

The role of quality of life in daily clinical oncology practice

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The role of quality of life in daily clinical oncology practice

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Contents

Chapter 1	Introduction	1
Chapter 2	How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality of life issues	17
Chapter 3	Patient-physician communication during outpatient palliative treatment visits: an observational study	35
Chapter 4	The role of health-related quality of life in palliative chemotherapy treatment decisions	55
Chapter 5	Quality of life assessment in daily clinical oncology practice: a feasibility study	69
Chapter 6	A randomized study of the value of health-related quality of life assessments in daily clinical oncology practice	85
Chapter 7	Summary and discussion	113
	Samenvatting	129
	Nawoord	139
	Curriculum Vitae	141

Chapter 1

Introduction

Palliative treatment setting

Cancer is a life-threatening illness; approximately 50% of cancer patients can not be cured and receive treatment with a palliative intent. The two principal goals of palliative cancer treatment are to prolong the patient's life and to alleviate debilitating symptoms of the disease.¹⁻³ In both of these cases, health-related quality of life (HRQL) considerations, defined most typically in terms of the patient's physical, psychological and social functioning and well-being,⁴⁻⁹ may be of central importance in selecting among available treatment options and in monitoring the effects of such treatments over time. Where palliative treatment is aimed primarily at prolonging life, HRQL information can be useful in weighing the burden of (often aggressive) anti-tumor therapies against the potential survival benefits. Where the goal is primarily the palliation of symptoms, evidence of improvement in the patients' HRQL is, by definition, of primary interest.

Hence, a prerequisite for optimal palliative cancer treatment is that physicians have adequate information about their patients' physical and psychosocial health problems and that they are able to monitor these problems over time. Moreover, the available evidence suggests that the exchange of information between physicians and their patients will have an impact on patient satisfaction with care, compliance with treatment, and even on patients' health status.¹⁰⁻¹⁴ In other words, effective information-exchange is the basis of good patient care.

Doctor-patient communication

Although, to date, no studies have been directed at doctor-patient communication with regard to HRQL issues in the palliative setting, there is a substantial literature on the content of doctor-patient communication in other medical settings. The available literature indicates that communication between physicians and their patients is often less than optimal. There are a number of barriers to effective doctor-patient communication. Structural factors operating in the typical clinical setting, such as time constraints, may play an important role¹⁵⁻¹⁹ Additionally, variations in both physicians' and patients' sociodemographic and cultural background, attitudes and communication styles, as well as the nature of patients' complaints can influence the degree to which the patients' physical and psychosocial problems are identified and discussed during a medical consultation.
20-29

All this may result in a situation in which physicians are often inadequately informed about the nature and extent of their patients' problems.²⁷⁻³⁷ Physicians frequently underestimate their patients' level of physical dys-functioning and the severity of important symptoms such as pain and fatigue. They also tend to rate

their patients as having a more compromised HRQL than do patients themselves.^{38;39} Additionally, physicians often fail to recognize the presence of heightened levels of psychological distress among their patients.^{28;40-43} Whether this is also the case for patient-physician communication in a palliative treatment setting is not known.

HRQL considerations have, of course, always played a role, albeit often implicit and informal, in patient care. The typical question asked by a physician at the beginning of a medical visit: “How are you doing” can be viewed as a global inquiry into the patient’s HRQL. More targeted questions about patient symptom experience and level of functioning, as well as the patient’s spontaneous remarks or questions, form an integral part of doctor-patient communication.

Although it is important for all patients that their physician is well informed about their functioning and well-being, HRQL issues might play a somewhat secondary role when cure is the aim of therapy. However, in the case of patients receiving a palliative treatment, it is particularly important that physicians have detailed information about changes in their patients’ symptom burden and functioning over time.

Historically, efforts aimed at enhancing doctor-patient communication have focused primarily on the training of physicians in communication skills, both as a part of the medical school curriculum, and in continuing education programs.⁴⁴⁻⁴⁷ Additionally, increasing effort has been directed at encouraging patients to be actively involved in their care.⁴⁸⁻⁵¹ While both initiatives are unquestionably of great importance, we were interested in the possibility of employing standardized HRQL assessments as a means of structuring and facilitating the exchange of information between physicians and their patients. The use of such standardized assessments might help resolve some of the barriers to effective doctor-patient communication by making less demands on the consultation time, and on the physicians’ and patients’ social skills.

HRQL assessments

During the last decades, major strides have been made in developing brief, easy to complete, self-report questionnaires that yield valid and reliable information on patients’ HRQL.⁴⁻⁹ Typically, such questionnaires address an array of topics, including the patients’ recent symptom experience, their current level of physical, psychological and social role functioning, and often a global assessment of their HRQL.

The most common application of HRQL assessment has been in descriptive research, to characterize the burden of illness and/or treatment at an

aggregate group level.⁵²⁻⁵⁴ Additionally, the use of HRQL measures in clinical trials to evaluate treatment efficacy has increased tremendously in the last 10 years, which reflects recognition that most clinical interventions are directed at health outcomes other than mere survival.⁵⁵

More recently, there has also been interest expressed in the use of HRQL assessments with individual patients in daily clinical practice. In general, the procedure is as follows: patients are asked to fill in an HRQL questionnaire, the questionnaire is computer-scored and a (graphic) summary is provided to the physician. In this way, physicians receive structured feedback about their patients' HRQL. It has been suggested that incorporation of HRQL measures in clinical practice could serve a variety of purposes, the most basic being as an aid in detecting physical or psychosocial problems that otherwise might be overlooked. Physicians are often unaware of their patients' level of functioning.^{30;37;56;57} In particular psychosocial problems may remain unrecognized.^{27-29;41;42;58} While many patients want their physician to ask about their functioning and well-being, few actually do so.^{11;24;59}

Secondly, it has been suggested that such assessments could be useful for monitoring the disease course and treatment benefits over time for a given patient. This would especially be useful for patients with a chronic disease, as is often the case in the elderly.^{60;61}

Finally, it has been proposed that standardized HRQL information might be of use in clinical decision-making; acting as an adjunct to the standard clinical interview to inform medical practitioners of the HRQL of their patients.^{62;63}

Despite a large number of position papers in which these possible applications have been mentioned, and in which the use of standardized HRQL assessments has been encouraged,^{62;64-70} relatively few studies have actually investigated the effectiveness of such measurements in routine clinical practice. These studies, summarized in two recently published reviews,^{71;72} can roughly be divided in those focusing on the feasibility of incorporating standardized assessments in routine clinical practice, and in studies investigating the effects of such assessments on patient management and patient outcomes. The results of the feasibility studies are consistent and encouraging. Administration of report questionnaires in a busy clinic can be accomplished without disruption of patient flow.⁷³⁻⁷⁶ However, mixed results have been reported in a number of randomized studies that investigated the potential value of standardized HRQL assessments on patient management and outcomes.^{73;75;77-84} For example, Wasson et al. tested the effect of HRQL assessment on the process of care for adult primary care patients. HRQL information, obtained by a patient-administered questionnaire, was made

available during a single clinical encounter. With the availability of the HRQL information, no significant change in the process of care for men, but a slight increase in the ordering of tests and procedures for women, was observed⁷⁵. Magruber-Habib reported that feedback to physicians of the results of depression scores of previously unrecognized depressed patients made a significant difference in recognition (56.2% vs. 34.6%) and treatment (56.2% vs. 42.3%) of depression over the 12-month study period.⁸³ Conversely, Dowrick and Buchan did not find any effect on recognition or outcome of depression for patients in which depression scores were disclosed to their primary care physicians.⁸⁴ In a large study that evaluated office-based screening for 8 common problems in the elderly, Moore et al. reported that only hearing loss was more commonly detected (40% intervention versus 28% control) and further evaluated (29% versus 16%) by physicians in the intervention group. No other significant differences between groups were found, either in the frequency of problem detection or intervention, or in self-reported health status.⁷³ In none of the studies was an improvement in patients' satisfaction or HRQL reported. In summary, there is little evidence to suggest that the use of HRQL measures in routine practice improved the outcomes of patient care.

Thus, there seems to be a discrepancy between the high expectations regarding the value of HRQL assessments in clinical practice and the modest outcomes of empirical studies. Both general and study-specific factors may have contributed to this discrepancy. First, the effect of some general methodological and attitudinal issues on the results of the empirical studies may have been underestimated. Many HRQL instruments lack evidence for their responsiveness to change over time, and do not have adequate normative data.⁸⁵ In addition, no currently available HRQL instrument adequately meets the psychometric criteria necessary for use with individual patients.^{70;86} Thus, the meaningful interpretation of scores and score changes remains problematic.⁶⁷

Additionally, there are conflicting results regarding physicians' views of the relevance and value of HRQL information in the care of their patients. Some studies report that physicians are skeptical about the validity of existing measures; they often consider informal assessments of HRQL to be superior to the information provided by standardized instruments and question the extent to which they would be able to intervene, should the instruments reveal any problems.^{65;87;88} Conversely, Bezjak et al. found that physicians have a positive attitude towards measuring their patients' HRQL and using the data in practice.⁸⁹

Second, the studies themselves have exhibited a number of limitations: of particular importance is the fact that not all of the interventions were timed to coincide with a specific medical visit. Rather, the HRQL information was

sometimes elicited from patients and provided to the physicians at fixed time intervals, irrespective of the patient's outpatient clinic appointment schedule.^{77;82} It is likely that HRQL assessments will prove of greater value when they are linked directly to specific medical consultations.

In several of the studies the assessments were made at a single point in time, thus precluding the possibility of monitoring changes in patients' HRQL over time.^{73;75;81;83} One of the most potentially attractive features of routine, periodic HRQL assessments is that they yield a temporal record, allowing comparison of individual patients' HRQL profiles over time.

Additionally, none of the intervention studies provided the patients themselves with summaries of their responses to the HRQL questionnaires that they had completed. Such a procedure might be a useful way of familiarizing patients with the types of reports their physicians are receiving, and may encourage patients to assume an active role during medical consultations.^{66;67}

Most notable, however, is the lack of attention to the effect of HRQL assessments on the nature or content of doctor-patient communication. None of the empirical studies employed observational techniques to investigate the extent to which the HRQL information was actually used, or whether (and how) it influenced the patterns of doctor-patient communication. Although, in a number of studies, the participating physicians reported that the availability of the HRQL data facilitated communication with their patients^{75;77;80} such self-reports need to be confirmed by direct behavioral measures.⁹⁰ In only one study were patients asked to give their opinion about the role of standardized HRQL assessments in the communication with their physician; but, again, this study reported only self-reported communication behavior.⁷⁸ Given that effective communication is the first step in the care process,²⁴ it seems only logical that doctor-patient communication be included as the most proximal outcome in evaluating the effect of the routine use of standardized HRQL assessments in daily clinical practice. If no effect on communication is found, it is very unlikely that any effect on more distal outcomes, such as patient satisfaction or HRQL will be observed.

