions. After the fourth focus group, we believed we had reached data saturation, as hardly any new quality of radiation care aspects was introduced. During the discussions, participants had difficulty keeping focused on radiotherapy treatment instead of discussing their overall treatment. However, sharing experiences with peers and learning from each other was considered as helpful in coping.

The focus group interviews resulted in 361 different aspects concerning the quality of radiation care. These qualities of care aspects can be categorised and illustrated according to the following themes:

(1) information provision, (2) patient-centred approach, (3) professional competence, (4) planning and waiting times, (5) accessibility, (6) cooperation and communication between healthcare providers, and (7) follow-up care.

Information provision

In all four focus group interviews, the importance of appropriate and comprehensible information about radiotherapy was emphasised. This theme included aspects such as the amount of information that is received (“I think we didn’t receive enough information about radiotherapy; what the consequences can be...”), the source of the information (verbal or written) and the fact that information should be understandable for all patients (“When the doctor explained the side-effects of radiotherapy, I was dazzled by words - I didn’t understand”). When talking about the content of information, important aspects referred to information about the treatment itself, possible side-effects and the course of treatment.

Differences in opinion do exist, for example in the amount of information they prefer to receive. Some like to receive all available (written) information at once, whereas others like it to be given more in stages. A further complicating factor is that the desire for information can change over time. In addition to printed material such as books and brochures, verbal information appeared to be the most important source.

One point that was highly appreciated was an extensive intake consultation in which all the various aspects relating to the examinations and treatment are explained by the radiation oncologist. There seems to be a relatively clear desire for full details about the side-effects of treatment. Most of the experiences shared during the focus group discussions concerned these consultations with the radiation oncologist.

Patient-centred approach

A patient-centred approach characterised by a friendly and open attitude and personal attention is greatly appreciated. The possibility to ask questions and being taken seriously are aspects that were mentioned in all focus groups. Patients emphasised that they want to be treated as a person: “They ask you how you feel and how things are going every time. That feels so good; you don’t feel like a number or just another cancer patient. It makes you feel unique...”. Respect for privacy was also mentioned, for example that permission is asked when another person (e.g. a doctor in training) attends the irradiations.

Professional competence

Patients expect a radiation oncologist to be competent and skilled, although a majority find it hard to define this ‘professional competence’. Examples mentioned refer to explaining information in clear language (“His/her ability and knowledge to explain the risks and the proven statistics to me, so we can make the decision together...”) or a convincing manner (“They should give me the information in a convincing manner...”) and a decisive way of acting on behalf of the patient. However, other patients liked to be involved more in decision making. Also, a radiation oncologist should sense the desire for further explanation, psychosocial help or additional educational material. Furthermore they expect the radiation oncologist to be up to date about the patients’ file, i.e. to have appropriate knowledge of the patient’s state of health, the progress of the treatment and history. (“That radiation oncologist looked at my whole medical file. He said that he had to do some research first to see what possibilities there are. Well, as a patient that makes you feel great!”).

Furthermore, most patients trusted in the skills of the therapeutic radiographers during the technical execution of radiotherapy. However, they emphasised the feeling of powerlessness when actually receiving radiotherapy.

Planning and waiting times

Patients' experiences with the planning of the appointments were mostly positive. ("You receive a schedule, which they stick to quite well. And any changes will be discussed with you. They will also try to squeeze you in sometimes if you are early."). A good appointments system also means the absence of waiting times or short waiting times for irradiations ("I had 33 irradiation sessions and just once they were 5 min late, due to technical problems..."). The possibility of bringing along a partner or relatives was emphasised many times and highly appreciated.

Accessibility

Aspects relating to the facilities and accessibility of the radiotherapy department or centre were discussed to a certain extent. These aspects referred to the parking facilities, telephone accessibility, the reception desk, facilities in the waiting rooms and the absence of any toilets nearby. This last aspect was frustrating for patients with cancer in the reproductive or gastrointestinal tract. Problems with taxis and travelling expenses came up more frequently in one group discussion than in the others.

Cooperation and communication between healthcare providers

Participants frequently mentioned a lack of communication or miscommunication between healthcare providers ("He didn't even know when I'd had surgery..."). Especially when radiotherapy takes place outside their regular treatment hospital, good cooperation and communication are essential ("...I had chemotherapy there at the same time and the cooperation between those two hospitals was fine; those doctors really told each other everything..."). Both aspects can be seen as examples of the broader 'continuity of care' dimension.

Furthermore, patients disliked the continuous change of therapeutic radiographers, although this is an unavoidable feature of organisations nowadays ("There are so many therapeutic radiographers and you get a different one every time. That is a negative aspect, I think"). At the start of treatment, this in fact even led to feelings of distrust towards the therapeutic radiographers.

