Needs and preferences of patients with cancer

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Needs and preferences of patients with cancer

Behoeften en voorkeuren van patiënten met kanker
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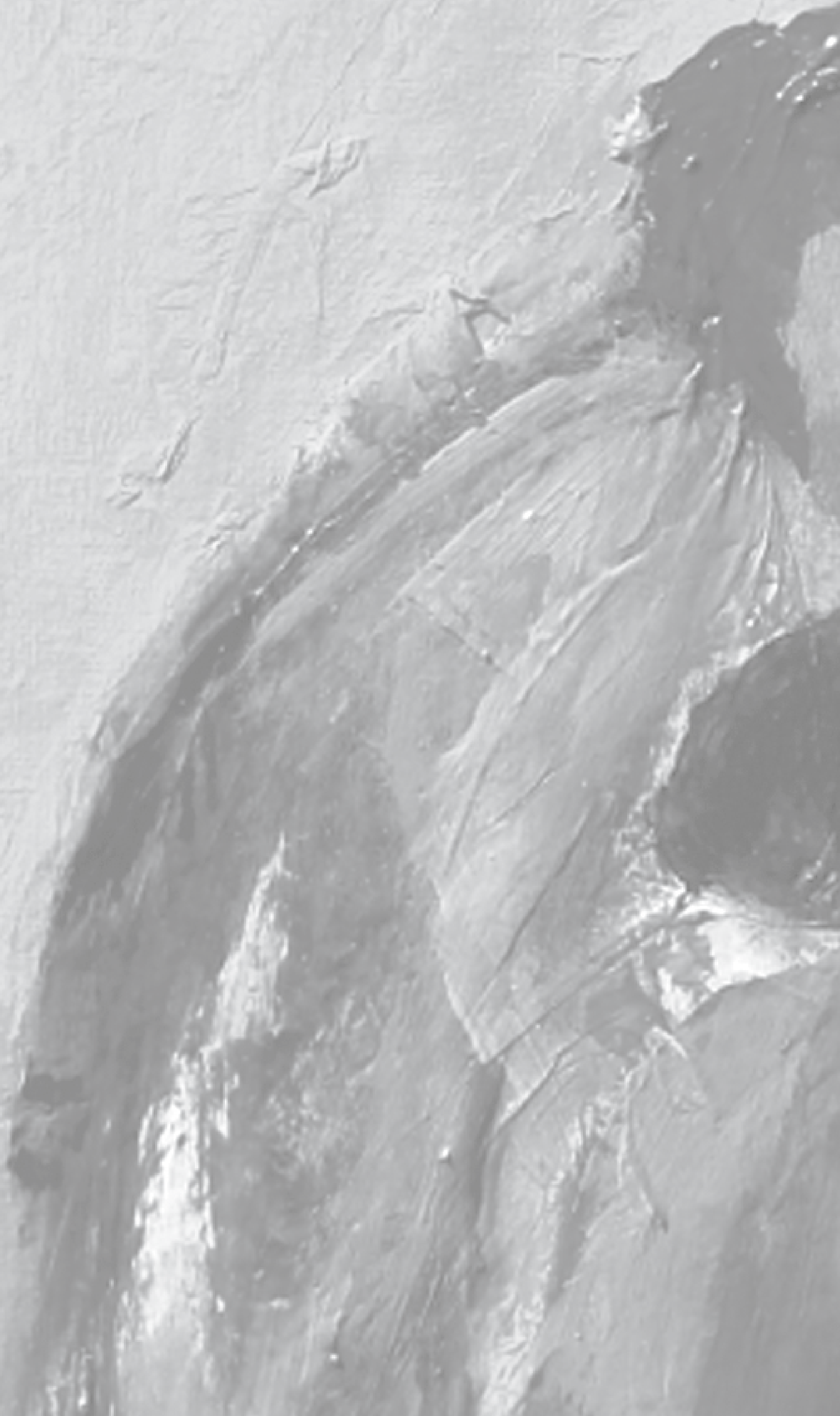
Contents

Chapter 1



General introduction

In 2008, there were 89.200 newly-diagnosed patients with cancer in the Netherlands: 46.200 men and 43.000 women. Since 2008, cancer has replaced cardiovascular disease as the leading cause of death in the Netherlands; 31% of all deaths are due to a malignancy. The exact prevalence of cancer in the Netherlands is not known, but is estimated to be about 400.000 persons (2.5 % of the Dutch population) [1, 2]. Cancer patients therefore represent a major target group in Dutch health care, and high quality care and treatment for these patients is of great importance. At the same time, assessment and evaluation of quality of care for cancer patients has become increasingly important.

Deeper insight into cancer patients' views on what matters in health care will create more opportunities to deliver true patient-centred cancer care. Therefore, the objective of this thesis is to obtain a valid and reliable insight into the cancer patients' needs and preferences concerning care and treatment in (Dutch) hospitals.

In this chapter, the background and main issues related to the objective of this thesis are described. Subsequently, the aims and outline of the thesis are specified.

A changing health care system

Health care reforms that have been implemented since the mid-1990s in the Dutch health care system have resulted in increasing market competition and decreasing governmental control. The decision-making power shifted from the government to the health care market with the introduction of financial incentives for all stakeholders and deregulation of planning and tariffs, which in turn was expected to lead to greater competition between health care providers and between health care insurers. As a consequence, there is an ongoing shift in the organization of the health care system from service-centred and fragmented to integrated and patient-centred.

Along with this changing health care system, value is increasingly placed on patients' opinions on (quality of) health care [3-6]. Consequently, for health care organizations it is important to involve patients in organizing and improving health care [7, 8]. All these developments aim to improve quality of care.

Quality of care

These new issues in the quality of care discussion raise questions such as 'What is quality of care and who is going to define it?', and 'How can this quality of care be measured in a reliable, valid and feasible way?'. The literature on quality of health care is extensive, but there is no consensus on how to define quality and there is no agreement on a systematic framework to assess it. As a result there is a wide diversity in the language used to define and operationalize this concept [9].

The most frequently-used and influential definitions of quality of care are the definition of the Institute of Medicine (IOM) and of the World Health Organization (WHO). In 1990, the Institute of Medicine (IOM) in the United States proposed the following definition, based on many years of experience and extensive research: 'Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge' [10]. More recently (2008), the WHO incorporated the patient perspective in their definition: 'Quality of care is the level of attainment of health systems' intrinsic goals for health improvement and responsiveness to legitimate expectations of the population' [9]. In these definitions 'health outcome' and 'health improvement' are defined as the main outcome. At the same time these definitions illustrate that the opinion about the strongest qualifying party is shifting from the health care professionals to the patients. The definition of quality of care from the patients' perspective used by the Netherlands Institute of Primary Health Care (NIVEL) underlines this opinion about the patient as most important qualifier: 'the totality of features and characteristics of a health care product or services, that bear on its ability to satisfy stated or implied needs of the consumers of these products or services' [4].

Donabedian proposed a framework of structure, process and outcome to assess quality of care. He defined structure as 'the attributes of the setting in which care occurs and the resources needed for health care' [11,12]. This includes material resources, intellectual resources and human resources [13]. Processes of care denote the use of resources in terms of the actual provision and receipt of care. Two key processes of care have been identified: technical processes and inter-personal processes [6, 12]. Outcomes are consequences of health care. There are two principal domains of outcome: 1) health status or quality of life and 2) user evaluation of quality of care [14]. These concepts have been used as a basis for assessing quality of care in numerous studies over many years.

Quality of care and patient-centredness

In the effort to achieve optimal quality of care, 'patient-centred care' has gained increasing attention over the past years. The concept of 'patient-centredness' was introduced by Enid Balint in 1969 [15]. She expressed the belief that each patient 'has to be understood as a unique human being'. The International Alliance of Patients' Organizations concluded in their 2007 review that 'there are numerous proposed definitions of patient-centred health care, which encompass many of the same principles, but no global accepted definition has been formulated' [16]. Frequently used are the dimensions of patient-centred care of the Picker Institute and the IOM influential definition of patient-centred health care.

The Picker Institute identified and defined the following dimensions of patient-centred care [17,18]: ‘Respect for patients’ values’, preferences and expressed needs’, ‘Coordination and integration of care’, ‘Information, communication and education’, ‘Physical comfort’, ‘Emotional support and alleviation of fear and anxiety’, ‘Involvement of family and friends’, ‘Continuity and transition’ and ‘Access to care’.

The IOM defined patient-centred care as ‘care that is respectful of and responsive to individual patient preferences, needs and values, ensuring that patient values guide all clinical decisions’ [19]. Both dimensions and definition reflect the importance of ‘respect for patients’ values, preferences and needs’ in patient-centred health care.

Patients’ needs and preferences

One of the problems in implementing patient-centredness in practice is knowing which elements are the most important [20]. Providing patient-centred care requires insight into patients’ needs and preferences concerning health care. Foot [21] defined needs as ‘the requirement of some action or resource that is necessary, desirable or useful to attain optimal well-being’. An inspiring model on this subject is ‘Maslow’s hierarchy of needs’ which, from the bottom to the top of a pyramidal structure, includes physiological needs, safety needs, the need for love/belonging, the need for respect and esteem, and the need for self-realization or self actualization. Maslow proposed that an individual will only be motivated to meet higher needs once the needs below have been satisfied [22]. According to Bonevski et al. assessment of patients’ perceived needs offer advantages. First, they allow a more direct indication of needed resources. Second, they allow the identification of the magnitude of need for help, thereby allowing some prioritization of service needs so that resources can be allocated where the need is most urgent. Third, needs assessment enables the identification of individuals and/or patient subgroups with higher level needs, thereby potentially enabling prevention or at least reduction of problems through appropriate early intervention [23].

The concept of ‘patient preferences’ in relation to health care lacks a consistent definition. Many definitions are either implied or explicitly used for the term [5]. The definition that is used by Wensing et al., states that ‘preferences are ideas about what should occur in health care systems’ [24]. According to Casper et al., ‘patient preferences result from cognition, experience and reflection and exist as the relatively enduring consequences of patients’ values’ [25]. Despite the differences in definition, there appears to be convergence in the view that patient preferences are statements made by individuals regarding their relative desirability of a range of health experiences, treatment options or health states [5].

Evaluating quality of care from the patient's perspective

Generally, the patient's perspective on quality of care is assessed using patient satisfaction questionnaires. One argument for increasing patient satisfaction is the belief that patients who are satisfied with their care are more likely to cooperate with their treatment, to continue their use of medical services and to maintain a good relationship with their physicians [26-28]. Furthermore, greater patient satisfaction has been associated with better clinical outcomes [27-29]. Satisfaction studies are therefore important and also reveal useful insight into the perceived quality of existing care. However, as the questionnaires used in patient satisfaction studies have often been developed by health care professionals, they may reflect not only the needs and wishes of patients, but also the perspective of the health care professionals [4, 26, 30]. Moreover, patient satisfaction studies evaluate the quality of existing care and patients give their opinion within the existing framework (How was it?).

In recent years there has been a trend away from global satisfaction measures towards more detailed (and individualized) measurements of patient experiences [4, 31, 32]. Patients are also more explicitly involved in the development of the instruments to measure quality of care.
Examples of recently developed measures in which patients have had a clear role in composing the questionnaire are the QUOTE (QUality Of care Through the patients' Eyes) questionnaires and the Consumer Assessment of Health care Providers and Systems (CAHPS®) questionnaires. The QUOTE questionnaires are disease-specific measures which were developed in the Netherlands and conceptualize patients' experiences with quality of care according to an importance and performance conception [4, 33, 34]. The second family of surveys, the CAHPS, is well-established and widely used in the USA [35-37]. CAHPS surveys are generic (i.e. not disease-specific) measures designed to collect data that will enable consumers to compare patients' perspectives on the quality of care.
These two families of surveys were combined to create a new family of surveys in the Netherlands, called the Consumer Quality Index (CQI). The CQI measures are based on the health care consumer's perspective and designed to assess patients or consumers experiences with health care [38]. The main goal of a CQ Index measure is to improve quality of care from the patient's perspective and to improve the opportunities for patient-centred care for individual patients.

In truly improving patient-centred care, it is important to gain insight into the patient's view on health care and into their specific needs and preferences [3, 4, 12, 16, 18, 26, 30]. To identify these preferences patients should be asked how they would design health care (How should it be?), *without* primarily paying attention to the feasibility of their wishes and *without* the influence of health care professionals and a minimal influence of researchers. To our knowledge, no such instruments to gain better insight into patients' preferences and to improve quality of care have been developed for cancer patients in general.

Cancer patients may encounter physical, existential and emotional problems. Organizing the best possible health care for cancer patients concerns aspects that are not only medical, but also includes aspects that are directly linked to the patient's quality of life, personal aspirations, needs, values and the quality of their relations. These aspects should be implemented in integrated patient-centred care.

Aim of the thesis

The focus of this thesis is the assessment of cancer patients' preferences for health care, the impact of patient- and disease-related factors on patients' preferences and the impact of integrated hospital care on the cancer patients' satisfaction with care.

This thesis has the following objectives:

- To obtain valid and reliable insight into cancer patients' needs and preferences concerning hospital care, and into patient- and disease-related factors influencing these needs and preferences.
- To examine the extent to which health care professionals are aware of patients' needs and preferences.
- To evaluate the impact of integration of hospital care on cancer patient satisfaction.

These objectives led to the formulation of the following research questions:

1. Which care aspects do patients mention when they are asked 'How would you design health care if you were in charge?'?
2. How do patients evaluate the level of importance of the care aspects mentioned in the focus group interviews?
3. Which patient- and disease-related factors have an impact on cancer patients' preferences for health care?
4. Which additional or deepening insights into context and motivation for certain needs and preferences of patients are revealed by appealing to the patients' unconscious?
5. To what extent is there concordance between cancer patients' preferences for health care and the estimate of those preferences by health care professionals?
6. What is the impact of physical integration of clinical and outpatient units on patient satisfaction?

To achieve these objectives and to answer the research questions, five studies were undertaken. The first was a qualitative study with 51 cancer patients, carried out to answer the first research question. The second study was a quantitative study among 386 cancer patients who completed a preliminary questionnaire that was based on the results of the focus group interviews (second and third research question). The third study was a qualitative study among fifteen cancer patients using a specialized interview technique, making use of pictures and images that appealed to the unconscious, to examine additional or deepening insight into context and motivation for certain needs and preferences (research question 4). The fourth study involved quantitative research among 60 health care professionals (doctors, nurses and policy makers) specialized in cancer care. These health care professionals were asked to complete the preliminary questionnaire used in the second study and to indicate preferences they thought cancer patients would have (research question 5). Finally, the fifth study was a prospective study on the impact of integration of hospital units and care processes on cancer patient satisfaction (research question 6).

Outline of the thesis

Chapter 2 reports on the results of the focus group interviews, the development of a questionnaire using the items generated during these interviews and the data provided by this questionnaire.
Chapter 3 describes the impact of patient- and disease-related factors on cancer patients' health care preferences, with a focus on gender.
Chapter 4 reports on the results of using the ZMET research method to examine additional, deepening insights into context and motivation for certain needs and preferences of patients in cancer care, and on gender differences in thoughts and feelings concerning the 'ideal' health care professional.
Next, *Chapter 5* describes the extent to which there is concordance between cancer patients' preferences for health care and the health care professionals' estimates of patient preferences, and whether gender of health care professionals affects the degree to which they correctly estimate patients' preferences.
In *Chapter 6*, the focus is on the impact of a change in hospital structure (physical integration of three units into one unit) on the hospital processes (increased meeting, cooperation and communication between professionals and patients) and on the outcome (patient satisfaction).
In *Chapter 7*, the main results of the thesis are summarized, followed by a reflection on the methodology. Finally, the general conclusions concerning the main objectives of the thesis are formulated and implications for further research and practice are described.

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Chapter 2

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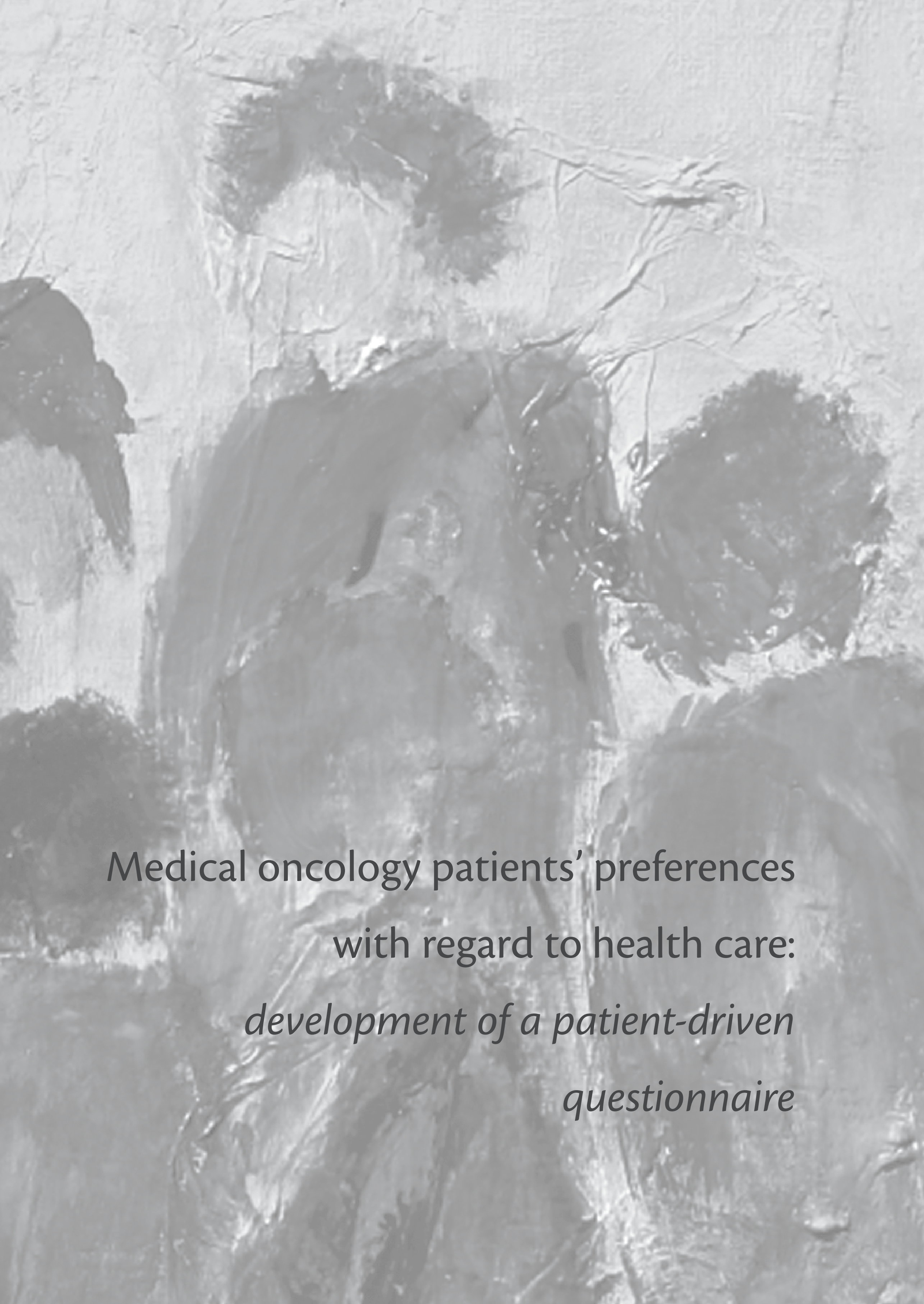

Medical oncology patients' preferences with regard to health care: *development of a patient-driven questionnaire*

Abstract

Background

To improve quality of care for cancer patients, it is important to have insight into the patients' view on health care and into their specific wishes, needs, and preferences, without restriction and without influence of researchers and health care providers. The aim of this study was to develop a questionnaire assessing medical oncology patients' preferences for health care based on their own input.

Patients and methods

Items were generated using 10 focus group interviews with 51 cancer patients. A preliminary questionnaire was handed out to 681 patients of seven Dutch departments of medical oncology. Explorative factor analysis was carried out on the 386 returned questionnaires (response 57%).

Results

Focus group interviews resulted in a preliminary questionnaire containing 136 items. Explorative factor analysis resulted in a definitive questionnaire containing 123 items (21 scales and eight single items). Patients rated expertise, safety, performance and attitude of physicians and nurses as the most important issues in cancer care.

Conclusion

This questionnaire may be used to assess preferences of cancer patients and to come to a tailored approach of health care that meets patients' wishes and needs.

Introduction

During the last decade, patient-centred care is an issue of growing importance. Patient-centred care can be defined as 'care that is respectful of and responsive to individual patient preferences, needs and values, ensuring that patient values guide all clinical decisions' [1]. Due to an increasingly competitive environment, health care organizations need to deliver demonstrable quality of care. As a result, organizations need to make a shift in health care from being service centred and fragmented to being integrated and patient centred.

Cancer patients encounter physical and emotional problems that are substantially different from patients without a life-threatening disease. Evaluation of the best possible care for cancer patients concerns aspects that not only are medical but also include aspects that are directly linked to the patient's quality of life and to personal aspirations, values and quality of their relations and needs [2-4]. Several studies assessing cancer patients' satisfaction with care show that patients who are satisfied with their care are more likely to cooperate with their treatment, to continue their use of medical services and to maintain a good relationship with their physicians [3-7]. Moreover, greater patient satisfaction is associated with better clinical outcomes [3, 4, 8-11].

Furthermore, there is an increasing wish of patients to play an active role in the quality of care they receive and of health care organizations to involve patients to determine the spectrum of care they would like to receive [12]. For these reasons, value is increasingly set on patients' opinions on (quality of) health care [13, 14]. In truly improving patient-centred care, it is important to have insight into the cancer patients' view on health care and into their specific wishes, needs and preferences, without restriction and without influence of researchers and health care providers [15]. Generally, the patients' perspective is assessed with patient satisfaction questionnaires. Satisfaction studies are very important and reveal useful insights on the quality of existing care. However using satisfaction questionnaires may present a potential pitfall, because these instruments assess the quality of existing care and patients give their opinion within the existing framework (how was it?). Moreover, these questionnaires may reflect not only the needs and wishes of patients but also the perspective of the health care professionals [2, 16-18]. Furthermore, existing patient satisfaction questionnaires often provide highly skewed scores (75%-90% typically satisfied) casting doubt on their ability to measure patient dissatisfaction [11, 18]. In recent years there has been a trend away from global satisfaction measures towards a more detailed and individualised measurement of patient experiences [19]. Still, questionnaires used in this type of research are mostly developed by health care professionals with only a limited input of patients.

To identify the preferences of cancer patients in health care, it is important to ask them in a standardized unrestricted way (how should it be?) how they would design health care, without primarily paying attention to the feasibility of their wishes and without the influence of health care workers. To our knowledge, no such instruments to improve quality of care exist for cancer patients in general. Therefore, the aim of this study was to develop a questionnaire assessing cancer patients' preferences for health care, based on their own input.

Patients and methods

Study design

The study consisted of two consecutive phases:

- a qualitative phase in which items for a preliminary questionnaire were generated through focus group interviews [20-22].
- a quantitative phase in which the preliminary questionnaire was tested in a large group of patients.

The research protocol was approved by the Medical Ethics Commission of the University Medical Center Utrecht.

Generating the preliminary questionnaire

Patients and methods

Patients for the focus group interviews were recruited by medical oncologists of the Department of Medical Oncology of the University Medical Center Utrecht during consultation at the outpatient clinic. In addition, patients were approached for participation during meetings of the Dutch Federation of Cancer Patient Organizations. Eligible patients should have a sufficient physical condition to participate in the interview and should also speak and understand the Dutch language. Eligible patients received a letter to inform them about the aim and procedure of the study and the importance of their participation. Participants were assured that their information would be kept confidential and that the data would be processed anonymously.

Focus groups consisted of four up to eight participants per group. During the interviews (lasting for 2 h), only one question was put forward by the panel leader: 'How would you design health care if you were in charge?' Participants were stimulated to exchange individual opinions and experiences and to express feelings, views and ideas, without interference and control by the panel leader. They were explicitly asked to think out of the box and forget potential constraints.

The result of the focus group interview was a list of important health care aspects, conceptions, ideas and points of view. New focus groups meetings were organized until data saturation occurred [23].

Data-analysis and generation of the preliminary questionnaire

Each interview was digitally recorded and a complete transcription was generated. A summary of the focus group interview was presented for approval to the participants. Next, the interviews were processed by the software program Nvivo© (Version 2.0; SR International Pty Ltd., Melbourne, Australia 2002) for data processing and analysing such as classifying, sorting, arranging and coding large amounts of qualitative information. Text fragments were coded by two authors (HW and MdH), working independently. In case of discrepancy, consensus was reached through discussion. Codes of the text fragments were set down in an analysis diagram, consisting of three levels of decreasing detail: item level, scale level (items were categorized in scales) and topic level (scales were categorized in topics). For example, participants of the focus group interviews mentioned short waiting periods at the outpatient clinic (diagnostic tests, consultation, treatment) to be important. We categorized this as follows - item level: time spent at the outpatient clinic as short as possible; scale level: waiting periods; topic level: organization of the hospital. Each statement explicitly expressed during the focus groups was classified in the analysis diagram in this way.

Each focus group interview was analysed according to this approach. During this process the classification was revised continuously. Items brought up in only one focus group interview were not included in the questionnaire. After 10 focus group interviews, data saturation was reached.

Based on the result of the focus group interviews, a preliminary questionnaire was generated. Items mentioned during the focus groups were translated into questions evaluating the level of importance on a four-point scale, ranging from ‘Not important’ (1), ‘Somewhat important’ (2), ‘Important’ (3), to ‘Extremely important’ (4). To specify for respondents what was exactly meant by a question, sometimes examples mentioned by patients during the focus groups were added (see Appendix 1). In these cases patients were only required to answer the main question.

Using this preliminary questionnaire, we also asked patients to indicate priorities by ranging the topics in order of importance. Additional items assessed sociodemographic and medical data-debriefing questions and an open-ended question asking patients if there were additional important topics in their treatment and care that were not included in the questionnaire. An instruction for completing the questionnaire was included.

Testing the preliminary questionnaire

Patients and methods

Before submitting the preliminary questionnaire to a broad sample of patients, a concept version was tested for feasibility in eight patients. Only minor changes of an explanatory nature had to be made.

Next, 100-150 questionnaires (depending on the size of the hospital) were distributed to Departments of Medical Oncology of the University Medical Center Utrecht and six affiliated hospitals in the region of Utrecht, the Netherlands. Doctors and nurses of these departments handed out the questionnaires to an unselected sample of consecutive cancer patients. The questionnaires were encoded by hospital. A cover letter informed patients about the aim of the study and the importance of their input. Respondents were assured that their answers would be kept confidential and that the data would be processed anonymously.

A phone number and email address to contact the project manager were provided. Respondents could complete the questionnaire at home and send it back anonymously in a self-addressed pre-stamped envelope. A reminder was sent to each patient after 4 weeks.

Data analyses

Data were analysed using the Statistical Package for the Social Sciences version 14.0 (SPSS Inc., Chicago, IL). Factor analysis (principal component analysis) with Varimax rotation was carried out. Communalities, eigenvalues, scree plots, explained variance and factor loadings were examined to determine the factor structure. Items with a factor loading ≥0.40 were included into scales [24, 25]. Items with a factor loading <0.40 were selected or rejected for scale construction by two of the authors (HW and AdG) based on content validity, item scores (selected items > 70) and applicability of the item for the entire patient population. Items that did not fit in a scale and were considered to be important and relevant for the entire patient population were included in the final questionnaire as single items.

Next, the scores of scales and single items were transformed to a scale of 0-100 by using the following formula: $F=((i_1 + i_2 + \dots + i_n) - n) \times 100/3n$ (n = number of items). High scores indicate high levels of importance.

Reliability of the scales was examined with the internal consistency coefficient (Cronbach's alpha) and the mean inter-item correlation coefficient (MICC) for each scale. Cronbach's alpha coefficient was considered sufficient if ≥0.70 [25] and MICC-values should fall in the range of 0.15 to 0.50 [26].

Results

Generating the preliminary questionnaire

Ten focus groups interviews (N = 51 patients) were needed to obtain data saturation. Patient characteristics are depicted in *Table 1*. The interviews were conducted between June 2004 and December 2005. The focus group meetings proceeded smoothly and in an open and pleasant atmosphere. Patients were pleased to be involved in improving patient care. The focus group interviews resulted in a comprehensive list of relevant issues. At scale level these issues referred to appointments (two items), waiting periods (six items), privacy (five items), consultation and transfer (six items), main health care coordinator (one item), eating and drinking (five items), regulations about visitors (three items), safety (two items), services (two items), fellow patients (three items), content of communication (13 items), process of communication (seven items), rooms and services in general (eight items), rooms and services at the out-patient clinic (three items), rooms and services at the day-care center (two items), rooms and services at the ward (17 items), support in dealing with emotions (seven items), rehabilitation (six items), physician attitude (10 items), nurses attitude (nine items), independency (10 items), physician expertise (four items) and nurse expertise (five items)

The preliminary questionnaire contained these 136 items, covering seven topics: organization (35 items), communication (20 items), rooms and facilities (30 items), counselling and support (13 items), physician and nurse attitude (19 items), individual input/autonomy (10 items) and professional expertise (nine items).

Testing the preliminary questionnaire

Between October 2006 and March 2007, questionnaires were handed out to 681 patients. In total, 396 questionnaires were returned, translating into a 57% response rate. Ten questionnaires were received after the cut-off date and were not included in the analysis. The data are based on responses from 386 patients. Patient characteristics are summarized in *Table 1*. Patients completing the questionnaire were older than the focus group patients and had more advanced disease.

The mean time to complete the questionnaire was 47 min. In all, 97% of the respondents found the questions comprehensible and 12% experienced completing the questionnaire as a burden. After completing the questionnaire, 96% of the respondents indicated it as important to participate in the study.

We found no statistically significant differences in mean item scores between hospitals. Therefore, factor analysis was carried out on the complete sample. This resulted in 21 scales (containing 115 items) and eight single items (*Table 2*). Five items were deleted because of lack of applicability for the entire patient population. These items referred

Table 1 Characteristics of patients

Characteristic	**Patients participating in the focus group interviews** *(N = 51)*	**Patients completing the questionnaire** *(N = 386)*
	Percent	**Percent**
Sex		
Male	33	35
Female	67	66
Age, years		
18-35 years	39	5
36-50 years	16	28
51-65 years	27	38
66-79 years	6	26
Unknown	12	4
Level of education		
Less than high school	NA	9
High school	NA	62
More than high school	NA	30
Type of cancer patients were treated for		
Gastrointestinal	6	21
Breast	18	45
Skin	0	1
Urological	20	10
Genital	10	10
Head and neck	4	2
Lung	4	1
Other	25	12
Unknown	14	0
Type of treatment (concurrent or previous)*		
Chemotherapy	35	78
Hormonal therapy	4	26
Experimental treatment	2	4
Radiation therapy	16	46
Chemoradiation	2	3
Surgery	35	72
Other	6	0
Unknown	37	0

Table 1 continued

Characteristic	Patients participating in the focus group interviews *(N = 51)*	Patients completing the questionnaire *(N = 386)*
	Percent	**Percent**
Stage		
Metastases present	NA	72
Metastases absent	NA	28
Years since diagnosis		
<1 year	NA	38
1-5 years	NA	39
>5 years	NA	23
Previous hospitalization		
Yes	NA	85
No	NA	15
Days of previous hospitalization		
<1 week	NA	52
1-2 weeks	NA	31
2-3 weeks	NA	8
>3 weeks	NA	9

* Patients could tick off several answers
NA, not asked

to prostheses and support devices (two items), information on hereditary types of cancer (one item), availability of physiotherapy (one item) and opportunity to participate in clinical studies (one item). Eight items were deleted because they did not fit into a scale and/or had low items scores. These items referred to the possibility for patients or their loved ones to use the kitchen to prepare food (one item), possibility for patients to wait in the consulting room instead of in the waiting area (one item), decoration of hospital wards (one item), arrangements of beds in hospital rooms (one item), availability of rooms with an outside view (one item), costs of telephone and television rental (one item), telling of test results by the doctor in person and not over the telephone, even if that means that patients have to wait longer for the information (one item) and emailing health care professionals with a question (one item).
The internal consistency of the 21 scales was sufficient for most of the scales (*Table 2*).