The present study

In this thesis we focus on the potential use of a brief, self-report questionnaire as a means of facilitating and structuring the communication between oncologists and their patients receiving palliative treatment with regard to HRQL issues. Additionally, because little information exists regarding HRQL communication in clinical practice, we explore patients' and physicians' preferences for discussing these issues, the 'natural' pattern of communication

between physicians and patients regarding HRQL issues, and the role of HRQL issues in treatment decisions.

Chapter 2 reports on the attitudes of cancer patients toward discussing HRQL issues, the association between such attitudes and patients' characteristics, and, oncologists' attitudes and self-reported behavior regarding these issues.

Chapter 3 describes the actual communication behavior of cancer patients and their physicians with regard to HRQL issues as observed during outpatient clinic visits. In addition, patient-, physician- and visit-specific factors are identified which are significantly associated with the discussion of such issues.

Chapter 4 investigates the role of HRQL considerations in treatment decisions in terms of: 1) the frequency with which *discussed* HRQL considerations are the primary reason to modify or stop palliative chemotherapy treatment; and, 2) the extent to which standardized HRQL *assessments* are associated with such treatment decisions.

Chapters 5 and 6 deal with the primary study question: the usefulness of introducing HRQL into clinical practice. Chapter 5 describes the results of a pilot study which investigated the feasibility of introducing individual HRQL assessments into the daily routine of an outpatient oncology practice, and the potential impact of such investigations on doctor-patient communication. Chapter 6 presents the results of a randomized study in terms of two primary outcomes: 1) facilitating doctor-patient communication, and 2) increasing physicians' awareness of patients' physical and psychosocial health problems. Additional outcome parameters included patients' and physicians' satisfaction with their medical interactions, and patients' self-reported HRQL over time.

Finally, in chapter 7 we summarize the results of these investigations, discuss their implications for clinical practice, and suggest directions for future research.

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Chapter 2

How are you feeling? Who wants to know?

Patients' and oncologists' preferences for discussing health-related quality of life issues

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S.B. Detmar, M.J. Muller, L.D.V. Wever, J.H. Schornagel, N.K. Aaronson: How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality of life issues. J Clin Oncol 2000, 18: 3295-3301

Abstract

PURPOSE: This study investigated: (1) the attitudes of cancer patients towards discussing health-related quality of life (HRQL) issues; (2) the association between such attitudes and patients' characteristics; and (3) oncologists' attitudes and self-reported behavior regarding these same issues. **PATIENTS AND METHODS:** Two hundred seventy-three patients receiving palliative chemotherapy and ten physicians were asked to complete a series of questionnaires. **RESULTS:** Almost all patients wanted to discuss their physical symptoms and physical functioning, and were also willing to address their emotional functioning and daily activities. However, 25% of the patients were only willing to discuss these latter two issues at the initiative of their physician. Patients varied most in their willingness to discuss their family and social life, with 20 % reporting no interest in discussing these issues at all. Female patients were more reluctant to discuss various HRQL issues than male patients. Older and less well-educated patients were more likely to prefer that their physician initiate discussion of HRQL issues. All physicians considered it to be primarily their task to discuss the physical aspects of their patients' health, while 4 physicians indicated that discussion of psychosocial issues was a task to be shared with other health care providers. All physicians indicated that they generally defer to their patients in initiating discussion of psychosocial issues. **CONCLUSION:** Although both patients and oncologists seem willing to discuss a wide range of HRQL issues, communication regarding psychosocial issues may be hampered by competing expectations as to who should take the lead in initiating such discussions.

Introduction

Over the course of the past several decades the assessment of patients' health-related quality of life (HRQL) has come to play an increasingly prominent role in the field of clinical oncology. Most efforts, to date, have focused on the use of HRQL assessments in clinical research, where the aim is to better understand the impact of cancer and its treatment at the *aggregate* level (i.e., in descriptive and evaluative studies among groups of patients undergoing both standard and experimental treatments).^{1,2} Although the process has been a gradual one, the use of HRQL assessments in clinical studies is now widely accepted and, in fact, is advocated by the major clinical trials groups both in the United States and in Europe.³⁻⁵

More recently, interest has been expressed in using standardized HRQL assessments in daily clinical practice as a means of monitoring changes in the symptom experience and self-reported functional health of *individual* patients over time, and of facilitating communication between doctors and their patients.⁶⁻¹⁰ An important assumption underlying such use of HRQL assessments is that both patients and their physicians perceive the value of discussing a wide range of physical *and* psychosocial health issues during routine medical encounters, and are willing to do so.

Although there is a substantial body of empirical literature addressing communication between cancer patients and their physicians, most studies have focused on a unidirectional information-exchange process, i.e., *from* the physician *to* the patient. The available evidence indicates that almost all patients want to be fully informed by their physician about the various aspects of their disease and their treatment.¹¹⁻¹³ However, while the expressed desire for information is uniformly high, patients vary widely in the type and amount of information-seeking behavior they actually exhibit during medical visits. In general, younger, better-educated, and female patients tend to ask for and receive more information from their doctors than do older, less well-educated, and male patients.¹⁴⁻¹⁶

Relatively little research has been done on the preferences of patients for disclosing information about themselves to their doctors. Higher patient satisfaction and even better health outcomes have been found to be related to a communication style in which physicians ask their patients not only about their physical health problems, but also about their emotional concerns.¹⁷⁻¹⁹ Not surprisingly most patients express a desire to feel understood by their physician.^{20,21} This implies that patients want their doctor to be aware, at least in general terms, of the impact of their disease and of their treatment on the quality of their lives. However, it remains unclear as to whether patients consider it appropriate, and are

willing to discuss with their doctor the full range of psychosocial issues incorporated typically into HRQL assessments.

With regard to physicians' attitudes and behavior, studies in the primary care setting indicate that general practitioners vary widely in their willingness to discuss psychosocial issues with their patients.^{16,22-24} Importantly, it has been demonstrated that patients often look to their doctor for cues as to whether it is appropriate to discuss such issues during medical visits. For example, Levinson and Roter²² found that patients disclose significantly more information about their emotional and social functioning when their doctor has a positive attitude toward the psychosocial aspects of patient care.

There are only few data available on the attitude of oncologists towards discussing and incorporating (standardized) HRQL assessment in clinical practice. In a survey of 60 medical oncologists, Taylor and her colleagues²⁵ found that the majority of respondents considered it important to elicit HRQL information from their patients, but that they tended to do so informally. Only 7% of respondents reported that they assessed the HRQL of their patients in a structured manner, while an additional 14% stated that they routinely used published HRQL data in discussions with their patients.

The current study was undertaken to investigate: (1) the attitudes and preferences of cancer patients toward discussing a range of HRQL issues with their oncologists; (2) the association between such attitudes and patients' sociodemographic characteristics, performance status, and self-reported HRQL; and (3) oncologists' attitudes and self-reported behavior regarding the discussion of HRQL issues with their patients.

Study sample and procedures

The patients and physicians were participating in a longitudinal study carried out between May 1996 and January 1999 in the Antoni van Leeuwenhoek Hospital, a specialized cancer treatment center located in Amsterdam. This study investigated the efficacy of incorporating standardized quality of life assessments as a routine part of the outpatient palliative treatment of cancer patients as a means of facilitating doctor-patient communication, and of increasing physicians' awareness of their patients' physical and psychosocial health problems. The study employed a prospective, randomized, control group design. Prior to randomization, the patients and physicians were queried about their attitudes toward and preferences for discussing specific HRQL issues, and the physicians were asked to report the extent to which they generally raised such issues with their patients. These baseline data form the basis of the current report.

Physician sample

The physician sample was composed of medical oncologists working in the Department of Internal Medicine. This group of physicians was selected for study because they provide long-term care for patients undergoing palliative treatment. In contrast, the physicians working in the Departments of Surgery and Radiotherapy tend to provide short-term palliative treatment, with patients then being referred back to the medical oncologist for further treatment and follow-up.

Patient sample

The patient sample was composed of a consecutive series of patients with incurable cancer receiving outpatient palliative chemotherapy in the Department of Internal Medicine. We chose to focus on this group of patients because it was expected that they would be most likely to experience a wide range of physical, functional and psychosocial problems and could, therefore, realistically consider their preferences for discussing HRQL with their doctor. Patients were excluded who lacked a basic proficiency in Dutch, were younger than 18 years of age, or who were participating in a concurrent (clinical) study in which HRQL was being assessed.

Assessment of patients' attitudes and preferences

After completing two cycles of chemotherapy, patients were mailed a brief questionnaire in which they were asked to state their preference for discussing with their oncologist the impact of their illness and treatment on six areas of HRQL: (1) physical symptoms; (2) general physical condition; (3) daily activities; (4) feelings; (5) social activities; and (6) relationship with partner and family. These HRQL categories were chosen because they are included in most of the generic and cancer-specific HRQL questionnaires in current use (e.g., the FACT, the EORTC QLQ-C30, the SF-36). The questions were posed in terms of the patients' preferences, in general (i.e., if they were to experience problems in these areas), rather than in relation to a specific, upcoming medical visit. The questions were asked in broad terms, paralleling the topic areas found in the majority of HRQL questionnaires in use today (e.g., "Would you like to discuss with your physician the effects of your disease and/or your treatment on your daily activities, including your work, household activities, etc.?"). Three response categories were available: (1) "No, preferably not"; (2) "Yes, but only if my doctor raises the issue"; or (3) "Yes, I would like to discuss this issue." Prior to the data collection period these questions were pilot-tested among 20 patients for comprehension and ease of use. None of these patients expressed any difficulty in responding to the questions.

Assessment of physicians' attitudes and behavior

The physicians were asked to complete a questionnaire assessing their attitudes and behavior with regard to the discussion of various HRQL issues with their patients. Four questions were posed about their perceived responsibility for discussing the impact of the disease and its treatment on their patients': (1) physical symptoms; (2) general physical condition; (3) daily activities and (4) feelings. The three response categories were: (1) I consider this to be primarily my task; (2) it is partially my task, and partially that of other health care providers; or (3) it is not my task. Additionally, they were asked to report the extent to which they agreed with the statement: "I encourage my patients to raise psychosocial issues during outpatient consultations." Response categories ranged on a five-point scale from (1) strongly agree to (5) strongly disagree. Finally, the physicians were asked who tended to initiate the discussion of six specific categories of HRQL issues (i.e., physical symptoms, general physical condition, daily activities, feelings, social activities, and relationship with partner and family). The response categories were: (1) me; (2) the patient; (3) both of us, equally; or (4) neither of us.