Follow-up care

When treatment is completed, patients would like to have a better picture of their follow-up care ("Actually, I think each follow-up consultation should be linked to the next..."). Patients are also interested in the progress made during treatment. A contact person (e.g. nurse specialising in radiotherapy/oncology) if problems occur after radiotherapy treatment is greatly appreciated ("I would really like to have someone who I can contact after treatment. Just in case there are problems or I have specific questions...").

Results from the concept mapping procedure

The results of the first rating assignment of the concept mapping are presented as the top 10 mean importance scores (Table 2). Quality aspects that were highly valued refer to the professional competence of healthcare providers, information services, a patient-centred approach and good cooperation between healthcare professionals and (hospital) departments. An overview of all the quality aspects and their mean importance scores as included in the concept mapping procedure is presented in Appendix A.

[TABLE 2]

Subgroup analysis based on Spearman rank correlation coefficients showed no differences between region A and B or gender. Nevertheless, some striking differences can be seen in the ranking list of importance scores. For example the statement; 'The same radiotherapist throughout the course of irradiation' was ranked third out of 70 by importance in region B, but 43 out of 70 in region A. Looking at gender differences, the availability of a 'Fixed person as the contact after completing the course of irradiation' was appreciated more by men (27/70) than by women (58/70). Furthermore, women considered a 'Radiation oncologist is familiar with my medical file' the most important aspect (1/70) whereas for men it was 8/70, and they put greater emphasis on the importance of the 'Explanation of the lines and/or tattoos' used as markers for radiotherapy. Aspects with the lowest importance scores, i.e. considered relatively unimportant, were much the same overall, referring to peer contact, waiting rooms and travelling expenses.

Concept map

Data from the concept mapping assignments yielded a graphical presentation of all the quality aspects and their interrelationships. A nine-cluster solution was chosen as this resulted in the best interpretation of clusters (Fig. 1). The distance between the aspects, which are represented as dots with numbers, illustrates

the degree of similarity between quality aspects. Clusters indicated by squares represent groups of mean statements based on similarity. The nine clusters are more or less the same as the themes derived from the focus group discussions. The density of the dots in cluster patient-centred approach illustrates the high agreement in similarity, whereas a mean cluster score of 3.57 (see Appendix A) demonstrates the high importance assigned to these aspects. In the same way, agreement exists on aspects concerning the clusters Radiation Oncologist & Irradiation Sessions, Information and Appointments & Waiting Times. However, these clusters were generally found to be somewhat less important.

[FIGURE 1]

Some aspects illustrate the discrepancy between opinions of similarity. At one point the division of aspects into nine clusters became inconsistent with the interpretation. For example, quality aspects concerning patients' autonomy in decision making, privacy and follow-up care were all classified in the same cluster therefore called Miscellaneous. Furthermore, the single dot on the concept map of cluster Peer Contact illustrates that either participants find it hard to classify this aspect in a conceptual logic cluster, or that opinions on its interpretation vary substantially.

A list of all 70 quality aspects included in the concept mapping procedure plus the clusters to which they were assigned and their mean importance scores are included in Appendix A.

DISCUSSION

In this study, we explored patients' experiences with radiation care and how important these aspects are in determining the quality of radiation care from the patients' perspective. As a result, we gained more insight into the variety and especially the importance of quality of aspects. These can be arranged in seven themes: information provision, a patient-centred approach, professional competence, planning and waiting times, accessibility, cooperation and communication, and follow-up care. All these themes correspond to the results of other studies assessing the quality of care in general as mentioned by Hall and Dorman [22] and [23], other studies assessing experiences with radiation care [13], [12] and [14] and the eight principles of patient-centred care as argued by the Picker Institute [24].

Analysing the transcripts of all four focus group discussions revealed that a patient-centred approach was a topic that was important and frequently discussed. This observation is not only supported by the results of the concept mapping procedure but is also in line with the results of studies assessing patient satisfaction with medical care [22] and [23] or cancer care [4], [12] and [13]. Furthermore, group members frequently discussed the amount and content of the information they would like to receive. This information dimension was also rated as important in the concept mapping. Patients want to receive sufficient information, but the amount and kind of information that radiotherapy patients would like to receive can change over time; this is confirmed by other studies [14] and [25]. Information provision is essential as it allows patients to prepare for the process of receiving radiotherapy [26]. There seemed to be a desire for appropriate information about the short and long-term side-effects of radiotherapy which again corresponds to previous studies on communication and information [14]. A similar result to earlier research is that poor quality of care is most commonly due to problems in receiving information and guidance [14], [27] and [28] L.E. Long, Being informed: undergoing radiation therapy. Cancer Nurs, 24 (2001), pp. 463–468. [28]. Gradually providing patient information can significantly reduce anxiety and raise satisfaction levels [29].