Table 2 Mean scores of scales and single items[a], Cronbach's alpha values and mean inter-item correlations (MICC) (for scales only)

Scale	**Number of items**	**Mean score (SD)**	**Cronbach's alpha**	**MICC**
Mistakes by professionals	2	90 (13)	0.61	0.44
Physician and nurse expertise	8	89 (11)	0.83	0.37
Consultation and transfer	3	84 (14)	0.67	0.40
Physician attitude	9	81 (13)	0.87	0.42
Patient file confidentiality	2	81 (18)	0.66	0.49
Opportunity to choose in care and treatment	5	80 (14)	0.79	0.43
Nurse attitude	7	78 (14)	0.88	0.51
Communication and information	12	77 (12)	0.84	0.30
Accessibility of services	4	77 (14)	0.66	0.33
Waiting periods	4	76 (16)	0.75	0.42
Support, counselling and rehabilitation	7	61 (20)	0.88	0.52
Alternate sources of information	4	60 (23)	0.83	0.55
Appointments	3	59 (18)	0.55	0.29
Rooms and facilities	9	57 (14)	0.77	0.27
Food and beverages	3	56 (19)	0.73	0.49
Presence of loved ones	2	49 (26)	0.75	0.60
Privacy	4	46 (22)	0.72	0.39
Patient habits	4	43 (22)	0.86	0.61
Patient interest groups	3	37 (23)	0.77	0.53
Conveniences	17	37 (16)	0.88	0.31
Fellow-patient interaction	3	17 (19)	0.57	0.30
Hospital equipment (SI)	1	84 (20)	-	-
Consultation at ER by own doctor (SI)	1	79 (20)	-	-
Written information (SI)	1	77 (21)	-	-
Support of a case manager (SI)	1	74 (24)	-	-
Continuity in care (SI)	1	72 (22)	-	-
Support by paramedical staff (SI)	1	68 (18)	-	-
Attention for nutrition (SI)	1	68 (22)	-	-
Leaving choices to doctors and nurses (SI)	1	66 (32)	-	-

[a] A higher score indicates a higher level of importance (range 0-100)
ER, emergency room; SI, single item; -, no Cronbach's alpha and MICC values calculated as this was not relevant.

Six scales ('Mistakes by professionals', 'Consultation and transfer', 'Patient file confidentiality', 'Accessibility of services', 'Appointments' and 'Fellow-patient interaction') had a Cronbach's alpha value < 0.70, probably due to the low number of items (two to four) in these scales. As the MICC was sufficient, we decided to keep these scales in the questionnaire.

The questions of the definitive questionnaire are shown in the Appendix (see appendix 2 and available as supplementary data in *Annals of Oncology* online).

Table 2 shows the mean scores of the scales and single items, ranked in level of importance. Most of the mean scores of the scales and single items were high, indicating the importance of the issues assessed by the questionnaire. Most important (mean score ≥ 80) in the opinion of the respondents were the scales 'Mistakes by professionals', 'Physician and nurse expertise', 'Consultation and transfer', 'Physician attitude', 'Patient file confidentiality', 'Opportunity to choose in care and treatment' and the single item 'Hospital equipment'. Of relatively low importance (mean score <50) were the scales 'Presence of loved ones', 'Privacy', 'Patient habits', 'Patient interest groups', 'Conveniences' and 'Fellow-patient interaction' .

Of the topics addressed in the preliminary questionnaire (before factor analysis), patients rated 'Professional expertise' as the most important aspect of health care, followed by 'Communication' and 'Counselling and support'.

Discussion

In this study, a questionnaire was developed to assess medical oncology patients' health care preferences. This questionnaire is unique as it is completely based on the input of patients. The strength of our questionnaire is the way in which the items were generated. Patients were asked in a proactive and unrestricted way to identify their preferences in health care, without primarily paying attention to the feasibility of their wishes and without the influence of health care workers. The questionnaire is solely based on the input of 51 patients from 10 focus groups, ensuring that its content really represents the needs and preferences of patients themselves. No items were added by health care workers or researchers. This approach has been used by other groups, for example patients suffering from rheumatism, inflammatory bowel disease, diabetes or specific types of cancer, such as breast cancer [17,27,28]. However, as far as we know, this is the first systematically tested questionnaire to address this issue for cancer patients in general, based on their own input and focusing on preferences instead of satisfaction.

Our questionnaire differs from most existing questionnaires, as these questionnaires assess the quality of received care instead of patients' needs and preferences. Richardson et al. [29] reviewed existing tools to assess patients' needs and found only 15 instruments, most of which related to needs in relation to symptoms and problems and not primarily to preferences for health care. They concluded that none of the questionnaires was complete for all dimensions of needs assessment. In most cases, patients were involved only at that stage when there was already a provisional or pilot version of the questionnaire.

We experienced in the focus groups that involving patients in care innovation is fruitful, motivating and inspiring. It yielded a wealth of information and judging by the considerable response, patients were closely involved in this topic and willing to make a positive contribution. Patients could indicate clearly to what requirements care and treatment of oncology patients should comply. The relevance of issues provided by the focus groups is in line with previous research. The Picker Institute Adult Inpatient survey [28] resulted in eight patient-centred dimensions of care: 'Respect for patients values, preferences and expressed needs', 'Coordination and integration of care', 'Information and education', 'Physical comfort', 'Emotional support and alleviation of fear and anxiety', 'Involvement of family and friends', 'Transition and continuity' and 'Access to care'. All these dimensions have been discussed in the focus groups and are well represented in the scales of our questionnaire.

An important conclusion of this study is that of all aspects of care, patients set highest value on treatment in a safe environment by skilled and communicative doctors and nurses. The highest scoring scales and single items are mostly related to the expertise, performance and attitude of doctors and nurses, indicating the importance of training and education. This is in line with other studies [3, 4, 9, 10, 30]. Highly qualified nurses and doctors are essential to provide optimal health care. Considerably less important are the organizational and environmental factors. Nowadays much attention is given to these factors (such as hotel services, comfort nursing, process management and all kinds of comfort-raising supplies). These types of effort are without any doubt important for the well-being of patients, but have a low impact when inadequate care (in terms of expertise and communication) is provided by doctors and nurses.

The results of this study are a valid and reliable starting point in care renewal processes and may be used to guide decisions in improving care for cancer patients. The mean scores per factor or item in order of importance may be utilized for an efficient and efficacious use of means by really focusing on the aspects of care that are the most important to patients.

Our questionnaire is applicable to medical oncology patients, regardless of type of cancer. It may be argued that such a questionnaire should focus on a specific type of cancer, as needs and preferences may differ between diagnoses. However, a multivariable analysis did not show a significant influence of type of cancer on outcome (H. Wessels, submitted). Therefore, our questionnaire can be used in heterogeneous groups of cancer patients.

Although it took patients a mean time of 47 min to fill out the questionnaire, compliance was good and few patients found the questionnaire burdensome.

The length of the questionnaire makes it unsuitable for use in daily clinical practice. If used for that purpose, a shorter version will have to be developed.

The questionnaire performed well with regard to psychometrical properties and had a high level of content validity (as illustrated by the high mean scores of scales and single items). As there is no 'gold standard' to measure patients' needs and preferences, its criterion validity could not be assessed.

A possible limitation is the relatively small sample of typical-age cancer patients in the focus groups. A comparatively large group of younger patients (<35 years) participated in the focus group interviews. It is possible that the items might have been slightly different if more age-representative focus groups had been used. Younger patients may differ with regard to needs and preferences as compared with their elder counterparts. In the focus group interviews, young people expressed specific needs and wishes concerning care and treatment, related to their phase of life and differing from those of elder patients. Further research should focus on differences between age groups.

Obviously, the results of this study apply at group level. Patients have a much differentiated range of specific needs in what they expect of cancer care, but these needs do not identify a 'uniform' patient. Although all cancer patients suffer from a life-threatening disease, they differ in biological, cultural, psychological and socioeconomic respect from each other. Moreover, each patient has his/her own frame of reference modifying their needs and preferences in health care. Clinicians, therefore, always need to customize their service.

This questionnaire may be used to assess preferences of cancer patients and to come to a tailored approach of health care adapted to their wishes and needs, either at group level (for example tailored to gender) or at the individual level. (Departments of) Hospitals may need to make changes in their health care based on such assessments.

In future research the items of the questionnaire may be used as a basis for a questionnaire to assess the experiences of patients on the most important aspects of care.

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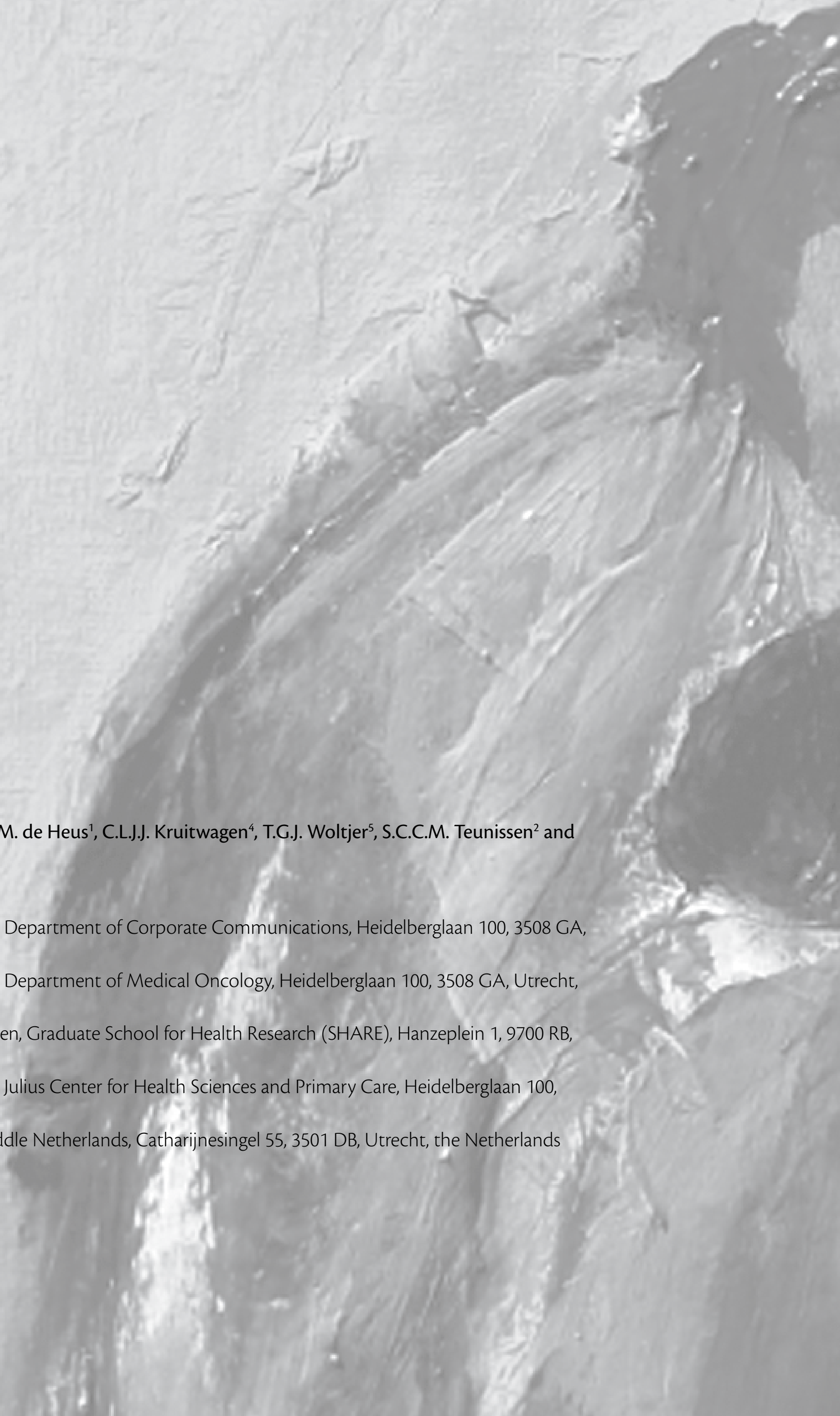
Chapter 3



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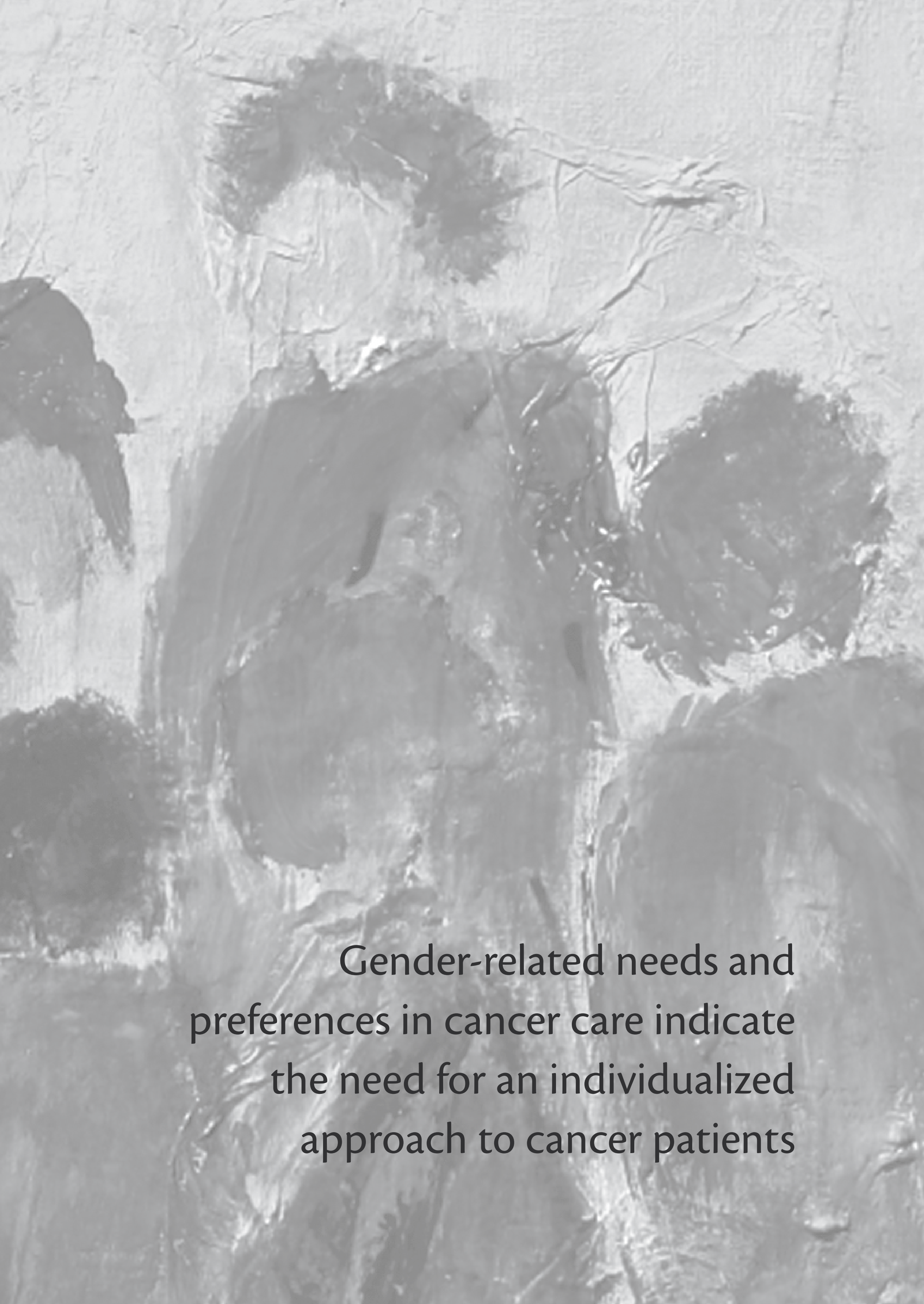

Gender-related needs and preferences in cancer care indicate the need for an individualized approach to cancer patients

Abstract

Aim

Improving quality of care for cancer patients requires insight into their specific wishes, needs, and preferences concerning cancer care. The aim of this study was to explore the impact of gender on cancer patients' needs and preferences.

Patients and Methods

Data were obtained from 386 questionnaires assessing cancer patients' preferences for health care. Multivariate regression analyses were performed with data obtained from medical oncology patients treated in seven Dutch hospitals, using the scales of the questionnaire as dependent variables.

Result

Patients rated safety, expertise, performance, and attitude of physicians and nurses highest on their list of preferences. There were significant differences between male and female patients concerning preferences in health care in 15 of the 21 scales and in two of the eight single items. Without exception, women found the care aspects mentioned in these scales and items more important than men. Multivariate regression analysis showed that, of all the patient- and disease- related factors, gender was the most important independent predictor of patient preferences.

Conclusion

Gender impacts cancer patients' needs and preferences and should be taken into account for optimal cancer care. Cancer care might be tailored toward gender, for example, with regard to the means and extent of communication, manner and extent of support, counselling and rehabilitation, consultation length, and physician assignment. The results of this study may guide health care professionals and organizations to develop a gender-specific health care approach to further improve cancer patient-centred care.

Introduction

In a report from the Institute of Medicine (Washington) from 2001, 'patient-centred care' was defined as 'care that is respectful of and responsive to individual patient preferences, needs and values, ensuring that patient values guide all clinical decisions' [1]. Today, health care organizations put effort into making their care and treatment based as much as possible on the wishes of patients. An important argument for health care organizations to increase patient satisfaction is the belief that satisfied patients are more likely to cooperate with their treatment, continue their use of medical services, and maintain a good relationship with their physicians. Greater patient satisfaction is associated with better clinical outcomes [2-7].

At the same time, health care organizations need to save costs in an increasingly competitive environment that compels them to deliver demonstrably efficient, effective, and high-quality care. As a result of these developments, the emphasis on providing health care is shifting from a service-centred and fragmented care organization to integrated patient-centred care. To further improve health care, organizations have therefore focused on assessments of specific needs and wishes of patients.

Patients with cancer are a specific subgroup of patients. They encounter severe physical, existential, and emotional problems. Evaluation of the best possible health care for cancer patients concerns not only aspects that are medical but also aspects that are directly linked to the patients' quality of life, their personal aspirations, needs, and values, and the quality of their relations. Therefore, it seems likely that cancer patients have different needs and expectations with regard to their care than other patients [2,3,8,9]. The severe impact of cancer on the patient and his/her family results in the desire for information and a more critical appraisal of the care received. Consequently, there is an increasing demand from patients to play an active role in improving the quality of care they receive [10]. To reach this goal, it is important to gain insight into cancer patients' views on health care and their specific wishes, needs, and preferences [11].

To obtain insight into the specific preferences of cancer patients, we developed a patient health care preference questionnaire, based on the patients' unrestricted input [12]. It should be noted that this questionnaire is not a satisfaction questionnaire, but a questionnaire that evaluates the importance of care aspects.

Over the last decade, there has been increasing attention on differences between men and women concerning health care. Therefore, we wondered whether the gender of cancer patients would influence their preferences as assessed by our questionnaire. Generally, men and women differ with regard to thinking, solving problems, memory, and sensitivity to danger or threat [13, 14]. The literature suggests significant differences concerning health care between men and women with respect to communication styles [15], confiding in crisis [16], coping with illness-related distress [17, 18], the use of psychosocial support [16-21], and their involvement in medical decision making [22, 23].

The aim of this analysis was to determine the impact of gender on cancer patients' preferences for health care. We compared the influence of gender with that of other patient- and disease-related variables that might influence patient preferences (including age, educational level, type of cancer, presence or absence of metastatic disease, years since diagnosis, and days of hospitalization) [24 -28].

Patients and methods

The research protocol was approved by the Medical Ethics Commission of the University Medical Center Utrecht.

Questionnaire

The development of the Cancer Patients' Health Care Preference Questionnaire is described elsewhere [12]. Briefly, items were generated during 10 focus group interviews between June 2004 and December 2005 with a total of 51 cancer patients. During the focus group interviews, participants were stimulated to have a free flow of ideas without any interruption from the interviewer.

Based on the focus group interviews, a questionnaire containing 136 items was generated. Each item evaluates the level of importance on a four-point scale, ranging from not important (1) to somewhat important (2), important (3) and extremely important (4). All scores of scales and single items are transformed to a score of 0-100, with high values indicating a high level of importance.

After a pre-test, the questionnaire was distributed among patients in care of medical oncologists from six community hospitals and one university medical center. Doctors and nurses of these departments handed out the questionnaires to an unselected sample of consecutive cancer patients. The questionnaires were encoded by hospital. A cover letter informed patients about the aim of the study and the importance of their input. Respondents were assured that their answers would be kept confidential and that the data would be processed anonymously. A phone number and email address to contact the project manager were provided. Respondents could complete the questionnaire at home and send it back anonymously in a self-addressed prestamped envelope. A reminder was sent to each patient after four weeks.

Patients did not sign a consent form for the study.

An explorative factor analysis was performed, resulting in 21 scales containing 115 items and eight single items. The process of deleting and including items into scales is described elsewhere [12]. The internal consistency of the 21 scales was sufficient for most of the scales. Six scales (Mistakes by professionals, Consultation and transfer, Patient file confidentiality, Accessibility of services, Appointments, and Fellow-patient interaction) had a Cronbach's alpha value < 0.70, probably because of the low number of items (two to four) in these scales. Because the mean inter item correlation coefficient was sufficient, we decided to retain these scales in the questionnaire [12].

Statistical analyses

Data were analyzed using the Statistical Package for the Social Sciences, version 15.0 (SPSS Inc., Chicago, IL).

Differences between male and female patients with regard to the means of the scales and single items of the questionnaire were studied using Mann-Whitney tests and by calculating effect sizes for statistically significant differences. According to Cohen's thresholds [29], an effect size (ES) < 0.20 indicates a trivial effect, an ES ≥ 0.20 to < 0.50 indicates a small effect, an ES ≥ 0.50 to < 0.80 indicates a moderate effect, and an ES ≥ 0.80 indicates a large effect. An ES ≥ 0.20 reflects a relevant difference between groups [30].

Next, each of the 21 scales was analyzed separately. First, a simple regression analysis was performed, analyzing which of the following patient and disease characteristics (independent variables) had a significant influence on the scales of the questionnaire (dependent variables): gender (male or female), age (< 50 years, 50-65 years, or > 65 years), educational level (high or low), presence or absence of metastases (as indicated by the patients), type of cancer (breast, gastrointestinal, urogenital or other), years since diagnosis (< 1 year, 1-5 years or > 5 years), days of previous hospitalization (< 1 week, > 1 week) and hospital (academic or affiliated).

Variables with a p-value <.2 in the simple regression analysis were included in a multivariate regression analysis, using a forward stepwise method. To avoid an inflated type I error resulting from multiple testing, we applied a Bonferroni-type correction procedure, considering independent variables to be significant in the multiple regression model only if they had a p-value < .0024 (p=.05/21 variables).

Results

Between October 2006 and March 2007, 681 questionnaires were handed out to patients. In total, 396 questionnaires were returned. Ten questionnaires were received after the cut-off date and were not included in the analysis. The data are based on responses from 386 patients, translating into a 57% response rate. The characteristics (self-reported) of these patients are summarized in *Table 1*.

Table 1 Patient characteristics (n=386)

	N (%)
Sex	
Male	134 (35)
Female	252 (66)
Age	
18-50 yrs	126 (33)
51-65 yrs	145 (38)
≥ 66 yrs	115 (30)
Level of education	
High	162 (42)
Low	222 (58)
Type of cancer patients were treated for	
Breast cancer	174 (45)
Gastrointestinal cancer	79 (21)
Urogenital cancer	76 (20)
Other (head and neck, lung, skin)	57 (15)
Type of treatment*	
Chemotherapy	300 (78)
Hormonal therapy	99 (26)
Experimental treatment	17 (4)
Radiation therapy	176 (46)
Chemoradiation	12 (3)
Surgery	278 (72)
Stage	
Metastases present	273 (72)
Metastases absent	108 (28)
Years since diagnosis	
< 1 year	143 (38)
1 – 5 years	145 (39)
> 5 years	88 (23)
Previous hospitalization	
Yes	324 (85)
No	58 (15)
Days of previous hospitalization	
<1 week	166 (52)
>1 week	155 (48)

* Patients could tick off several answers

The mean scores of scales and single items for the whole group and by gender are shown in *Table 2*.

Table 2 Mean (SD) scores of scales and single items for the whole group and by gender

	Total	**Gender**		
		Female	Male	
	(*n*=386)	(*n*=252)	(*n*=134)	ES
Scales				
Mistakes by professionals	90 (13)	92 (13)	87 (14)**	.37
Physician and nurse expertise	89 (11)	90 (10)	88 (11)	-
Consultation and transfer	84 (14)	86 (13)	82 (14)*	.30
Physician attitude	81 (13)	83 (13)	78 (13)**	.38
Patient file confidentiality	81 (18)	84 (18)	75 (19)***	.49
Opportunity to choose in care and treatment	80 (14)	82 (14)	77 (15)***	.35
Nurse attitude	78 (14)	81 (14)	74 (13)***	.51
Communication and information	77 (12)	79 (11)	74 (13)***	.43
Accessibility of services	77 (14)	78 (14)	73 (13)**	.37
Waiting periods	76 (16)	80 (14)	69 (18)***	.71
Support, counselling and rehabilitation	61 (20)	65 (19)	55 (20)***	.52
Alternate sources of information	60 (23)	63 (24)	54 (21)***	.39
Appointments	59 (18)	61 (17)	55 (21)*	.32
Rooms and facilities	57 (14)	58 (15)	54 (14)*	.27
Food and beverages	56 (19)	56 (19)	56 (19)	-
Presence of loved ones	49 (26)	50 (27)	48 (26)	-
Privacy	46 (22)	49 (21)	42 (21)**	.33
Patient habits	43 (22)	43 (23)	43 (21)	-
Patient interest groups	37 (23)	40 (23)	32 (22)***	.35
Conveniences	37 (16)	37 (17)	36 (16)	-
Fellow-patient interaction	17 (19)	17 (19)	17 (20)	-
Single items				
Hospital equipment	84 (20)	83 (20)	84 (20)	-
Consultation at ER by own doctor	79 (20)	80 (21)	77 (20)	-
Written information	77 (21)	80 (20)	73 (22)**	.34
Support of a case manager	74 (24)	76 (23)	71 (25)	-
Continuity in care	72 (22)	77 (20)	65 (23)***	.57
Support by paramedical staff	68 (18)	69 (19)	66 (16)	-
Attention for nutrition	68 (22)	68 (22)	67 (22)	-
Leaving choices to doctors and nurses	66 (32)	67 (31)	63 (33)	-

- : ES not calculated as the difference was not statistically significant.

*p<.05, **p<.01, ***p<.001 (Mann Whitney tests)

Abbreviations: ES, effect size; SD, standard deviation

Patients set the highest value on treatment in a safe environment by skilled doctors and nurses, able to communicate well. Of relatively less importance were the organizational and environmental factors.

There were significant differences between male and female patients concerning preferences in health care for 15 of 21 scales (71%) and for two of the eight single items (25%). For all these scales and single items, without exception, women found the care aspects mentioned in these scales and the single items more important than did their male counterparts. A moderate to large effect was found for the scales Waiting periods, Nurse attitude, and Support, counselling and rehabilitation, and for the single item Continuity in care.

The *p*-values of the simple regression analysis are shown in *Table 3*. Of the variables examined, gender, age, and type of cancer showed the lowest *p*-values. With regard to age, there were significant differences (*p*-value < .05) among age groups for 13 scales. In all these 13 scales, patients aged > 65 years showed the lowest mean scores; the scores for the age groups < 50 years and 50 – 65 years were generally comparable. In other words, older patients attached the lowest value to care aspects mentioned in 62 % of the scales (data not shown).

Because there was a clear pattern of differences in mean scores of scales and single items between breast cancer on the one hand (invariably showing higher scores) and gastrointestinal, urogenital, and other tumours on the other hand (data not shown), we dichotomized type of cancer (breast cancer versus other) for the multivariate regression analysis.

The multivariate analysis (*Table 4*) showed that gender had the strongest impact on patient preferences. It was an independent predictor for eight of the 21 scales (38%): Physician attitude, Opportunity to choose in care and treatment, Nurse attitude, Communication and information, Accessibility of services, Waiting periods, Support, counselling and rehabilitation, and Privacy.

Furthermore, type of cancer (three scales), educational level (three scales) and presence/ absence of metastases (two scales) independently influenced the degree to which patients found care aspects important.

In all scales for which type of cancer influenced the degree to which patients found care aspects important, breast cancer patients scored highest. Concerning educational level, patients with a lower educational level found communication and information and fellow-patient interaction more important than did higher educated patients. Higher educated patients found aspects related to alternate sources of information more important. The presence or absence of metastases was a predictor for rooms and facilities and for the presence of loved ones. In these cases, patients with metastases found the mentioned care aspects in these scales more important than did patients without metastases.

Table 3 *p*-values for simple regression analyses

	Gender	**Age**	**Educational level**	**Metastases**	**Type of cancer**	**Yrs since diagnoses**	**Days of hospitalization**	**Hospital**
Scales	*Female vs Male*	*<50 yrs vs 50-65 yrs vs >65 yrs*	*High vs Low*	*Yes vs No*	*Breast cancer vs other*	*< 1 yr vs 1-5 yrs vs > 5 yrs*	*< 1 week vs >1 week*	*Academic vs affiliated*
Mistakes by professionals	.004	.022	.020	.644	.001	.907	.518	.595
Physician and nurse expertise	.058	.044	.516	.368	.353	.164	.555	.026
Consultation and transfer	.017	.119	.145	.508	.279	.477	.516	.847
Physician attitude	.001	.009	.443	.027	.007	.867	.738	.979
Patient file confidentiality	.000	.000	.447	.154	.000	.361	.255	.800
Opportunity to choose in care and treatment	.000	.001	.657	.063	.001	.442	.477	.505
Nurse attitude	.000	.007	.273	.514	.001	.200	.074	.123
Communication and information	.000	.042	.000	.037	.000	.129	.303	.834
Accessibility of services	.001	.065	.727	.240	.017	.451	.860	.534
Waiting periods	.000	.000	.499	.389	.000	.163	.034	.024
Support, counselling and rehabilitation	.000	.005	.015	.042	.000	.171	.026	.123
Alternate sources of information	.000	.000	.000	.919	.000	.144	.008	.398
Appointments	.003	.011	.075	.986	.038	.420	.163	.407
Rooms and facilities	.016	.352	.039	.001	.268	.539	.213	.043
Food and beverages	.830	.742	.104	.023	.506	.903	.033	.792
Presence of loved ones	.334	.143	.886	.001	.571	.684	.954	.538
Privacy	.002	.009	.066	.624	.015	.113	.930	.812
Patient habits	.910	.129	.243	.063	.946	.633	.236	.147
Patient interest groups	.000	.004	.231	.668	.001	.056	.008	.588
Conveniences	.388	.174	.358	.002	.815	.479	.059	.645
Fellow-patient interaction	.778	.701	.000	.310	.255	.819	.270	.198

Table 4 Multivariate regression analyses

Scale	**Predictor**	***p*-value**	**Regression coefficient**
Mistakes by professionals	Type of cancer	.001	4.510
Physician and nurse expertise	-		
Consultation and transfer	-		
Physician attitude	Gender	.001	4.708
Patient file confidentiality	Type of cancer	.000	8.401
Opportunity to choose in care and treatment	Gender	.000	5.647
Nurse attitude	Gender	.000	6.822
Communication and information	Gender	.000	5.334
	Educational level	.001	4.238
Accessibility of services	Gender	.001	4.981
Waiting periods	Gender	.000	10.620
Support, counselling and rehabilitation	Gender	.001	7.901
Alternate sources of information	Type of cancer	.000	8.791
	Educational level	.001	8.274
Appointments	-		
Rooms and facilities	Metastases	.001	5.437
Food and beverages	-		
Presence of loved ones	Metastases	.002	9.410
Privacy	Gender	.002	7.281
Patient habits	-		
Patient interest groups	-		
Conveniences	-		
Fellow-patient interaction	Educational level	.000	7.038

Age, years since diagnoses, days of hospitalization, and hospital had no influence on the scales. Seven scales were not influenced by any independent variable, namely, Physician and nurse expertise, Consultation and transfer, Appointments, Food and beverages, Patient habits, Patient interest groups and Conveniences.

Discussion

Providing optimal care for patients with cancer requires insight into the true preferences and wishes of this vulnerable patient group. The aim of this study was to determine the impact of gender on cancer patient preferences for health care. Although several studies have been published on the relationship between patient characteristics and patient satisfaction [25-27, 31, 32], there is limited information about the impact of gender on cancer patient preferences.

Previous studies concerning gender and satisfaction with care have reached inconsistent conclusions. Some studies found a clear relation between patient gender and satisfaction [25, 26, 31], whereas others did not [24, 33, 34]. In the studies in which a relation was found between gender and satisfaction, men tended to be more satisfied with several aspects of care than women [25, 26, 31]. Larsson et al. [35] found that female patients receiving medical and surgical care attached significantly more value to the quality of care.

Our study showed that there are significant differences between female and male cancer patients with regard to health care preferences. Generally, men regarded most care aspects as less important than women did.

Multivariate analyses revealed that gender had much more impact on patient preferences than other patient- and disease-related factors. Women particularly attached higher value to aspects as measured by the scales Nurse attitude, Support counselling and rehabilitation, and Continuity of care. These scales and single item are related to attitude and support issues. That women attach more value to psychosocial support is consistent with other research [18, 21, 36]. Compared with men, women may access support services more readily [16,17,19-21], and they value the opportunity to share their feelings and concerns with more confidantes [20, 21]. Men tend to seek out psychosocial support from different sources than women (i.e., often from their wives) [16,17, 20, 21]. Female patients report higher levels of unmet support needs [36] and feel less satisfied even if emotional support is available [21]. The importance of nurse attitude in this study is probably related to the important role nurses play with regard to psychosocial support.

For some types of cancer (e.g., breast, ovarian, gynaecological, or prostate cancer), gender and type of cancer are obviously interrelated. If type of cancer is found to be associated with health care preferences, this may be a result of the influence of gender. As our multiple regression analysis showed, gender was more important than type of cancer for most preference variables. Having breast cancer was the strongest independent predictor for only three scales.