Patients' current performance status and HRQL

At the time of the medical visit closest in time to the completion of the second cycle of chemotherapy, the physicians rated the patients' performance status using the ECOG scale, ranging from 0 ("normal activity") to 4 ("completely disabled"). Prior to the same medical visit, the patients' were asked to rate their self-perceived HRQL by means of the COOP/WONCA Charts.²⁶ This brief instrument incorporates 6 questions assessing a core set of HRQL domains: physical fitness, emotional functioning, functioning in daily living, social functioning, overall health and pain. Two additional charts assessing fatigue and overall HRQL were also included. Each chart consists of a descriptive title, a question referring to a single aspect of the patient's HRQL during the past two weeks, and five response categories illustrated by drawings. For example, the question referring to daily activities is as follows: "...How much difficulty have you had doing your usual activities or task, both inside and outside the house because of your physical and emotional health?" Scores range from 1 to 5, with "1" representing the best, and "5" representing the worst level of functioning. The reliability and validity of these charts have been shown to be high when used among a wide range of patient populations, including patients with cancer.²⁷

Patients' and physicians' sociodemographic data

Data on the patients' age, gender, education and marital status were obtained via questionnaire. Information on the patients' primary diagnosis was

obtained from the medical records. Information on physicians' age, gender, and years of work experience was obtained via questionnaire.

Statistical analysis

Descriptive statistics were generated with the SPSS computing program. Given the nominal nature of the data on patients' preferences, the chi-square statistic was considered the most appropriate to test the relationship between patients' sociodemographic and functional characteristics and their communication preferences. For purpose of these analyses, patients' age was collapsed into two categories (≤ 60 years and > 60 years), and the 5 response categories of the COOP/WONCA charts were collapsed into two (no to limited problems versus moderate to severe problems). The statistical significance level was set at $p < 0.05$.

Results

Physician and patient sample

Ten of the 12 medical oncologists from the Department of Internal Medicine agreed to participate in the study. The two oncologists who declined to participate, both male, expressed difficulty with having their consultations audiotaped (a procedure employed as part of the larger experimental study in which they were being asked to participate). Of the 10 participating oncologists, 4 were female. Their mean age was 44 years (range 35-53 years) and they had, on average, 11 years of work experience in oncology (range = 2-24 years).

A total of 382 patients were invited to participate in the study, of whom 273 agreed (response rate = 71%). Of the 109 non-participants, 50 declined due to very poor physical or emotional condition, 43 reported insufficient interest or lack of time, and 16 had difficulty with the audiotape recording.

The demographic and clinical characteristics of the patient sample are shown in Table 1.

Seventy-two percent was female, with a mean age of 56 years (range = 24 to 85 years). Nearly 80% of the patients lived with their spouse and/or other family members. Approximately one-quarter of the patients had completed primary school/lower-level high school (6 to 10 years of schooling), approximately half had completed middle-level high school (11 to 14 years of schooling), while the remaining one-quarter had attended higher level vocational training/university (16 years of schooling or more). Patients had a wide range of cancer diagnoses, with breast cancer being the most prevalent (45%).

Table 1 Demographic and clinical characteristics of the patient sample (n=273)

mean age (years)		56
(range)		24-85
Gender		
Male		28%
Female		72%
Marital status		
single/divorced, widowed		22%
married		78%
Education		
Primary school/lower level high school		26%
middle level high school		45%
advanced vocational/university		28%
Cancer diagnosis		
Breast		45%
Gynecological		6%
Gastrointestinal		20%
Lymphoma		10%
Other		18%
ECOG performance status		
0		19%
1		51%
2		22%
3		7%
4		0.5%
COOP/WONCA charts (mean score)		Patients (%) reporting moderate to severe problems
Physical fitness	3.3	43.6%
Emotional functioning	2.3	18.5%
daily activities	2.9	29.6%
social activities	2.3	17.1%
overall health	3.4	52.3%
pain	2.3	12.3%
fatigue	2.9	24.0%

A substantial minority of patients (30%) was assessed as having a relatively impaired performance status (ECOG 2, 3 or 4). The patients showed substantial variation in scores on the COOP/WONCA charts, with the full range of scores observed on all charts. Combining the two response categories indicating the highest levels of symptoms or impaired functioning, approximately half of the patients reported moderately to severely compromised physical fitness and overall health, while approximately 30% reported moderate to severe limitations in daily role activities. Impaired emotional and social functioning was reported by approximately 18% of the patients. Moderate to severe fatigue and pain was reported by approximately 25% and 12% of the sample, respectively.

Patients' preferences

Patients' preferences for discussing various HRQL issues are shown in Table 2. More than 95% of the patients expressed a desire to discuss physical aspects of their disease and treatment, and between 80% and 90% was willing to initiate such discussions themselves. Similarly, more than 90% of patients expressed a desire to discuss problems in their daily lives and their feelings with their doctor; however, approximately one-quarter of these patients were willing to do so only at the initiative of their doctor.

There was substantially greater reluctance on the part of patients to discuss their family and social life, with approximately 20% stating that they would prefer not to do so at all, and another 28% to 36% indicating that they would do so only if their doctor raised the issue first.

Table 2 Patients' preferences for discussing HRQL issues (n=273)

	no (%)	yes, but the physician has to initiate (%)	yes (%)
physical symptoms	1.1	8.7	90.2
physical condition	0.7	17.6	81.7
emotional functioning	6.2	26.4	67.4
daily activities	9.5	25.5	65.0
social functioning	19.1	36.6	44.3
the relationship with partner and family	18.7	28.6	52.7

Correlates of patients' preferences

Several factors were found to correlate significantly with patients' preferences for discussing various HRQL issues (not shown in tabular form). Particularly striking was the finding that female patients were more reluctant to talk to their physician about their relationship with their partner and friends than were male patients (22.7% versus 8.1%, respectively; $p < 0.05$, after adjusting for marital status). Similar gender differences were observed for the other HRQL domains, although they did not reach conventional levels of statistical significance. Previous research has been found that patients' actual disclosure of concerns is the highest during consultations where patients and physicians are both female²⁸. We therefore tested for differences in patients' preferences for female-female dyads versus other gender combinations. Women reported greater reluctance than men to talk about HRQL issues, regardless of whether their physician was male or female. Although women in the sample whose treating physician was female reported somewhat less reluctance to discuss their HRQL than those women whose physician was male, these differences were small and did not reach conventional levels of statistical significance.

Older patients (> 60 years) were more likely than younger patients to prefer that their physician initiate discussion of all HRQL issues. These differences were statistically significant for physical symptoms, functioning in daily living, and relationship with partner and family. Education was found to be associated significantly only with preferences for discussing physical condition, with a greater percentage of patients with lower levels of education preferring physician-initiation of such discussions as compared to those with higher levels of education. Neither patients' performance status as rated by the physicians nor their self-reported HRQL was related significantly to preferences for discussing various HRQL issues.

Physicians' attitudes and self-reported behavior

As shown in Table 3, all of the physicians considered it to be primarily their task to discuss the physical aspects of their patients' health, while 4 of the 10 physicians indicated that discussion of their patients' level of functioning in daily life and their emotional condition was a task to be shared with other health care providers. None of the physicians indicated that it was *not* their (shared) responsibility to discuss the various categories of HRQL issues with their patients. Six of the physicians (strongly) agreed with the statement: "I encourage my patients to raise psychosocial issues during outpatient consultations," 2 physicians neither agreed nor disagreed, and 2 physicians disagreed.

Table 3 Physicians' attitude towards discussing HRQL issues (N=10)

	primarily my task	partially my task	not my task
physical symptoms	10	0	0
physical condition	10	0	0
emotional functioning	6	4	0
daily activities	6	4	0

Physicians self-reported communication behavior during medical consultations is reported in Table 4. Half of the physicians reported that they were generally the one to initiate discussion of the physical aspects of their patients' health, with the remaining half indicated that such discussions were initiated equally by themselves and by their patients. In contrast, none of the physicians indicated that they were generally the one to initiate discussion of their patients' emotional functioning. Rather, in the majority of cases this was left up to the patient. For the remaining HRQL domains, five of the 10 physicians reported that their patients' social functioning was generally not discussed at all during the consultations, and 3 reported this to be the case for their patients' relationship with their partner or family.

Table 4 Physicians' self-reported behavior regarding initiating discussion of HRQL issues

	physician	patient	Both	neither
physical symptoms	5	0	5	0
physical condition	5	1	4	0
emotional functioning	0	6	4	0
daily activities	3	1	5	1
social functioning	2	2	1	5
relationship with partner and family	1	3	3	3

Discussion

The aims of the current study were to assess cancer patients' preferences for and oncologists' attitudes and self-reported behavior towards discussing various HRQL issues during outpatient medical visits in the palliative treatment setting. In general, the results indicate a willingness on the part of both patients and their physicians to discuss a wide range of such issues. However, this general conclusion

needs to be qualified, in that the results varied as a function of the specific HRQL domain under consideration. As one might expect, the large majority of patients expressed a desire to discuss their physical condition and their symptom experience, and they were generally willing to initiate such discussions themselves. While almost all patients also wanted to discuss the impact of their disease and its treatment on their daily lives and on their emotional condition, approximately one-quarter of patients considered it appropriate to do so only if such issues were raised by their physician. An even larger percentage of patients (between 29% and 37%) indicated that they would generally await some signal from their doctor before discussing issues surrounding their relationship with their partner or family and their social functioning. Approximately 20% of patients indicated no interest at all in discussing these latter issues with their doctor. Similar results have been reported in other medical settings,^{16,29} suggesting that patients may feel uncertain as to whether it is appropriate to raise psychosocial issues with their doctor, and that they, in a sense, await “permission” to do so. This seems to be particularly the case among older and less well-educated patients.

Patients' self-reported health status was not found to be associated significantly with their preferences for discussing HRQL issues with their physician. This finding is consistent with other research³⁰, and suggests that patients are willing to discuss a range of HRQL issues, even when they are not actually experiencing problems or symptoms in a specific HRQL domain at a given moment in time.

Interestingly, we found that women were less likely than men to report interest in discussing their social or family life with their doctor. A possible explanation for this finding is that women may be more inclined to discuss such issues within their informal social network, and thus may feel less of a need to do so with their health care provider. Such an interpretation is in line with previous research indicating that female cancer patients have significantly larger networks of support and are more likely than male patients to rely on friends or family for affective support.³¹

Strikingly similar findings were obtained when querying the oncologists about their attitudes and behavior toward discussing various HRQL issues with their patients. All of the physicians considered discussion of the physical aspects of their patients' health to be primarily their responsibility. This was less so in the case of psychosocial health issues, where a number of the physicians indicated that this task was only partly their responsibility, and was to be shared with other health care providers. Importantly, a number of the physicians in our sample reported that they tend to defer to their patients in raising psychosocial health issues during

outpatient consultations. In some cases, this appears to lead to a “conspiracy of silence” whereby psychosocial topics are left unaddressed because both physicians and their patients are reluctant to raise such issues without a clear signal from the other that this is appropriate and desired. Further research is needed to determine whether there are specific topic areas which patients and/or their physicians are particularly reluctant to discuss (e.g., sexuality), and the perceived reasons for such hesitation (e.g., lack of time, lack of experience, embarrassment, etc.). Additionally, it would be of interest to determine whether patients feel more comfortable discussing certain issues with other health care providers (e.g., nurses, social workers, etc.).