As the top 10 of mean importance scores illustrates, a radiation oncologist who knows the patient's medical file and history is a most important item. Furthermore, an extensive and informative intake consultation is essential as doctors are the most important sources of information for the patient [30].

The use of both focus groups and concept mapping gives a good insight into the patients' interpretation of the quality of radiation care, and both methods fit well with the aim of this study, which is to explore the different quality aspects of radiation care. In addition to focus groups alone, concept mapping differentiates between aspects according to their importance and similarity. This combination of methods provides structure and lends credibility to the data [17]. In this way, transcripts of focus groups are made quantifiable, resulting in some striking differences in the importance of quality aspects between focus groups and concept mapping. For example, men in particular emphasised the importance of nearby toilets in three out of four focus groups. This aspect was therefore included in the concept mapping procedure. However, further analysis of this aspect showed a relatively low mean importance score (1.86/5) not only for men, but also for women. This example illustrates that in the end more value is attached to aspects of

care itself than to facilities. In our opinion, the differences in importance between both methods increase the validity of our results.

There are some limitations to this study that need attention as well. First, patients in this study were selected from three participating radiotherapy centres in two regions in the Netherlands. Therefore, at this point, we are unable to generalise our conclusions for the broader population of cancer patients in the Netherlands or elsewhere. Second, we planned four focus group discussions; two in both regions.

Nevertheless, we experienced difficulty in recruiting enough participants and dividing them in equal groups. As a result group sizes varied between 3 and 14 participants which are both not ideal sizes for discussing a topic. However, experiences of patients were similar between groups. We believe four groups were appropriate since gathering new information became more difficult after the second focus group.

It is also expected that working with focus group interviews and concept mapping meetings will not give a representative sample of participants. Mays and Pope (1995) emphasise that the purpose of qualitative research is not to establish a random or representative sample of people drawn from a population, but rather to identify the people either possessing certain characteristics or live in certain circumstances called [31]. In our study, the objective was trying to understand how patients experience radiation care and importance they award to quality of care aspects. We noticed in our study that the participants' willingness and motivation to share their experiences were high. Also the more physically affected patients were absent due to the exclusion of patients receiving radiotherapy as palliative treatment since this will only cost them valuable time and effort in their end-of-life phase. As a result, experiences of those critically ill remain unclear. However, from literature it appears that similar aspects of care are important such as professional competence, personal attention, cooperation with other professionals and the continuity of care [32]. Age and gender distribution were however representative for the Dutch cancer patient population [33]. Nevertheless, the aim of this study was to explore the different aspects of quality of radiation care rather than increase the representativeness of our data for a larger population.

In conclusion, our results suggest that in order to improve the quality of care from the perspective of radiotherapy patients, time should be taken and efforts should be made to give clear and understandable information, adjusted to the individual's needs during the course of their radiation treatment. In addition, an extensive intake consultation with a radiation oncologist who is up to date on the patients' medical file and history is of paramount importance. Furthermore, a radiation oncology contact person (e.g. oncology nurse) is recommended, as this healthcare professional can provide information not only about cancer in general but also about the different treatment options and the management of symptoms [34]. Cooperation and communication between radiation oncologists and other healthcare professionals or hospitals is essential as it can optimise both the quality of treatment itself and the experienced quality of care.

Follow-up research will focus on incorporating those quality aspects of importance for patients receiving radiotherapy into a Consumer Quality Index questionnaire that assesses the quality of radiation care from the patients' perspective in a more quantitative way. In the next development phase, a draft CQI Radiation Care needs to be tested according to the CQI protocols among approximately 200 patients from over 20 radiotherapy centres, to explore the psychometric characteristics of the instrument and its ability to differentiate between radiotherapy centres [35]. An overall long term goal is to use this questionnaire as a module of a CQI Cancer Care (under development) or Breast Cancer Care [3]. In addition, it can be used complementary of the CQI Palliative Care to address the quality of palliative radiation care in specific [36]. By using a standardised instrument, the quality of radiation care between different radiotherapy centres can be compared as part of larger-scale benchmark studies.

CONFLICT OF INTEREST STATEMENT

The author(s) declare that they have no competing interests.

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TABLES AND FIGURES

Table 1

Patient characteristics of participants of focus group interviews and concept mapping sessions.