Contrary to our expectations, age was not an independent predictor for cancer care needs and preferences. Age was only significant in the simple regression analyses and not in any one of the final models. Satisfaction studies generally show a tendency for older patients to be more satisfied than young and middle-aged patients [25, 26, 32]. Younger patients prefer a more active role in decision making and participation in health care [22, 23]. It is important to realize that our study had a relatively low number of young people with cancer (patients aged 18 – 35 years comprised only 5% of the study population). This reflects the low incidence of cancer at this young age, but it may lead to an underestimation of the specific needs of young patients. The younger generation today is more educated and trained to find information when needed, is more critical toward authorities, and demands dialog, respect, and good service [28]. During the focus group interviews, young people expressed specific needs and preferences concerning care and treatment, including continued support to reintegrate into their previous daily routine (home, work, school, etc), clustering patients of roughly the same age during their hospital stays, access to leisure activities, and being able to maintain their own individual daily rhythm. Additional studies of this younger patient group are required.

A possible limitation to our study is patient selection. Because our patient population was recruited through medical oncologists, our findings may only reflect the need of this patient group and not that of other cancer patients. This aspect warrants further study.

Furthermore, the impact of gender may be nationally or culturally determined and not be valid in other countries or cultures.

The results of our study may be used to make health care more patient-centred. Health care organizations have recognized that patient-centred care not only provides a benefit for the patient but also saves costs. True patient-centred care should ensure that each patient receives the best possible care. For example, the optimal care for a highly educated woman with metastatic breast cancer will be different from the optimal care for a lower-educated man with a nonmetastasized form of cancer. With regard to gender, care should be tailored to certain aspects of care, for example, the extent and manner of communication, extent and manner of support, counselling and rehabilitation, length of consultation, assignment of physician, choices in treatment and care, and offering privacy.

Conclusion

Male and female cancer patients differ in their preferences concerning health care. While gender is but one of the aspects influencing patients' health care preferences, in our study population it is apparently the most important. These results should encourage health care professionals to become more aware of gender differences and help them to better recognize, understand, and address the specific needs and wishes of patients. Therefore, in striving for providing optimal patient-centred cancer care, gender should be taken into account. Based on our findings, future research should focus on the impact of gender on health care preferences in a prospective setting.

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Chapter 4

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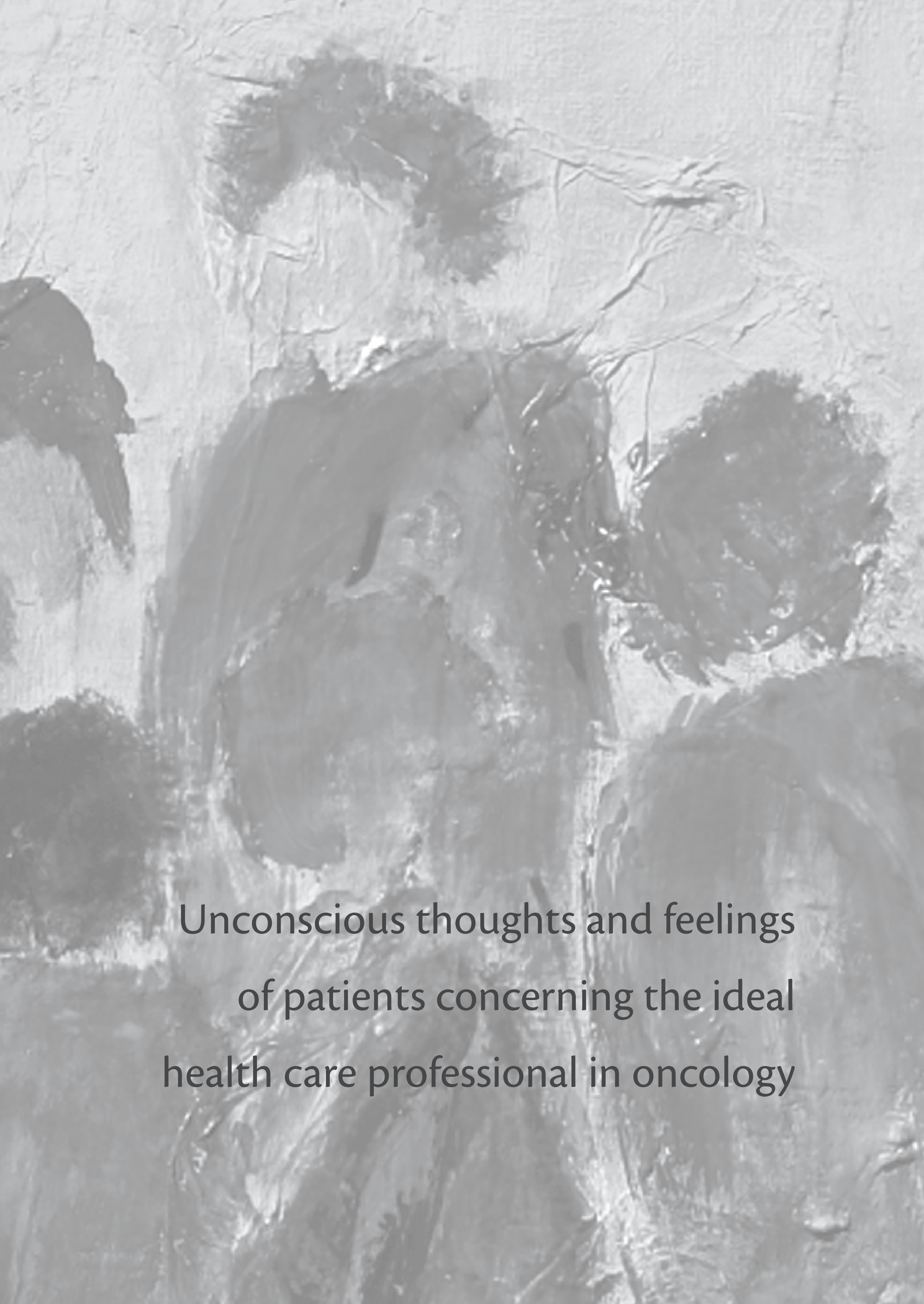

Unconscious thoughts and feelings of patients concerning the ideal health care professional in oncology

Abstract

Background/Aim

Improving quality of care for cancer patients requires insight into their specific needs and preferences concerning cancer care. Earlier research (using focus group interviews and questionnaires) showed that patients set highest value on care aspects related to the expertise, performance and attitude of health care professionals. The aim of this study was to examine whether application of the ZMET research method (mental maps of unconscious thoughts and feelings) provides a deeper insight into context and motivation of needs and preferences concerning 'the ideal health care professional'. We also examined any gender differences between patients with regard to their thoughts and feelings concerning the ideal health care professional.

Methods

In addition to our earlier research (n=386) we applied the Zaltman Metaphor Elicitation Technique (ZMET). ZMET is a qualitative research tool appealing to the unconscious and designed to elicit latent and emerging needs and to find common assumptions between people. ZMET is characterized by the use of a specialized interview technique, making use of pictures and images collected by the respondent that reflects his/her ideas and feelings with respect to the research topic. In this study a part of the results of our earlier study was taken as starting point for deeper exploration, appealing to the unconscious.

Results

In the ZMET study patients (n=15) of the three departments of the Cancer Center of the University Medical Center Utrecht (Medical Oncology, Radiotherapy and Surgery) selected a colourful and telling collection of pictures and images. Based on the clusters of connected constructs (thoughts, feelings, opinions, views and needs) manifested in all interviews, five key themes were formulated by the research team, presenting thoughts and feelings of patients concerning expertise and attitude of the health care professionals, shared decision making and communication and coordination between health care professionals. A consensus map presented the relationship between the needs and preferences for an ideal health care professional, exhibiting the reasons for these needs.

Conclusion

The ZMET method provided valuable additional information concerning the ideal health care professional by producing illustrative information in pictures paying special attention to the connotation of aspects related to the 'ideal' health care professional in the form of metaphors and figure of speech.

Introduction

During the last decade patient-centred care is an issue of growing importance. Patient-centred care can be defined as 'care that is respectful of and responsive to individual patient preferences, needs and values, ensuring that patient values guide all clinical decisions' [1]. To further improve quality of care for (cancer) patients it is important to have insight into their specific needs and preferences [1, 2]. Therefore we carried out several studies to obtain a valid and reliable insight into the specific preferences of cancer patients. First we asked patients during focus group interviews (n = 51) how they would design health care, without primarily paying attention to the feasibility of their wishes and without influence of the researcher. Next, based on the focus group interviews, a (preliminary) questionnaire was generated [3]. This questionnaire evaluated the importance of care aspects and was given to a large cohort of patients treated by medical oncologists. Data are based on responses from 386 patients (response rate 57%). An explorative factor analysis with varimax rotation resulted in the final 'Cancer patients' health care preferences questionnaire', containing 21 scales with 115 items and 8 single items. High values on these scales and items indicate a high level of importance. The highest values were related to the expertise, performance and attitude of doctors and nurses represented in the scales: 'Mistakes by professionals', 'Physician and nurse attitude', 'Consultation and transfer', 'Physician attitude', 'Patient file confidentiality', 'Opportunity to choose in care and treatment', 'Nurse attitude', 'Communication and information'. Of relatively less importance were the organizational and environmental factors.

In our third study the aim was to explore the impact of gender on cancer patients' needs and preferences. We therefore performed a multivariable regression analysis [4]. This analysis showed that out of all the patient- and disease- related factors, gender was the most important independent predictor for 38% of the scales. Without exception, women found the care aspects mentioned in the statistical significant scales more important than men.

This structured and systematic approach provided an extensive valid and reliable insight into needs and preferences of cancer patients in care and treatment.

Nevertheless, during the last decade there is an increasing attention for the impact of unconscious processes on human thoughts, feelings and processes and the belief that human consciousness is only the tip of the iceberg [5, 6]. Much of mental life is unconscious, including cognitive, affective and motivational processes [5]. Our subconscious stipulates, with a processing capacity which is approximately 200.000 times larger than that of the conscious [6, 7], our behaviour, thoughts and feelings. With this in mind we wondered whether appealing to the unconscious would produce a deeper insight into context and motivation of certain needs and preferences in cancer care, mentioned by patients in our former research. Furthermore, considering the advantages of the use of multiple methods (triangulation) the application of an additional research method might result in deeper insight into context and motivation of needs and preferences and could enrich our earlier study results [8].

We therefore initiated a study with specific attention to cancer patients' thoughts, feelings and behaviour, appealing to the subconscious. We applied the 'Zaltman Metaphor Elicitation Technique' (ZMET), a qualitative research tool designed to surface the mental models that drive consumer thinking and behaviour and characterize these models in actionable ways using consumers' metaphors [9]. On the basis of several scientific disciplines including sociology, neurology, biology and psychological sciences, Zaltman developed a theory to elicit latent and emerging needs and to find common assumptions between people. The method is based on the knowledge that 90-95% of our range of thoughts takes place in sub-consciousness and mainly occurs in the form of images [10].

Based on the care aspects rated highest by patients in our former study (aspects related to the expertise, performance and attitude of doctors and nurses), we presented patients the question: What are your thoughts and feelings concerning the 'ideal' health care professional (physician and nurse). Furthermore, given the significant impact of gender on patients' needs and preferences for health care that we found in our former study [4] we also examined in this study whether there are gender differences in thoughts and feelings concerning the 'ideal' health care professional.

In short, the aim of this study was to examine which additional, deepening insights into context and motivation for certain needs and preferences of patients in cancer care, application of the ZMET research method would produce.

Patients and methods

ZMET® research

Aim of the qualitative ZMET-studies is a better understanding of thoughts and feelings of people (their aims, ambitions, needs, wishes and values) concerning a specific topic. ZMET is characterized by the use of a specialized interview technique, making use of pictures and images collected by the respondent that reflects his/her ideas and feelings with respect to the research topic.

A comprehensive explanation of the development and application of the method has been described elsewhere [9]. *Figure 1*. shows a schematic representation of the method. Briefly, the ZMET method (typically) selects only a very small research population (n = 12 - 15 respondents). With this number of participants the method should be able to retrieve ideas which are representative for an extensive (target) group. During a personal interview with the participant (lasting for two to two and a half hours), the interviewer penetrates different levels of thinking in successive steps. Each step functions as a justification of the previous steps and an enrichment of acquired insights. Because the ZMET interviewers have an important role during data collection and the analysis of each participants data, they are extensively trained (beyond that associated with typical personal interviewing) to apply the ZMET interview method.

Essence of this qualitative research method is the use of associations and metaphors. Participants are asked to collect 6 – 8 photographs/ pictures (from magazines, books, newspapers, or other sources) which reproduce their thoughts and feelings concerning the research topic (preferably no functional characteristics). The interviews can provide insights into latent and emerging ideas, which are categorized in so called *mental models*. Mental models of the various participants are joined together in a *consensus map*, representing the common thoughts and feelings of the respondents [11].

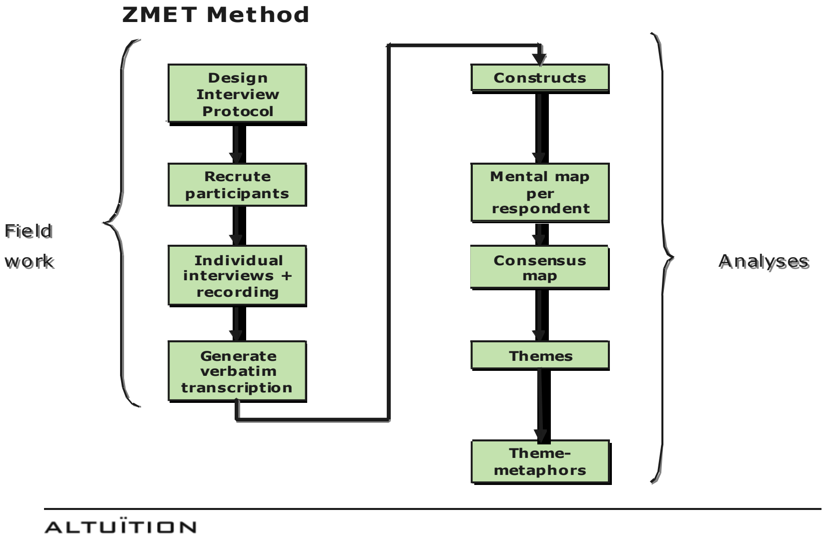

Figure 1 Schematic representation of the ZMET method

The main question during the personal interviews in this study was: 'What are your thoughts and feelings concerning the 'ideal' health care professional (physician and nurse)'. Sub questions concerned: Communication with the ideal health care professional, cooperation between health care professionals, attitude of the ideal health care professional and the degree in which patients can participate in decision making concerning care and treatment.

Patients ZMET interviews

During the first trimester of 2009, patients treated in the Cancer Center of the University Medical Center Utrecht, the Netherlands were invited to participate in this study. Knowing what was expected of patients in this study, doctors selected those patients suitable for participation in the interview (qualifying for participation). Patients should be able to communicate well and were excluded if they could not understand the Dutch language or if their physical condition prohibited them to participate in the interview. Due to the burden of participating in an interview during the diagnostic phase of the disease only advanced cancer patients were recruited. Furthermore to be able to address our second research question with regard to possible gender differences in thoughts and feelings of cancer patients concerning the ideal health care professional, an equal number of male and female respondents were selected.

During a period of nine weeks physicians of the departments of Medical Oncology, Radiotherapy and Surgery informed patients at the out-patient clinic about the study and asked them to consider participation in an interview. Patients received a letter with further information to inform them about the aim of the study and the importance of their participation. An instruction for collecting pictures and images was included (see Appendix of this chapter). Respondents were assured that their answers would be kept confidential and that the data would be processed anonymously. A phone number and email-address to contact the project manager were provided.

Three days after the physicians' request to consider participation in the study, patients received a phone call at home by the project manager to hear their decision concerning participation in the study and if needed, to provide additional information and address questions regarding process and content of the research. If positive, an appointment for the personal interview was planned. Patients could indicate their preference for giving the interview at their home or in the hospital.

Data analyses ZMET

A comprehensive description of the way the interviews were analyzed is published elsewhere [9, 11, 12]. Briefly, each interview was digitally recorded and a complete verbatim transcription was generated. First the personal interviews, stories and pictures were interpreted independently in the form of constructs (opinions and assumptions) by two researchers, where special attention was given to surface or linguistic metaphors [13, 14]. Following, consensus on the constructs to be used was reached by cross-case comparison of both researchers' findings. Next, constructs were connected per respondent in a mental model. The third step in analyzing the results was setting up a consensus map based on similarity between thoughts and feelings of the various respondents. Finally key themes could be identified.

Results

Between January and March 2009 eighteen patients in treatment at the Cancer Center in the departments Medical Oncology, Radiotherapy and Surgery were invited to participate in the study. Three potential respondents renounced participation because they had some trouble finding pictures/images. Fifteen interviews were usable. Participants were equally divided over the departments (Department of Medical Oncology: male n=3, female n=3, Department of Radiotherapy: male n=2, female n=2 and Department of Surgery: male=2 and female=3). So patient characteristics were as follows: 53% female, mean age 60 years, tumour types were: breast cancer (n = 5), gastrointestinal cancer (n = 6), uro-genital cancer (n = 4), other (brain, lung, pancreas) (n = 3). Three patients had two types of cancer.

The interviews resulted in a telling and colourful collection of pictures and images reflecting the participants' thoughts and feelings concerning the 'ideal' health care professional. *Figure 2*. shows a compilation of these pictures and images collected by respondents in preparation for the interview. Each interview was translated into constructs based on the transcription of the interview. This resulted in an extensive construct list. Next the relations between the defined constructs made by the respondent were examined. By linking these related constructs, a mental map was created. All mental maps were analyzed based on consensus.

Figure 2 A compilation of pictures and images collected by respondents in preparation for the interview

Next, a consensus map was developed for all respondents together. Constructs belonging together were grouped in key themes. It should be noted that the number of constructs per key theme does not reflect the degree of importance of the theme. *Figure 3*. shows an overview of the consensus map.
Based on the clusters of connected constructs (thoughts, feelings, opinions, views and needs) manifested in all interviews, the research team formulated five key themes:

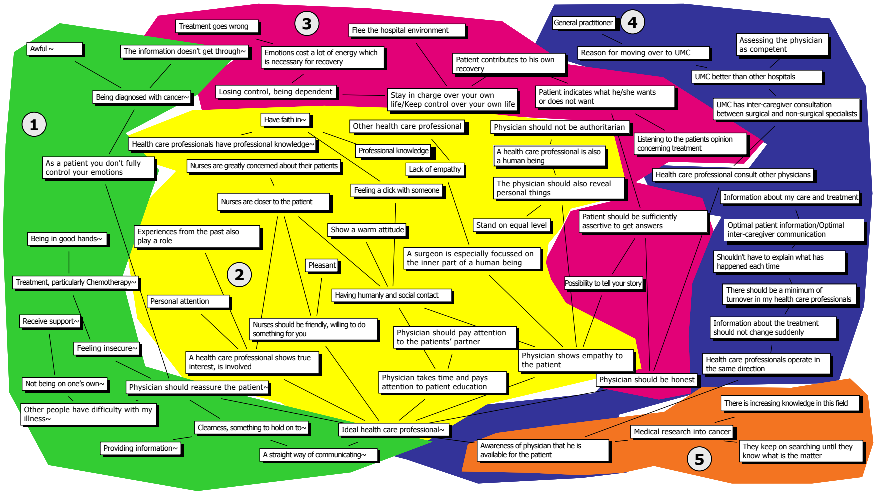

Figure 3 Overview of the consensus map

Right to the point

To limit uncertainty, the ideal health care professional provides clear information and support to the patient and his/her loved ones in all phases of care and treatment, even after dismissal form the hospital. Information about the illness and possible treatment is given in a direct, clear and understandable way. Support is not limited to what happens inside the hospital, but is also focused on the patients' home situation.

Make yourself comfortable

The ideal health care professional is empathetic, humanly and warm. He/she grants patients and their loved ones enough time and attention. A physician needs to have adequate knowledge and experience and gives patients the feeling that they receive the best possible treatment. Assessing the knowledge or experience is problematic for non-experienced patients, so they look for cues like empathy, friendliness and even humour to get an idea of the professionals' skills. The physician takes into account what the patient has been through already. He/she is not authoritative and has an open attitude. Nurses need to stand closer to the patient and should be focused on making the patients' situation as comfortable as possible. Nurses are friendly and personal, pay adequate attention to patients and their loved ones and understand their feelings.

You stay in charge

Patients want to stay in control over their own life and treatment. Therefore doctors and nurses should involve patients in considerations and decision making concerning their care and treatment. Health care professionals need to listen carefully to patients' needs and wishes and should be honest in their information concerning prognosis and expected outcome of treatment. They should be aware of the difficulty patients experience in losing control over their lives and being dependent of health care professionals and others. Health care professionals need to consolidate the feeling of control in patients as much as possible.

Together the same

The patients' interest always comes first for health care professionals. The ideal physician works according to certified national guidelines. The various professionals involved in care and treatment communicate well with each other concerning the patient's situation and act in the same direction. In case of turnover in caregivers, there is a consistent line in care and treatment. If necessary, the physician in attendance will consult another specialized colleague, regarding the patient's situation.

They get better every day

The ideal health care professional is an expert in treating patients with cancer and his/her knowledge is up to date with the latest developments. A physician is able to adapt protocols for tailored care based on the patient's situation.

From our earlier study we found a clear difference between men and women regarding their preferences in cancer care [4]. Female patients valued a substantial part of the aspects of care as more important than their male counterparts. Concerning gender differences Taute found [15] that female patients exhibit greater emotional empathy ability than male patients, whereas male patients exhibit greater emotion regulation ability. Women concentrate on characters in communication and excel in establishing emotionally empathetic connections, while men attempt to control their responses to emotional appeals. This is exemplified in our research by the finding that females seek more protection against being exposed to the daily life and possible negative responses from the environment too early compared to male patients. Furthermore men mention expertise and professional knowledge (although they cannot test it) as the most important quality of the ideal health care professional, while women pay more attention to an empathetic attitude of the health care professional.

Discussion

The aim of this study was to examine whether application of the qualitative research method (ZMET) that appeals to unconscious thoughts and feelings, would produce deeper or more affective insights into context and motivation of specific needs and preferences of cancer patients concerning the ideal health care professional obtained in an earlier study. The prime conclusion of this study is that patients diagnosed with cancer experience a feeling of losing control over their lives. They feel dependent on health care professionals and because they can not rationally and objectively judge the quality of treatment, they evaluate based on advice and attitude of health care professionals (aspects such as a friendly, respectful and helpful approach, granting enough time and attention) and the way their bodies react on treatment. The "ideal" health care professional is ascribed particularly psycho-social characteristics. Relatively less attention is paid to functionalities like education and technical acting.

In addition to the results of our earlier research the ZMET interview yielded useful information and tools which might contribute to an easy translation of a part of our earlier results into practice. The pictures and images collected by patients visualize their thoughts and feelings concerning the "ideal" health care professional in a revealing way. Pictures and themes might be useful for educational purposes for health care professionals or in the communication with patients. The findings could also be of importance in branding or positioning of the Cancer Center UMC Utrecht; using words and images chosen by patients might generally appeal more to patients than formulations of professionals. The ZMET study furthermore produced a map showing the relations between patients' needs and preferences.

These results could enable health care professionals to assess their own care projected against perceived ideal care from the perspective of cancer patients.

Furthermore, based on our earlier findings, we examined if there are gender differences in thoughts and feelings concerning the excellent health care professional, albeit in a small sample group. In general the ZMET research method showed a difference between genders in nuance: men seemed to have a more functional attitude to regulate their emotions, women a more emotional-empathy attitude. These findings correspond with our former study in which female patients attached statistically significant more value to aspects related to 'Support, counselling and rehabilitation' and 'Physician attitude' and 'Nurse attitude'[4].

With respect to content the ZMET research method did not reveal new care aspects compared to our former study. A possible explanation may be due to the intensity of the emotion associated with having a severe illness such as cancer, which may make unconscious thoughts and feelings more conscious. Another explanation could be that we already gave a clear direction with our phrasing of the (ZMET) question for patients. A final explanation may be linked to the use and interpretation of metaphors. Metaphors are often used as tools of reasoning. Sometimes they are overtly obvious and clear to receivers. At other times they are so subtle that we are not even aware that a metaphor or analogy is at work in providing the justification for reaching a certain conclusion. In this specific ZMET study, as in other, the researchers encountered several occasions within an interview where respondents were unable or had problems identifying and articulating the relation between a metaphor and their feelings, which frequently led to rationalization of the metaphor.

A potential limitation concerning interpretation of the interview results is that it is to some extent subjected to the interpretation of the researchers. Other potential limitations of the method are described elsewhere [9]. Briefly application of ZMET requires special trained interviewers, post interview data analyses is intensive and demanding and it does not provide (because of the sample size) quantitative estimates of the percentage of a large population.

In conclusion the ZMET interviews added value to the results of our earlier study by producing illustrative information in pictures and images paying special attention to the connotation of aspects related to the ‘ideal’ health care professional in the form of metaphors and figure of speech. This vizualisation of thoughts and feelings concerning the ideal health care professionals can contribute to educational and communication purposes and may be helpful in providing cancer patient centred care.

Acknowledgements

We gratefully thank the cancer patients who spent time in the interviews and were willing to share their ideas concerning the ideal health care professional with us. We also wish to thank drs. C.A. van Es (Radiotherapy), dr. A. Witkamp (Surgery) and dr. A. Menon (Surgery) who were kind enough to ask patients if they wanted to consider participation in an interview. This work was financed by the UMC Utrecht Cancer Center.

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Appendix

Information about the perception survey

What is the precise aim of the survey?
The research organization, Altuition, has a great deal of experience in surveying desires and expectations by means of in-depth interviews. The interviews last about 2.5 hours. You can determine where the interview will take place. If you like, it can take place at your home, so that you won't have to worry about travelling or the inconvenience of strange surroundings. You will be interviewed only once.

Preparation for the interview
To prepare for the interview we would like you to:
1. Consider what the ideal doctor or nurse involved in your care and treatment is for you. This is about your personal thoughts and feelings, so you don't need to be restricted by what is achievable in terms of organization.
2. Find <u>6-8 pictures</u> that express your thoughts and feelings about the ideal doctor or nurse. This could be difficult, so here are a few hints that might help you: the pictures might come from magazines, newspapers, your own material, the internet, etc. The most important thing is that the images and photos are meaningful to you and express your feelings about the ideal doctor or nurse.

Examples of pictures
To help you get started, here are a few examples of the types of picture that people in other surveys have used to express their thoughts and feelings. In a survey for a bank, for instance, a man brought a photo of a padlock, because he wanted to express the feeling of safety that he had at his bank. In a study for a children's clothes manufacturer, a young mother brought a photo of a clock to express her thoughts about her children growing up so quickly.

Please do <u>not</u> use pictures of hospitals, operating rooms, healthcare works, etc.

What happens to the pictures?
Your choices are a personal matter. The pictures that you bring with you (or the answers you give) are therefore never "wrong". We are interested in your opinions and ideas. You don't have to worry either about choosing the "right" picture or about the quality of a photo, for example. Collecting pictures is just a tool the investigators can use to help them understand your personal thoughts and feelings better.

During the in-depth interview, you will be asked about your expectations and perceptions about the ideal healthcare worker, using the pictures you have brought.

Participation

A few days after receiving this letter you will be called by your doctor who will ask you whether you want to participate in the survey and whether the above information and instructions were clear, understandable and feasible for you. If you decide to take part in the survey, with your consent we will give your name and telephone number to the interviewer from Altuition. The interviewer will then contact you to arrange a date, time and place for the interview.

As a thank for your cooperation and efforts you will receive a sum of € 50,-.

Chapter 5

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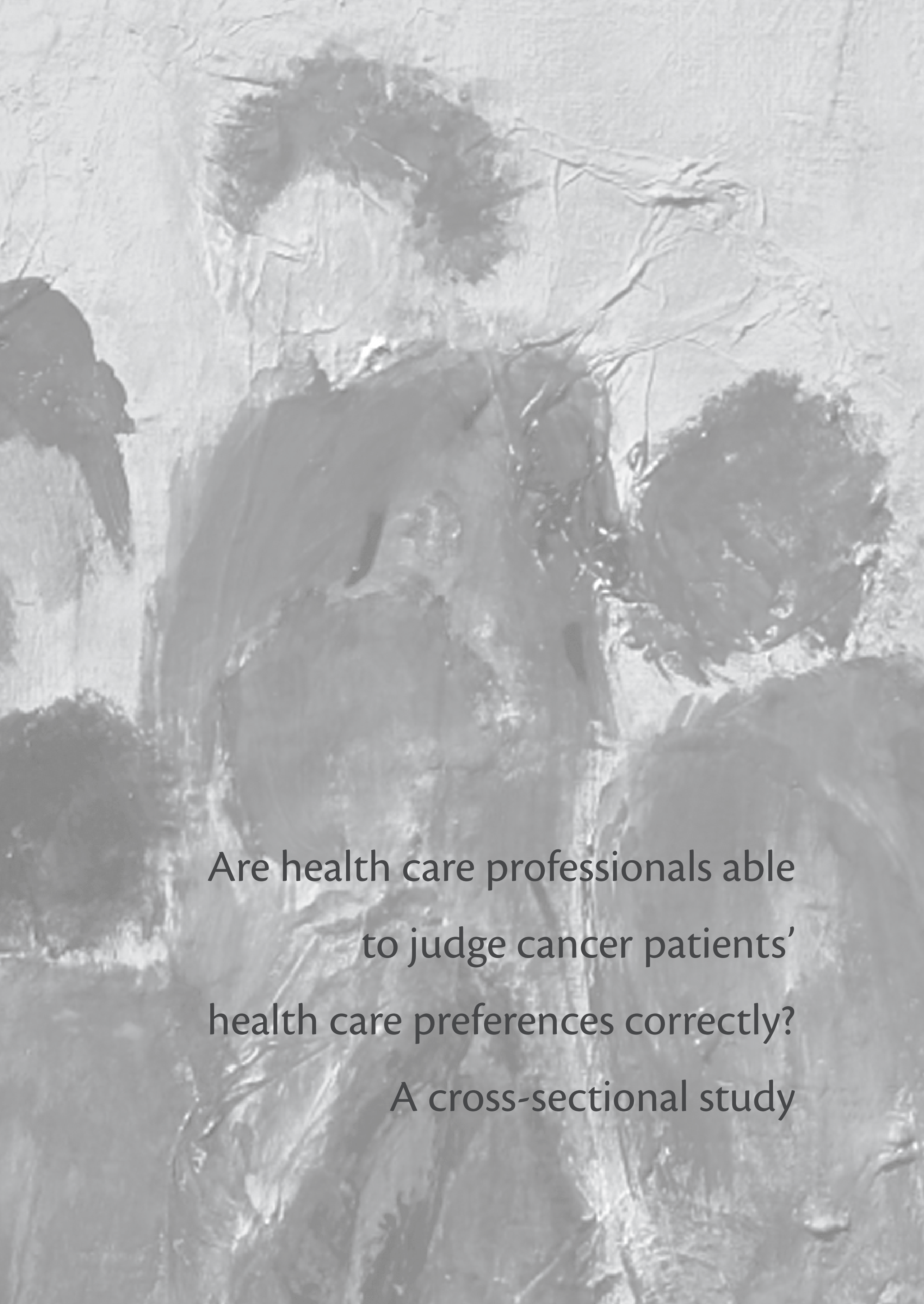

Are health care professionals able to judge cancer patients' health care preferences correctly? A cross-sectional study

Abstract

Background

Health care for cancer patients is primarily shaped by health care professionals. This raises the question to what extent health care professionals are aware of patients' preferences, needs and values.

The aim of this study was to explore to what extent there is concordance between patients' preferences in cancer care and patients' preferences as estimated by health care professionals. We also examined whether there were gender differences between health care professionals with regard to the degree in which they can estimate patients' preferences correctly.

Methods

To obtain unbiased insight into the specific preferences of cancer patients, we developed the 'Cancer patients' health care preferences' questionnaire'. With this questionnaire we assessed a large sample of cancer patients (n = 386). Next, we asked health care professionals (medical oncologists, nurses and policymakers, n = 60) to fill out this questionnaire and to indicate preferences they thought cancer patients would have. Mean scores between groups were compared using Mann-Whitney tests. Effect sizes (ESs) were calculated for statistically significant differences.

Results

We found significant differences (ESs 0.31 to 0.90) between patients and professionals for eight out of twenty-one scales and two out of eight single items. Patients valued care aspects related to expertise and attitude of health care providers and accessibility of services as more important than the professionals thought they would do. Health care professionals overestimated the value that patients set on particularly organizational and environmental aspects.

We found significant gender-related differences between the professionals (ESs 0.69 to 1.39) for eight out of twenty-one scales and two out of eight single items. When there were significant differences between male and female healthcare professionals in their estimation of patients' health care preferences, female health care professionals invariably had higher scores. Generally, female health care professionals did not estimate patients' preferences and needs better than their male colleagues.

Conclusions

Health care professionals are reasonably well able to make a correct estimation of patients preferences, but they should be aware of their own bias and use additional resources to gain a better understanding of patients' specific preferences, for each patient is different and ultimately the care needs and preferences will also be unique to the person.

Background

Health care providers search for solutions to deliver patient-centred care that is respectful of and responsive to individual patient preferences, needs and values. Although patient advocacy groups have increasing influence on health care organizations, health care is mostly shaped by health care professionals. An important condition for health care professionals to provide optimal patient-centred care, is a good insight into the patients' needs and preferences concerning health care [1, 2].