We recognize that these results need to be interpreted with some caution for several reasons. First, the study was conducted in a single hospital and, although the patient sample was large, the number of physicians involved was limited. The setting in which this study was carried out, a specialized cancer treatment center, probably reflects a “best case scenario,” with very experienced oncologists and an integrated, multidisciplinary approach to patient treatment and care.

Second, our results are based on expressed attitudes and self-reported behavior, which may differ from the actual communication behavior exhibited during medical consultations. Any bias introduced by the self-reported nature of the data would probably be in the direction of overestimating the attention directed toward psychosocial issues during outpatient medical consultations.^{32,33}

Third, while the same range of HRQL issues was employed when querying both patients’ and physicians’ about their communication behavior, a slightly truncated list of HRQL issues was used in assessing physicians’ attitudes. This was done primarily out of concern with respondent burden. Our concern was that the physicians, whose cooperation was required for a longer period of time (for the longitudinal part of the study), would be annoyed by being asked a set of identical questions twice, once in reference to their attitudes, and again in reference to their behavior. Nevertheless, we do not believe that fielding a few additional attitudinal questions would have led to different conclusions. The physicians in our study reported discussing “social functioning” and “relationship with family” (the two topics not included in the physicians’ attitude list) least often of all HRQL topics. We believe that this self-reported verbal behavior most likely reflects a parallel attitude; that it is not (entirely) their role to discuss such issues with their patients.

Finally, patients’ were asked about their preferences for discussing various HRQL issues during the period of active treatment. Although the issues addressed would seem of general relevance, one cannot rule out the possibility that patients’

preferences may vary as a function of their location along the disease and/or treatment trajectory (e.g., around the time of diagnosis, during active treatment, during follow-up, at the time of disease relapse, etc.). Use of a longitudinal study design could uncover any such patterns over time.

In conclusion, while both patients and oncologists generally appear willing to discuss a wide range of HRQL issues during outpatient consultations, communication regarding psychosocial issues may, in some cases, be hampered by competing expectations as to who should take the lead in initiating such discussions. A number of studies have demonstrated that training programs can be effective in enhancing physicians' communication skills^{21,34-37} and in encouraging patients' to verbalize their needs and concerns.^{38,39} More recently, the introduction of standardized HRQL assessments has been advocated as a means of both identifying HRQL issues of concern to individual patients and of triggering or cueing the discussion of those issues in routine outpatient clinical practice.⁴⁰⁻⁴³ Future research efforts should be directed at testing empirically the value of such interventions in enhancing doctor-patient communication.

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Chapter 3

Patient-physician communication during outpatient palliative treatment visits: An observational study

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Abstract

Context Improving health-related quality of life (HRQL) is an important goal of palliative treatment, but little is known about actual doctor-patient communication regarding HRQL topics during palliative treatment.

Objectives To investigate the content of routine communication regarding 4 specific HRQL issues between oncologists and their patients and to identify patient-, physician- and visit-specific factors significantly associated with discussion of such issues.

Design Observational study conducted between June 1996 and January 1998.

Setting Outpatient palliative chemotherapy clinic of a cancer hospital in the Netherlands.

Participants Ten oncologists and 240 of their patients (72% female; mean age 55 years) who had incurable cancer and were receiving outpatient palliative chemotherapy.

Main Outcome Measures Patient and physician questionnaires and audiotape analysis of communication regarding daily activities, emotional functioning, pain, and fatigue during an outpatient consultation using the Roter Interaction Analysis System.

Results Physicians devoted 64% of their conversation to medical/technical issues and 24% to HRQL issues. Patients' communication behavior was divided more equally between medical/technical issues (41%) and HRQL topics (48%). Of the independent variables investigated, patients' self-reported HRQL was the most powerful predictor of discussing HRQL issues. Nevertheless, in between 20% to 54% of the consultations in which patients were experiencing serious HRQL problems, no time was devoted to the discussion of those problems. In particular, these patients' emotional functioning and fatigue were unaddressed 54% and 48% of the time, respectively. Discussion of HRQL issues was not more frequent in consultations in which tumor response was evaluated.

Conclusion Despite increasing recognition of the importance of maintaining patients' HRQL as a goal of palliative treatment, the amount of doctor-patient communication devoted to such issues remains limited, and appears to make only a modest contribution, at least in an explicit sense, to the evaluation of treatment efficacy in daily clinical practice.

Introduction

The principal goals of palliative cancer treatment are to prolong the patient's life and to alleviate debilitating symptoms of the disease.¹⁻³ In both cases, health-related quality of life (HRQL) issues, defined in terms of the patient's physical, emotional and social functioning, and well-being^{4,5}, may be of central importance in selecting among available treatment options, and in monitoring the effects of such treatments over time. An essential condition for optimal palliative cancer treatment is that physicians communicate effectively with their patients to obtain as complete a picture as possible of the patients' physical and psychosocial health status.

Although, to the best of our knowledge, no studies have been directed at doctor-patient communication regarding HRQL in the palliative treatment setting, there is a substantial amount of literature on the content of patient-physician communication in other medical settings.⁶⁻¹¹ Results from these studies indicate that a number of elements play a role in the way in which information is exchanged between physicians and their patients. First, the nature of the symptoms themselves can influence doctor-patient communication. For example, Funch, investigating the symptom-reporting behavior of colorectal cancer patients, found that 54% of experienced symptoms were spontaneously reported, and that chronic, a-specific and mild symptoms were less likely to be discussed than more concrete, acute and severe symptoms.¹⁰

Second, patients vary in their willingness and ability to talk about their problems and concerns. Female patients tend to ask more questions and to receive more information than their male counterparts.^{12,13} Similar results have been reported for patients with relatively high levels of education as compared to those who are less well-educated.¹⁴

Physicians also vary widely in their interest in and their ability to elicit relevant information from their patients.^{6,11,15} Levinson and Roter¹¹ found that patients disclose significantly more information about their emotional and social functioning when their doctor has a positive attitude towards the psychosocial aspects of patient care. Maguire et al¹⁵ found that patient disclosure of psychosocial information was inhibited when physicians used closed-ended questions and when they focused their attention on physical health issues.

Finally, structural factors may play a role in the exchange of information. For example, perceived time pressure may decrease the amount of information exchanged.¹⁶⁻¹⁸

Taken together, these studies indicate that patient-physician information-exchange may not always be optimal. In particular, nonspecific symptoms and

psychosocial issues are often left unaddressed.¹⁹⁻²¹ Whether this also holds true for the palliative treatment setting is unclear. Particularly in the realm of palliative treatment, there is increasing recognition that HRQL is an outcome that is as important, if not more important, than traditional outcomes such as survival.^{22,23} Thus, one might expect more discussion about HRQL issues in the palliative treatment setting, and in particular during consultations in which the effect of the treatment is being evaluated.

In a previous paper we described the preferences of cancer patients being treated with palliative chemotherapy, and the attitudes and self-reported behavior of their physicians toward discussing HRQL issues.²⁴ In this article, we present results based on actual communication during outpatient consultations. We chose to focus on 4 key HRQL issues affecting the broad spectrum of patients receiving palliative treatment: daily activities, emotional functioning, pain and fatigue.²⁵

Methods

Study sample and procedures

The patient and physician samples were drawn from the outpatient clinics of the Netherlands Cancer Institute. The physician sample consisted of the physicians working in the department of medical oncology. The patient sample comprised a consecutive series of patients with incurable cancer who were receiving outpatient palliative chemotherapy, and who were under the care of one of the participating physicians. Inclusion criteria included the following: older than 18 years, basic proficiency in Dutch, not participating in a concurrent HRQL study, and having received at least two cycles of chemotherapy. This latter criterion was applied to increase the likelihood that both the patients' HRQL and, at least in some cases, evaluation of tumor response would be relevant topics for discussion. The institutional review board of the hospital approved the study.

Patients were invited to participate by means of a letter that explained that the study was designed to obtain a better understanding of patient-physician communication during the palliative treatment period. After providing informed consent, patients and physicians were asked to complete several questionnaires. The first subsequent outpatient consultation was audiotaped. The audiotaping procedure was pilot-tested with all physicians and two of their patients. The physicians and patients indicated that the audiotaping did not influence their 'natural' communication, which is in line with the literature.²⁶ Patients who declined to participate were asked to respond to a brief questionnaire by telephone.

Study measures

Patients' characteristics and self-reported health status

Patients' sociodemographic characteristics and their preferences for discussing HRQL issues were obtained by means of a questionnaire. Preferences were assessed in general terms, rather than in relation to a specific consultation. The response categories were: "No, I would prefer not to discuss this topic"; "Yes, but my physician has to initiate discussion of this topic"; and "Yes, I want to discuss this topic."

The patients' self-reported HRQL was assessed by means of the COOP/WONCA functional health assessment charts assessing physical fitness, emotional functioning, daily and social activities, overall health, and pain.²⁷ Two additional charts assessing fatigue and overall HRQL were also included. The timeframe used was the previous two-week period. Response categories ranged from 1 (excellent) to 5 (very poor). Only the charts assessing patients' daily activities, emotional functioning, pain and fatigue were employed in the current analysis.

Physicians' characteristics and attitudes

Questionnaires were used to obtain data on physicians' sociodemographic and professional characteristics and on their perceived responsibility for discussing various HRQL issues with their patients. Response categories for the latter questions included: "Discussing this topic is completely my task"; "Discussing this topic is partially my task, and partially the task of other health care providers" and "Discussing this topic is not my task".

Patient-physician communication

Analysis of the audiotaped consultations was conducted by means of an adapted version of the Roter Interaction Analysis System (RIAS) which places each utterance of the patient and physician into a mutually exclusive category.^{28,29} The categories are organized into 3 conceptual clusters: process, affective, and content cluster (Table 1). The process cluster includes utterances intended to give direction to the flow of the visit and facilitate communication. The affective cluster consists primarily of statements that show involvement with the situation. The content cluster includes all statements relating to medical/technical issues, HRQL issues, and administrative issues. Coding was carried out directly from audiotape by 3 trained raters. All raters coded a random sample of 15% of the audiotapes in order to assess inter-rater reliability. The mean inter-rater reliability was 0.87 (range, 0.66-0.99) for physician categories, and 0.84 (range, 0.64-0.99) for patient categories. These reliability estimates are comparable to those achieved in other studies.³⁰⁻³²

Additionally, a content checklist was used to code whether the selected HRQL topics were discussed at any time during the consultation, regardless of the amount of time devoted to the topic and who had initiated discussion of these topics.