Characteristics	Focus group interviews (N = 35)	Concept mapping (N = 28)
<i>Gender</i>		
Male	20 (57%)	16 (57%)
Female	15 (43%)	12 (43%)
<i>Age (years)</i>		
40–49	2 (6%)	1 (4%)
50–59	7 (20%)	9 (32%)
60–69	10 (28%)	6 (21%)
70–79	13 (37%)	11 (39%)
80–89	3 (9%)	1 (4%)
<i>Level of education</i>		
None or lower education	3 (9%)	1 (3%)
Vocational education	11 (31%)	9 (32%)
Higher education	14 (40%)	11 (39%)
University	7 (20%)	1 (4%)
Other	0	1 (4%)
Unknown	0	5 (18%)
<i>Type of cancer</i>		
Breast	12 (34%)	11 (39%)
Gastrointestinal	5 (14%)	0
Prostate	13 (37%)	12 (43%)
Head or neck	2 (6%)	2 (7%)
Other	3 (9%)	1 (4%)
Unknown	0	2 (7%)

Table 2

Top 10 mean importance scores of quality aspects of radiation care.

	Statements of quality aspects	Mean importance score
1	Radiation oncologist is familiar with my medical file	4.36
2	Confidence in the expertise of the healthcare professionals	4.25
3	Intake consultation at which the radiation oncologist explains everything in detail	4.21
4	Cooperation between doctors from different departments or hospitals	4.19
5	Healthcare professionals who take me seriously	4.07
6	Healthcare professionals who take enough time for me	4.04
7	Healthcare professionals who give honest answers to my questions	4.04
8	Treating physician is informed about the radiotherapy treatment	3.93
9	Healthcare professionals who give me the opportunity to ask questions	3.93
10	Healthcare professionals who do their work conscientiously	3.89

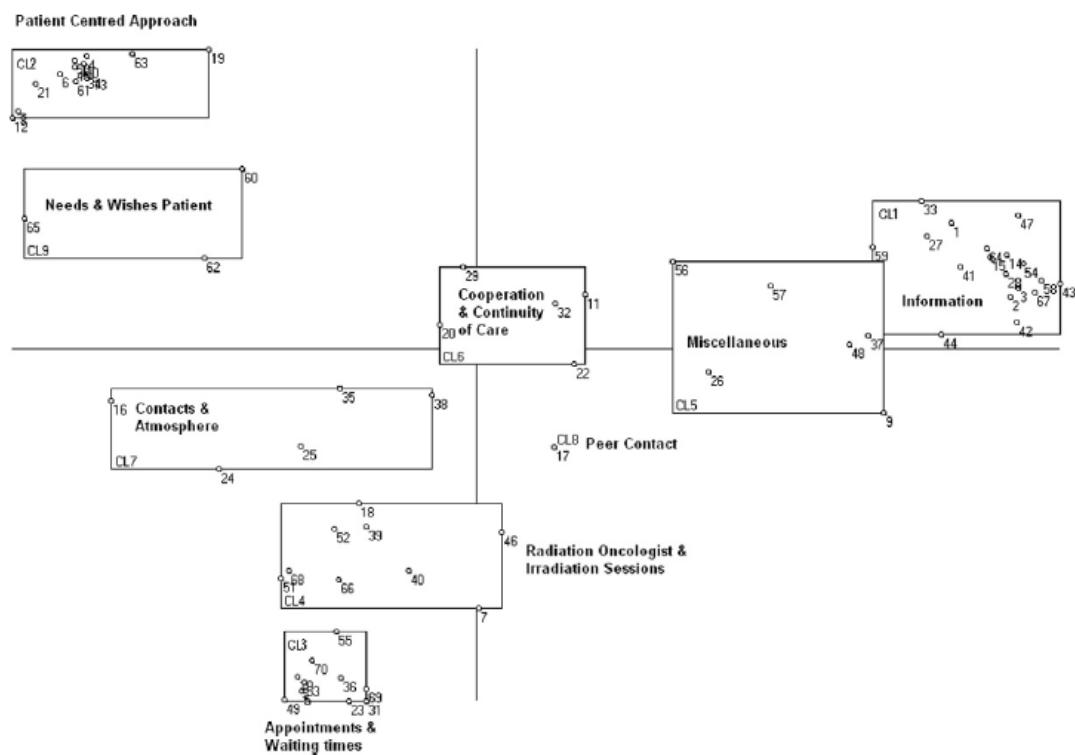


Fig. 1. Results of the analysis of a nine-cluster concept map with distances between the aspects (shown as dots with numbers) illustrating the interrelationships between aspects, and the clusters illustrating the degree of similarity between aspects.