To obtain insight in the specific preferences of cancer patients, we have developed the 'Cancer patients' health care preferences' questionnaire', based on patients' unrestricted input [3]. This questionnaire is not a satisfaction questionnaire, but a questionnaire that evaluates the importance of care aspects. The questionnaire was given to a large sample of patients treated by medical oncologists. In a previous study [3], it appeared that patients set highest value on safety and on the expertise, attitude and communicative skills of doctors and nurses. Of relatively less importance are the organizational and environmental factors.

Patients with cancer may encounter physical, existential and emotional problems. Information about cancer patients' needs and preferences can, to some extent, be derived from the literature [4-14]. Still, tailoring care as much as possible to the patients' needs and preferences will especially be based on the insight of the individual health care professional. This raises the question to what degree health care professionals are able to estimate patients' needs and preferences correctly.

Previous research examining the estimation of patient needs by health care professionals focuses on the impact of cancer and the side effects of chemotherapy [15] , psychological concerns and needs [16,17] and patient reported physical and psychosocial problems [18,19]. These studies show that there is a considerable discrepancy on various issues between patients' and health care professionals' perceptions. Lack of concordance between patients and health care providers may result in less than optimal health care. In relation to these findings Brennan et al. [20] state that if nurses, physicians and health care planners knew more about patients' health-related preferences, care would most likely be cheaper, more effective and closer to the individuals' desires.

To our knowledge, the question of whether health care professionals estimate cancer patients' preferences for health care (in general) correctly, has not been studied systematically. Therefore, the aim of the present study was to examine to what extent there is concordance between cancer patients' preferences for health care, and the estimation of patient preferences by health care professionals.

In a previous study we found significant differences between male and female patients concerning their preferences in health care [21]. As gender differences with regard to communication style, practice style and relationship with patients were also found for health care professionals [22-25] we decided to examine additionally whether there are gender differences between health care professionals with regard to the degree in which they can estimate patients' preferences correctly.

Methods

Questionnaire and patients

The research protocol was approved by the Medical Ethics Commission of the University Medical Center Utrecht.

The development of the 'Cancer patients' health care preferences' questionnaire' has been described elsewhere [3]. Briefly, items concerning preferences for health care were generated during focus group interviews with cancer patients. Patients for the focus group interviews were recruited by medical oncologists of the University Medical Center Utrecht and through the Dutch Federation of Cancer Patient Organizations. Eligible patients had a sufficient physical condition to participate in the interview and were able to speak and understand the Dutch language. Finally 51 patients participated. Patient characteristics were: 67% female, 39% < 35 year, main tumour types were breast (18%), urological (20%), genital (10%) and gastrointestinal (6%). During the two hours lasting focus groups only one question was put forward by the panel leader: 'How would you design health care if you were in charge?' Participants were explicitly asked to think out of the box and forget potential constraints. Each interview was digitally recorded and transcribed. Text fragments were independently coded and categorized by two authors (HW, MdH). Based on analysis diagrams questions were formulated by two researchers and a questionnaire containing 136 items was generated. Each item evaluates the level of importance on a 4-point scale, ranging from 'Not important' (1), 'Somewhat important' (2), 'Important' (3), to 'Extremely important' (4).

The questionnaire was distributed among patients in care of medical oncologists from one university medical center and six community hospitals in the region of Utrecht, the Netherlands. Doctors and nurses of these departments handed out the questionnaires to an unselected sample of consecutive cancer patients. The questionnaires were encoded by hospital. A cover letter informed patients about the aim of the study and the importance of their input. Respondents were assured that their answers would be kept confidential and that the data would be processed anonymously. A phone number and email-address to contact the project manager were provided. Respondents could complete the questionnaire at home and send it back anonymously in a self addressed pre-stamped envelope. A reminder was sent to each patient after four weeks. The Medical Research Ethics Committee judged that it was not necessary for patients to sign a consent form for the study.

An explorative factor analysis with Varimax rotation was performed, resulting in the final questionnaire containing 21 scales with 115 items and 8 single items. Internal consistency of the scales was sufficient to good. The process of deleting and including items into scales is described elsewhere [3].

All scores of scales and single items are transformed to a score of 0 -100, with high values indicating a high level of importance.

Health care professionals

Health care professionals involved in the delivery and organization of care for cancer patients (doctors and nurses of the departments of medical oncology and members of hospital management) of the seven participating hospitals were asked to participate in the study and to fill out the 'Cancer patients' health care preferences' questionnaire' [3]. Per participating hospital questionnaires were handed to a contact person who distributed the questionnaires to the health care professionals. We asked respondents to indicate health care preferences they thought cancer patients would have. Questions regarding respondents' gender, age and discipline were added. A cover letter informed participants about the aim of the study and the importance of their input. Respondents returned the questionnaire anonymously. A reminder was sent to each health care professional after three weeks.

Data analyses

Data were analyzed using SPSS version 15.0 (SPSS Inc., Chicago, IL). Mean scores between groups were compared using Mann-Whitney tests. In case of significant differences ($p<.05$) between groups, effect sizes (ESs) were calculated to estimate the magnitude of these differences. According to Cohen's thresholds [26], an effect size of <0.20 indicates a trivial effect, an ES of ≥0.20 to <0.50 a small effect, an ES of ≥0.50 to <0.80 a moderate effect and an ES of ≥0.80 a large effect. An ES ≥0.20 reflects a relevant difference between groups [27].

Results

Patients and health care professionals

Between October 2006 and March 2007, 681 questionnaires were handed out to patients. In total 386 questionnaires were returned (57% response rate) and included in the analysis. Characteristics (based on self-report) of these patients are summarized in *Table 1*.

Between May and August 2007, 165 questionnaires were distributed to health care professionals. Sixty questionnaires were returned (36% response rate) and included in the analysis. Characteristics of the health care professionals are provided in *Table 1*.

Table 1 Characteristics of patients and health care professionals

Characteristic	Patients (n = 386) Percent	Health care professionals (n = 60) Percent
Hospital		
University Medical Center	27	35
Affiliated hospital	73	65
Sex		
Male	35	20
Female	66	78
Unknown	-	2
Age, years		
18-35 years	5	32
36-50 years	28	53
51-65 years	38	12
66-79 years	26	-
Unknown	4	2
Level of education		NA
Less than high school	9	.
High school	62	.
More than high school	30	.
Discipline	NR	
Physician	.	13
Nurse	.	67
Policymaker	.	10
Unknown	.	10
Type of cancer patients were treated for		NR
Gastrointestinal	21	.
Breast	45	.
Skin	1	.
Urological	10	.
Genital	10	.
Head and neck	2	.
Lung	1	.
Other	12	.

Table 1 continued

Characteristic	**Patients** **(n = 386)** **Percent**	**Health care professionals** **(n = 60)** **Percent**
Type of treatment *(concurrent or previous)**		NR
Chemotherapy	78	.
Hormonal therapy	26	.
Experimental treatment	4	.
Radiation therapy	46	.
Chemo radiation	3	.
Surgery	72	.
Other	NA	.
Stage		NR
Metastases present	72	.
Metastases absent	28	.

* Patients could tick off several answers
NA= not applicable/not asked
NR = not relevant

Comparison of results of patients and health care professionals

Table 2 shows the results of the scales and single items (ranked in level of importance according to the mean scores as indicated by the patients) for both health care professionals and patients. Overall there is a strong correlation between both groups (Spearman correlation coefficient 0.92).

However, for 8 of the 21 scales and 2 of the 8 single items, we found statistically significant differences between health care professionals and patients. All effect sizes of these scales and single items were between 0.31 and 0.44 with the exception of the single item concerning the quality of hospital equipment, which had a very strong effect size (0.90).

Table 2 Comparison of the importance scores of health care professionals and patients

	Health care professionals (n= 60) mean (SD)	**Patients (n=386) mean (SD)**	**Profs vs Patients ES#**
Scales			
Mistakes by professionals	86 (15)	90[1] (13)	
Physician and nurse expertise	85 (13)	89 (11)*	- 0.35
Consultation and transfer	83 (15)	84 (14)	
Physician attitude	76 (13)	81 (13)**	- 0.38
Patient file confidentiality	85 (16)	81 (18)	
Opportunity to choose in care and treatment	78 (13)	80 (14)	
Nurse attitude	80 (16)	78 (14)	
Communication and information	78 (10)	77 (12)	
Accessibility of services	72 (13)	77 (14)**	- 0.36
Waiting periods	76 (13)	76 (16)	
Support, counselling and rehabilitation	67 (15)	61 (20)*	+ 0.31
Alternate sources of information	64 (13)	60 (23)	
Appointments	62 (14)	59 (18)	
Rooms and facilities	55 (14)	57 (14)	
Food and beverages	56 (22)	56 (19)	
Presence of loved ones	57 (21)	49 (26)	
Privacy	54 (18)	46 (22)*	+ 0.37
Patient habits	50 (18)	43 (22)**	+ 0.33
Patient interest groups	45 (20)	37 (23)**	+ 0.35
Conveniences	44 (16)	37 (16)**	+ 0.44
Fellow-patient interaction	19 (16)	17 (19)	
Single items			
Hospital equipment	66 (20)	84 (20)***	- 0.90
Consultation at ER by own doctor	70 (23)	79 (20)**	- 0.44
Written information	78 (20)	77 (21)	
Support of a case manager	69 (22)	74 (24)	
Continuity in care	67 (20)	72 (22)	
Support by paramedical staff	68 (16)	68 (18)	
Attention for nutrition	63 (23)	68 (22)	
Leaving choices to doctors and nurses	62 (28)	66 (32)	

[1] A higher score indicates a higher level of importance (range 0-100);
*p<.05, **p<.01, ***p<.001 (Mann Whitney tests)
Effect size (ES) only calculated for scales and items tested as statistically significant different.
+ ES: the professionals score is higher than the patient score; - ES: the professionals score is lower than the patient score.

Of these ten scales and single items, patients rated five scales and single items as more important than health care professionals expected: ‘Physician and nurse expertise’ (items concerning knowledge and experience, complete information about the patients situation and specialization in cancer care), ‘Physician attitude’ (items concerning friendliness, time, personal attention, respect, empathy, attention to the patients loved ones, accuracy, opportunity for the patient to ask questions and trust), ‘Accessibility of services’ (e.g. access to all professionals involved in various situations), ‘Hospital equipment’ (‘The hospital equipment is modern’) and ‘Consultation at the emergency room by own doctor’. The largest (18 points) and strongest (ES 0.90) difference between the estimation of health care professionals and patients was found for the single item ‘Hospital equipment’. Patients valued modern hospital equipment much higher than health care professionals expected the patients to do.

Patients rated five scales less important than health care professionals expected: ‘Support, counselling and rehabilitation’ (offering professional support to help patients and their loved ones to deal with emotions and to help patients to re-integrate into their previous daily routine (home, work, school, etc), attention for late effects of treatment)‘, ‘Privacy’ (both at the outpatient clinic and on the ward), ‘Patient habits’, (items concerning individual preferences and requirements, decoration of the room, dietary habits and requirements), ‘Patient interest groups’ and ‘Conveniences’ (items concerning the waiting room and the patients room, access to sport and recreation facilities, availability of tea, coffee, soft drinks and soup).

Comparison of male and female health care professionals

We found gender-related differences within the health care professionals for eight scales and two single items (effect sizes between 0.69 and 1.39) (*Table 3*). When there were clinically relevant differences, female health care professionals invariably had higher scores. We found the same pattern of gender differences for patients in a previous study [21]. Female patients valued a substantial part of the aspects of care as more important than their male counterparts (*Table 3*). However, gender differences for patients were much more pronounced and partly for different scales and single items compared to the differences between male and female health care professionals. Generally, female health care professionals did not estimate patients’ preferences and needs better than their male colleagues.

Table 3 Comparison of the importance scores between female and male patients and female and male health care professionals

	Gender Patient			**Gender Health care professional**		
	Female (n=252)	**Male (n=134)**	**ES**	**Female (n= 47)**	**Male (n=12)**	**ES**
Scales						
Mistakes by professionals	92 (13)	87 (14)**	.37	86 (14)	86[1] (17)	-
Physician and nurse expertise	90 (10)	88 (11)	-	87 (12)	79 (13)	-
Consultation and transfer	86 (13)	82 (14)*	.30	84 (14)	75 (18)	-
Physician attitude	83 (13)	78 (13)**	.38	77 (12)	71 (16)	-
Patient file confidentiality	84 (18)	75 (19)***	.49	87 (15)	79 (19)	-
Opportunity to choose in care and treatment	82 (14)	77 (15)***	.35	78 (14)	77 (8)	-
Nurse attitude	81 (14)	74 (13)***	.51	83 (13)	67 (20)*	1.09
Communication and information	79 (11)	74 (13)***	.43	79 (9)	74 (12)	-
Accessibility of services	78 (14)	73 (13)**	.37	72 (12)	72 (16)	-
Waiting periods	80 (14)	69 (18)***	.71	78 (12)	69 (11)*	.76
Support, counselling and rehabilitation	65 (19)	55 (20)***	.52	69 (13)	58 (17)*	.79
Alternate sources of information	63 (24)	54 (21)***	.39	66 (13)	57 (13)*	.69
Appointments	61 (17)	55 (21)*	.32	64 (13)	57 (16)	-
Rooms and facilities	58 (15)	54 (14)*	.27	58 (12)	41 (13)***	1.39
Food and beverages	56 (19)	56 (19)	-	61 (19)	37 (22)***	1.22
Presence of loved ones	50 (27)	48 (26)	-	58 (22)	50 (17)	-
Privacy	49 (21)	42 (21)**	.33	55 (20)	52 (11)	-
Patient habits	43 (23)	43 (21)	-	54 (17)	37 (20)**	.96
Patient interest groups	40 (23)	32 (22)***	.35	47 (18)	35 (21)	-
Conveniences	37 (17)	36 (16)	-	47 (15)	32 (13)**	1.02
Fellow patient interaction	17 (19)	17 (20)	-	19 (17)	20 (15)	-
Single items						
Hospital equipment	83 (20)	84 (20)	-	68 (20)	58 (21)	-
Consultation at ER by own doctor	80 (21)	77 (20)	-	72 (22)	61 (28)	-
Written information	80 (20)	73 (22)**	.34	81 (18)	66 (20)*	.82
Support of a case manager	76 (23)	71 (25)	-	71 (19)	64 (33)	-
Continuity in care	77 (20)	65 (23)***	.57	68 (20)	66 (20)	-
Support by paramedical staff	69 (19)	66 (16)	-	70 (15)	61 (19)	-
Attention for nutrition	68 (22)	67 (22)	-	68 (18)	41 (25)***	1.38
Leaving choices to doctors and nurses	67 (31)	63 (33)	-	61 (29)	63 (26)	-

*p<.05, **p<.01, ***p<.001 (Mann Whitney tests)
ES = Effect Size
- = no statistically significant difference

Discussion

Results of this study showed that health care professionals were able to make a correct estimation of the value cancer patients attribute to most aspects of care. In establishing preferences, there was a clear similarity between patients and health care professionals. For both patients and health care professionals safety and the expertise, performance and attitude of doctors and nurses rated highest and the organizational and environmental factors were of relatively less importance. Thus, health care professionals were reasonably well able to make a correct estimation of patients' preferences. From the perspective of delivering patient-centred care, these results are certainly encouraging, but there still is room for improvement. We found statistically significant differences for 8 out of 21 scales and 2 out of 8 single items. Health care professionals *underestimated* patients' valuation of the expertise of physicians and nurses, physician attitude, the accessibility of services, a modern hospital equipment and the possibility to be seen by the own doctor directly in case of an emergency. On the other hand, health care professionals *overestimated* the value that patients set on particularly organizational and environmental aspects.

These findings may be of interest to improve care for cancer patients. Our finding suggest that health care professionals may focus too much on aspects of care that patients attach less value to and may pay less attention to aspects that are in the opinion of the patient most important. Failure to tailor care as much as possible to patients' needs and preferences may lead to (unnecessary) dissatisfaction and distress among patients. Patients with unmet needs in the terminal stage of cancer for example, show significantly higher psychological and symptom distress [28].

Prioritization of care aspects by patients is a valid starting point in care renewal processes and may be used to guide decisions in improving care for cancer patients. However, in reorganizing care, the knowledge and experience of health care professionals and logistical and financial constraints should also be taken into account.

Our study also showed that – similar to patients - female health care professionals set higher value on many care aspects than male professionals do. However, in general female health care professionals did not make better estimates of patients' preferences than their male counterparts.

To deliver patient-centred care and thereby effectively meet patients' needs and wishes, health care professionals should take into account context characteristics of individual patients and customize their services as much as possible. The literature shows that patient characteristics impact upon patients' experiences and preferences in health care [21, 29-32]. In interpreting the results of this study it is important to be aware of the fact that individual patient characteristics were not taken into account by health care professionals while estimating patient preferences in the questionnaire. The result of the study among patients is an average of 386 respondents and we asked health care professionals to fill out the questionnaire for the average cancer patient. In improving cancer care at the organizational level, health care professionals generally use the average patient as starting point, but standardised care does not meet the need of the individual patient. Further research should therefore focus on the estimation of patient preferences by health care professionals for specific patients or groups of cancer patients (paying attention to the influence of, for example, gender, age, level of education, phase of illness).

There are some limitations of this study. A possible limitation concerning the representativeness of our sample of patients participating in the focus group interviews is the overrepresentation of young patients. It is possible that age may be a confounder in the items addressed. Other potential limitations of this study are the relatively small number of participating health care professionals compared to the number of patients, the (unexplained) low response rate of health care professionals and the relative overrepresentation of nurses and female health care professionals, due to the fact that there are many more nurses working at the departments of medical oncology than physicians and policymakers. Therefore, in future research it is important to expand and confirm these findings in a larger population of health care professionals, including a larger proportion of physicians and policymakers.

Conclusions

In conclusion, this study showed that health care professionals are reasonably well able to make a correct estimation of cancer patients' preferences in general. Nevertheless there are some blind spots. Health care professionals both underestimate and overestimate the value patients attach to a number of care aspects. They should be aware of their own bias and use additional resources to make it possible to optimally differentiate towards patient specific preferences for each patient is different and ultimately the care needs and preferences will also be unique to the person. This indicates the need to develop interventions aimed at supporting professionals in gaining a better insight and understanding of patients' specific preferences, to be fully informed on the patients' preference pattern and thereby to ensure that health care truly meets patients' preferences. Furthermore, patients should be encouraged and supported to supply the necessary information for health care professionals to get insight into their specific needs and preferences concerning cancer care. Tailoring care for cancer patients should be a multidisciplinary action of health care professionals and patients to avoid potential biases in perceived needs and preferences of these patients.

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Chapter 6

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Impact of integration of clinical and outpatient units on cancer patient satisfaction

Abstract

Objective

There is an ongoing drive to measure and improve quality of care. Donabedian's quality framework with structure, process and outcome domains provides a useful hold to examine quality of care. The aim of this study was to address the effect of an intervention in hospital structure (integration of three units into one) with the purpose of improving processes (increase meeting, cooperation and communication between professionals and patients) and its effect on the outcome (cancer patient satisfaction).

Design

Pre-test – post-test.

Setting

University Medical Center Utrecht, the Netherlands, Department of Medical Oncology.

Participants

Cancer patients (*n* = 174, *n* = 97).

Interventions

Physical integration by bringing separately located units (outpatient clinic, day-care clinic, clinical ward) together in one wing of the hospital and adjustments in communication and coordination structures.

Main Outcome Measure

Patient satisfaction questionnaire.

Results

Satisfaction with care improved for six scales (27%) after integration. ESs ranged from 0.36 to 0.80, indicating a small to moderate effect. The most important improvement was found at the day-care clinic on aspects like ‘the degree in which the nurses were informed about a patients situation’, ‘privacy’, ‘interior design’, ‘quality of hospital equipment’, ‘sanitary supplies’ and ‘waiting periods’. With regard to continuity and coordination of care, satisfaction increased for five items (28% of items concerning continuity and coordination of care). ESs ranged from 0.42 to 0.75.

Conclusions

Integration of three oncology units into one unit had a positive impact on care delivery processes and resulted in improved patient satisfaction concerning care and treatment.

Introduction

As a result of the increasing competition in health care, there is currently an ongoing drive to improve the quality of care of health care organizations. The literature on quality of care in health care systems is increasing.

In 1990, a definition of quality of care was proposed by the Institute of Medicine (IOM) in the USA: 'Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge' [1]. In 2008, the WHO incorporated the patient perspective in their definition: 'Quality of care is the level of attainment of health systems' intrinsic goals for health improvement and responsiveness to legitimate expectations of the population' [2].

A generally accepted and useful framework of structure, process and outcome for assessing quality of care was introduced by Donabedian in 1966 [3,4]. He defined structure as the attributes of the setting in which care occurs and the resources needed for health care [5]. Processes of care denote the use of resources in terms of the actual delivery and receipt of care. Outcomes are consequences of health care. There are two principal domains of outcome: health status and user evaluation of quality of care (satisfaction) [6]. According to Donabedian, both structure and process aspects contribute to the outcomes, implicating that change of the structure or processes of health care delivery will have impact on the health related quality of life or patient assessed quality of care. Therefore, understanding how structure impacts processes and outcomes is an important condition for efforts to improve the quality of care [7,8]. The relevance of this approach is supported by Brien *et al*. [9] who stated that in quality of care studies that address two or more of Donabedian's structure, process and /or outcome criteria are the most insightful in locating problems in the provision of health care and subsequent quality improvement programs.

Because cancer is a disease that requires a large and complex care delivery system with numerous different professionals and often complex diagnostic and therapeutic programs, a considerable demand is placed upon quality of care for cancer patients. Traditionally, in the Netherlands care delivered by departments of medical oncology is organized in three separate units: an outpatient facility, a day-care (treatment) center and a clinical ward.

Generally, medical oncology patients will frequently visit all three units. From the perspective of the cancer patient, an integrated approach where patients will see the same health care professionals, regardless the unit they visit seems optimal [10-12]. Furthermore, the expectation is that integration will result in more timely and efficient care, aspects of health care which were highlighted by the IOM in their report Crossing the Quality Chasm [13].

With this in mind, the Department of Medical Oncology of the University Medical Center of Utrecht, the Netherlands was re-organized in 2007, integrating their three unit-based facility into one unit, with the aim of improving patient care. To determine the impact of this intervention on the patients' evaluation of quality of care, we performed a pre-and post-re-organization survey.

The aim of this study was to address the effect of integration of units with the purpose of improving the processes (to increase cooperation and communication amongst health care professionals and between healthcare providers and patients) and its effect on the outcome (satisfaction of patients with care).

Patients and methods

Design

A pre-test – post-test design [14] was used to assess patients' satisfaction with care, treatment and services provided. Data were collected before and after the physical integration of three units (clinical ward, day-care center and outpatient facility) of the Department of Medical Oncology of the University Medical Center Utrecht, the Netherlands, into one.

Questionnaire

The cancer patient care satisfaction questionnaire used in this study was based on a review of the literature and of existing questionnaires [15-20], focus group interviews with patients [11], the opinion of health care providers and a manual for the development of patient questionnaires [19]. Questionnaire items were arranged in scales based on their content by two of the authors (H.W. and M.H.) to reach content validity. A concept questionnaire was reviewed by a panel of experienced health care professionals of different disciplines, with the aim of evaluating the questionnaire on clarity, relevance, thoroughness and coherence. We also asked them which additional questions they wanted to ask the patients. The final questionnaire is a self-report questionnaire, containing 132 items to evaluate the competence and attitude of physicians and nurses, as well as aspects of organization of care and hospital environment.

Items were organized in 22 scales grouped in five categories: sociodemographic and medical information, outpatient clinic, day-care center, clinical ward and general questions concerning the department of Medical Oncology. In the categories outpatient clinic, day-care center and clinical ward, questions were asked concerning expertise, communication and attitude of doctors and nurses, patient education by doctors and nurses, expertise and attitude of secretaries, privacy, accommodation and organization. Questions concerning psychosocial support and counselling, food and beverages, research and some general questions, e.g. concerning attention for patient habits, lodging a complaint and attitude of supporting services, were added in the category 'General questions'. Patients had to complete only the questions concerning the unit(s) where they had been treated. Patients were invited to rate their satisfaction on a four point scale, ranging from 'Poor' (1), 'Reasonable' (2), 'Good' (3) to 'Excellent' (4).

This questionnaire was used before and after the re-organization. After re-organization the questionnaire was extended with four single items concerning the new department ['Privacy at the counter' (clinical ward), 'Helpfulness of volunteers' (clinical ward), 'Integration of the clinical ward, day-care center and out-patient clinic' (general) and 'Coordination between the units' (general)].

Patients

In 2005 and 2007, patients treated in the department of Medical Oncology, University Medical Center Utrecht, were approached to participate in this study. During a period of 6 weeks doctors and nurses handed out the questionnaires to an unselected sample of consecutive cancer patients at the outpatient clinic, the day-care clinic and the inpatient clinic. Names and addresses of all patients to whom a questionnaire was handed out, were registered. Patients were excluded if they could not understand the Dutch language or if their physical condition prohibited them to complete the questionnaire. Patients received an envelope with the questionnaire and a cover letter to inform them about the aim of the study and the importance of their participation. An instruction for completing the questionnaire was included. A phone number and email-address to contact the investigator were provided. Respondents could complete the questionnaire at home and return it anonymously in a self addressed pre-stamped envelope. After checking their current health care status, a reminder was sent after 3 weeks to each patient who received a questionnaire.

Intervention (physical integration of units and re-assessment of procedures)

The intervention consisted of a physical integration by bringing the separately located units (outpatient clinic, day-care center and clinical ward) together in one wing of the University Medical Center Utrecht and adaptations in care processes. The outpatient clinic is used for follow-up visits and decision-making concerning treatment. The day-care center is used for short courses of chemotherapy and interventions such as blood transfusions, paracenteses and fluid administrations; whereas the clinical ward is used to administer complex chemotherapy and to provide intensive palliative and terminal care for cancer patients. The medical oncology department yearly has over 600 new patients, 800 admissions at the clinical ward, 1600 administrations of chemotherapy and 1000 other interventions at the day-care clinic. There have been no significant changes in patient volume and number of beds (18) in the ward and the day-care clinic during the study period.

The integration (and renovation) took place between January and October 2006. The results of the pre-test questionnaire were assessed by all health care professionals involved (i.e. medical oncologists, nurses, secretaries, managers) and used for the re-organization.

The results of focus group interviews with patients obtained in an unbiased manner and without interference by health care professionals were also used for the re-organization. The results of these interviews have been described elsewhere [11]. Briefly, we asked patients in a standardized and unrestricted way how they would design health care, without primarily paying attention to the feasibility of their wishes and without the influence of health care workers. The latter study was included to maximize patients' input in the improvements made.

By bringing the separately located units together in one wing, the distances between the units was physically brought back to zero where before it took 5 min to walk between day-care center/outpatient clinic and clinical ward. The new department was arranged and decorated on the basis of needs and preferences concerning the environment expressed by patients [11]. On the basis of patient wishes, adaptations were made in the lighting of the patient rooms and the unit, the design and accessibility of the sanitary unit, a more colourful decoration of rooms, arrangement of beds at the day-care clinic and more comfortable chairs and beds. Furthermore in the new situation there are mainly single and double rooms, better possibilities for privacy during hospital stay either with or without visitors and in the waiting room of the outpatient clinic.

Since the integration of units oncology nurses work in so-called core teams. These teams include nurses with specific expertise concerning either the outpatient clinic, the day-care clinic or the ward. The teams are supported by oncology nurses that rotate through the various entities. Furthermore there is a structural 'briefing' (exchange of information between care givers) between doctor and nurse before visiting patients, so that both parties are always well informed of the patients' current situation. Furthermore models for nursing assessment and reporting differed between the units and are now geared to each other. This improved the coherence between the teams and the efficiency in finding patient related information.

Finally, since the integration there is more uniformity in technical actions. Technical operations (e.g. blood transfusions) are now carried out in a more standardized way and with the same resources within the different units.

Data analysis

Data were analyzed using SPSS version 15.0 (SPSS Inc., Chicago, IL, USA). The reliability of the scales of the questionnaire was examined by analyzing the internal consistency coefficient (Cronbach's alpha) and the mean inter-item correlation coefficient (MICC) for each scale. Cronbach's alpha coefficient was considered sufficient if ≥0.70 [21] and MICC-values should fall in the range of 0.15 - 0.50 [22].

Scale scores were transformed to a scale range of 0-100, with high scores indicating high levels of satisfaction. Mean scores and standard deviations for both groups were calculated.

Mean scores of pre- and post-test were compared using Mann-Whitney tests. In case of significant differences ($p< 0.05$) between groups, effect sizes (ESs) were calculated to estimate the magnitude of these differences. According to Cohen's thresholds [23], an ES of < 0.20 indicates a trivial effect, an ES of ≥ 0.20 to < 0.50 a small effect, an ES of ≥0.50 to < 0.80 a moderate effect and an ES of ≥0.80 a large effect. An ES ≥0.20 reflects a relevant difference between groups [24].

In the post-test, we asked patients a question concerning 'coordination between units'. This question was not asked in the pre-test and therefore we could not compare results of pre- and post-test on this particular point. To get insight into satisfaction concerning continuity and coordination of care we selected those items (18 items out of all items) which were related specifically to this subject. On item level results of pre- and post-test were compared (only for these items) by using Mann-Whitney tests.

Results

Patients

In September and October 2005, questionnaires were handed out to 243 patients. In total, 174 (72%) questionnaires were returned. Of the respondents, 99% visited the outpatient clinic, 74% the day-care center and 53% the clinical ward.

Between September and November 2007 (after the re-organization), questionnaires were handed out to 125 patients. In total, 97 (78%) questionnaires were returned. Of the respondents, 99% visited the outpatient clinic, 51% the day-care center and 47% the clinical ward.

Patient characteristics are summarized in *Table 1*. There were slightly more males and more elderly patients in the pre-test sample.

Table 1 Characteristics of respondents

Characteristic	**Patients completing the questionnaire in 2005** *(n=174)*	**Patients completing the questionnaire in 2007** *(n = 97)*
Gender, *n(%)*		
Male	114 (66)*	50 (52)*
Female	59 (34)	46 (48)
Age, years, *n(%)*		
< 20 years	1 (1)*	-*
20-39 years	20 (12)	18 (19)
40-59 years	55 (32)	34 (35)
60-79 years	93 (54)	40 (42)
>80 years	4 (2)	4 (4)
Level of education, *n(%)*		
Less than high school	39 (23)*	23 (24)
High school	72 (42)	44 (45)
More than high school	61 (36)	30 (31)
Period since start treatment at the department of Medical Oncology, *n(%)*		
<3 months	14 (8)*	3 (3)
3-6 months	18 (11)	11 (11)
6-12 months	27 (16)	31 (32)
1-2 years	41 (24)	14 (14)
> 2 years	69 (41)	38 (39)

* Some missing value

Reliability of the questionnaire

The internal consistency was sufficient for most scales. In the pre-test questionnaire Cronbach's alpha was > 0.70 for all but two scales ('Privacy at the outpatient clinic' and 'Privacy at the day-care center'). In the post-test questionnaire only one scale had a Cronbach's alpha value < 0.70, ('Privacy at the outpatient clinic'). As the MICC was satisfactory for these scales, we decided to keep the scales in the questionnaire.

Comparison satisfaction scores pre- and post-test

Table 2 shows the mean scores of the scales and the single items. Both in the pre- and post-test analysis patients were satisfied with the quality of care, treatment and services they received, with all mean scores > 60. For all scales and single items, there was a wide range of scores, with minimum values varying from 0 to 33 and maximum values of 100 for every scale and single item.

Table 2 Patient satisfaction before and after integration

	Number of items	2005 mean (SD)	2007 mean (SD)	*P*-value	ES
Satisfaction at outpatient clinic with:		*(n=173)*	*(n=96)*		
Physicians	9	87 (15)[1]	86 (14)	0.80	-[2]
Patient education by physicians	10	79 (17)	80 (14)	0.68	-
Secretaries	4	86 (16)	83 (17)	0.17	-
Privacy	3	75 (15)	76 (14)	0.70	-
Accommodation	5	60 (17)	73 (15)	0.000	0.80
Organization	6	75 (16)	75 (15)	0.76	-
Mean score for this category		77 (12)	79 (11)	0.27	
Satisfaction at day-care clinic with:		*(n=129)*	*(n=49)*		
Nurses	8	77 (15)	85 (16)	0.001	0.52
Patient education by nurses	8	71 (19)	78 (15)	0.056	-
Privacy	3	64 (18)	73 (21)	0.006	0.47
Accommodation	6	64 (15)	75 (15)	0.000	0.72
Organization	5	68 (15)	78 (15)	0.001	0.67
Mean score for this category		69 (13)	79 (13)	0.000	0.77
Satisfaction at inpatient clinic with:		*(n=92)*	*(n=26)*		
Physicians	7	76 (18)	79 (17)	0.46	-
Patient education by physicians	8	74 (18)	72 (17)	0.63	-
Nurses	8	79 (15)	80 (14)	0.99	-
Patient education by nurses	9	72 (17)	71 (16)	0.68	-
Privacy	3	73 (20)	70 (16)	0.27	-
Accommodation	7	67 (18)	74 (13)	0.075	-
Organization	7	72 (16)	73 (14)	0.79	-
Mean score for this category		74 (12)	74 (12)	0.78	
Satisfaction at Department of Medical Oncology (general) with:		*(n=122)*	*(n=80)*		
Psychosocial support	5	66 (22)	69 (20)	0.11	-
Food and beverages	5	66 (21)	63 (18)	0.26	-
Clinical Research	2	66 (23)	67 (23)	0.91	-
General items	5	66 (24)	74 (18)	0.009	0.36
Single items					
Privacy at the counter (in patient clinic) (n=96)			68 (17)		
Helpfulness of volunteers (in patient clinic) (n=80)			81 (18)		
Integration of inpatient clinic, day-care clinic and outpatient clinic (general) (n=66)			86 (18)		
Coordination between the units (n=64)			80 (18)		

[1] A higher score indicates a higher level of satisfaction (range 0-100)

[2] - = not statistically significant

There were statistically significant and relevant increases of satisfaction with care in the post-test analysis for six scales ('Accommodation at the outpatient clinic', 'Nurses at the day-care clinic', 'Privacy at the day-care clinic', 'Accommodation at the day-care clinic', 'Organization at the day-care clinic' and 'General aspects concerning the department of Medical Oncology'). ESs ranged from 0.36 to 0.80. A large effect (ES 0.80) was found for 'Accommodation at the outpatient clinic'. The most important progress in satisfaction was found at the day-care clinic. Judging the separate items in these scales, most of the progress had been achieved on aspects like the degree in which the nurses continuously were completely informed about a patient's situation, privacy, interior design of the day-care clinic, quality of the units equipment, sanitary supplies and waiting periods.