Table 1 Categories of the Roter Interaction Analysis System

Process categories	
Verbal attention	agreement (yes, ok), paraphrase/check for understanding (repetition of the other's words in declarative or interrogative form; "you say you don't feel well?"), clarifying the other's communication ("if I understand you well,")
Orientation	guide the patient in terms of what to expect during the visit ("Now I'm going to examine you") or give instructions ("please take off your shirt")
Affective categories	
Social talk	greetings, friendly gestures, response to greetings and friendly gestures, conversation on non-medical issues, laughter
Showing involvement	concern, indicating that a condition is worrisome and of particular concern ("this really doesn't look good"); optimism ("Things are going well"); asking for reassurance ("I am doing fine, aren't I?"); empathy ("I can imagine you are worried"), showing support and conveying a sense of partnership
Content categories	
Medical/technical	information, questions or counseling concerning the medical condition (<u>not</u> about symptoms) or the therapeutic regimen
Daily activities	information, questions or counseling regarding household, work or other activities
Emotional functioning	information, questions or counseling concerning emotional well-being and coping
Pain	information, questions or counseling concerning pain
Fatigue	information, questions or counseling concerning fatigue
Other symptoms	information, questions or counseling concerning other symptoms (eg, nausea/vomiting, sleeplessness, dyspnea)
Administrative issues	filling out forms, making appointments, providing directions to, for example, the laboratory or the computed tomography department

Other characteristics of the consultations

The audiotapes were also used to determine if tumor response had been discussed (labeled as an “evaluative” consultation). Also noted were the duration of the consultation and any interruptions that took place. Finally, the waiting time, an indirect indicator of the time pressure under which the consultation took place, was calculated by subtracting the scheduled visit time from the actual time at which the consultation took place.

Data analysis

Mean percentages of the total utterances devoted to the specific topics of discussion were calculated. Although verbal utterances differed in length, the correlation between the number of utterances and the consultation time was high ($r = 0.83$). Therefore, the frequency of utterances per topic corresponds approximately to the amount of time dedicated to that topic. To control for differences in consultation time, percentages were used instead of simple frequency counts.

Univariate statistics (Student’s t-tests and chi-square statistics) were used to assess the association between patient, physician and consultation characteristics and communication about the selected HRQL issues. For purpose of these analyses, patients’ age was categorized into 2 groups (≤ 60 years and > 60 years), the response categories of the COOP/WONCA charts were collapsed into 2 categories (no to limited problems versus moderate to severe problems), and the response categories of patients’ preferences and physicians’ attitude were categorized into 2 groups (wanting to discuss, either self- or physician-initiated, vs not wanting to discuss; full responsibility vs partial or no responsibility, respectively).

Because patients were nested within physicians, we considered the use of multi-level analysis in determining those factors related most strongly to the discussion of the selected HRQL issues. However, multi-level analysis requires a minimum of approximately 30 cases in the highest level³³. With only 10 physicians, the use of these methods can lead to inconsistent parameter estimates. To examine differences between physicians, intraclass correlations were computed for the selected outcome measures. All intraclass correlations were non-significant and low (intraclass correlation, <0.05), indicating that the variance components between physicians were very small and thus that regression models for the total patient sample would yield unbiased standard errors. Therefore, both linear and logistic regression analyses (forward, stepwise procedures) were used to test the simultaneous effect of the independent variables. Variables were included in the regression models if they were associated with the relevant outcomes at the

univariate level ($p < .10$). For all other statistical tests, the significance level was set at $p = 0.05$.

Results

Study sample

All medical oncologists ($n = 12$) were invited to participate in the study, and 10 agreed. The 2 oncologists who declined raised objections to having their consultations audiotaped. Of the participating physicians, 4 were female, their mean age was 44 years with, on average, 11 years of work experience in oncology (Table 2).

Between June 1996 and January 1998, a total of 382 patients were asked to participate, of whom 273 (71%) agreed. Of the 109 nonrespondents, 50 declined because they thought the study would be too burdensome, 43 indicated insufficient interest or lack of time, and 16 expressed difficulty with the audiotaping. A nonrespondent analysis indicated that patients who declined to participate had less education ($p < .001$) and rated their overall HRQL as significantly lower (mean = 3.7 vs. 3.1, $p < 0.05$) than the participants.

In 33 cases, the consultation was either not recorded due to logistical reasons or the tape recording was of insufficient quality for analysis. Thus, audiotaped consultations of 240 patients were available (between 19 and 30 per physician). Seventy-three percent of the patients was female, with a mean age of 55 years. Patients had a wide range of cancer diagnoses, with breast cancer being the most prevalent. The patients showed substantial variation in scores on the COOP/WONCA charts. All patients had visited their physician previously (mean = 9 previous visits) (Table 2).

Table 2 Demographic and clinical characteristics of the study sample *

Physicians (N)	10
Mean age (years)	44
(range)	35-53
Gender	
male	60
female	40
Work experience in oncology (years)	11
(range)	2-24
Patients (N)	240
Mean age (years)	55
(range)	24-84
Gender	
male	27
female	73
Marital status	
single, divorced, widowed	21
married	79
Education	
primary school/lower level high school	27
middle level high school	44
advanced vocational/university	29
Primary cancer diagnosis	
breast	47
gynecological	6
gastrointestinal	21
lymphoma	10
other	16
COOP/WONCA charts mean score (SD)	
physical fitness	3.2 (1.06)
emotional functioning	2.3 (1.08)
daily activities	2.9 (1.13)
social activities	2.2 (1.18)
overall health	3.4 (0.95)
pain	2.3 (1.02)
fatigue	2.9 (0.96)
overall QL	3.1 (0.99)
Mean number of prior visits	9
(range)	(5-45)

* Data are presented as percentages unless otherwise indicated.

Content of the consultations

The mean duration of the consultations was 16.09 minutes (range = 4.10-40.25, SD = 6.82), with the physicians and patients exchanging a mean of 264 utterances (range = 35-711, SD = 117). Overall, the physicians generated slightly more discussion than the patients (53.5% versus 46.5%). Approximately one-quarter of the physicians' and patients' utterances were coded into the process category, and approximately 13% of utterances conveyed emotional affect and social talk.

Slightly more than 60% of all utterances was substantive and fell into the content category. The focus of interest is on the division of topics within this content category. Approximately two-thirds of the physicians' substantive communication was medical/technical; for patients, this was 41%. Physicians and patients devoted approximately one-quarter and one-half of their substantive conversation, respectively, to HRQL issues, with symptoms (pain, fatigue and other symptoms combined) being most often discussed (Table 3).

Table 3 Mean number and percentage of physician and patient utterances regarding the content of communication.

	physician		patient	
	mean N ¹	mean % ²	mean N ¹	mean % ²
Total content utterances	83	100	71	100
MEDICAL/TECHNICAL	53.8	64	27.9	41.4
HRQL	19.7	23.4	35.3	48.0
daily activities	2.1	2.7	5.5	7.3
emotional functioning	4.4	5.0	7.8	10.1
pain	3.2	3.7	6.5	9.2
fatigue	0.5	0.7	1.3	2.1
other symptoms	9.5	11.3	14.2	19.3
OTHER: administrative	9.9	12.6	7.9	10.7

¹ no. = the mean number of utterances within the content category per speaker per consultation

² % = the mean percentage of utterances per speaker within the content category

As indicated in Table 4, patients' daily functioning was discussed in approximately two-thirds of the consultations, most often initiated by the physician. Pain was discussed in approximately three-quarters of the consultations, with physicians taking the lead half of the time. Fatigue and emotional problems

were brought up in 46% and 35% of the consultations, respectively, primarily by the patients. The mean percentage of the physicians' substantive utterances devoted to these 4 topics was less than 5% per topic. For the patients, the range was from 2.1% (fatigue) to 10.1% (emotional functioning).

Table 4 Communication about the selected HRQL issues

	consultations in which the topic was discussed (%)	physician utterances (mean %)	patient utterances (mean %)	if discussed, % in which the physician initiated the topic
daily activities	64	2.7	7.3	73
emotional functioning	35	5.0	10.1	21
pain	72	3.7	9.2	52
fatigue	46	0.7	2.1	32

Patients' characteristics and HRQL communication

Emotional problems and pain were discussed significantly more often during consultations with female than with male patients (38% vs 26%, and 76% vs 63% respectively, $p = 0.05$). No other significant associations were found between patients' sociodemographic characteristics and HRQL communication.

Detailed results pertaining to patients' communication preferences are described elsewhere.²⁴ While the large majority (between 80% and 95%) of the patients expressed a desire to discuss the various HRQL topics, no significant associations were found between patients' preferences and the frequency of actual discussion.

Table 5 shows the relationship between patients' self-reported HRQL and HRQL communication. Emotional functioning, pain and fatigue were discussed significantly more frequently in those cases where patients reported serious problems in these areas. Nevertheless, it is noteworthy that among those patients experiencing serious emotional problems or fatigue, these issues were discussed in only about half of the cases.

Table 5 Relationship between self-reported HRQL and HRQL communication

HRQL issue (No. Of patients)*	Consultations in which the topic was discussed mean %, (p value)	Utterances dedicated to the topic, mean %, (p value)
daily activities		
limited problems (87)	70.5	6.0
severe problems (143)	62.8 (0.22)	4.3 (0.06)
Emotional functioning		
Limited problems (151)	30.9	6.4
Severe problems (78)	46.3 (0.04)	9.5 (0.03)
Pain		
Limited problems (139)	66.4	4.1
Severe problems (91)	79.6 (0.03)	9.2 (<0.001)
Fatigue		
Limited problems (83)	34.5	1.0
Severe problems (146)	52.0 (0.01)	1.4 (0.20)

* Number varies due to missing COOP/WONCA Chart responses. In the first column of data, the association between discussion of HRQL issues (‘yes’ or ‘no’) and severity of HRQL problems (‘limited’ vs ‘severe’) is presented, the X^2 statistic was used to generate the p values. In the second column of data, the association between mean percentage of utterances dedicated to a given HRQL topic and severity of HRQL problems is presented; the t-test was used to generate the p values.

Physicians’ characteristics and HRQL communication

No statistically significant associations were observed between physicians’ age, sex, or years of work experience, and HRQL communication. However, the physicians’ attitude toward discussing their patients’ emotional problems was reflected in their actual communication behavior. More time was devoted to discussing patients’ emotional functioning by those physicians who felt a strong responsibility to do so as compared to those who did not. (9% vs 6% of total utterances, respectively, $p = 0.04$).

Consultation characteristics and HRQL communication

The effect of the treatment on tumor growth was addressed explicitly in 60% of the consultations. No significant differences were found in HRQL communication between consultations with or without such an evaluative component.

Forty percent of the patients were seen at their scheduled appointment time. Patients' emotional problems were more likely to be discussed during consultations held at the appointed time than during those that were delayed (49% versus 32%, $p=0.05$). In addition, more time was devoted to this issue during the on-time consultations (9% versus 5.5% of utterances, $p = 0.05$). This could not be explained by differences in the duration of on-time vs delayed consultations, which was approximately the same (16.4 minutes versus 15.7 minutes, respectively). The length of the consultation, interruptions, and the number of prior visits had no significant effect on HRQL communication.

Multivariate prediction of HRQL communication

Multiple linear and logistic regression analyses were performed to test the simultaneous effect of patient-, physician- and consultation-related characteristics on the frequency and duration of communication about each of the 4 selected HRQL issues. Patients' self-reported problems, and consultation waiting time emerged as significant predictors of the *frequency* with which patients' emotional problems was discussed ($X^2=15$, $p = 0.009$). The percentage of time devoted to discussing emotional problems was related significantly to patients' self-reported problems, consultation waiting time and the attitude of the physicians ($F=6.7$, $p<.001$) The only variable found to be related significantly at the multivariate level to the discussion of pain and fatigue was the severity of these symptoms as reported by the patients. No variables emerged as significant multivariate predictors of the discussion of patients' daily activities.

Comment

The objectives of this study were to describe the content of patient-physician communication during outpatient palliative consultations, and to identify factors which play an important role in the discussion of 4 key HRQL issues: patients' daily activities, emotional functioning, pain and fatigue.

In general, patients' communication behavior was directed as equally to medical/technical issues (e.g., results of blood tests, the dose of the chemotherapy) as it was to HRQL issues. The content of physicians' communication was focused primarily on biomedical/technical issues and, to a lesser degree, on HRQL issues (a ratio of 3:1). This latter finding is in line with results found in other medical

settings^{31,32}, suggesting that there is not a substantial difference in HRQL communication between palliative treatment settings and other treatment settings such as primary care and curative treatment.

The discussion of HRQL issues varied depending on the specific topic under consideration. Whereas patients' daily activities and pain were discussed in the majority of consultations, fatigue was discussed in less than half, and emotional functioning in only one-third of the consultations. Importantly, the same variation was observed for those consultations in which patients experienced serious problems in one of these domains. Given that most patients with cancer consider these issues to be of importance and wish to discuss them with their physician^{24,34-36}, these results suggest that patients' communication needs may often be left unmet.

Physicians' attitudes had an observable impact on HRQL communication. Specifically, when physicians did not feel fully responsible for discussing their patients' emotional functioning, it was significantly less likely to be discussed. Additionally, patients' emotional problems were less frequently discussed during consultations that took place behind schedule, probably reflecting concern that their discussion would be too time-consuming. However, no significant differences were found in the duration of consultations as a function of whether or not emotional issues were discussed. Other studies have also failed to demonstrate an effect of the discussion of psychosocial issues on the length of medical consultations.^{37,38}

Despite its high prevalence, fatigue was discussed relatively infrequently and usually at the initiative of the patient. This finding is not unexpected in that previous research has shown that symptoms of a nonspecific and chronic nature are less likely to be discussed.¹⁰ Additionally, until quite recently, few therapeutic options were available for combating fatigue. Physicians may be reluctant to address what is often perceived to be an intransigent problem.³⁶

Consistent with the literature, we found that HRQL issues were discussed significantly more often with female than with male patients. This likely reflects sex differences in symptom awareness and reporting. In general, women are more likely than men to rate themselves as being impaired and to report symptoms.³⁹ This is probably the reason that in the regression analyses, after controlling for the severity of self-reported problems, gender was no longer associated significantly with the discussion of HRQL issues.

Contrary to expectations, the type of consultation (evaluative vs non-evaluative) was not related significantly to HRQL communication. This suggests that HRQL issues may play a lesser role, at least explicitly, in decisions

surrounding the (dis)continuation of treatment than one would expect given the importance expressed about such issues by physicians.^{22,40,41} Efforts directed toward increasing the frequency with which HRQL issues are discussed could enhance patient participation in decision-making, as patients often withdraw from communication that is of a very narrow biomedical and technical nature.^{32,42}

Several strategies have been proposed for increasing the likelihood of HRQL issues being discussed during medical encounters. The effectiveness of training programs to enhance physicians' communication skills and/or to encourage patients to verbalize their needs and concerns has been demonstrated.⁴³⁻⁴⁷ Recently, interest has been expressed in introducing formal HRQL assessments into daily clinical practice as a means of triggering doctor-patient communication.^{48,49} Promising results have been obtained from several studies of such procedures, although they have been based on self-report data^{50,51}

Some caution should be exercised in interpreting the results of the current study. First, the study was conducted in a single hospital and, although the patient sample was large, the number of physicians involved was limited. Second, all patients in the current study were white, reflecting the very low incidence of cancer in the relatively young immigrant population in the Netherlands. As ethnicity and culture can influence the patterns and content of patient-physician communication, future studies are needed that use more culturally diverse patient samples. Third, communication with regard to HRQL issues was observed during a single visit to the outpatient clinic. It is possible that patients and physicians had discussed these issues in one of their earlier contacts and, therefore, may not have found it necessary to discuss them again. However, one could argue that each medical encounter should include at least a minimum amount of question-asking by the physician to track changes in HRQL over time.

In conclusion, our results indicate that the likelihood that HRQL issues will be addressed is greater for patients who experience relatively serious problems, whose physician feels a sense of personal responsibility for discussing such issues, and whose visit takes place at the scheduled time. In general, however, only limited attention was paid to HRQL issues during outpatient palliative treatment, and in particular to patients' emotional problems and fatigue. Importantly, HRQL issues do not appear to play an especially prominent role, at least not in an explicit sense, in the evaluation of treatment efficacy.

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Chapter 4

The role of health-related quality of life in palliative chemotherapy treatment decisions

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Submitted for publication

Abstract

Purpose To establish the relative importance of health-related quality of life (HRQL) considerations in treatment decisions in palliative chemotherapy by investigating: (1) the frequency with which HRQL considerations are the primary reason to modify or discontinue palliative chemotherapy, based on actual discussions between physicians and their patients; and (2) the association between physicians' formal ratings of patients' HRQL and such treatment decisions.

Methods Between June, 1996 and January, 1999, a total of 203 outpatients receiving chemotherapy with a palliative intent were recruited into the study. Four consecutive consultations between patient and physician were audiotaped and content analyzed to determine how often and for which reasons treatment alterations were made. Additionally, physicians rated their patients' HRQL using the COOP/WONCA Charts. Data on tumor response and treatment toxicity were obtained from the audiotapes and, where necessary, were confirmed by medical chart audits.

Results Of the 203 patients, the treatment was modified in 54 (26%) cases and discontinued in 40 (20%) cases. The primary reason for modifying treatment, as discussed during the consultations, was toxicity (22 cases), followed by HRQL considerations (18 cases) and tumor progression (14 cases). The primary reason for discontinuation of treatment was tumor progression (23 cases), followed by HRQL considerations (6 cases) and treatment toxicity (3 cases). For 8 patients, a combination of tumor progression and HRQL considerations led to the decision to discontinue the treatment. Treatment decisions were significantly associated with physicians' global ratings of their patients' HRQL, but not with the more specific HRQL domains assessed by the COOP/WONCA charts. In the presence of either tumor progression or serious treatment toxicity, HRQL considerations played little or no role in treatment decisions. Further, approximately 70% of those patients without evidence of tumor progression or treatment toxicity, but with seriously impaired HRQL, continued to receive their treatment as planned.

Conclusion: Contrary to previous findings based on physicians' self-reported attitudes and behavior, HRQL considerations appear to play a relatively minor role in decisions regarding modification or discontinuation of palliative chemotherapy.

Introduction

Traditionally, the evaluation of cancer treatments has focused on biomedical outcomes, including disease-free and overall survival and treatment toxicity. Since the 1980s, however, there has been increased interest in evaluating the effect of cancer and its treatment on the patients' health-related quality of life (HRQL), typically defined in terms of physical, psychological and social functioning and well-being.¹ Assessment of patients' HRQL is particularly relevant in the palliative treatment setting. Palliative chemotherapy, for example, may alleviate tumor-related symptoms such as pain or dyspnea that, in turn, may improve patients' HRQL. Chemotherapy may, however, also carry with it substantial physical and psychological side-effects that adversely effect the patient's HRQL.²

The benefits and burdens associated with palliative treatment need to be continually monitored and weighed in deciding whether to continue, modify or discontinue the treatment. HRQL factors are often cited as being of major importance in palliative medicine²⁻⁹. In a 1990 survey of more than 500 health care professionals, HRQL was rated as the most important outcome in assessing the effect of palliative chemotherapy for advanced cancer.¹⁰ In a similar survey among medical oncologists¹¹, HRQL was ranked by 46% of the respondents as being the most important factor in deciding whether to continue palliative therapy, followed by treatment toxicity (25%) and tumor response (18%).

Both of these studies, however, were based on physicians' self-reported attitudes and behavior, which may or may not reflect the actual decision-making process in clinical practice.

The current observational study was undertaken to investigate: (1) the frequency with which HRQL considerations are the primary reason to modify or discontinue palliative chemotherapy, based on actual discussions carried out between physicians and their patients; and (2) the association between physicians' formal ratings of patients' HRQL and such treatment decisions.

Methods

Study sample and procedures

The study was conducted between June, 1996 and January, 1999 in the Antoni van Leeuwenhoek Hospital, a specialized cancer treatment center in Amsterdam. The physician sample included the medical staff of the Department of Medical Oncology. The patient sample was comprised of a consecutive series of patients receiving outpatient palliative chemotherapy, and under the care of one of the participating physicians. Inclusion criteria were: 18 years of age or older,

having received a minimum of two cycles of chemotherapy, basic proficiency in the Dutch language, and not participating in a concurrent HRQL study. The study was approved by the institutional review board of the hospital, and all patients gave their informed consent prior to participation.

Patients were followed during a maximum of four successive outpatient consultations with their treating physician. All consultations were audiotaped. The audiotapes were analyzed by three trained raters using a content checklist. Additionally, at the time of each consultation, the physicians were asked to rate the patients' HRQL using a brief, standardized questionnaire.

Study Measures

Treatment decisions

The audiotapes of the consultations were used to determine whether the treatment was given as planned, or was modified or discontinued during the study period (i.e., four consecutive consultations). Treatment modification included reduction of the dose, postponement of the treatment course, or change to a milder chemotherapeutic regimen. Cessation of therapy was noted when the treatment was discontinued prematurely and no other chemotherapy was offered. In case of treatment modification or cessation, the primary reason underlying this decision, as discussed during the consultation, was noted: (1) tumor progression; (2) treatment toxicity; (3) HRQL considerations; or (4) a combination of these. To make a clear distinction in the rating procedure between treatment toxicity and HRQL considerations, the former was noted in case of signs (e.g., blood values, values of liver or heart function), and the latter in case of symptoms (e.g., fatigue, pain, nausea). The HRQL category was also used when the decision was based on the patient's level of functioning (physical, emotional or social) or general well-being.

Ratings of tumor status and treatment toxicity

The audiotapes were also used as the primary source of information to classify *all* patients, including those who continued treatment, with regard to tumor response and treatment toxicity. In those cases where the information derived from the audiotapes was at all unclear, medical chart audits were conducted. Tumor status was classified into two categories: (1) tumor progression (increase in size and/or number of sites); or (2) stable disease or tumor regression. Toxicity was coded as either:

(1) serious (e.g., significant bone marrow suppression or inadequate liver function), or (2) mild/none.