Continuity and coordination of care

To get a better insight into satisfaction concerning continuity and coordination of care we selected 18 items out of 3 categories (outpatient clinic, day-care center, clinical ward) related specifically to this topic and compared the results of 2005 and 2007. *Table 3* shows the mean scores of these items. There were statistically significant and clinically relevant increases for five items. ESs ranged from 0.42 to 0.75, indicating a small to moderate effect. Most of the improvements (four out of five) were seen at the day-care clinic.

In the post-test questionnaire the patients indicated a high level of satisfaction with coordination between units (single item mean score 80).

Table 3 Items concerning coordination and continuity before and after integration

Item	2005 mean (SD) (N = 174)	2007 mean (SD) (N = 97)	*P*-value	ES
Satisfaction at outpatient clinic with:	(*n*=173)	(*n*=96)		
Degree to which the doctor is (continuously) completely informed about the patient's situation	86[1] (18)	84 (19)	0.40	-[2]
Uniformity of the information provided by the different doctors	72 (23)	72 (20)	0.93	-
Communication/continuity between different disciplines	72 (20)	74 (20)	0.39	-
Degree of treatment by the same doctor	84 (20)	82 (21)	0.65	-
Satisfaction at day-care clinic with:	(*n*=129)	(*n*=49)		
Degree to which the nurses are (continuously) completely informed about the patient's situation.	70 (20)	85 (20)	0.000	0.75
Uniformity of the information provided by the different nurses	69 (20)	77 (17)	0.031	0.42
Communication between the nurses	70 (17)	82 (17)	0.000	0.71
Communication/continuity between different disciplines	69 (18)	77 (17)	0.006	0.45
Communication between day-care clinic and inpatient clinic	72 (18)	78 (16)	0.10	-
Satisfaction at inpatient clinic with:	(*n*=92)	(*n*=26)		
Degree to which the doctor is (continuously) completely informed about the patient's situation	77 (22)	78 (19)	0.89	-
Uniformity of the information provided by the different doctors	74 (22)	71 (21)	0.62	-
Degree to which the nurses are (continuously) completely informed about the patient's situation.	74 (21)	78 (16)	0.59	-
Uniformity of the information provided by the different nurses	70 (18)	71 (21)	0.99	-
Degree of treatment by the same doctor	73 (20)	74 (20)	0.85	-
Communication between the nurses	73 (17)	78 (16)	0.22	-
Communication/continuity between different disciplines	69 (22)	74 (17)	0.47	-
Communication between day-care clinic and inpatient clinic	74 (14)	79 (17)	0.25	-
Communication with the general practitioner and home care	63 (27)	78 (16)	0.027	0.63

[1] A higher score indicates a higher level of satisfaction (range 0-100)

[2] - = not statistically significant

Discussion

The aim of this study was to analyze the effect of a change of hospital structure (physical integration of outpatient clinic, day-care facility and clinical ward, into one unit), with the purpose of improving the process of care (to increase cooperation and communication between professionals mutual and among healthcare providers and patients) and its effect on the outcome (satisfaction of patients with care and treatment). Our study showed that patient satisfaction with care increased significantly on six scales by bringing the separately located medical oncology units together in one wing of the University Medical Center. Improvements were mainly seen at the day-care clinic and were related both to accommodation and the processes of care (e.g. waiting periods, communication and information).

Improvements of the processes of care were probably at least partly the result of the proximity of the three units after the re-organization. Before the physical integration, there was not only a geographical separation, but also separation of the nursing and medical teams. Since the integration health care professionals of the different teams are more visible to each other and spend coffee and lunch breaks together. Moreover, nurses rotate between teams and at the outpatient clinic, doctors and nurses of the day-care center meet and discuss the patients prior to their visits to the clinic. As a consequence, there is an improvement of communication, coordination and continuity of care. Furthermore the patient will see familiar faces regardless of where they are treated. Formerly, in case of admission to the hospital, patients came to an entirely new part of the hospital with new employees. In the current situation, the patient remains in the same part of the hospital with familiar health care providers.

Because there are no boundaries anymore between the units, nurses and doctors of the day-care clinic and the outpatient clinic have a better opportunity to visit a patient when he/she is hospitalized and vice versa and show their involvement in that way. All these changes contribute to a better interaction between health care providers and patients and to an improvement of continuity in care and treatment.

Data showed that greatest increment in satisfaction was shown at the day-care clinic. The question is why especially the day-care clinic profited from these changes in structure and process. A possible explanation is that in the old situation this unit was most separate, was old fashioned and patients were treated in one and the same space with limited or no privacy. Moreover, the day-care clinic has a small and therefore a more vulnerable team. In the new situation they have the most benefit of flexible availability of nurses and separate adjacent rooms, offering more opportunity for privacy. The day care clinic now remains open up to the evening hours, and if necessary clinical patient rooms can be used for day treatment. Satisfaction at the day-care clinic is now more equal to satisfaction at the outpatient clinic and the inpatient clinic.

Considering the satisfaction scores of the post-test in the light of our earlier research in which we studied cancer patients' preferences with regard to health care [11], this study showed that the department of Medical Oncology scored well on aspects of care to which patients attach most value, namely expertise, performance and attitude of physicians and nurses. Satisfaction scores with doctors and nurses at the outpatient and day-care clinic were above 85. The lowest score (63) was found for 'food and beverages' at the department of Medical Oncology. In the patients' preferences study [11] 'food and beverages' was categorized in the relatively less important aspects of care. In spite of that, it is important that careful attention is given to the quality of the meals in hospitals.

A potential limitation of the study is that we did not explicitly ask the question concerning 'coordination and continuity between units' in the pre test. Therefore, pre- and post-test comparison of this important item was not possible. We have solved this limitation by selecting and comparing items concerning this subject. This comparison showed that there was a significant progress in coordination between units and health care professionals. The degree to which the physician and nurses were continuously completely informed about the patient's situation, the sameness of physicians at the outpatient clinic and coordination between nurses at the day-care clinic all had mean scores over 80 in the post-test. However, there still is room for improvement. The issue of uniformity of information by doctors and nurses needs extra attention in the future. Other potential limitations of the study were the impossibility to ask the same patients to participate in the pre- and post-test analysis and the (unexplained) lower number of patients in the post-intervention period. Furthermore the improved responses might reflect to a limited extent a 'halo-effect' from providing a nice, new facility, rather than the other aspects of the new design. However, our earlier research [11] into cancer patients' health care preferences showed that environmental aspects scored among the relatively less important care aspects. Furthermore at the moment of the post-test the new department was already in use for a year and therefore no longer brand-new. As patients are usually treated for a limited period in our department it is unlikely that patients participating in the post-test knew the old situation. So we therefore think that the impact of this aspect upon the overall appraisal of care is limited.

In conclusion, this study confirmed that an intervention in structure has impact on processes and outcome of care. Integration of three units into one resulted in an increased patient satisfaction on several aspects concerning care and treatment at the department of Medical Oncology of the UMC Utrecht Cancer Center. Care processes have been restructured finding synergies and new forms of cooperation. Departments that provide cancer care may benefit from a periodical structured evaluation of patient satisfaction and care processes with subsequent implementation and evaluation of changes.

Future research should focus on the impact of this (kind of) intervention on the satisfaction of staff.

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Chapter 7

Summary and general discussion

In this final chapter the main results of the thesis are summarized, followed by a reflection on the methodology. Next, the general conclusions concerning the main objectives of the thesis are formulated. Finally, implications for further research and practice are described.

7.1 Introduction

The prevalence of cancer in the Netherlands is estimated to be about 400.000 persons (2.5 % of the Dutch population). Therefore, cancer patients represent a significant target group in Dutch health care and the provision of high-quality care and treatment to this group of patients is an important issue. Consequently, over recent years, the assessment and evaluation of quality of care for cancer patients has gained increasing attention.

This thesis has the following objectives:

- To obtain valid and reliable insight into cancer patients' needs and preferences concerning hospital care, and into patient- and disease-related factors influencing these needs and preferences.
- To examine the extent to which health care professionals are aware of patients' needs and preferences.
- To evaluate the impact of integration of hospital care on cancer patient satisfaction.

7.2 Main results

This section presents the main results, which provide answers to the research questions formulated in Chapter 1.

Research question 1

Which care aspects do patients mention when they are asked 'How would you design health care if you were in charge?'?
To answer this research question, focus group interviews were conducted between June 2004 and December 2005 (see Chapter 2). Ten focus groups interviews, with a total of 51 participants, were needed to obtain data saturation. Patient characteristics were: 67% female, 39% age < 35 years, main tumour types: breast (18%), urological (20%), genital (10%) and gastrointestinal (6%). Focus group meetings proceeded smoothly, in an open and pleasant atmosphere, and patients were pleased to be involved in improving patient care. The focus group interviews resulted in a comprehensive list of 136 relevant issues covering seven topics: organization (35 items), communication (20 items), rooms and facilities (30 items), counselling and support (13 items), physician and nurse attitude (19 items), individual input/autonomy (10 items) and professional expertise (9 items).

Research question 2

How do patients evaluate the level of importance of the care aspects mentioned in the focus group interviews?
Based on the result of the focus group interviews, a preliminary questionnaire was generated. Items mentioned during the focus groups were translated into questions, evaluating importance on a four-point scale, ranging from not important (1) to somewhat important (2), important (3), and extremely important (4) (see Appendix 1 and Chapter 2). Between October 2006 and March 2007, this questionnaire was handed out to 681 cancer patients. In total 386 questionnaires were returned, translating into a 57% response rate. The patients who completed the questionnaire were older than those in the focus groups and had more advanced disease. Explorative factor analysis on the data resulted in a definitive questionnaire containing 21 scales (including a total of 115 items) and 8 single items, focusing on the importance of care aspects (see Appendix 2 and Chapter 2). The scores of scales and single items were transformed to a score of 0-100, with higher scores indicating a higher level of importance. The internal consistency of the scales was sufficient to good as shown by Cornbach's alpha values and mean inter-item correlation coefficients.
High mean scores on the scales and single items indicated the importance of the issues assessed by the questionnaire. According to the respondents, the most important

issues (mean score $\geq$ 80) were: 'Mistakes by professionals', 'Physician and nurse expertise', 'Consultation and transfer', 'Physician attitude', 'Patient file confidentiality', 'Opportunity to choose in care and treatment' and the single item 'Hospital equipment'. The following scales were considered to be of relatively low importance (mean score <50): 'Presence of loved ones', 'Privacy', 'Patient habits', 'Patient interest groups', 'Conveniences' and 'Fellow-patient interaction'. The results of this study show that cancer patients place greatest value on the expertise, performance and attitude of physicians and nurses.

Research question 3

Which patient- and disease-related factors have an impact on cancer patients' preferences for health care?
To answer this question, the data obtained from the 386 questionnaires assessing cancer patients' preferences for health care were used. The following patient- and disease-related variables were studied: gender, age, educational level, presence or absence of metastases, type of cancer, years since diagnosis, days of previous hospitalization and hospital (see Chapter 3). We found statistically significant differences between male and female patients concerning preferences in health care for 15 out of 21 scales (71%), and for two of the eight single items (25%), with effect sizes ranging from 0.27 to 0.71. Without exception, women found the care aspects mentioned in these scales and items more important than men. Multivariable regression analysis showed that of all the patient- and disease-related variables, gender was the most important independent predictor of patient preferences.

Research question 4

Which additional or deepening insights into the context and motivation for certain needs and preferences of patients are revealed by appealing to the patients' unconscious?
During the first trimester of 2009, patients were invited to participate in the Zaltman Metaphor Elicitation Technique (ZMET) study (see Chapter 4). Knowing what was expected of patients in this study, doctors selected patients suitable for participation in a personal interview. During the interview (lasting for two to two and a half hours) the interviewer penetrated different levels of thinking about the 'ideal health care professional'. Fifteen interviews were used for analysis. Both the interviews and the analyses were carried out by specially trained researchers. Patient characteristics were as follows: 53% female, mean age 60 years, main tumour types: breast, urogenital and gastrointestinal.

Appealing to the unconscious resulted in a colourful and telling collection of pictures and images associated with the 'ideal health care professional'. Based on the clusters of connected constructs (thoughts, feelings, opinions, views and needs) manifested in the interviews, the research team formulated five key themes concerning health care professional expertise and attitude, shared decision-making, and communication and coordination between health care professionals.

Research question 5

To what extent is there concordance between cancer patients' preferences for health care and the estimate of those preferences by health care professionals?

Between May and August 2007, 165 questionnaires (identical to the questionnaires completed by the patients in the second study) were distributed to health care professionals. Professionals were asked to indicate which health care preferences they thought cancer patients would have. In total, 60 questionnaires were returned (36% response rate) and included in the analysis. The characteristics of the professionals were as follows: 78% female, 32% < 36 years, 67% nurses, 13% physicians, 10% policy makers and 10% of unknown profession. The data from the questionnaires completed by the health care professionals were compared to those from the 386 cancer patients from the second study (see Chapter 5). Overall there was a strong correlation between patients and professionals. For both patients and health care professionals, safety and the expertise, performance and attitude of physicians and nurses were rated most highly, and the organizational and environmental factors were considered relatively less important. However, for eight of the 21 scales and two of the eight single items, we found statistically significant differences between health care professionals and patients (effect sizes ranged from 0.31 to 0.90). Health care professionals underestimated patients' valuation of physician and nurse expertise, physician attitude, the accessibility of services, modern hospital equipment and the possibility to be seen immediately by their own doctor in case of an emergency. On the other hand, health care professionals overestimated the value that patients set on particular organizational and environmental aspects.

We also found significant gender-related differences amongst the professionals (effect sizes ranging from 0.69 to 1.39) for eight scales and two single items. In those cases where there were significant differences between male and female health care professionals in their estimate of patients' health care preferences, female health care professionals invariably had higher scores. However, in general female health care professionals did not make a better estimate of patients' preferences and needs than their male colleagues.

Research question 6

What is the impact of physical integration of clinical and outpatient units on patient satisfaction?

In 2005 and 2007, patients treated in the Department of Medical Oncology, University

Medical Center Utrecht, the Netherlands, were invited to participate in this study. During a period of six weeks doctors and nurses handed out the questionnaires to an unselected sample of consecutive cancer patients at the outpatient clinic, the day-care clinic and on the clinical ward. In 2005, 174 questionnaires were returned (72% response rate) and in 2007 97 questionnaires were returned (78% response rate) (see Chapter 6). Shortly after the first assessment period, the separately located units (outpatient clinic, day-care centre and clinical ward) were brought together in one wing of the hospital and integration of care processes took place.

As a result of this integration, satisfaction with care improved statistically significantly for six scales. Effect sizes ranged from 0.36 to 0.80, indicating a small to moderate effect. The most important improvement was found at the day-care clinic for aspects like 'the degree to which the nurses were informed about a patient's situation', 'privacy', 'interior design', 'quality of hospital equipment', 'sanitary supplies' and 'waiting times'. With regard to continuity and coordination of care, satisfaction increased for five items, with effect sizes that ranged from 0.42 to 0.75. The close proximity of the different units facilitates exchange of information and mutual support between health care professionals, contributing to coordination and continuity in care and treatment.

7.3 Methodological considerations

The following considerations refer to the adequacy of the procedures employed in the five studies carried out to meet the objectives of this thesis.

The study design to answer the first three research questions consisted of two consecutive phases: a qualitative phase in which items for a preliminary questionnaire were generated through focus group interviews, and a quantitative phase in which the preliminary questionnaire was tested in a large group of patients.

The focus group interviews

The focus group interviews were found to be an efficient method to generate a large number of relevant care aspects. Patients were asked in an unrestricted and pro-active way ('How should it be?') to identify their preferences in health care, without primarily paying attention to the feasibility of their wishes and without the influence of health care professionals. We experienced that involving patients in care innovation is fruitful, motivating and inspiring. It yielded a wealth of information and, judging by the considerable response patients felt closely involved with this topic and were willing to make a positive contribution. The patients could indicate clearly their care and treatment requirements. An important positive aspect of generating items using this method is that the questionnaire is based solely on the patients' input, ensuring that its content truly represents the needs and preferences of the patients themselves.

No items were added by either health care professionals or researchers.

A potential limitation concerning our sample of patients participating in the focus group interviews was the overrepresentation of young patients (<36 years). As a result, it is possible that age may be a confounder in the items addressed since younger patients may differ from their elder counterparts with regard to needs and preferences.

Another possible limitation may be that, despite a very consistent and accurate approach, the processing and analysis of the data of the focus group interviews and the conversion of items identified during the focus groups into questions may have been influenced by the researchers' own interpretations.

The questionnaire study

Despite the extensiveness of the questionnaire and the fact that respondents were also dealing with having cancer, there was a satisfactory response rate (57%). Although it took patients a mean time of forty-seven minutes to complete the questionnaire, compliance was good and few patients found the questionnaire burdensome.

The questionnaire performed well with regard to psychometric properties and had a high level of content validity. As there is no 'gold standard' by which to measure patients' needs and preferences, the criterion validity of the questionnaire could not be assessed.

A potential limitation of this study could be the patient selection. Since the patient sample for the questionnaire was recruited through medical oncologists, our findings may only reflect the needs of this patient group and not those of cancer patients from other oncology departments.

Exploration of the impact of patient- and disease-related variables on cancer patients' needs and preferences

Due to our large and varied sample of cancer patients, it was possible to study the impact of gender, age, educational level, type of cancer, presence of metastases, years since diagnosis, days of hospitalization and hospital on the patients' needs and preferences. To avoid an inflated type I error due to multiple testing, we applied a Bonferroni-type correction procedure, considering independent variables only to be significant in the multiple regression model if they had a *p*-value <0.0024 (p=0.05/21 = the number of scales of the questionnaire).

It is important to note that few young people with cancer participated in our questionnaire study. This reflects the low incidence of cancer at a young age, but may also lead to an underestimation of the specific needs of young patients. According to Rosén et al., 'the younger generation today is more educated and trained to find information when needed, is more critical towards authorities and demands dialogue, respect and good service and might therefore have different preferences' [1].

Finally, in this study nationality or culture could be confounding factors (particularly with regard to the impact of gender), implying that the results may not be valid in other countries or cultures.

The ZMET method

The fifteen interviews in this study provided valuable visualization of patients' thoughts and feelings about the 'ideal health care professional' within a relatively short period. With respect to content, the ZMET research method did not reveal new care aspects compared to our former study, thus confirming the results of this earlier study. A possible explanation for not revealing the expected latent items by appealing to the unconscious may be due to the intensity of the emotion associated with having a severe illness such as cancer, which may make unconscious thoughts and feelings more conscious. Another explanation could be that, the phrasing of the (ZMET) question (based on our item sample), already gave the patient a clear direction. A final explanation may be linked to the use and interpretation of metaphors. Metaphors are often used as tools of reasoning. Sometimes they are overtly obvious and clear to receivers. At other times they are so subtle that we are not even aware that a metaphor or analogy is at work in providing the justification for reaching a certain conclusion. In this specific ZMET study, as in others, the researchers encountered several occasions within an interview where respondents were unable or had problems identifying and articulating the relation between a metaphor and their feelings, which frequently led to rationalization of the metaphor.

A potential limitation concerning interpretation of the interview results is that it was to some extent subjected to the researchers' interpretation. Other potential limitations of the method are that application of ZMET requires specially trained interviewers, post interview data analyses is intensive and demanding and it does not provide (because of the sample size) quantitative estimates of the percentage of a large population [2].

Estimate of patients' needs and preferences by health care professionals

Potential limitations of this study include the relatively small number of participating health care professionals compared to the number of patients, the (unexplained) low response rate of health care professionals, and the relative overrepresentation of nurses and female health care professionals, reflecting the fact that there are many more nurses working at the departments of medical oncology than physicians and policymakers.

The effect of physical integration of outpatient and inpatient units on patient satisfaction

The application of Donabedian's framework was useful in providing a theoretical background to our study. Although the value of measuring satisfaction with care is often discussed because of methodological and conceptual issues, in this study it proved to be a useful method to measure improvement in quality of care before and after the integration of units.

A potential limitation of the study was the absence of an explicit question on 'coordination and continuity between units' in the pre-test. Therefore, comparison of this important item between the pre- and post-test assessments was not possible. We solved this limitation by selecting and comparing items concerning this subject from the scales.

Other potential limitations of the study included the inability to ask the same patients to participate in the pre- and post-test assessment, and the (unexplained) lower number of patients in the post-test period. Furthermore, the higher satisfaction after the integration might, to a limited extent, reflect a 'halo-effect' caused by the pleasant, new facility, rather than by other aspects of the new design. However, our earlier research [see Chapter 2] into cancer patients' health care preferences showed that environmental aspects were relatively less important. Furthermore, at the time of the post-test assessment, the new department had already been in use for more than a year and was therefore no longer brand-new. As patients are usually treated for a limited period in our department, it is unlikely that patients participating in the post-test would have been familiar with the old situation. Therefore, we believe that the impact of a 'halo-effect' on the overall appraisal of care will be limited.

7.4 General conclusion

With this study we aimed to improve our insight into cancer patients' needs and preferences for health care in the Netherlands, and to create opportunities to deliver true patient-centred care for cancer patients.

Objective 1

To obtain valid and reliable insight into cancer patients' needs and preferences concerning hospital care, and into patient- and disease-related factors influencing these needs and preferences.

The combination of qualitative and quantitative methods [3] in consecutive phases resulted in a detailed and balanced picture of cancer patient preferences. The strength of the questionnaire developed in this study is that it is based as much as possible on the input of cancer patients. The issues provided by the focus groups were in line with previous research. All patient-centred dimensions of care indicated by the Picker institute [4] were formulated in the focus groups and included in the questionnaire. In terms of the prioritization of care aspects, an important conclusion was that the most highly-ranked aspects of care were mostly related to the expertise, performance and attitude of doctors and nurses. This is also in line with other studies [5 – 9]. Patients attached relatively less value to the organizational aspects and aspects concerning the environment.

The qualitative ZMET study added value to the results of the focus group interviews and the questionnaire study by paying special attention to the connotation of aspects related to the 'ideal' health care professional. With respect to content, the ZMET interviews did not add new items to our original sample of care aspects.

Furthermore our study showed that male and female cancer patients differed in their preferences concerning health care. Compared to male patients, female patients assigned greater importance to a number of care aspects. In particular, women attached greater value to aspects related to attitude and support issues. This observation that women attach more value to psychosocial support is consistent with other research [10 – 12]. While gender is but one of the aspects influencing patients' health care preferences, in our study population it appeared to be the most important. These findings could encourage health care professionals (in the Netherlands) to become more aware of gender differences and help them to better recognize, understand and address the specific gender-related needs and preferences of patients.

Objective 2

To examine the extent to which health care professionals are aware of patients' needs and preferences.

Our study showed that health care professionals were able to make a reasonably correct estimate of the value cancer patients attribute to most aspects of care; in establishing preferences, there was a clear similarity between patients and health care professionals. From the perspective of delivering patient- centred care, these results are encouraging, but there remains room for improvement. Health care professionals both underestimate and overestimate the value patients attach to some care aspects. These findings may be useful in improving care for cancer patients. They suggest that health care professionals may pay too much attention to those aspects of care to which the patients attach less value, and may pay too little attention to those aspects which the patients believe are most important. Failure to tailor care to patients' needs and preferences may lead to (unnecessary) dissatisfaction and distress among patients (see Chapter 5).

This study also showed that – similar to patients - female health care professionals ascribe greater value to many care aspects than male professionals. However, in general female health care professionals did not make better estimates of patients' preferences than their male counterparts.

In interpreting the results of this study it is important to be aware that individual patient characteristics were not taken into account by health care professionals when estimating patient preferences in the questionnaire. They were asked to complete the questionnaire for the average cancer patient (which of course, does not exist).
To provide optimal cancer patient-centred care, health care professionals should trust their knowledge and experience, and at the same time be aware of their own bias. The development of tools and interventions aimed at supporting health care professionals in gaining better insight and understanding of patients' specific preferences, might be helpful in daily practice since each patient is different and will ultimately have unique care needs and preferences.

Objective 3

To evaluate the impact of integration of hospital care on cancer patient satisfaction.
Our study confirmed Donabedian's statement [13] that an intervention in structure has impact on processes and outcome of care. Integration of three units into one resulted in increased patient satisfaction for several aspects concerning care and treatment at the Department of Medical Oncology of the University Medical Center Utrecht. Due to the integration, the care processes were restructured, resulting in synergies and new forms of cooperation between health care professionals.
Integration of the outpatient clinic, day-care facility and clinical ward into one unit, as well as the evaluation of care processes, contributed to a better interaction between health care professionals and between health care professionals and patients. As a consequence, continuity in care and treatment improved and patient satisfaction with care increased significantly on six scales.
Respect for patients' expressed needs and preferences is just one of the key dimensions of patient- centred health care formulated by the Picker Institute [4]. Other important aspects are 'Coordination and integration of care', 'Information, communication and education', 'Physical comfort', 'Emotional support and alleviation of fear and anxiety', 'Involvement of family and friends', 'Continuity and transition' and 'Access to care'. An important part of these dimensions was addressed in the Department of Medical Oncology of the University Medical Center Utrecht through the physical integration of the outpatient clinic, day-care facility and clinical ward into one unit.

7.5 Implications for further research

The findings in this thesis may have the following implications for further research.

Measuring experienced care

Now that we know which care aspects are important for cancer patients, the next step in research should be to focus on the development and psychometric evaluation of an outcome measure that evaluates the experienced care. As a tool, the Consumer Quality Index (CQI) would be a logical choice because CQ-Indexes are increasingly used within the Dutch health care system and are supported by the ministry of Health, Welfare and Sport [14]. A CQ Index is based on the health care consumers' perspective and is designed to assess patient or consumer experiences (not satisfaction) with care and health care providers. The items on our questionnaire could be used as a basis for developing a CQ Index.

Ongoing assessment of cancer patients' needs and preferences

Gender differences

To expand and confirm our findings concerning the impact of gender on cancer patients' health care preferences, future research could focus on this subject in a larger sample.

Young patients

Based on the results of our study, it could be of importance to further examine the needs and preferences of young people with cancer (age 18 – 35 years) in a larger sample, as the relatively low number of young people with cancer in our questionnaire study did not allow an analysis of their specific needs and preferences. During the focus group interviews, young people expressed specific needs and preferences concerning care and treatment, including continued support to re-integrate into their previous daily routine (home, work, school, etc.), clustering patients of roughly the same age during their hospital stays, access to leisure activities and being able to maintain their own individual daily rhythm.

Older patients

Because of the increasing number of older (age > 75 years) cancer patients and their relative under-representation in the questionnaire study, this age group also merits further study of its specific needs and preferences.

Patients in treatment in departments other than Medical Oncology (e.g. Surgery, Radiotherapy)

Because other cancer patients' needs and preferences may differ from those of our respondents, the needs and preferences of patients treated in departments other than the Department of Medical Oncology could be examined.

Patients in primary care

The results of our study apply only to cancer patients' needs and preferences regarding hospital care (inpatient and outpatient). To ensure continuity in care, it might be important to also have insight into cancer patients' needs and preferences concerning primary care.

Patients from other cultures

Considering the growing multiculturalism in the Netherlands, it is important to examine the needs and preferences of cancer patients from other cultures, and to compare the findings with the results of our ((mainly) autochthonous) population. Knowledge about these differences between cultures could be of importance for patient-centred care.

Family members and loved ones

As family members and loved ones are often actively and very closely involved, their needs and preferences could also be examined.

Obtaining insight into the health care needs and preferences of other patient groups

In view of the positive results (and potential spin-off) from our study, future research could include an ongoing assessment of health care consumers' needs and preferences. It would be interesting to find out whether patients with other (e.g. chronic, not life-threatening) diseases attach the same value to the various care aspects as cancer patients do. Other patient groups and health care organizations may benefit from the patient-centred approach and goals applied in our study.

Health care professionals and patient-centred care

In future research, it might be important to expand and confirm our study of health care professionals' estimates of patient preferences in a larger population of health care professionals, including a larger proportion of physicians and policymakers.

In particular, attention could be paid to the health care professionals' estimates of the preferences of individual cancer patients or groups of cancer patients, taking into account especially the influence of gender, type of cancer, level of education and phase of illness. Finally, it might also be important in future research to develop tools and interventions to support the estimate of cancer patients' needs and preferences by health care professionals.

7.6 Implications for clinical practice

The results of this thesis may contribute to a better insight into cancer patients' needs and preferences for health care in the Netherlands and may be used to improve patient-centred care.

Patient Priority Pyramid

The results of this study represent a valid and reliable starting point for care renewal processes based on patients' needs and preferences, and may be used to guide decisions to improve care for cancer patients. Arranging the aspects of care in order of importance, according to the mean scores of scales and single items in our questionnaire, may contribute to an efficient and efficacious use of means by focusing on those aspects of care that are most important to patients.

We developed the Patient Priority Pyramid [*Figure 1*] by categorizing health care issues by level of importance, in line with Maslow's pyramid for the 'Hierarchy of needs' [15]. The Patient Priority Pyramid for preferences in cancer care reflects five levels of importance, based on the importance scores on the scales and single items (see Table 2 in Chapter 2 and the 'Cancer patients' health care preferences questionnaire' (see Appendix 2)). The base of the pyramid reflects those issues which are most important to the patients (mean scores of the corresponding scales 80-100), and the top of the pyramid reflects those issues with the lowest priority for the patients, according to the mean scores (<20).

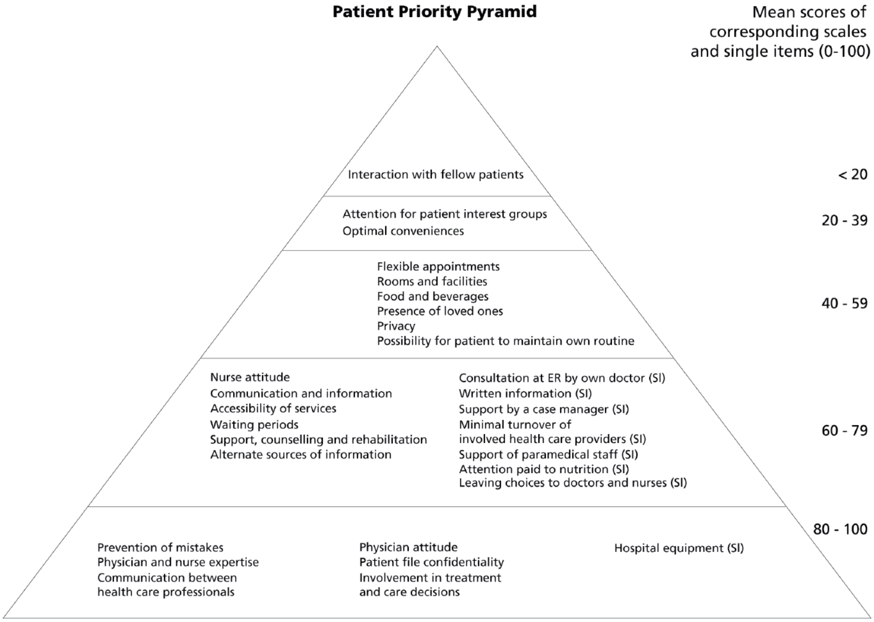

Figure 1 Patient Priority Pyramid

It is likely that in patient-centred care innovation projects, care aspects situated at the bottom of the pyramid may have the highest impact and therefore should be given priority. Once these aspects have been fulfilled, those in the next (higher) layer of the pyramid come into focus. Nowadays, much attention is paid to organizational and environmental factors (such as hotel services, comfort nursing and all kinds of comfort-raising provisions). Such factors are, without a doubt, important for the well-being of patients, but may have a relatively low impact when inadequate care (in terms of expertise and communication) is provided by doctors and nurses.

Taking patient- and disease-related factors into account

The patients in our study had a widely varying range of specific needs in terms of their expectations of cancer care. Although all cancer patients suffer from a life-threatening disease, they differ in biological, cultural, psychological and socio-economic respect from each other. Moreover, each patient has his/her own frame of reference that determines his/her health care needs and preferences. Considering the impact of some patient-related (especially gender) and disease-related factors on cancer patients' preferences, these factors should be taken into account when providing care to cancer patients. Providing true patient-centred care implies that each individual patient receives the best and most appropriate care as far as possible. For example, the optimal (patient-centred) care for a highly-educated woman with metastatic breast cancer will probably be different from optimal (patient-centred) care for a lower-educated man with a non-metastasized form of cancer. This is in line with De Haes who states that 'patients with less education, patients from ethnic minorities, more anxious patients and patients with a worse prognosis seem to be more likely to prefer less patient centeredness' [16].

With regard to gender, care could be tailored to certain aspects, for example the extent and manner of communication, the extent and manner of support, counselling and rehabilitation, length of consultation, opportunity to make choices in treatment and care, and privacy.

Tools for health care professionals

Although health care professionals were able to make reasonably correct estimates of cancer patients' health care preferences in general, they both overestimated and underestimated the value patients set on certain care aspects. The most important way to understand a patient and his or her specific needs and preferences, is through 'listening to the patient's story' [17]. Additionally, tools (e.g., a short version of the questionnaire developed in this study) to support professionals gain better insight and understanding of the patients' unique individuality may be helpful.

At the same time, patients could be encouraged and supported to supply the information required by health care professionals to gain insight into the patient's specific needs and preferences for cancer care. A potential tool to encourage patients to provide such information (and at the same time support health care professionals to get to know the individual patient better at a single glance), could be a 'Personal Patient Profile' that visualizes the 'patient's world' in pictures and which might be added to the patient's file. This tool is currently in development at the Department of Corporate Communications and the Department and Medical Oncology University Medical Center Utrecht, and may contribute to personalized communication between health care professionals and their patients.

Relation between patient experiences and the organization of health care
Given the benefits we have experienced through evaluating patient experiences and care processes, health care organizations might consider carrying out periodic, structured evaluations of patient experiences and care processes, with subsequent implementation and evaluation of changes. The outcomes of these evaluations could form an important basis for ongoing improvements in the hospital organization's structures and processes in the direction of optimal patient-centred care.

7.7 Conclusion

Cancer patients are an important target group in Dutch health care, and high-quality care and treatment for these patients is essential. Providing care that is as responsive to the patients' needs and preferences as possible may contribute to the quality of life and well-being of patients with cancer. Deeper insight into cancer patients' views on health care and their specific needs and preferences, as reported in this thesis, could create opportunities for the provision of true patient-centred care.

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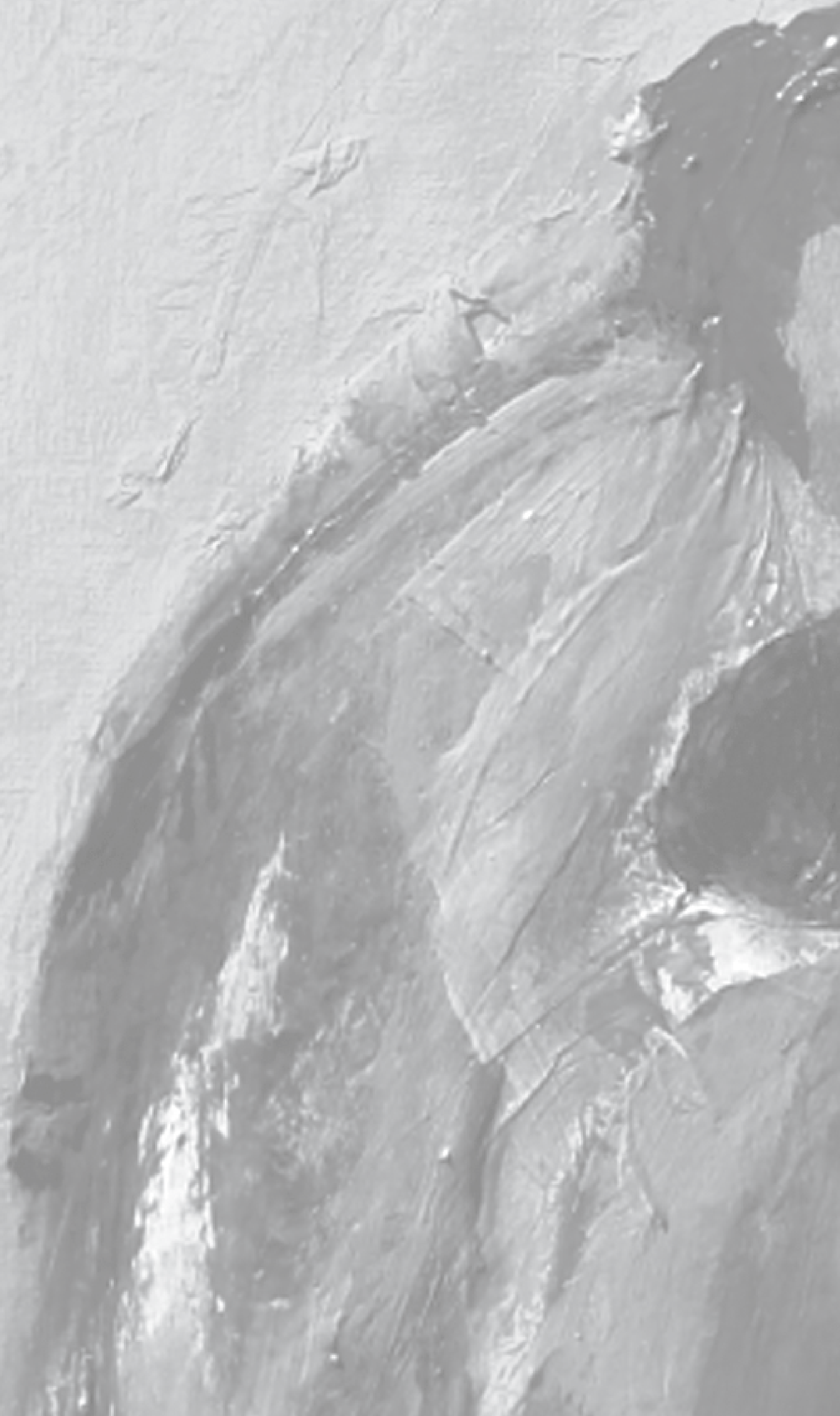
Chapter 8



Nederlandse samenvatting

Dankwoord

Curriculum Vitae

In 2008 werd in Nederland bij 89.200 mensen de diagnose kanker gesteld: bij 46.200 mannen en 43.000 vrouwen. Sinds 2008 is kanker doodsoorzaak nummer één in Nederland. 400.000 personen in Nederland (2.5% van de bevolking) hebben kanker of hebben kanker gehad. Mensen met kanker zijn daarmee een belangrijke doelgroep in de Nederlandse gezondheidszorg en goede zorg en behandeling zijn van groot belang. De laatste jaren is er in toenemende mate aandacht voor het meten en evalueren van de kwaliteit van zorg aan mensen met kanker. Bovendien is er door de toenemende marktwerking in de zorg een verschuiving te zien van instellingsgerichte en gefragmenteerde zorg naar een geïntegreerd en patiëntgericht systeem. Daarbij wordt steeds meer waarde gehecht aan de mening van de patiënt over zorg en behandeling en betrekken gezondheidszorginstelling patiënten steeds meer bij het organiseren en verbeteren van de zorg.
Om werkelijk patiëntgerichte zorg te kunnen bieden, is het belangrijk om inzicht te krijgen in de behoeften en voorkeuren van patiënten (hoe zou de zorg eruit moeten zien?), zonder beïnvloeding door professionele zorgverleners of onderzoekers en zonder direct rekening te houden met de (praktische) haalbaarheid van deze behoeften en voorkeuren.

Dit proefschrift gaat over de behoeften en voorkeuren van patiënten ten aanzien van de zorg en behandeling in het ziekenhuis.

De onderzoeken beschreven in dit proefschrift hebben tot doel om:

- inzicht te krijgen in de behoeften en voorkeuren van mensen met kanker ten aanzien van zorg en behandeling in een ziekenhuis en in (patiënt- en ziektegerelateerde) factoren die van invloed zijn op deze behoeften en voorkeuren.
- te bepalen in hoeverre professionele zorgverleners de behoeften en voorkeuren van patiënten goed kunnen inschatten.
- het effect te meten van het samenvoegen van klinische en poliklinische oncologie-afdelingen op de tevredenheid van mensen met kanker over de zorg.

Deze doelstellingen hebben geleid tot de volgende onderzoeksvragen:

1. Welke aspecten van zorg noemen patiënten als hen gevraagd wordt: “Hoe zou u de zorg inrichten als u het voor het zeggen had?’
2. Hoe belangrijk vinden patiënten deze zorgaspecten?
3. Welke patiënt- en ziektegerelateerde factoren hebben invloed op de behoeften en voorkeuren van patiënten ten aanzien van zorg en behandeling?
4. Welke aanvullende of verdiepende inzichten in bepaalde behoeften en voorkeuren van patiënten worden verkregen door een beroep te doen op het onderbewuste van patiënten?

5. In hoeverre is er overeenstemming tussen de behoeften en voorkeuren van patiënten en de inschatting van deze behoeften en voorkeuren door professionele zorgverleners?
6. Wat is het effect van het samenvoegen van klinische en poliklinische oncologieafdelingen op de tevredenheid van mensen met kanker over de zorg?

Om antwoord te geven op deze onderzoeksvragen zijn vijf studies uitgevoerd. De eerste studie was een kwalitatieve studie onder 51 mensen met kanker, waarbij tijdens zogenoemde focusgroepinterviews antwoord werd gezocht op de eerste onderzoeksvraag. De tweede studie was een kwantitatieve studie onder 386 mensen met kanker die de vragenlijst hebben ingevuld die was samengesteld op basis van de resultaten van de focusgroepinterviews (onderzoeksvraag 2 en 3). De derde studie was een kwalitatieve studie onder 15 mensen met kanker. Bij deze studie werd gebruik gemaakt van een speciale interviewtechniek (ZMET) die een beroep doet op het onderbewuste, om zodoende aanvullende of verdiepende inzichten te verkrijgen ten aanzien van bepaalde behoeften en voorkeuren van patiënten (onderzoeksvraag 4). De vierde studie was een kwantitatieve studie onder 60 professionele zorgverleners (verpleegkundigen, specialisten en beleidsmakers) gespecialiseerd in de zorg voor mensen met kanker. Hen werd gevraagd om dezelfde vragenlijst in te vullen als patiënten in de tweede studie hadden gedaan en in te schatten welke behoeften en voorkeuren zij dachten dat patiënten zouden hebben (onderzoeksvraag 5). De vijfde en laatste studie was een studie naar het effect van de integratie van ziekenhuisafdelingen en zorgprocessen op de tevredenheid van patiënten (onderzoeksvraag 6).

Samenvatting van de resultaten

Onderzoeksvraag 1 (Hoofdstuk 2)

Welke aspecten van zorg noemen patiënten als hen gevraagd wordt: "Hoe zou u de zorg inrichten als u het voor het zeggen had?'

Om deze onderzoeksvraag te beantwoorden zijn tussen juni 2004 en december 2005 focusgroepinterviews met patiënten in alle fasen van de behandeling gehouden. Er waren tien focusgroepinterviews nodig, met in het totaal 51 patiënten, om voldoende gegevens te verkrijgen. De patiëntenkenmerken waren: 67% vrouw, 39% was jonger dan 35 jaar, belangrijkste tumortypes waren: borst (18%), urologisch (20%), genitaal (10%) en gastrointestinaal (6%). De focusgroepinterviews verliepen gemakkelijk en in een prettige sfeer. Patiënten gaven aan het prettig te vinden om betrokken te worden bij het optimaliseren van de zorg voor mensen met kanker. De focusgroepinterviews resulteerden in een uitgebreide lijst van 136 relevante onderwerpen, verdeeld over zeven categorieën: organisatie van de zorg (35 items), communicatie (20 items), ruimtes en voorzieningen (30 items), begeleiding (13 items), bejegening (19 items), zelfstandigheid (10 items) en vakbekwaamheid (9 items).

Onderzoeksvraag 2 (Hoofdstuk 2)

Hoe belangrijk vinden patiënten de verschillende zorgaspecten die genoemd zijn tijdens de focusgroepinterviews?

Op basis van het resultaat van de focusgroepinterviews is een voorlopige vragenlijst ontwikkeld. Onderwerpen die tijdens de focusgroepinterviews werden genoemd zijn vertaald naar vragen ('ítems') die het belang van het onderwerp meten op een vierpuntsschaal, gerangschikt van 'niet belangrijk' (1) tot 'een beetje belangrijk' (2), 'belangrijk' (3) en 'van het allergrootste belang' (4) (zie bijlage 1). Tussen oktober 2006 en maart 2007 werd deze vragenlijst uitgedeeld aan 681 mensen met kanker. In het totaal werden 386 vragenlijsten ingevuld teruggestuurd (57% respons). De patiënten die de vragenlijst hadden ingevuld waren ouder en hadden een verder gevorderde ziekte.

Na een exploratieve factoranalyse (een statistische techniek waarbij items die betrekking hebben op hetzelfde zorgaspect worden samengevoegd tot zogenoemde schalen) werd een definitieve vragenlijst samengesteld, bestaande uit 21 schalen (met in het totaal 115 items) en 8 zelfstandige ('single') items. De scores van de schalen en de single items zijn omgerekend naar een score van 0-100, waarbij hogere scores wijzen op een groter belang.

De gemiddelde scores van de schalen en single items laten het belang zien van de onderwerpen die werden onderzocht met de vragenlijst. Patiënten hechten de meeste waarde (gemiddelde scores ≥ 80) aan de onderwerpen 'veiligheid/voorkomen van fouten', deskundigheid van artsen en verpleegkundigen', 'overleg en overdracht', 'bejegening door de arts', 'vertrouwelijke omgang met de gegevens van de patiënt', 'mogelijkheid om te kiezen in zorg en behandeling' en het single item 'moderne ziekenhuis apparatuur'. Relatief minder belangrijk (gemiddelde scores < 50) vonden patienten zorgaspecten gerelateerd aan 'aanwezigheid van naasten', 'privacy', 'gewoontes van patiënten', 'lotgenotencontact/ patiëntenvereniging', 'voorzieningen in het ziekenhuis', 'contact met medepatiënten'. De resultaten van deze studie laten zien dat patiënten de meeste waarde hechten aan die aspecten van de zorg die gerelateerd zijn aan de deskundigheid, het gedrag, het handelen en de bejegening van artsen en verpleegkundigen.

Onderzoeksvraag 3 (hoofdstuk 3)

Welke patiënt- en ziektegerelateerde factoren hebben invloed op de behoeften en voorkeuren van patiënten ten aanzien van zorg en behandeling?

Om deze vraag te beantwoorden is gebruik gemaakt van de gegevens verkregen uit het vragenlijstonderzoek onder 386 patiënten (zie tweede studie). In deze studie werd onderzocht welke invloed patiënt- en ziektegerelateerde factoren hebben op behoeften en voorkeuren van mensen met kanker ten aanzien van zorg en behandeling.

De volgende factoren werden onderzocht: geslacht, leeftijd, opleidingsniveau, aan- of afwezigheid van uitzaaiingen, vorm van kanker, jaren sinds de diagnose, aantal dagen van eerdere opnames en ziekenhuis. Van alle onderzochte factoren bleek dat geslacht het belangrijkste kenmerk was dat de voorkeuren in de zorg bepaalde. Er waren statistisch significante verschillen tussen mannelijke en vrouwelijke patiënten in hun voorkeuren in zorg en behandeling voor 15 van de 21 schalen (71%) en in twee van de acht single items (25%). Zonder uitzondering vonden vrouwen de zorgaspecten die genoemd werden in deze schalen en de single items belangrijker dan mannen.

Onderzoeksvraag 4 (Hoofdstuk 4)

Welke aanvullende of verdiepende inzichten in bepaalde behoeften en voorkeuren van patiënten worden verkregen door een beroep te doen op het onderbewuste van patiënten?

In de eerste drie maanden van 2009 werden patiënten van het UMC Utrecht Cancer Center benaderd met de vraag deel te nemen aan een onderzoek waarbij een beroep wordt gedaan op het onderbewuste met behulp van de zogeheten Zaltman Metaphor Elicitation Technique (ZMET). Op basis van de kennis over wat er voor dit onderzoek werd verwacht van patiënten, selecteerden artsen patiënten die geschikt waren voor deelname aan een persoonlijk interview. De onderzoeksvraag voor het interview was gebaseerd op de resultaten van het eerdere onderzoek en luidde: 'Wat zijn uw gedachten en gevoelens over de ideale zorgverlener (arts en verpleegkundige)?' Tijdens het interview dat 2 tot 2.5 uur duurde, drong de interviewer door tot verschillende niveaus van het denken over de 'ideale professionele zorgverlener'. Vijftien interviews waren geschikt voor analyse. De interviews en de analyse ervan werden uitgevoerd door speciaal getrainde onderzoekers. De patiëntenkenmerken waren: 53% vrouw, gemiddelde leeftijd 60 jaar, belangrijkste tumortypes borst, urogenitaal en gastrointestinaal. Een beroep doen op het onderbewuste resulteerde in een kleurrijke en gevarieerde verzameling van afbeeldingen geassocieerd met de 'ideale professionele zorgverlener'. Gebaseerd op de clusters van gedachten, gevoelens, meningen en behoeften die in alle interviews naar voren kwamen, werden vijf kernthema's geformuleerd door de onderzoekers. Deze kernthema's hadden betrekking op de deskundigheid en houding van de professionele zorgverleners, gedeelde besluitvorming (shared decision making) en communicatie en afstemming tussen professionele zorgverleners.

Onderzoeksvraag 5 (Hoofdstuk 5)

In hoeverre is er overeenstemming tussen de behoeften en voorkeuren van patiënten en de inschatting van deze behoeften en voorkeuren door professionele zorgverleners?

In mei en augustus 2007 werden 165 vragenlijsten (dezelfde als door patiënten zijn ingevuld in de tweede studie) verspreid onder professionele zorgverleners (artsen, verpleegkundigen en beleidsmakers). Hen werd gevraagd een inschatting te maken van de behoeften en voorkeuren van patiënten ten aanzien van zorg en behandeling. In het totaal werden 60 vragenlijsten ingevuld teruggestuurd en opgenomen in de analyse (36% respons). Kenmerken van de respondenten waren: 78% vrouw, 32% jonger dan 36 jaar, 67% verpleegkundige, 13% arts, 10% beleidsmedewerker en 10% beroep onbekend. De resultaten van het onderzoek onder professionele zorgverleners werden vergeleken met de resultaten van het onderzoek onder de 386 patiënten. Over het geheel was er een sterke samenhang tussen de inschatting van professionele zorgverleners en de daadwerkelijke behoeften en voorkeuren van patiënten. Voor beide groepen waren veiligheid en de deskundigheid, het gedrag, het handelen en de bejegening van artsen en verpleegkundigen het belangrijkst en werden organisatorische en omgevingsfactoren relatief minder belangrijk gevonden. Desondanks werden er voor acht van de 21 schalen en twee van de acht single items, statistisch significante verschillen gevonden tussen professionele zorgverleners en patiënten. Professionele zorgverleners onderschatten het belang dat patiënten hechten aan de expertise van artsen en verpleegkundigen, de bejegening door artsen, de toegankelijkheid van diensten (van zorg professionals), moderne ziekenhuisapparatuur en de mogelijkheid om in noodgevallen op de EHBO gezien te worden door de eigen behandelend arts. Professionele zorgverleners overschatten het belang dat patiënten hechten aan met name organisatorische en omgevingsgerelateerde factoren.

Verder werden in deze studie significante verschillen gevonden tussen mannelijke en vrouwelijke professionele zorgverleners voor acht schalen en twee single items. Als er significante verschillen waren in de inschatting van mannelijke en vrouwelijke zorgverleners, dan hadden vrouwen altijd hogere scores. Vrouwelijke zorgverleners maakten echter over het algemeen geen betere inschatting van de voorkeuren van patiënten dan hun mannelijke collega's.

Onderzoeksvraag 6 (Hoofdstuk 6)

Wat is het effect van het samenvoegen van klinische en poliklinische oncologieafdelingen op de tevredenheid van mensen met kanker over de zorg?

In 2006 zijn de klinische en poliklinische afdelingen medische oncologie van het Universitair Medisch Centrum Utrecht samengevoegd. In 2005 en in 2007 (dus voor en na de samenvoeging) werden de patiënten die werden behandeld op deze afdelingen, benaderd voor deelname aan een tevredenheidsonderzoek. Gedurende een periode van zes weken werden vragenlijsten uitgedeeld door artsen en verpleegkundigen aan een ongeselecteerde groep van opeenvolgende patiënten van de polikliniek, de dagbehandeling en de verpleegafdeling. In 2005 werden 174 vragenlijsten teruggestuurd (respons 72%) en in 2007 97 vragenlijsten (respons 78%). Kort na de eerste meting werden de apart gelegen units (polikliniek, dagbehandeling en verpleegafdeling) samengevoegd in één vleugel van het ziekenhuis en vond tevens integratie van de zorgprocessen plaats.

Na deze integratie was een statistisch significante toename van de tevredenheid te zien voor zes schalen. De belangrijkste verbetering was te zien op de dagbehandeling, met name ten aanzien van de mate waarin verpleegkundigen steeds op de hoogte zijn van de situatie van de patiënt, privacy, de inrichting van de dagbehandeling, de kwaliteit van de apparatuur waarmee wordt gewerkt, de sanitaire voorzieningen en wachttijden. Ten aanzien van de continuïteit en coördinatie van de zorg tussen professionele zorgverleners nam de tevredenheid toe voor vijf items.

De kleinere afstanden tussen afdelingen dragen bij aan de coordinatie tussen zorgverleners. Er is meer gelegenheid voor het uitwisselen van informatie onderling en het bieden van wederzijdse ondersteuning, resulterend in meer continuïteit in zorg en behandeling.

Aanbevelingen

Uitgaande van deze resultaten kan een aantal aanbevelingen voor verder onderzoek en voor de klinische praktijk worden geformuleerd.

Aanbevelingen voor verder onderzoek

- De vragenlijst ontwikkeld in de eerste studie kan als basis dienen voor de ontwikkeling van een vragenlijst voor het meten van ervaringen van mensen met kanker met de gezondheidszorg, zoals de Consumer Quality Index (CQI). Een CQI is gebaseerd op het patiëntenperspectief en ontworpen voor het meten van ervaringen van patiënten met zorg en professionele zorgverleners.
- Toekomstig onderzoek zou het effect van geslacht op behoeften en voorkeuren van patiënten verder kunnen uitdiepen.
- Het onderzoek naar behoeften en voorkeuren van patiënten zou uitgebreid kunnen worden onder specifieke patiëntengroepen zoals:
    - jongere patiënten (leeftijd 18-35 jaar), gezien de relatieve ondervertegenwoordiging van deze groep in onze studie en de veronderstelling dat deze groep andere behoeftes en voorkeuren zou kunnen hebben dan oudere patiënten.
    - oudere patiënten (leeftijd > 75 jaar), eveneens vanwege de relatieve ondervertegen-woordiging van deze groep in onze studie.
    - patiënten onder behandeling bij andere afdelingen dan medische oncologie, bijvoorbeeld chirurgie of radiotherapie, omdat deze patiënten wellicht andere behoeften en voorkeuren hebben dan de patiënten in onze studie.
    - patiënten die behandeld worden in de eerste lijn, om de continuïteit van zorg beter te kunnen waarborgen.

  - patiënten uit andere culturen, vanwege mogelijke culturele verschillen in behoeften en voorkeuren.
  - naasten en familie van patiënten, omdat zij vaak intensief betrokken zijn bij zorg en behandeling van de patiënt en hun visie op voorkeuren in zorg en behandeling een waardevolle aanvulling kan zijn.
- Gezien de positieve resultaten van onze studie zou het onderzoek naar behoeften en voorkeuren van patiënten op dezelfde wijze uitgevoerd kunnen bij patiënten met andere ziektes dan kanker. De vraag is of patiënten met een ander ziektebeeld (bijvoorbeeld chronisch en niet levensbedreigend) dezelfde waarde toekennen aan de verschillende zorgaspecten en dezelfde prioriteiten stellen als mensen met kanker.
- Om de bevinding ten aanzien van de inschatting van behoeften en voorkeuren van patiënten door professionele zorgverleners te bevestigen in een grotere groep (met een betere vertegenwoordiging van artsen en beleidsmakers), zou toekomstig onderzoek zich kunnen richten op dit onderwerp. Daarbij kan speciale aandacht worden besteed aan de inschatting van behoeften en voorkeuren van individuele patiënten of groepen mensen met kanker waarvan de achtergrondkenmerken bekend zijn.

Aanbevelingen voor de klinische praktijk

- De rangorde van zorgaspecten naar belangrijkheid zoals beschreven in dit proefschrift kan aangewend worden als leidraad bij het optimaliseren van de zorg aan mensen met kanker en een efficiënt en effectief gebruik van middelen door te focussen op die aspecten van zorg die door patiënten het meest belangrijk worden gevonden (zie Patient Priority Pyramid in hoofdstuk 7).
- Patiënten verschillen in biologisch, cultureel, psychologisch en sociaal-economisch opzicht van elkaar. Bovendien heeft elke patiënt een eigen referentiekader dat bepalend is voor zijn/haar behoeften en voorkeuren. Gezien het effect van patiënt- en ziektegerelateerde factoren (met name geslacht) op behoeften en voorkeuren van patiënten zou rekening gehouden kunnen worden met deze factoren. Voor wat betreft geslacht kan op basis van onze onderzoeksresultaten bijvoorbeeld gedifferentieerd worden qua uitgebreidheid en wijze van communiceren, uitgebreidheid en wijze van ondersteuning en begeleiding, de lengte van een consult, de mogelijkheid om te kiezen in zorg en behandeling en het bieden van privacy.
- Om professionele zorgverleners te ondersteunen in het leren kennen van de patiënt en diens behoeften en voorkeuren ten aanzien van zorg en behandeling is het wellicht zinvol instrumenten te ontwikkelen die daarbij behulpzaam zijn. Een voorbeeld zou een verkorte versie van de vragenlijst ontwikkeld in dit onderzoek kunnen zijn. Een ander mogelijk hulpmiddel is een persoonlijk patiëntenprofiel.

Dit is een pagina die ‘de wereld van de patiënt’ in beeld brengt met foto’s en enkele vragen. Dit profiel kan toegevoegd kan worden aan het patiëntendossier. Een dergelijk profiel kan patiënten ondersteunen bij het verstrekken van informatie over de eigen situatie. Dit creëert betere mogelijkheden voor het bieden van patiëntgerichte zorg.

- Op basis van onze ervaringen met het evalueren van de patiëntervaringen en zorgprocessen, kunnen zorginstellingen overwegen om periodiek een gestructureerde evaluatie uit te voeren met vervolgens een implementatie en evaluatie van veranderingen. De uitkomsten van dit soort evaluaties kunnen een belangrijke basis vormen voor voortdurende optimalisatie (in structuren en processen binnen een ziekenhuisorganisatie) in de richting van patiëntgerichte zorg.

Algemene conclusie

Mensen met kanker zijn een belangrijke doelgroep in de Nederlandse gezondheidszorg en goede zorg en behandeling voor deze patiënten is essentieel. Het bieden van zorg die zoveel mogelijk beantwoordt aan de behoeften en voorkeuren van patiënten kan een bijdrage leveren aan de kwaliteit van leven en het welzijn van mensen met kanker. Meer inzicht in de zienswijze van patiënten en hun specifieke behoeften en voorkeuren, zoals beschreven in dit proefschrift, biedt mogelijkheden voor het bieden van patiëntgerichte zorg.

Chapter 8

Nederlandse Samenvatting

Dankwoord

Curriculum Vitae

Aan de totstandkoming van dit proefschrift is door veel mensen een bijdrage geleverd. Een aantal van hen wil ik graag in het bijzonder bedanken.

Allereerst dank ik de patiënten die bereid waren hun ideeën over zorg en behandeling te delen. Zij deden dat tijdens focusgroepinterviews en door het invullen van de vragenlijst. Ondanks de extra belasting die dit voor hen betekende, heb ik tijdens het onderzoek veel positieve en bereidwillige reacties gekregen op het verzoek om deelname. Ik was daar steeds weer van onder de indruk. Zonder de inzet en bijdrage van patiënten was dit onderzoek niet mogelijk geweest.

Prof. dr. E.E. Voest, beste Emile, wat was ik blij met je voorstel om dit onderzoek te beginnen! Je hebt me daarmee een bijzondere kans geboden om binnen te stappen in de wereld van het onderzoek en een proefschrift te schrijven over een onderwerp dat me na aan het hart ligt. In de afgelopen jaren heb ik je leren kennen als een scherpzinnige, gedreven en heel sympathieke promotor. Dank voor je deskundige en altijd motiverende begeleiding. Je hebt me over heel wat drempels heen geholpen! Je leerde me de resultaten van het onderzoek met een wetenschappelijke blik te bekijken, kritisch te denken en de resultaten toegankelijk te verwoorden in artikelen. Door je positieve en relativerende houding tijdens al onze overleggen gaf je me steeds het vertrouwen om door te gaan. Veel dank daarvoor!

Dr. A. de Graeff, beste Alexander, veel dank voor alle tijd en energie die je als copromotor hebt besteed aan het begeleiden van mij tijdens dit promotietraject! Je deskundige, pragmatische en betrokken houding gedurende het hele traject heb ik bijzonder gewaardeerd. Ondanks je volle agenda kon ik altijd een beroep op je doen als ik vragen had en je voorzag de concept manuscripten steeds van helder en waardevol commentaar. Ik heb veel van je geleerd op het gebied van data-analyse en het 'to the point' schrijven van artikelen. Dank voor de altijd leerzame en inspirerende overleggen.

Dr. K. Wynia, lieve Klas, hoe kan ik jou bedanken voor je grote betrokkenheid en hulp als zus, maar vooral ook als deskundige op het gebied van vragenlijstontwikkeling en het doen van onderzoek. Je had ook copromotor moeten zijn, maar helaas kon dat niet geformaliseerd worden. De tijd en energie die je hebt besteed aan mijn begeleiding waren een copromotorschap in iedergeval dubbel en dwars waard! Dank je voor je zussenliefde, wijze raad, aanmoedigingen, vertrouwen, relativering, talloze mailtjes en telefoontjes en zo veel meer....Ik ben blij en trots dat je mijn zus bent, je bent er één van goud!

Prof.dr. I.H.M. Borel Rinkes, Prof.dr. E. van der Wall, Prof.dr. J.C.J.M. de Haes, Prof.dr. J.M. Bensing en Prof.dr. S.A. Reijneveld, leden van de beoordelingscommissie, hartelijk dank voor het beoordelen van mijn manuscript!

Drs. A. M. Hetharia en Drs. J.A.M. van der Giessen, lieve Annelies en Jeanine, lieve paranimfen,
we zijn vriendinnen en collega's van het eerste uur. Veel hoogte- en dieptepunten in onze levens hebben we samen gedeeld. Het was dan ook meteen duidelijk dat ik jullie zou vragen mijn paranimfen te worden. Fijn dat jullie zo enthousiast instemden! Veel dank voor jullie inspanningen.
Jeanine, dank voor onze hechte vriendschap en verbondenheid, je altijd luisterend oor, humor, wijze adviezen, relativeringsvermogen en zo veel meer.....
Annelies, dank voor je warme betrokkenheid en vriendschap, je energie en creativiteit, je gezelligheid en zo veel meer.... Ook wil ik je bedanken dat je me als direct leidinggevende de gelegenheid gaf om het onderzoek uit te voeren. Jouw deur stond altijd open om me te adviseren en mee te denken over het onderzoek en het schrijven van artikelen.
Jullie zijn dierbare vriendinnen en ik zie uit naar wat we samen nog allemaal gaan meemaken.

Artsen en verpleegkundigen van de afdelingen Medische Oncologie van het St. Antonius Ziekenhuis in Utrecht en Nieuwegein, het Diakonessenhuis in Utrecht, Ziekenhuis Rivierenland in Tiel, Meander Medisch Centrum in Amersfoort en het Zuwe Hofpoort Ziekenhuis in Woerden, hartelijk dank voor uw inzet en betrokkenheid bij het onderzoek door het uitdelen van vragenlijsten aan patiënten. Dankzij uw inspanningen heb ik veel patiënten kunnen betrekken bij het onderzoek.

Beste collega's van de Nederlandse Federatie van Kankerpatiëntenverengingen (NFK) en Integraal Kankercentrum Midden Nederland (IKMN), hartelijk dank voor jullie interesse voor het onderzoek en jullie betrokkenheid bij het werven van patiënten voor de focusgroepinterviews.
Dank ook aan de collega's van het IKMN voor jullie betrokkenheid en de steun bij het verwerken van de data in de beginfase van het onderzoek.

Dr. H. J. Sixma (Nederlands Instituut voor Onderzoek van de Gezondheidszorg (NIVEL)), beste Herman, de leerzame gesprekken en je adviezen als ervaren onderzoeker op het gebied van kwaliteit van zorg vanuit patiëntenperspectief in het begin van het onderzoekstraject waren voor mij heel waardevol. Veel dank daarvoor!

Drs. C.L.J.J. Kruitwagen (Julius Centrum voor Gezondheidswetenschappen en Eerstelijns Geneeskunde – UMC Utrecht), beste Cas, veel dank voor je hulp bij de statistische verwerking van de data. Het blijft ingewikkeld, maar ik heb veel van je geleerd de afgelopen jaren!