The level of agreement between the three raters, as assessed during the initial period of the study, was high (mean = 95%). Nevertheless, throughout the

course of the study weekly meetings were held to discuss any discrepancies in ratings until consensus was reached.

Ratings of patients' HRQL

Immediately following each consultation, the physicians rated the patients' HRQL by means of the Dartmouth COOP/WONCA Charts.^{12,13} These charts assess HRQL at a generic level, covering a core set of domains, including physical fitness, feelings, daily and social activities, general well-being, and pain. An additional chart was included to assess fatigue. Each chart consists of a descriptive title, a question referring to a single aspect of the patient's HRQL during the previous two weeks, and five response choices illustrated by drawings. Scores range from 1 to 5, with 1 representing the best and 5 indicating the worst level of functioning or well-being. The rationale for using physicians' ratings rather than patients' self-reports was that, despite an increased call for shared decision-making, many seriously ill patients still prefer to follow their physician's recommendations.¹⁴ Thus the physician's perspective and opinions are often a key factor in treatment decisions.^{15,16}

Statistical Analysis

Frequency counts were used to calculate the number of patients for whom treatment was modified or discontinued, and the *primary* reason cited during the consultations for doing so (i.e., tumor progression, treatment toxicity, the patient's HRQL, or a combination of these).

Chi-square analyses were performed to assess the bivariate association between between tumor response, treatment toxicity and physicians' assessments of patients' HRQL (COOP/WONCA charts), and the decision to continue, modify or discontinue treatment. For these analyses, the 5 response choices of the COOP/WONCA charts were collapsed into two categories: no to mild HRQL impairment (response categories 1-3) versus moderate to severe HRQL impairment (response categories 4-5). For those patients whose treatment was modified or discontinued, the COOP/WONCA charts completed at the time of that decision were used. For those patients whose treatment was continued without modification throughout the course of the study, the COOP/WONCA charts from the last recorded visit were used. For all statistical testing, the level of significance was set at $p \leq 0.05$.

To examine the conjoint role of tumor response, treatment toxicity and HRQL in treatment decisions, these three variables were dichotomized as follows: (1) tumor progression: yes versus no; (2) treatment toxicity: none/mild versus moderate/severe; and (3) HRQL: good versus poor (based on the COOP/WONCA "general well-being" chart). This resulted in a 2 x 2 x 2 matrix, forming 8 distinct

profiles (e.g., stable disease/tumor regression, no/mild toxicity, good HRQL; progressive disease, no/mild toxicity, poor HRQL; etc.). For each of these profiles, the percentage of patients whose treatment was continued, modified or discontinued was calculated.

Results

Characteristics of the study sample

Of the 12 medical oncologists invited to participate, 10 agreed and 2 declined due to objections to having their consultations audiotaped. The 10 participating oncologists (4 female, 6 male) had a mean age of 44 (range 35-53) years, with an average of 11 (range 2-24) years of experience in oncology.

Of the 382 patients asked to participate in the study, 273 agreed. Of the remaining 109 patients, 50 declined because they thought that the study would be too burdensome, 43 indicated insufficient interest or lack of time, and 16 expressed difficulty with the audiotaping.

In 61 cases, one or more of the consultations was either not recorded due to logistical reasons or the recording was of insufficient quality for analysis. In another 9 cases definitive treatment decisions were not made during the consultations, but were deferred to a later telephone appointment. Because audiotapes were not made of telephone conversations, these latter patients were also excluded from the analysis. This resulted in a final sample of 203 patients with, in total, 740 audiotaped consultations (4 consecutive consultations were available for 155 patients; fewer than 4 consultations were available for 48 patients, primarily due to death or cessation of treatment).

The sociodemographic and clinical characteristics of the participating patients are presented in Table 1. Approximately two-thirds of the patients were female, with a mean age of 56 years (range 24-78 years). The patients had a wide range of cancer diagnoses, with breast cancer being the most prevalent (39%). Two-thirds of the patients were undergoing first-line palliative chemotherapy.

Table 1 Sociodemographic and clinical characteristics of the study sample (N=203)

Gender	
male	32%
female	68%
Mean age (years)	56
range (years)	24-78
Marital status	
married	79%
single/divorced, widowed	21%
Education	
primary school/lower level high school	29%
middle level high school	41%
advanced vocational/university	30%
Cancer diagnosis	
breast	39%
gynecological	7%
gastrointestinal	25%
lymphoma	12%
other	17%
Number of previous chemotherapeutic treatments	
1 st line palliative chemotherapy	64%
2 nd line palliative chemotherapy	24%
3 rd or higher line of palliative chemotherapy	12%

Primary reasons for treatment modification or discontinuation as discussed during the consultations

During the course of the study, the treatment was given as planned in 109 cases (54%), was modified in 54 cases (26%), and was discontinued in 40 cases (20%). As can be seen in Table 2, the primary reason for modifying treatment, as

discussed during the medical consultations, was toxicity (22 cases), followed by HRQL considerations (18 cases), and tumor progression (14 cases).

The primary reason expressed for discontinuation of treatment was tumor progression (23 cases), followed by HRQL considerations (6 patients) and treatment toxicity (3 cases). For the remaining 8 patients, a combination of tumor progression and HRQL considerations led to the decision to discontinue the treatment.

Table 2 Primary reasons for treatment modification or discontinuation as discussed during the consultations

Reason discussed	Treatment modified	Treatment stopped
	n=54 (100%)	n=40 (100%)
Tumor progression	14 (26%)	23 (58%)
Treatment toxicity	22 (41%)	3 (8%)
HRQL considerations	18 (33%)	6 (15%)
Tumor progression and HRQL considerations	0 (0%)	8 (20%)

Association between tumor status, toxicity, HRQL and treatment decisions

Table 3 displays the bivariate association between tumor status, treatment toxicity, HRQL as assessed by the COOP/WONCA charts, and treatment decisions. Tumor progression ($p<.001$) and treatment toxicity ($p<.001$) were significantly associated with the decision to modify or discontinue treatment. While the physicians' rating of the patients' general well-being was also associated significantly with the decision to modify or stop the treatment ($p <.001$), this was not the case for any of the more specific HRQL domains (i.e., physical functioning, feelings, daily activities, social activities, pain and fatigue).

Table 3 Association between tumor status, treatment toxicity, HRQL and treatment decisions

Assessment criteria	No. of patients	Treatment continued (%)	Treatment modified (%)	Treatment stopped (%)	P-value
tumor progression	yes	47	-	36	64
	no	156	69	25	6
treatment toxicity	yes	26	-	88	12
	no	177	62	18	20
general well being	poor	92	42	27	30
	good	110	66	24	10
physical functioning	poor	92	51	23	26
	good	107	59	27	14
feelings	poor	38	50	29	21
	good	160	56	24	19
daily activities	poor	47	53	21	26
	good	151	56	26	18
social activities	poor	37	49	27	24
	good	159	57	24	19
pain	severe	37	54	24	22
	mild	161	55	26	19
fatigue	severe	40	53	27	25
	mild	158	56	26	18

* The number of cases varies due to missing data for the COOP/WONCA charts

The conjoint influence of tumor status, toxicity and HRQL on treatment decisions

As can be seen in Table 4, the decisions to continue, modify or discontinue the treatment varied predominantly as a function of tumor status and treatment toxicity. In case of tumor progression, an equal percentage of decisions to modify or stop the treatment were made for patients with a good HRQL (32% and 68%, respectively) versus those with an impaired HRQL (31% and 69%, respectively). The same pattern of results was observed in case of serious toxicity. Thus, in the case of tumor progression or serious toxicity, treatment was always modified or discontinued, regardless of the HRQL of the patients.

For those patients without evidence of tumor progression and without serious toxicity, treatment decisions were found to vary significantly as a function

of HRQL ratings. Specifically, when the patients' HRQL was rated as good, treatment was modified in only 6% of the cases and discontinued in none. Conversely, for those patients rated as having an impaired HRQL, treatment was modified or discontinued in 17% and 14% of the cases, respectively. Notably, in 69% of the cases where the patients' HRQL was rated as poor, the treatment was continued without any modification.

Table 4 The conjoint influence of tumor status, toxicity and HRQL on treatment decisions

no. of patients *	tumor response	toxicity level	overall HRQL	continue % of patients	modify % of patients	stop % of patients
79	stable/regression	low	good	94	6	0
53	stable/regression	low	poor	69	17	14
18	stable/regression	high	good	0	89	11
6	stable/regression	high	poor	0	83	17
13	progression	low	good	0	32	68
32	progression	low	poor	0	31	69
0	progression	high	good	-	-	-
1	progression	high	poor	0	0	100

* The number of patients is 202 due to one missing case for the assessment of overall HRQL

Discussion

This study investigated the role of HRQL in treatment decisions for patients receiving palliative chemotherapy. Such a study, based on a large sample of patients and using audiotapes of doctor-patient consultations, has not been performed previously.

HRQL considerations were found to be the *primary* reason to either modify or discontinue the treatment in 33% and 15% of the cases in which these decisions were made, respectively. Further, although a statistically significant association was found between physicians' global ratings of their patients' HRQL and treatment decisions, this was not the case for the more specific HRQL domains assessed by the COOP/WONCA charts. In the presence of either tumor progression or serious treatment toxicity, HRQL considerations played little or no role in treatment decisions. More striking, however, is the finding that approximately 70%

of those patients without evidence of tumor progression or toxicity, but with seriously impaired HRQL, continued to receive their treatment as planned. Thus HRQL considerations, in and of themselves, appear to trigger changes in treatment in only a minority of cases. These results are in contrast with the findings from previous surveys^{10,11} in which the majority of physicians rated the patients' HRQL as the most important factor to be considered in making treatment decisions in the palliative treatment setting.

There are several possible explanations for the relatively modest role that HRQ issues appear to play, at least in an explicit sense, in treatment decisions surrounding palliative chemotherapy. First, cessation of active treatment runs contrary to the prevailing ethos in clinical medicine; physicians are trained to intervene, and when this is no longer feasible or appropriate, it may engender feelings of powerlessness.¹⁷

Second, physicians may decide to continue administering chemotherapy because of concern that the HRQL of their patients would deteriorate further if active treatment were to be stopped. While the few randomized studies comparing palliative chemotherapy with best supportive care have yielded mixed findings¹⁸⁻²⁰, they do tend to suggest that patients receiving active anti-tumor therapy function better emotionally than those receiving supportive care only. Slevin has posited that the HRQL benefits associated with active treatment may reflect, at least in part, the provision of hope and the increased social support often experienced as a result of close medical supervision²¹. Whether these are sufficient grounds for continuing active therapy is an ethical question that cannot be resolved empirically.