Drs. M.E.A. Weber (Altuition), beste Marcel, dank je wel voor de prettige samenwerking bij het uitvoeren van het ZMET-onderzoek!

Raad van Bestuur UMC Utrecht. Graag wil ik de Raad van Bestuur van het UMC Utrecht bedanken voor het bieden van de gelegenheid om dit onderzoek te doen binnen onze directie. Personalized Cancer Care is een belangrijk speerpunt in de UMC Utrecht strategie en ook op deze manier komt tot uitdrukking dat veel waarde wordt gehecht aan patiëntgerichte zorg voor deze nog steeds groeiende patiëntengroep.

E.A. Mulder MCC, beste Else, veel dank voor je betrokkenheid, wijze raad, aanmoedigingen en vooral voor de ruimte die je me als hoofd van de afdeling Interne en Externe Communicatie gaf om dit onderzoek te realiseren. Ik ben je daar heel dankbaar voor!

Collega's Patiëntencommunicatie en Webmedia, lieve naaste collega's van de afdeling Patiëntencommunicatie en Webmedia, Annelies Hetharia, Jeanine van der Giessen, Miranda Wildenbeest, Anne Koehorst, Renata van Wijck, Paul Jenniskens, Liesbeth Stoorvogel, Miriam de Heus, Vincent de Widt en Yvonne Brink, wat hebben we toch een heerlijk leuk, creatief en dynamisch team! Ik ben blij dat ik er deel van mag uitmaken. Jullie deskundigheid, betrokkenheid, humor, gezellige koffiemomenten en relativeringsvermogen zorgden voor een fijne 'thuisbasis'.
Miriam, speciale dank voor jou voor je inzet en betrokkenheid bij het uitwerken en analyseren van de gegevens van de focusgroepinterviews in het begin van het onderzoek. 't Was superfijn samenwerken!

Collega's van de afdeling Medische Oncologie en het UMC Utrecht Cancer Center, dank voor jullie collegialiteit en betrokkenheid bij het onderzoek, onder andere door het uitdelen van de vragenlijsten en de vele leerzame gesprekken over de zorg aan mensen met kanker. Speciale dank aan de collega's betrokken bij het schrijven van de manuscripten voor jullie waardevolle commentaar.
Dr. S.C.C.M. Teunissen, beste Saskia, speciale dank voor jou voor alles wat je me hebt geleerd over de zorg voor mensen met kanker. Ik heb je leren kennen als een betrokken, enthousiaste en gedreven collega met hart voor de patiënt. Onze gesprekken waren altijd leerzaam en inspirerend.

Drs. G.J.C.M. Engwirda, beste Geranne, met het ZMET onderzoek heb je me de gelegenheid geboden om een aantal voorkeuren en behoeften van patienten dieper te onderzoeken vanuit het onbewuste. Veel dank daarvoor!
Paofi Tjia, beste Paof, we kennen elkaar al van ver vóór dit onderzoek. De kennis die ik heb opgedaan door met je samen te werken in verschillende projecten (o.a. bij het schrijven van het Patiënten Informatie Dossier over Chemotherapie) heb ik als zeer waardevol ervaren tijdens dit onderzoek. Veel dank daarvoor en ook voor je betrokkenheid bij dit onderzoek.
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Hanneke de Jong-Le Clercq, lieve Han, jij hebt het prachtige schilderij gemaakt voor de omslag van het proefschrift. Het is helemaal goed en ik ben je er bijzonder dankbaar voor!

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Lieve vrienden in IJsselstein, dank voor jullie belangstelling en meeleven tijdens het hele promotietraject. Dank voor alle gezellige koffie- en wijnmomenten zo aan het eind van de middag en voor de talloze keren opvang van de kinderen. Heerlijk zo’n veilig en vertrouwd netwerk. Monique, veel dank voor het kritisch meekijken in de drukproeven van dit boekje.

Lieve kerngroep, dank voor jullie interesse en meeleven tijdens het onderzoek. De verbondenheid die we als groep hebben, ervaar ik als heel waardevol. Ik hoop dan ook dat we nog lang op dezelfde voet verder gaan.

Lieve Mam, ik ben zo dankbaar dat jij mijn moeder bent! Dank voor je levenslange onvoorwaardelijke liefde, steun, vertrouwen en zoveel meer..... ’t Is jammer dat papa dit moment niet kan meemaken. Ik weet zeker dat hij trots zou zijn! Ik ben jullie samen dankbaar voor een fijne jeugd in een groot en heel gezellig gezin. ’t Heeft me de ruimte gegeven om me te ontwikkelen zoals ik wilde. Nu de klus geklaard is zie ik uit naar meer tijd voor elkaar!

Lieve Dirkje, lieve schoonmoeder, mijn dank aan jou is groot! Niet alleen voor alle keren oppassen op de kinderen, bergen was wegstrijken en heerlijk koken, maar vooral voor je liefde, gezelligheid, levenswijsheid en zoveel meer..... ’t Was altijd inspirerend om met je van gedachten te wisselen over de zorg aan mensen met kanker en waar het in het leven werkelijk om gaat.

Lieve broers en zussen, zwagers en schoonzussen, lieve neefjes en nichtjes, dank voor jullie liefde en verbondenheid, gezelligheid en veel afleiding door menig family-event. Dat was altijd een welkome afleiding. Dikke kus voor jullie allemaal.

Henk, Evy, Suze, mooie lieve kinderen, jullie zijn geweldig! Dank voor jullie geduld met een moeder die er soms met haar gedachten maar half bij was. Jullie waren hoe dan ook mijn grootste supporters! Henk, die van die krokodil waar je tegen moet praten en niet voor weg moet lopen, neem ik de rest van m'n leven mee. Evy, je lieve sms-jes komen altijd net op het goede moment. Dank je voor je leuke 'gouden hart-idee' voor de omslag. Suus, jouw knuffels zijn de beste na een lange werkdag. Dank lieve schatten, we gaan eens lekker genieten van meer tijd voor elkaar. Jullie zijn super en zo veel meer...!

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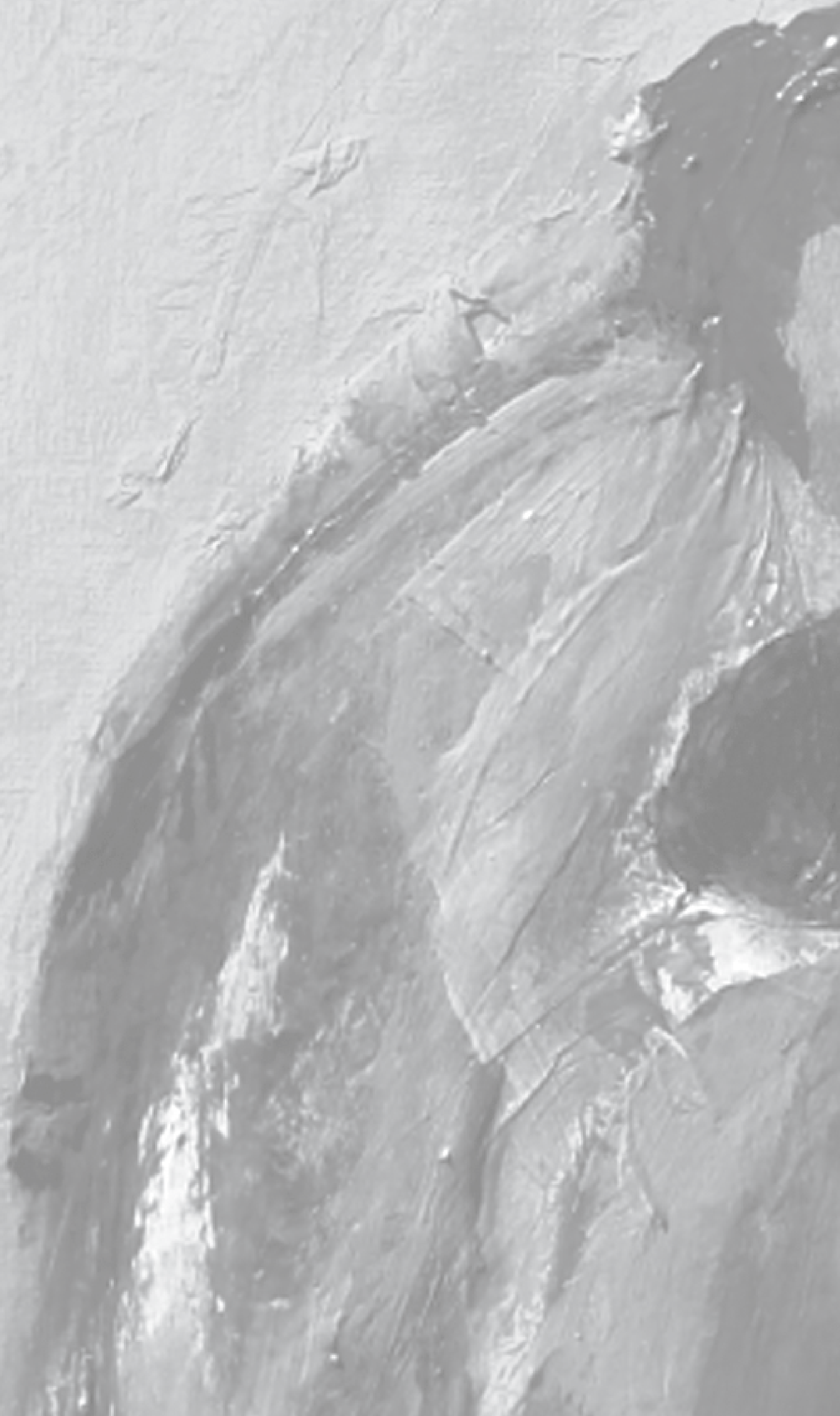
Naast al deze personen, dank ik God voor Zijn liefdevolle nabijheid en trouw in de afgelopen jaren.

Chapter 8



Nederlandse Samenvatting

Dankwoord

Curriculum Vitae

Hester Wessels-Wynia werd geboren in Dieren op 14 juni 1968. Na het behalen van het MAVO diploma aan de Da Costa MAVO te Dieren en haar HAVO diploma op het Christelijk Lyceum te Arnhem, is zij in 1987 begonnen met de Inservice opleiding voor verpleegkundigen bij het UMC Utrecht. Na het eerste studiejaar stapte zij in 1988 over naar de tweedegraads Lerarenopleiding Nederlands en Gezondheidskunde aan de Hogeschool Midden Nederland, die zij in 1992 afrondde. Na een stageperiode bij de afdeling Patiëntencommunicatie (Directie Raad van Bestuur, Interne en Externe Communicatie) van het Universitair Medisch Centrum Utrecht (UMC Utrecht) kreeg zij een vaste aanstelling als lid van het team.

Vanaf de start van haar loopbaan zijn het patiëntenperspectief en protocollering van patiëntencommunicatie centrale aandachtsgebieden in haar werk geweest. In dat kader stond Hester aan de wieg van de ontwikkeling van het Patiënten Informatie Dossier (PID)[1]. Het concept 'Patiënten Informatie Dossier' heeft landelijk navolging gekregen en meerdere ziekenhuizen gebruiken deze methodiek. Verder heeft zij een bijdrage geleverd aan de ontwikkeling van methoden en technieken om patiëntenraadpleging een structurele plek te geven in zorginnovatieprojecten en adviestrajecten.

In diverse communicatieprojecten heeft Hester gesproken met patiënten over de impact van ziekte op hun leven en de beleving van zorg en behandeling. Hierdoor groeide haar interesse en overtuiging voor het betrekken van het patiëntenperspectief in kwaliteit van zorg. In haar functie als adviseur Patiëntencommunicatie en Webmedia kreeg zij de gelegenheid om binnen de afdeling Medische Oncologie diepgaander onderzoek te doen naar het perspectief van mensen met kanker op zorg en behandeling, wat resulteerde in dit proefschrift.
Hester is getrouwd met Gert Wessels en moeder van Henk (1996), Evy (1998) en Suze (2001).

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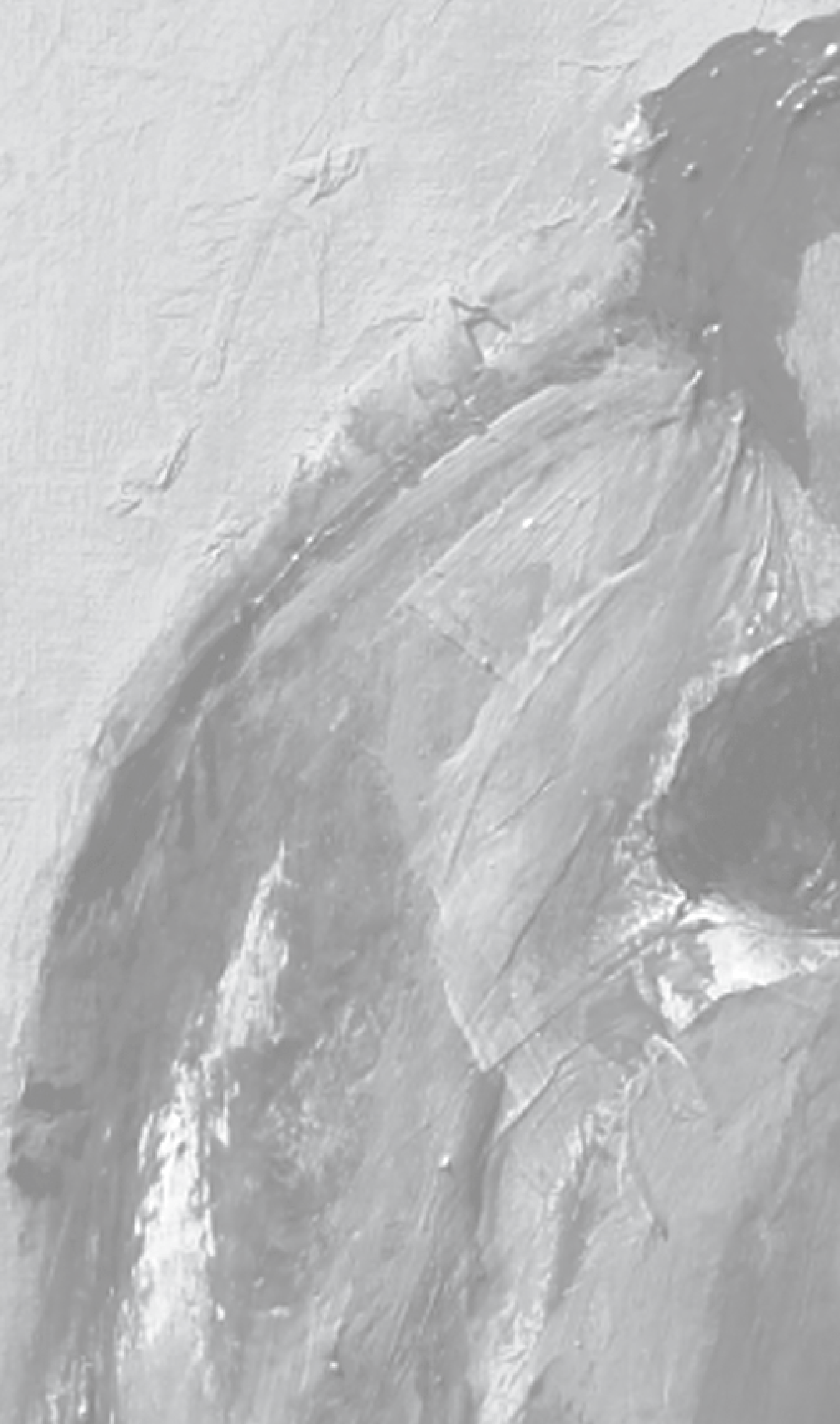
[1] Een PID is een losbladig systeem met schriftelijke informatie over (meestal ingrijpende) ziektebeelden en behandeling(en). De informatie in het PID komt tot stand volgens een vaste methodiek tijdens multidiscipinaire communicatieprojecten. Doordat de informatie losbladig is, kunnen zorgverleners de informatie gefaseerd en op maat aan de patiënt aanbieden. Naast een informatiedeel bevat het PID ook een communicatiedeel: de bijbehorende communicatierichtlijn voor zorgverleners en de aandachtspuntenlijst voor de patiënt ondersteunen de mondelinge communicatie tussen hen.

Appendix 1



Vragenlijst

‘Als je het mij vraagt….’

Een onderzoek naar de vraag hoe mensen

met kanker de zorg inrichten als

zij het voor het zeggen hebben.

Locatie
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Universitair Medisch Centrum
Utrecht

Als je het mij vraagt...

Een onderzoek naar de vraag hoe mensen met kanker de zorg inrichten als zij het voor het zeggen hebben

Oktober / november 2006

Universitair Medisch Centrum
Utrecht

Instructie

De vragenlijst

Naast een aantal algemene vragen, is de vragenlijst opgedeeld in zeven onderdelen waarin vragen worden gesteld over:

- Organisatie in het ziekenhuis
- Communicatie
- Ruimtes en voorzieningen
- Begeleiding
- Bejegening
- Zelfstandigheid
- Vakbekwaamheid

Tot slot stellen we nog enkele vragen over de vragenlijst zelf.

Het invullen

We zijn ons er van bewust dat dit een uitgebreide vragenlijst is, toch is het voor het onderzoek belangrijk dat u de vragenlijst zo volledig mogelijk invult en geen vragen overslaat. Alleen dan krijgen we een totaalbeeld van datgene wat patiënten belangrijk vinden in zorg en behandeling in het ziekenhuis.

Natuurlijk hoeft u de vragenlijst niet in één keer in te vullen. U kunt ook steeds enkele onderdelen doen. Daarnaast adviseren we u de vragenlijst eerst even door te bladeren voordat u begint. U weet dan ongeveer wat u kunt verwachten.

De antwoordmogelijkheden

Er zijn verschillende antwoordmogelijkheden:

Voorbeeldvragen:

A.
Wat is uw leeftijd?

☐ tussen de 18 en 35 jaar
☒ tussen de 36 en 50 jaar
☐ tussen de 51 en 65 jaar
☐ tussen de 65 en 79 jaar
☐ 80 jaar of ouder

→ *Bij dit soort vragen verzoeken wij u aan te kruisen wat voor u van toepassing is.*

B.
Wilt u voor elke uitspraak aangeven hoe belangrijk het voor u is?

1.	**Planning van afspraken**	**Niet belangrijk**	**Beetje belangrijk**	**Belangrijk**	**Van het allergrootste belang**
a.	Meerdere afspraken in het ziekenhuis worden op één dag gepland.	☐	☐	☒	☐
b.	Afspraken met meerdere specialisten (consulten) worden op één plaats in het ziekenhuis gepland.	☐	☒	☐	☐

→ *Bij dit soort vragen verzoeken wij u aan te kruisen hoe belangrijk u het genoemde onderdeel van zorg vindt.*

C

Zoals gezegd bestaat de vragenlijst uit zeven onderdelen. Elk onderdeel is opgebouwd uit vragen (aspecten van zorg). Aan het einde van elk onderdeel vragen we u om aan te geven welke drie aspecten van zorg u het belangrijkst vindt?

De drie allerbelangrijkste aspecten bij dit onderdeel zijn wat mij betreft:

1) 4d

2) 2b

3) 7b

→ *Bij dit soort vragen verzoeken wij u een rangorde te maken: Het nummer van de vraag en de letter van het aspect dat u het allerbelangrijkste vindt, zet u op 1.*

Opmerkingen en toelichtingen

Eventuele opmerkingen of toelichtingen bij vragen kunt u, onder vermelding van het nummer en de letter van de vraag, noteren in de daarvoor bestemde ruimte aan het einde van elk onderdeel.

Wat u verder moet weten:

- **Er bestaan geen goede of foute antwoorden, het gaat ons om uw mening.**
- **In de vragenlijst wordt regelmatig de term** "zorgverlener(s)" gebruikt. Hiermee bedoelen we niet alleen artsen en verpleegkundigen, maar ook andere disciplines die bij uw zorg betrokken zijn. U kunt bijvoorbeeld denken aan de diëtist, de maatschappelijk werker of de fysiotherapeut.
- **Mochten u tijdens het invullen punten te binnen schieten die u mist in de vragenlijst en die u wel belangrijk** vindt, dan kunt u deze noteren op de één na laatste pagina (vraag 1).
- Wij verzoeken u vriendelijk de ingevulde vragenlijst **binnen 2 weken** aan ons te retourneren in bijgevoegde antwoordenvelop. Een postzegel is niet nodig.
- **Met vragen en onduidelijkheden kunt u contact opnemen met Hester Wessels of Miriam de Heus**
  - Telefoon: 030 – 2507320 (op maandag en donderdag)
  - E-mail: H.Wessels@umcutrecht.nl (de mail wordt dagelijks gelezen en beantwoord).

Bij voorbaat hartelijk dank voor uw medewerking!

Met vriendelijke groet,

Prof. Dr. Emile Voest, medisch afdelingshoofd oncologie
Drs. Miriam de Heus, onderzoeksmedewerker
Hester Wessels, onderzoeker

Algemene vragen

De volgende vragen gaan over uw persoonsgegevens en over uw ziekte.

1. Datum waarop u deze vragenlijst invult:

.... / .... / 200......

Uw persoonsgegevens

2. Wat is uw geslacht?

☐ Man
☐ Vrouw

3. Wat is uw leeftijd?

☐ tussen de 18 en 35 jaar
☐ tussen de 36 en 50 jaar
☐ tussen de 51 en 65 jaar
☐ tussen de 65 en 79 jaar
☐ 80 jaar of ouder

4. Wat is de hoogste opleiding die u voltooid heeft?

☐ Lager onderwijs
☐ Lager (beroeps)onderwijs
☐ MAVO / MULO / MBO / VMBO
☐ HAVO / MMS / HBS / Gymnasium / VWO
☐ HBO
☐ Universitaire opleiding

Vragen over uw ziekte

5. Welke vorm van kanker is bij u vastgesteld en wanneer?

Vorm van kanker

☐ Maag / darm kanker
☐ Borstkanker
☐ Huidkanker
☐ Kanker aan de urinewegen (blaas, nieren, nierbekken, prostaat)
☐ Kanker aan de geslachtsorganen (baarmoeder (hals), eierstok, vagina, zaadbal, penis)
☐ Kanker in het hoofd- halsgebied (lip, mondholte, keelholte, strottenhoofd)
☐ Longkanker
☐ Anders, namelijk ....

De diagnose is gesteld in:

.... (maand) .... (jaar)

Zijn er uitzaaiingen bij u geconstateerd?

☐ Ja
☐ Nee

6. Bent u (langer dan één dag) opgenomen geweest in het ziekenhuis in verband met de behandeling van kanker?

☐ Ja*
☐ Nee

* Zo ja, wat was de duur van de langste opname?

☐ Korter dan een week
☐ Tussen een week en twee weken
☐ Tussen twee weken en drie weken
☐ Langer dan drie weken

7. Waaruit heeft uw behandeling tot nu toe bestaan? *(er zijn meerdere antwoorden mogelijk)*

☐ Chemotherapie
☐ Hormonale therapie
☐ Experimentele behandeling
☐ Bestraling (radiotherapie)
☐ Gelijktijdig bestraling en chemotherapie (Chemoradiatie)
☐ Operatie
☐ Anders, namelijk ....

8. Bent u lid van een patiëntenvereniging op het gebied van kanker?

☐ Ja*
☐ Nee

*Zo ja, van welke patiëntenvereniging bent u lid?

Organisatie in het ziekenhuis

In dit gedeelte vragen we u hoeveel waarde u hecht aan bepaalde onderdelen van de organisatie van het ziekenhuis. Geef voor elke uitspraak aan hoe belangrijk het voor u is, door een kruisje te zetten in het vakje van uw keuze.

1.	**Planning van afspraken**	**Niet belangrijk**	**Beetje belangrijk**	**Belangrijk**	**Van het allergrootste belang**
a.	Meerdere afspraken in het ziekenhuis worden op één dag gepland.	☐	☐	☐	☐
b.	Afspraken met meerdere specialisten (consulten) worden op één plaats in het ziekenhuis gepland.	☐	☐	☐	☐

2.	**Wachttijden**	**Niet belangrijk**	**Beetje belangrijk**	**Belangrijk**	**Van het allergrootste belang**
a.	Aanvullend onderzoek om tot een diagnose te komen, vindt binnen één week plaats.	☐	☐	☐	☐
b.	De wachttijd bij poliklinische afspraken (onderzoeken, consulten bij de arts, behandelingen), is niet langer dan 15 minuten.	☐	☐	☐	☐
c.	Als het spreekuur uitloopt, wordt dit aan mij gemeld.	☐	☐	☐	☐
d.	Ik hoef niet langer dan drie werkdagen te wachten op de uitslag van een onderzoek.	☐	☐	☐	☐
e.	Na het stellen van de diagnose kan ik, zo snel als ik dat wil, starten met de behandeling.	☐	☐	☐	☐
f.	In noodgevallen hoef ik niet eerst naar de EHBO, maar kan ik direct door een specialist worden gezien.	☐	☐	☐	☐

3.	**Privacy**	**Niet belangrijk**	**Beetje belangrijk**	**Belangrijk**	**Van het allergrootste belang**
a.	In de wachtkamer op de polikliniek kan ik mij terugtrekken als ik behoefte heb aan rust en niet geconfronteerd wil worden met andere patiënten.	☐	☐	☐	☐
b.	Ik kan bij (dag)opname kiezen tussen een éénpersoons of een meerpersoonskamer.	☐	☐	☐	☐
c.	Tijdens (dag)opname zijn er voldoende mogelijkheden om me, al dan niet met bezoek, in rust af te zonderen.	☐	☐	☐	☐
d.	Zorgverleners gaan zorgvuldig om met mijn patiëntgegevens.	☐	☐	☐	☐
e.	Privacygevoelige informatie wordt niet in het bijzijn van andere patiënten aan mij verstrekt.	☐	☐	☐	☐

4.	**Overleg tussen zorgverleners**	**Niet belangrijk**	**Beetje belangrijk**	**Belangrijk**	**Van het allergrootste belang**
a.	Ik heb toegang tot alle zorgverleners die voor mij belangrijk zijn, direct na het stellen van de diagnose.	☐	☐	☐	☐
b.	Ik heb toegang tot alle zorgverleners die voor mij belangrijk zijn tijdens de behandeling en daarna.	☐	☐	☐	☐
c.	De zorgverleners die betrokken zijn bij mijn zorg, dragen informatie over mij goed aan elkaar over.	☐	☐	☐	☐
d.	Er is weinig wisseling in de zorgverleners die betrokken zijn bij mijn zorg.	☐	☐	☐	☐
e.	Zorgverleners in het ziekenhuis dragen informatie over mij goed over aan zorgverleners in de thuissituatie.	☐	☐	☐	☐
f	Mijn behandelend arts overlegt zo nodig met artsen in een gespecialiseerd oncologisch centrum over mij.	☐	☐	☐	☐

5.	Contactpersoon	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	Ik heb, vanaf het moment dat de diagnose kanker is gesteld, een vaste contactpersoon in het ziekenhuis. Dit houdt in één zorgverlener (arts of verpleegkundige), die mij tijdens de hele onderzoek- en behandelperiode begeleidt.	☐	☐	☐	☐

6.	Eten en drinken in het ziekenhuis	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	De warme maaltijden tijdens (dag)opname zijn vers, gevarieerd en goed bereid.	☐	☐	☐	☐
b	Ik kan kiezen wat ik wil eten en drinken.	☐	☐	☐	☐
c	Ik kan buiten de reguliere etenstijden om het eten en drinken (warm en koud) krijgen, waar ik op dat moment behoefte aan heb.	☐	☐	☐	☐
d	Er wordt op gelet dat ik voldoende eet en drink om in een goede conditie te blijven.	☐	☐	☐	☐
e	Tijdens een (dag)opname kan ik of mijn naaste gebruik maken van een keuken om zelf iets te eten te maken.	☐	☐	☐	☐

7.	Bezoekregels (tijdens opname op de dagbehandeling of de verpleegafdeling)	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	Ik ondervind geen hinder van het bezoek van medepatiënten.	☐	☐	☐	☐
b.	Mijn naaste (partner, kind, ouder) mag de hele dag bij mij zijn.	☐	☐	☐	☐
c.	Mijn naaste (partner, kind, ouder) kan 's nachts bij mij blijven.	☐	☐	☐	☐

8.	Veiligheid	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	De zorgverleners die betrokken zijn bij mijn zorg en behandeling, werken volgens een systeem, waarbij de kans op fouten minimaal is.	☐	☐	☐	☐
b.	Als een zorgverlener een fout maakt tijdens mijn zorg en behandeling, dan bespreekt deze zorgverlener dit met mij.	☐	☐	☐	☐

9.	Service	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	De kosten van het huren van telefoon en televisie komen overeen met de tarieven die ik thuis betaal.	☐	☐	☐	☐
b.	Er zijn voldoende parkeervoorzieningen dicht bij de ingang van het ziekenhuis.	☐	☐	☐	☐

10.	Medepatiënten	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	Tijdens een (dag)opname lig ik bij leeftijdsgenoten.	☐	☐	☐	☐
b.	Tijdens een (dag)opname lig ik alleen samen met mensen die kanker hebben.	☐	☐	☐	☐
c.	Tijdens een (dag)opname lig ik samen met mensen die geen kanker hebben.	☐	☐	☐	☐

Wilt u tenslotte voor het onderdeel *organisatie in het ziekenhuis* aangeven welke drie aspecten u het belangrijkst vindt?
Maak een rangorde: Het nummer van de vraag en de letter van het onderdeel dat u het allerbelangrijkste vindt zet u op 1.

De drie allerbelangrijkste aspecten bij het onderdeel organisatie in het ziekenhuis zijn wat mij betreft:

1) ___________

2) ___________

3) ___________

Ruimte voor opmerkingen en toelichtingen op uw antwoord (onder vermelding van het nummer en de letter van de deelvraag)

____

____

____

Communicatie

Bij communicatie gaat het om het contact en de interactie tussen personen. Geef voor elke uitspraak aan hoe belangrijk het voor u is, door een kruisje te zetten in het vakje van uw keuze.

1.	Inhoud van communicatie	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
	Ik krijg <u>mondelinge informatie</u> over: ...				
a.	... mijn ziekte.	☐	☐	☐	☐
b.	... eventuele erfelijkheid van mijn ziekte.	☐	☐	☐	☐
c.	... onderzoeken. Dit houdt in: • de reden van het onderzoek • de gang van zaken tijdens het onderzoek • de duur van het onderzoek • het moment dat uitslag bekend wordt	☐	☐	☐	☐
d.	... mogelijke behandelingen. Dit houdt in: • waaruit bestaat de behandeling • het te verwachten effect van de behandeling • de duur van de behandeling • risico's en bijwerkingen van de behandeling • gevolgen op langere termijn	☐	☐	☐	☐
e.	... mogelijkheden voor deelname aan medisch wetenschappelijk onderzoek/experimenteel onderzoek	☐	☐	☐	☐
f.	... protheses en hulpmiddelen (indien van toepassing)	☐	☐	☐	☐
g.	... de gang van zaken in het ziekenhuis	☐	☐	☐	☐
h.	... relevante patiëntenverenigingen	☐	☐	☐	☐
i.	Ik word regelmatig geïnformeerd over het effect van de behandeling.	☐	☐	☐	☐
	In gesprekken met mijn arts krijg ik de ruimte om te spreken over: ...				
j.	... het gebruik van alternatieve geneeswijzen en medicijnen[1]	☐	☐	☐	☐
k.	... informatie die ik op het internet heb gelezen over mijn ziekte en mogelijke behandeling	☐	☐	☐	☐
l.	... mijn eventuele voorkeur voor een andere arts	☐	☐	☐	☐
m.	... mijn eventuele wens voor een second opinion.	☐	☐	☐	☐

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[1] Alternatieve geneeswijzen en medicijnen: acupunctuur, homeopathie, diëten en voedingssupplementen, vitaminen.

2.	Proces van communicatie	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	Artsen communiceren met mij op een manier die bij mij past[2].	☐	☐	☐	☐
b.	Informatie over ziekte en behandeling wordt in stukjes verdeeld, afhankelijk van wat ik aan kan, zodat ik niet teveel informatie in één keer krijg.	☐	☐	☐	☐
c.	Ik krijg het advies iemand mee te nemen naar gesprekken waarin belangrijke informatie wordt verstrekt.	☐	☐	☐	☐
d.	Mondelinge informatie wordt herhaald als ik daar behoefte aan heb.	☐	☐	☐	☐
e.	Onderzoeksuitslagen krijg ik in een persoonlijk gesprek met mijn arts en niet per telefoon.	☐	☐	☐	☐
f.	Onderzoeksuitslagen krijg ik in een persoonlijk gesprek met mijn arts en niet per telefoon, ook al betekent dit dat ik daardoor langer op de informatie moet wachten.	☐	☐	☐	☐
g.	Mondelinge informatie wordt ondersteund met goede schriftelijke informatie. Dit houdt bijvoorbeeld in dat de schriftelijke informatie: • volledig is • begrijpelijk is • te gebruiken is voor het informeren van mijn omgeving.	☐	☐	☐	☐

Wilt u tenslotte voor het onderdeel *communicatie* aangeven welke drie aspecten u het belangrijkst vindt? Maak een rangorde: Het nummer van de vraag en de letter van het aspect dat u het allerbelangrijkste vindt zet u op 1.

De drie allerbelangrijkste aspecten bij het onderdeel communicatie zijn wat mij betreft:

1) ___________

2) ___________

3) ___________

Ruimte voor opmerkingen en toelichtingen op uw antwoord (onder vermelding van het nummer en de letter van de deelvraag)

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[2] Communiceren op een manier die bij mij past: bijvoorbeeld alles vertellen of alleen het hoognodige, uitslagen van onderzoeken telefonisch of persoonlijk in het ziekenhuis, tutoyeren of juist niet.

Ruimtes en voorzieningen

Tijdens de focusgroepinterviews is door patiënten aangegeven waaraan de accommodatie volgens hen moet voldoen. Geef voor elke uitspraak aan hoe belangrijk het voor u is, door een kruisje te zetten in het vakje van uw keuze.

1.	Algemeen	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	De ziekenhuisafdelingen (polikliniek, dagbehandeling en verpleegafdeling) zijn sfeervol[3] ingericht.	☐	☐	☐	☐
b.	De ziekenhuisapparatuur is modern.	☐	☐	☐	☐
c.	In het hele ziekenhuis is het mogelijk om ramen open te zetten.	☐	☐	☐	☐
d.	Ik kan gemakkelijk naar buiten tijdens (dag) opname.	☐	☐	☐	☐
e.	Patiëntenverblijven hebben altijd uitzicht naar buiten.	☐	☐	☐	☐
f.	De toiletten zijn goed. Dit houdt onder andere in dat: • er voldoende toiletten zijn • ze steeds schoon zijn • ze ruim genoeg zijn om gemakkelijk in te kunnen met een infuuspaal.	☐	☐	☐	☐
g.	De bedden zijn comfortabel. Dit houdt in dat: • ze elektrisch verstelbaar zijn • ze voorzien zijn van goede matrassen, kussens en dekbedden.	☐	☐	☐	☐
h.	De opstelling van de bedden is zo dat ik andere patiënten niet steeds aankijk.	☐	☐	☐	☐

2.	Polikliniek	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	De stoelen in de wachtkamer zijn comfortabel.	☐	☐	☐	☐
b.	In de wachtkamer zijn ontspanningsmogelijkheden aanwezig. Dit houdt in dat de wachtkamer bijvoorbeeld voorzien is van: • televisie • actuele en gevarieerde tijdschriften • computers met internetaansluiting.	☐	☐	☐	☐
c.	Tijdens een poliklinische afspraak hoef ik niet in een wachtkamer te wachten, maar kan ik direct in een behandelkamer plaatsnemen, waar ik wacht tot de arts bij mij komt.	☐	☐	☐	☐

3.	Dagbehandeling	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	Op de dagbehandeling is een automaat waar ik thee, koffie, fris en soep kan krijgen.	☐	☐	☐	☐
b.	Mijn bezoek kan ook gebruik maken van deze automaat.	☐	☐	☐	☐

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[3] Sfeervol: een gezellige sfeer uitstralend, huiselijk, kleurrijk, voorzien van planten en mooie wanddecoratie.

4.	Verpleegafdeling	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
	Patiëntenkamers zijn voorzien van: …				
a.	… telefoon	☐	☐	☐	☐
b.	… een koelkast	☐	☐	☐	☐
c.	… een koffiezetapparaat en waterkoker	☐	☐	☐	☐
d.	… een magnetron	☐	☐	☐	☐
e.	… een internetaansluiting bij elk bed	☐	☐	☐	☐
f.	… TV en DVD	☐	☐	☐	☐
g.	… cd-speler	☐	☐	☐	☐
h.	… een ruime, afsluitbare kast	☐	☐	☐	☐
i.	… comfortabele stoelen voor het bezoek.	☐	☐	☐	☐
	Sanitaire voorzieningen op de verpleegafdeling:				
j.	Ik kan gebruik maken van een ligbad.	☐	☐	☐	☐
k.	Het toilet en de doucheruimte zijn gescheiden.	☐	☐	☐	☐
	Ontspannings- en recreatiemogelijkheden: Tijdens een opname kan ik (naast de voorzieningen op mijn kamer) binnen het ziekenhuis gebruik maken van: …				
l.	… een recreatieruimte[4]	☐	☐	☐	☐
m.	… een bibliotheek	☐	☐	☐	☐
n.	… de mogelijkheid om films te kijken op een groot scherm	☐	☐	☐	☐
o.	… sportgelegenheid (bijvoorbeeld fitnessruimte en zwembad)	☐	☐	☐	☐
p.	… ontspanningsmogelijkheden (bijvoorbeeld muziek luisteren, massage, uiterlijke verzorging, etc)	☐	☐	☐	☐
q.	… creatieve activiteiten (bijvoorbeeld schilderen, boetseren, handwerken, etc).	☐	☐	☐	☐

Wilt u tenslotte voor het onderdeel *ruimtes en voorzieningen* aangeven welke drie aspecten u het belangrijkst vindt? Maak een rangorde: Het nummer van de vraag en de letter van het aspect dat u het allerbelangrijkste vindt zet u op 1.

De drie allerbelangrijkste aspecten bij het onderdeel ruimtes en voorzieningen zijn wat mij betreft:

1) ___________

2) ___________

3) ___________

Ruimte voor opmerkingen en toelichtingen op uw antwoord (onder vermelding van het nummer en de letter van de deelvraag)

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[4] Recreatieruimte: een ruimte met allerlei ontspanningsmogelijkheden. Te denken valt aan: poolbiljart, tafeltennistafel, tafelvoetbal, spellen, dartbord, computers, etc.

Begeleiding

"In een onzekere periode van ziek zijn, is goede begeleiding belangrijk".
Wilt u voor elke uitspraak aangeven hoe belangrijk het voor u is, door een kruisje te zetten in het vakje van uw keuze?

1.	Begeleiding bij het verwerken van gevoelens die de ziekte en behandeling oproepen	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	Tijdens mijn behandeling krijg ik meerdere malen de mogelijkheid aangeboden voor steun bij het verwerken van gevoelens die de ziekte en behandeling oproepen.	☐	☐	☐	☐
b.	Na afronding van mijn behandeling krijg ik vanuit het ziekenhuis meerdere malen de mogelijkheid aangeboden voor steun bij het verwerken van gevoelens die de ziekte en behandeling oproepen.	☐	☐	☐	☐
c.	Na afronding van de behandeling krijg ik meerdere malen vanuit het ziekenhuis de mogelijkheid voor steun aangeboden bij de terugkeer in het dagelijks leven, zoals dat was voordat ik ziek werd (thuis, school, werk, etc…)	☐	☐	☐	☐
d.	Ik kan zelf (tijdens en na de behandeling) rechtstreeks contact opnemen met een psychosociaal medewerker[5] van het ziekenhuis als ik daaraan behoefte heb.	☐	☐	☐	☐
e.	Ook mijn partner/naaste kan steun krijgen van een psychosociaal medewerker van het ziekenhuis, bij het verwerken van gevoelens die mijn ziekte en behandeling oproepen.	☐	☐	☐	☐
	Contact met lotgenoten				
f.	Het ziekenhuis organiseert bijeenkomsten met lotgenoten.	☐	☐	☐	☐
g.	Ik kan advies van lotgenoten krijgen (georganiseerd door het ziekenhuis) bij het omgaan met de gevolgen van de behandeling, zoals bijvoorbeeld kaalheid of het aanmeten van protheses.	☐	☐	☐	☐

2.	Revalidatie en herstel	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	Binnen een week na een behandeling (chemotherapie, radiotherapie of een operatie) word ik thuis gebeld door een zorgverlener om te bespreken hoe het met me gaat.	☐	☐	☐	☐
b.	Fysiotherapie is een vast onderdeel van de behandeling en de nazorg.	☐	☐	☐	☐
c.	Informatie over revalidatieprogramma's[6] wordt zowel mondeling als schriftelijk aan mij bekend gemaakt en actief aangeboden.	☐	☐	☐	☐
d.	Ik krijg vanuit het ziekenhuis begeleiding bij het aanmeten van protheses en hulpmiddelen[7] (indien van toepassing).	☐	☐	☐	☐
e.	Vanuit het ziekenhuis wordt serieus aandacht besteed aan de late effecten[8] van de behandeling.	☐	☐	☐	☐
f.	Met praktische vragen[9] kan ik altijd terecht bij mijn arts of een andere zorgverlener in het ziekenhuis, ook na afronding van mijn behandeling.	☐	☐	☐	☐

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[5] Psychosociaal medewerker: een maatschappelijk werker, psycholoog, geestelijk verzorger.

[6] Revalidatieprogramma's: bijvoorbeeld "Herstel en Balans", Fysiotherapie, Ergotherapie, "Goed verzorgd, beter gevoel".

[7] Protheses en hulpmiddelen: te denken valt aan een pruik, borstprothese of hulpmiddelen in verband met incontinentie.

[8] Late effecten: gevolgen van de behandeling. Te denken valt aan: staar, overgangsklachten en verminderde vruchtbaarheid.

[9] Praktische vragen: bijvoorbeeld over vaccinaties, weer naar een zwembad gaan, in grote groepen mensen verkeren, schriftelijke verklaringen etc.

Wilt u tenslotte voor het onderdeel *begeleiding* aangeven welke drie aspecten u het belangrijkst vindt?
Maak een rangorde: Het nummer van de vraag en de letter van het aspect dat u het allerbelangrijkste vindt zet u op 1.

De drie allerbelangrijkste aspecten bij het onderdeel <u>begeleiding</u> zijn wat mij betreft:

1) ___________

2) ___________

3) ___________

Ruimte voor opmerkingen en toelichtingen op uw antwoord (onder vermelding van het nummer en de letter van de deelvraag)

____

____

____

<u>Bejegening</u>

Tijdens de focusgroepinterviews is het onderwerp bejegening uitgebreid aan de orde geweest. In dit gedeelte wordt u gevraagd hoeveel waarde u hecht aan bijvoorbeeld de vriendelijkheid en aandacht van artsen en verpleegkundigen. Wilt u voor elke uitspraak aangeven hoe belangrijk het voor u is, door een kruisje te zetten in het vakje van uw keuze?

1.	**De <u>arts</u> die mij behandelt, ...**	**Niet belangrijk**	**Beetje belangrijk**	**Belangrijk**	**Van het allergrootste belang**
a.	... is vriendelijk	☐	☐	☐	☐
b.	... geeft mij genoeg tijd en persoonlijke aandacht	☐	☐	☐	☐
c.	... gaat respectvol met mij om	☐	☐	☐	☐
d.	... is empatisch. Dit houdt onder andere in dat mijn arts: • zich kan inleven in mijn situatie • goed kan omgaan met mijn emoties.	☐	☐	☐	☐
e.	... is zorgvuldig. Dit houdt onder andere in dat mijn arts: • afspraken nakomt • onnodige handelingen voorkomt.	☐	☐	☐	☐
f.	... heeft voldoende aandacht voor mijn naasten (partner, kinderen, ouders)	☐	☐	☐	☐
g.	... geeft mij tijdens consulten alle ruimte om vragen te stellen	☐	☐	☐	☐
h.	... is telefonisch goed bereikbaar als ik een dringende vraag heb	☐	☐	☐	☐
i.	... kan mij goed inschatten. Dit houdt bijvoorbeeld in dat mijn arts: • in de gaten heeft op welke manier ik het liefst communiceer, • kan inschatten wat ik psychisch en emotioneel aan kan.	☐	☐	☐	☐
j.	Ik heb een vertrouwensband met mijn arts.	☐	☐	☐	☐

2.	**De <u>verpleegkundigen</u> die mij verzorgen, ...**	**Niet belangrijk**	**Beetje belangrijk**	**Belangrijk**	**Van het allergrootste belang**
a.	... zijn vriendelijk	☐	☐	☐	☐
b.	... geven mij genoeg tijd en persoonlijke aandacht	☐	☐	☐	☐
c.	... gaan respectvol met mij om	☐	☐	☐	☐
d.	... zijn empatisch. Dit houdt onder andere in dat zij: • zich kunnen in inleven in mijn situatie • goed kunnen omgaan met mijn emoties	☐	☐	☐	☐
e.	... zijn zorgvuldig. Dit houdt onder andere in dat zij: • afspraken nakomen • onnodige handelingen voorkomen	☐	☐	☐	☐
f.	... hebben voldoende aandacht voor mijn naasten (partner, kinderen, ouders)	☐	☐	☐	☐
g.	... kunnen mij goed inschatten. Dit houdt bijvoorbeeld in dat de verpleegkundigen: • in de gaten hebben op welke manier ik het liefst communiceer, • kunnen inschatten wat mijn emotionele draagkracht is.	☐	☐	☐	☐
	En verder...				
h.	... zijn de mensen van de ondersteunende diensten[10] vriendelijk en behulpzaam.	☐	☐	☐	☐
i.	... kan ik bij het stellen van vragen gebruik maken van e-mail.	☐	☐	☐	☐

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[10] Medewerkers van de ondersteunende diensten: secretaresses, voedingsassistentes of medewerkers van de huishoudelijke dienst

Wilt u tenslotte voor het onderdeel *bejegening* aangeven welke drie aspecten u het belangrijkst vindt?
Maak een rangorde: Het nummer van de vraag en de letter van het aspect dat u het allerbelangrijkste vindt zet u op 1.

De drie allerbelangrijkste aspecten bij het onderdeel bejegening zijn wat mij betreft:

1) ____________

2) ____________

3) ____________

Ruimte voor opmerkingen en toelichtingen op uw antwoord (onder vermelding van het nummer en de letter van de deelvraag)

Zelfstandigheid

Met de vragen in dit gedeelte gaan we na in welke mate u wilt meedenken en meebeslissen over uw zorg en behandeling. Geef voor elke uitspraak aan hoe belangrijk het voor u is, door een kruisje te zetten in het vakje van uw keuze.

1	Zelfstandigheid	Niet belangrijk	Beetje belangrijk	Belangrijk	Van het allergrootste belang
a.	Ik krijg van de artsen en verpleegkundigen de ruimte om mee te denken over de zorg en behandeling.	☐	☐	☐	☐
b.	Ik hoef niet mee te denken over mijn zorg en behandeling, ik kan blind vertrouwen op de artsen en verpleegkundigen.	☐	☐	☐	☐
c.	Als ik te ziek ben, krijgen mijn naasten de ruimte om mee te denken over de zorg en behandeling voor mij.	☐	☐	☐	☐
d.	Ik krijg voldoende informatie over de voor- en nadelen van verschillende behandelingen, om een weloverwogen keuze te kunnen maken.	☐	☐	☐	☐
e.	Ik krijg voldoende tijd om na te denken en tot een weloverwogen keuze voor behandeling te komen.	☐	☐	☐	☐
f.	De arts overlegt altijd met mij over de noodzaak van onderzoeken of behandelingen.	☐	☐	☐	☐
g.	Bij opname ben ik vrij om mijn eigen sfeer aan te brengen in de kamer waarin ik lig.	☐	☐	☐	☐
h.	Bij opname wordt rekening gehouden met mijn eigen dagritme.	☐	☐	☐	☐
i.	Ik kan vasthouden aan mijn eigen gewoontes en behoeften ten aanzien van voeding.	☐	☐	☐	☐
j.	Er wordt bij opname rekening gehouden met mijn specifieke wensen en voorkeuren.	☐	☐	☐	☐

Wilt u tenslotte voor het onderdeel *zelfstandigheid* aangeven welke drie aspecten u het belangrijkst vindt?
Maak een rangorde: Het nummer van de vraag en de letter van het aspect dat u het allerbelangrijkste vindt zet u op 1.

De drie allerbelangrijkste aspecten bij het onderdeel zelfstandigheid zijn wat mij betreft:

1) ____________

2) ____________

3) ____________

Ruimte voor opmerkingen en toelichtingen op uw antwoord (onder vermelding van het nummer en de letter van de deelvraag)

Vakbekwaamheid

De onderstaande vragen gaan in op de vaardigheden en kwaliteiten van artsen en verpleegkundigen. Graag horen we hoe belangrijk u deze vaardigheden en kwaliteiten vindt. Geef voor elke uitspraak aan hoe belangrijk het voor u is, door een kruisje te zetten in het vakje van uw keuze.

1.	**Mijn arts…**	**Niet belangrijk**	**Beetje belangrijk**	**Belangrijk**	**Van het allergrootste belang**
a.	… beschikt over voldoende kennis en ervaring	☐	☐	☐	☐
b.	… geeft mij het gevoel mij de best mogelijke behandeling te geven. Hij/zij geeft er blijk van: • op de hoogte te zijn van de nieuwste ontwikkelingen • te werken volgens landelijk geldende richtlijnen • flexibel om te gaan met protocollen en de zorg af te stemmen op mijn situatie.	☐	☐	☐	☐
c.	… is (steeds) volledig op de hoogte van mijn situatie	☐	☐	☐	☐
d.	… communiceert goed. Dit houdt onder andere in: • helder • open en eerlijk • zorgvuldig en met tact • afgestemd op mij	☐	☐	☐	☐

2.	**De verpleegkundigen die voor mij zorgen, …**	**Niet belangrijk**	**Beetje belangrijk**	**Belangrijk**	**Van het allergrootste belang**
a.	… beschikken over voldoende kennis en ervaring	☐	☐	☐	☐
b.	… geven mij het gevoel mij de best mogelijke verpleegkundige zorg te geven. Zij geven er blijk van: • op de hoogte te zijn van de nieuwste ontwikkelingen op verpleegkundig gebied • te werken volgens landelijk geldende richtlijnen • flexibel om te gaan met protocollen en hun zorg af te stemmen op mijn situatie.	☐	☐	☐	☐
c.	… zijn (steeds) volledig op de hoogte van mijn situatie	☐	☐	☐	☐
	Kwaliteit van zorg en behandeling				
d.	Mijn behandeling vindt plaats in een ziekenhuis dat gespecialiseerd is op het gebied van kanker (oncologisch centrum).	☐	☐	☐	☐
e.	De zorgverleners (artsen en verpleegkundigen) die betrokken zijn bij mijn behandeling hebben zich gespecialiseerd in de behandeling en verzorging van kanker.	☐	☐	☐	☐

Wilt u tenslotte voor het onderdeel *vakbekwaamheid* aangeven welke drie aspecten u het belangrijkst vindt? Maak een rangorde: Het nummer van de vraag en de letter van het aspect dat u het allerbelangrijkste vindt zet u op 1.

De drie allerbelangrijkste aspecten bij het onderdeel vakbekwaamheid zijn wat mij betreft:

1) ___________

2) ___________

3) ___________

Ruimte voor opmerkingen en toelichtingen op uw antwoord (onder vermelding van het nummer en de letter van de deelvraag)

Tot slot

Wilt u tot slot nog de zeven hoofdcategorieën van de vragenlijst rangschikken naar belangrijkheid?
Achter het onderdeel dat u het allerbelangrijkst vindt zet u een 1, het onderdeel dat u daarna het belangrijkst vindt een 2 etc.

•	Organisatie	
•	Communicatie	
•	Ruimtes en voorzieningen	
•	Begeleiding	
•	Bejegening	
•	Zelfstandigheid	
•	Vakbekwaamheid	

1. Zijn er onderwerpen die u belangrijk vindt in zorg en behandeling en die niet aan de orde zijn gekomen in deze vragenlijst?

☐ Ja*
☐ Nee

*Zo ja, welke onderwerpen zijn niet aan de orde gekomen?

2. Hoeveel tijd heeft het invullen van de vragenlijst u gekost?

☐ Ja
☐ Nee

Graag een toelichting op uw antwoord

3. Waren de vragen duidelijk/helder/goed te begrijpen?

☐ Ja
☐ Nee

Graag een toelichting op uw antwoord

4. Vond u het invullen van de vragenlijst belastend?

☐ Ja
☐ Nee

Graag een toelichting op uw antwoord

5. Vindt u het zinvol om deel te nemen aan dit onderzoek?

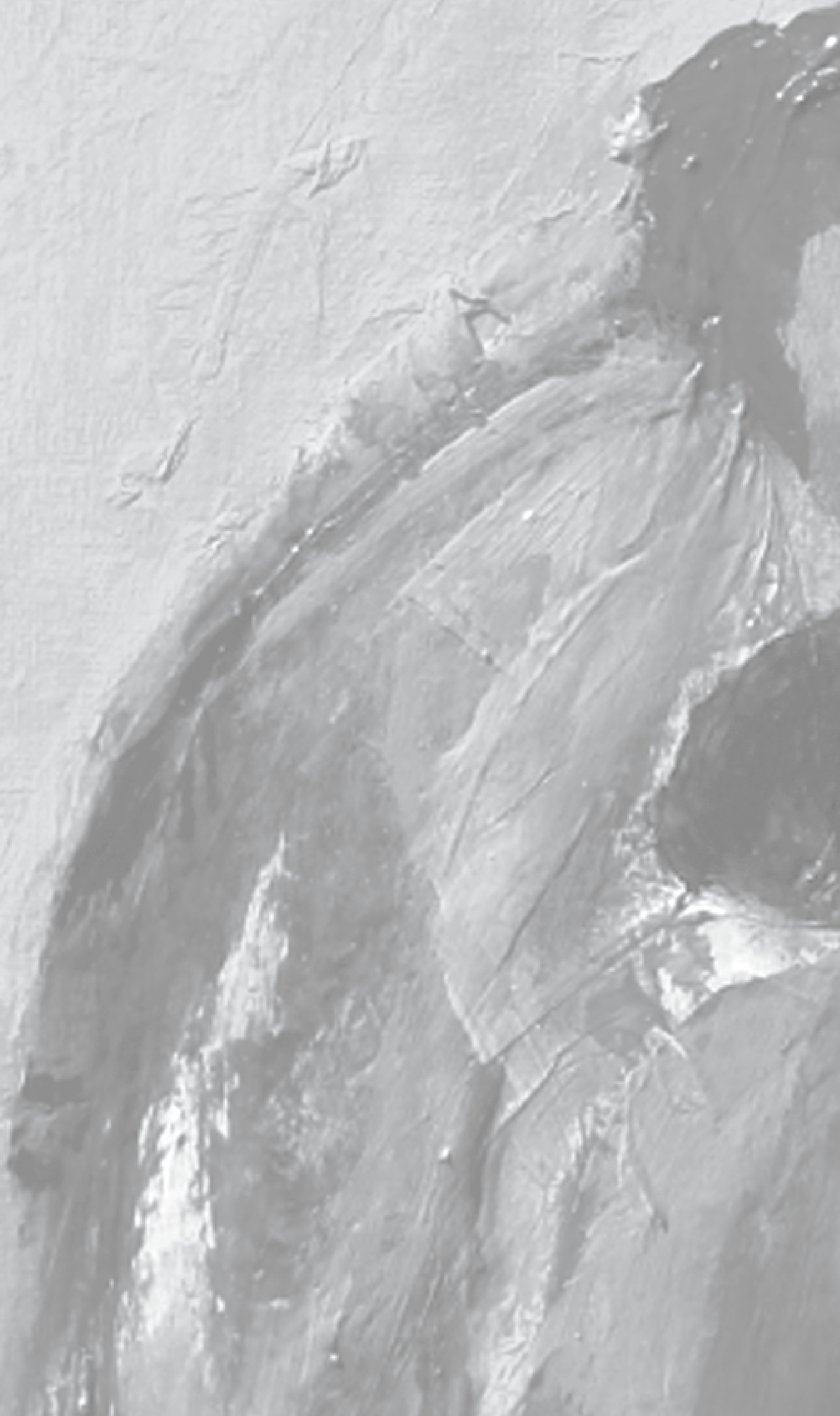
☐ Ja
☐ Nee

Graag een toelichting op uw antwoord

Einde

Hartelijk bedankt voor het invullen van deze vragenlijst!

Appendix 2



Cancer patients' health care preferences questionnaire

appendix

This questionnaire was carefully translated from Dutch into English by a native American speaker and checked afterwards by two of the authors (AdG and HW). We did not follow a forward–backward procedure. The appendix has been added to illustrate the items included in the questionnaire. It is not intended for use by others as a standardised questionnaire.

Scales and single items

Response options

1 = Not important
2 = Somewhat important
3 = Important
4 = Extremely important

Indicate for each statement how important it is for you.

Mistakes by health care providers

- The health care providers involved in my care and treatment work according to a system which minimises mistakes.
- If a health care provider makes a mistake during the course of my care and treatment, then this health care provider will discuss this mistake with me.

Physician and nurse expertise

- My doctor has adequate knowledge and experience.
- My doctor gives me the feeling that I am receiving the best possible treatment. He/she appears to
  - ○ be up to date with the latest developments
  - ○ be working according to certified national guidelines
  - ○ deal flexibly with protocols and tailor his or her care to my situation.
- My doctor is (continuously) completely informed about my situation.
- The nurses who take care of me have adequate knowledge and experience.
- The nurses who take care of me give me the feeling that I am receiving the best possible nursing care. They appear to
  - ○ be up to date with the latest developments
  - ○ be working according to certified national guidelines
  - ○ deal flexibly with protocols and tailor their care to my situation.
- The nurses who take care of me are (continuously) completely informed about my situation.
- The health care providers (doctors and nurses) involved in my treatment are specialised in the treatment and care of cancer patients.
- My treatment is carried out in a specialised cancer hospital (oncology centre).

Consultation and transfer

- The various health care providers involved in my care communicate well with each other concerning my situation.
- Health care providers in the hospital communicate my situation effectively to home care providers.
- If necessary, my doctor will consult with specialised cancer centre doctors concerning my situation.

Physician attitude

The doctor who treats me

- is friendly
- grants me enough time and personal attention
- treats me respectfully
- is empathetic, meaning that
  - ○ he/she understands my situation
  - ○ he/she is able to deal well with my emotions
- pays adequate attention to my loved ones (spouse, children and parents)
- is accurate, meaning that he/she
  - ○ follows up on our mutually agreed plan
  - ○ prevents unnecessary interventions
- gives me adequate opportunity to ask questions during appointments
- understands me, meaning that he/she
  - ○ considers and accommodates to the way I like to communicate
  - ○ can determine the mental and emotional level I can manage.
- I have a relationship with my physician built on trust.

Patient file confidentiality

- Health care providers handle my medical data carefully.
- Sensitive information is not divulged to me in the presence of other patients.

Opportunity to choose in care and treatment

- The doctors and nurses involve me in discussions concerning my care and treatment.
- If I am too ill, then my loved ones are involved in discussions concerning my treatment and care.
- I receive adequate information concerning the pros and cons of various treatments in order to make a well-considered choice.
- I get enough time to consider and make a well-informed choice.
- The doctor always discusses with me the necessity of a certain test or treatment.

Nurse attitude

The nurses who take care of me

- are friendly
- grant me enough time and personal attention
- treat me respectfully
- are empathetic, meaning that:
  - ○ they understand my situation
  - ○ they are able to deal well with my emotions
- pay adequate attention to my loved ones (spouse, children, parents)

- are accurate, meaning that they
  - follow up on our mutually agreed plan
  - prevent unnecessary interventions
- understand me, meaning that they
  - consider and accommodate to the way I like to communicate
  - can determine the mental and emotional level I can manage.

Communication and information

I receive verbal information about

- my illness
- tests to be carried out; this includes:
  - the reason for the test
  - what will happen during the test
  - the duration of the test
  - when I can expect test results
- possible treatments; this includes
  - what the treatment involves
  - the expected effect of the treatment
  - the duration of the treatment
  - risks and side-effects of the treatment
  - long-term consequences of the treatment
- standard procedures of the hospital.
- I am regularly updated about the effect of my treatment.
- My doctor communicates well, because he/she is
  - clear
  - open and honest
  - thoughtful and tactful
  - attuned to my needs.
- Doctors tailor their communication with me to my preferences. For example, whether all details or only essential facts of my condition are discussed, whether test results are discussed by telephone or in person at the hospital and whether the doctor's approach is informal or formal.
- Information concerning my condition and treatment is dispensed in a comprehensible manner, according to my ability, as to prevent being overwhelmed with information.
- I am advised to bring someone with me to appointments where important information will be given.
- Verbal information is repeated if I need to hear it again.
- Test results are told to me by my doctor in person and not over the telephone.
- I am called at home by a health care provider within a week after treatment (chemotherapy, radiotherapy or surgery) to check in on me.

Accessibility of services

- Immediately after I have received my diagnosis, I have access to all professionals who I deem important.
- I have access to any and all professionals who I deem important during and after treatment.
- The doctor who treats me can be contacted by telephone if I have an urgent question.
- I can ask my doctor or any other health care provider about practical matters, even after my treatment has ended (for example vaccinations, whether or not swimming is allowed, health certification).

Waiting periods

- Additional tests required to reach a final diagnosis take place within 1 week.
- Time spent in the waiting area at the outpatient clinic (diagnostic tests, consultation and treatment) is not longer than 15 minutes.
- I do not have to wait more than three business days for test results.
- After receiving a diagnosis I can start with treatment as soon as I want to.

Support, counselling and rehabilitation

- I am offered professional support on multiple occasions during my treatment to help me to deal with emotions brought about by the disease and treatment.
- I am offered professional support on multiple occasions after my treatment has ended to help me to deal with emotions brought about by the disease and treatment.
- The hospital offers me support on multiple occasions to help me to reintegrate into my previous daily routine (home, work, school, etc.).
- I can directly contact a psychosocial specialist during or after my treatment.
- My loved ones are also able to get help from a psychosocial specialist for dealing with feelings that have surfaced due to my disease and treatment.
- Information about rehabilitation programmes is actively offered, both verbally and written.
- The hospital pays serious attention to delayed effects of treatment (for example cataracts, menopausal complaints, diminished fertility).

Alternate sources of information

Discussions with my doctor offer me the opportunity to discuss

- the use of alternative medicine (acupuncture, homoeopathic, diet, food supplements, vitamins)
- information that I have read on the Internet concerning my disease and possible treatments
- my potential preference for another doctor
- my potential wish for a second opinion.

Appointments

- Multiple appointments are scheduled on a single day.
- Appointments with multiple specialists are scheduled at one location within the hospital.
- If the consultation is running overtime, then I am informed.

Rooms and facilities

- It is possible to open the windows throughout the hospital.
- I can easily go outside during my hospital stay.
- The toilet and shower are separated.
- The waiting room chairs are comfortable.
- Patient rooms are equipped with a large lockable cabinet.
- Patient rooms are equipped with comfortable chairs for visitors.
- I have access to a bathtub.
- The beds are comfortable. This includes that
    - they are electrically adjustable
    - they are equipped with good mattresses, pillows and blankets.
- The toilets are good. This includes that
    - there are enough toilets
    - they are adequately cleaned
    - they are sufficiently spacious to allow an IV trolley

Food and beverages

- The hot meals in the hospital are fresh, varied and well prepared.
- I can choose what I want to eat and drink.
- I can request meals/beverages outside the regular meal times, according to my wish.

Presence of loved ones

- My loved ones (spouse, child or parent) may stay the entire day with me.
- My loved ones (spouse, child or parent) may stay the night with me.

Privacy

- While waiting in the outpatient clinic I am able to be alone if I require privacy and do not want exposure to other patients.
- Upon (day) admission to the hospital, I am able to choose between a single or shared room.
- Upon (day) admission to the hospital, I have sufficient opportunities to be left undisturbed either with or without my visitors.
- I am not disturbed by visitors to my fellow patients.

Patient habits

- During hospital stays, I have the liberty to decorate my room as I wish.
- During hospital stays, my daily rhythm is taken into consideration.
- I can maintain my dietary habits and requirements.
- Upon admission to the hospital, my individual preferences and desires are taken into consideration.

Patient interest groups

- I receive verbal information about relevant patient interest groups.
- The hospital organises support groups with fellow patients.
- I can receive advice from fellow patients (facilitated by the hospital) about dealing with side-effects of treatment, such as hair loss or fitting prostheses.

Conveniences

- The waiting room features entertainment options, such as:
    - television
    - various recent magazines
    - computers with an Internet connection.

  Patient rooms are equipped with

- a telephone
- a TV and DVD
- a refrigerator
- a coffee machine and water boiler
- a microwave
- an Internet connection at every bed
- a CD player.
- There are adequate parking facilities close to the hospital entrance.

In addition to entertainment in my room I have access in the hospital to

- a recreation room (table tennis, games, darts, etc.)
- a library
- see movies on a big screen
- sport facilities (gym and/or swimming pool)
- recreational activities, such as listening to music, massage, beauty treatments
- arts and crafts activities.
- At the day hospital I can get tea, coffee, soft drinks, and soup from automatic dispensers.
- My visitors also have access to these dispensers.

Fellow–patient interaction

- I share rooms with people roughly my age during my hospital stays.
- I share rooms only with people with cancer during my hospital stays.
- I share rooms with people who do not have cancer during my hospital stays.

Single items

- The hospital equipment is modern.
- In case of emergency I do not need to go to the ER first, but can directly be seen by a specialist.
- Verbal communication is supplemented with clear written information. This objective includes, for example that the written information

  - ○ is complete
  - ○ is clear
  - ○ can be used to inform others.

- ■ From the moment cancer is diagnosed, I am assigned a health care provider (nurse or doctor) who will guide me through the entire testing and treatment procedure.
- ■ There is a minimum turnover of my health care providers.
- ■ The janitors, secretaries, dieticians and other support staff are friendly and helpful.
- ■ The health care providers maintain awareness of my daily nutrition to ensure sufficient intake.
- ■ I am not required to discuss my care and treatment. If desired, then I can blindly trust the doctors and nurses.