Third, patients themselves may be willing to accept even major limitations in their HRQL for relatively small survival benefits.²²⁻²⁴ They may also have unrealistic expectations of the effect of treatment on survival.^{25,26} For example, in a study of women with advanced ovarian cancer receiving palliative chemotherapy, 42% believed that the treatment was potentially curative, despite the fact that their physician had informed them that this was not the case.²⁶

We would note that the current results need to be interpreted with some caution for several reasons. First, the study was conducted in a specialized cancer treatment center and, although the patient sample was large, the number of physicians involved was limited. Although we have no reason to believe that the results are in any way atypical of what would be found in other hospitals, we would encourage similar investigations in other treatment settings.

Second, the primary source of information used in this study was recorded conversations between oncologists and their patients. It is possible that, in those cases where HRQL issues were not explicitly mentioned as a reason for modifying

or discontinuing chemotherapy, they may have been taken into account in an implicit, unspoken manner. However, we believe that it is appropriate that factors contributing significantly to treatment decisions be discussed openly in order to ensure that the decision-making process is as transparent as possible to both patients and physicians.

Finally, while consistent rules were applied to distinguish between treatment toxicity (i.e., objective signs) and HRQL (i.e., subjective symptoms), we recognize that they may, in some cases, be correlated. For example, chemotherapy may be discontinued if there is evidence of moderate renal failure, even though the patient may not yet be experiencing symptoms. If the treatment were to be continued, however, the patient would become symptomatic. In such a case, the explicit reason given for treatment cessation, abnormal renal function, may reflect an underlying but implicit concern with the future HRQL of the patient. Again, however, we would argue that, in such cases, the implications of objective indicators of toxicity for the functioning and well-being of the patient need to be made explicit.

In conclusion, although physician surveys have indicated that HRQL considerations play a prominent role in the decision to modify or stop palliative cancer treatment, the results of the present study, based on actual patient-physician encounters, suggest that this is so in only the minority of cases. Not surprisingly, tumor progression and serious treatment toxicity virtually always result in treatment modification or cessation. However, in the absence of these traditional, objective indicators of treatment failure, the patient's HRQL, even when seriously compromised, often does not trigger a change in treatment. With the increased interest in oncology in patient-reported outcomes and patient-centered treatment, additional efforts should be directed toward incorporating HRQL factors, both formally and informally, in patient-physician communication and in clinical decision-making.

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Chapter 5

Quality of life assessment in daily clinical oncology practice: a feasibility study

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S.B. Detmar, N.K. Aaronson. Quality of life assessment in daily clinical oncology practice: a feasibility study. Eur J Cancer 1998, 34: 1181-1186

Abstract

Quality of life (QL) assessments are increasingly being included in clinical trials, but their use in clinical practice is still uncommon. The objectives of this study were to investigate the feasibility of introducing individual quality of life assessments into the daily routine of an outpatient oncology clinic, and the potential impact of such assessments on doctor-patient communication.

The study sample included 6 physicians and 18 of their patients from the outpatient clinic of the Netherlands Cancer Institute/Antoni van Leeuwenhoek Hospital in Amsterdam. For each patient, three follow-up consultations were observed. The first visit was employed for purposes of a baseline measurement. At the two subsequent visits, the patients were asked to complete the EORTC QLQ-C30, a standardized cancer-specific QL questionnaire. The patients' responses were computer-scored and transformed into a graphic summary. The summary included current scores as well those elicited at the previous visit. Both the physicians and the patients received a copy of the summary just prior to the medical consultation.

Completing, scoring and printing the QL data could be done during waiting room time. The availability of the summary did not lengthen the average consultation time. A small increase was noted in the average number of QL issues discussed per consultation. However, the most notable trend was the increased responsibility taken by the physicians in raising specific QL issues for discussion. When the QL summary was available, the physicians raised 3 times as many topics then was the case prior to its use ($p < .05$). All of the physicians and the majority of the patients believed that the QL summary facilitated communication, and expressed interest in continued use of the procedure.

The introduction of individual QL assessments in routine outpatient oncology practice is feasible and appears to stimulate physicians to inquire into specific aspects of the health and well-being of their patients.

Introduction

In recent years major strides have been made in developing brief, easy to complete, self-report questionnaires that yield valid and reliable information on patients' health status and quality of life. Typically, such questionnaires address an array of topics, including recently experienced symptoms, current levels of physical, psychological and social functioning, as well as overall perceived health status and quality of life. Most work in this area has focused on quality of life questionnaires as tools for use in clinical research. More recently, a number of studies have investigated their potential use in daily clinical practice in monitoring disease progression or therapeutic response, screening for physical or psychosocial problems and improving the delivery of care.¹⁻⁵

The use of standardized quality of life information in facilitating communication between physicians and patients can be seen as a first step toward its use in the care process, in that the form, content and quality of such communication may influence decisions about treatment.⁶ Especially in the case of cancer, a disease which has a major impact on all aspects of patients' lives, physicians need to be well-informed about the range of physical, functional and psychosocial problems confronting their patients.

Of course, quality of life considerations have always played a role in oncology care, albeit often implicitly and informally. The typical question asked by a doctor at the beginning of a medical visit-- "How are you feeling?" -- can be viewed as a global inquiry into the patient's quality of life. More targeted questions about the patient's symptoms and level of functioning, as well as the patient's spontaneous remarks or questions, form an integral component of doctor-patient communication. However, the available literature suggests that physicians vary widely in their ability to elicit relevant information from their patients, and patients vary in their ability to articulate their problems and concerns.⁷⁻¹² The resulting situation is one in which physicians are often inadequately informed about the nature and extent of their patients' problems.¹³⁻¹⁷ Physicians frequently underestimate their patients' level of physical functioning and the severity of important symptoms such as pain, yet they also tend to rate their patients as having a more compromised quality of life than do the patients themselves.^{18,19} Additionally, physicians often fail to recognize the presence of heightened levels of psychological distress in their patients.^{11,20-22}

To structure and facilitate doctor-patient communication and increase physicians' awareness of their patients' concerns, it could be helpful to direct concrete attention to particular aspects of patients' quality of life. More specifically, the availability of standardized quality of life information might form a useful basis

for identifying issues of concern to patients and thereby provide physicians with potential topics to discuss during medical consultations.

A number of studies have reported positive effects of standardized quality of life information on physicians' perceived awareness of their patients' problems and concerns.²³⁻²⁶ To our knowledge, however, only one study has investigated the impact of such information on physicians' actual behavior during medical consultations. Street et al²⁷ found that the standard provision of quality of life information had little effect on the communication between obstetricians and their (pregnant) patients. However, the authors suggested that this may have been due to the specific patient and physician sample under study. The patients were healthy, pregnant women, 50% of whom expressed little or no desire for their doctor to inquire specifically about psychosocial issues. The physicians were residents in obstetrics and gynaecology with relatively little experience in routine prenatal care.

In the pilot study reported here, the focus is on patients with more serious medical conditions, and on medical specialists with extensive clinical experience. The primary objectives of the study were: (1) to determine the feasibility, in a practical sense, of administering a brief, self-report quality of life questionnaire to patients in the course of routine daily practice in an outpatient oncology clinic; (2) to investigate whether the information generated by such a questionnaire increases physicians' awareness of the physical and psychosocial problems of their patients, and facilitates doctor-patient communication regarding these problems; and (3) to evaluate patients' and physicians' attitudes toward incorporating such standardized quality of life information into routine outpatient oncology care.

Methods

Study sample

The study was carried out at the Antoni van Leeuwenhoek Hospital, a specialized cancer treatment center located in Amsterdam. The physician sample included 6 medical specialists; 2 from each of the three major disciplines involved in the care of patients with cancer: medical oncology, surgery, and radiotherapy. Twenty outpatients participated in the study; 10 under the care of the medical oncologists, 5 surgical patients, and 5 radiotherapy patients. These patients were selected consecutively from the outpatient clinic caseload of the participating physicians. All patients had seen their physician previously (the median number of previous contacts was 8.4, with a range of 2 to 30 contacts). The only exclusion criteria were: (1) a frequency of scheduled outpatient visits lower than once per two months; and (2) lack of literacy in the Dutch language. All patients asked to

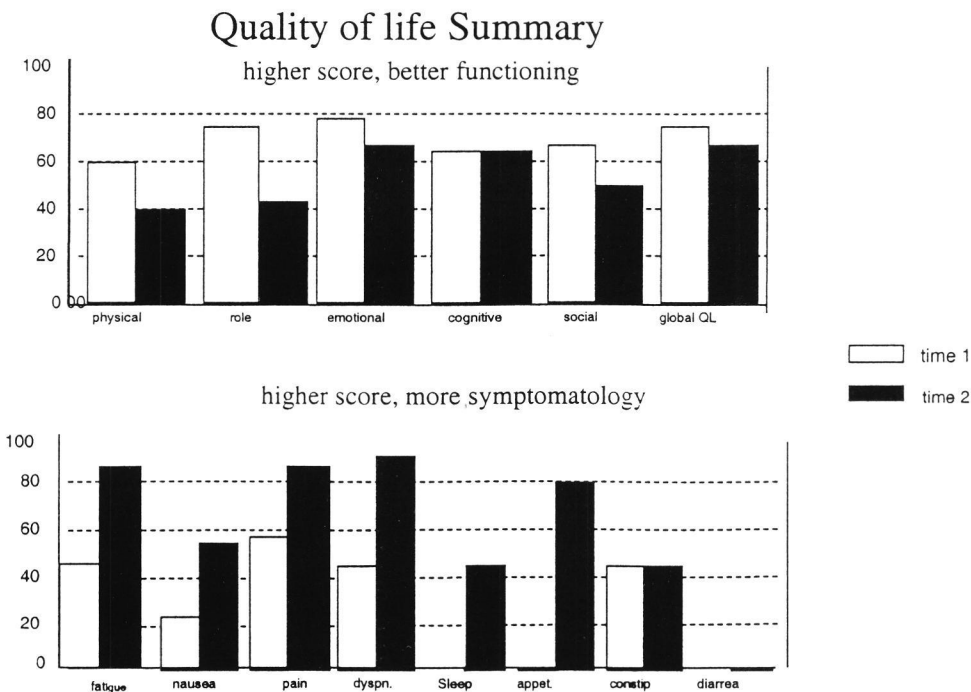
participate in the study agreed to do so. The study was approved by the institutional review board of the hospital.

Study procedures

For each patient, three successive follow-up visits were observed. The first visit was employed as a baseline assessment. At the subsequent two visits, the patients were asked to complete a quality of life (QL) questionnaire, the EORTC QLQ-C30²⁸, during waiting room time. Immediately upon completing the questionnaire, the patient's responses were computer-scored, and a converted into a graphic summary (i.e., a series of bar charts). The QL summary generated at the third visit included both the patients' current scores, as well as those generated at the previous visit. Figure 1 provides an example of such a QL summary.

Both the patient and the physician received a copy of the QL summary just prior to the medical consultation, and both were given a brief explanation of how the scores should be interpreted. After the consultation, one copy of the QL summary was filed in the patient's medical chart.

Figure 1 Example of the QL summary



Quality of life assessment

The patients' quality of life was assessed with the EORTC QLQ-C30, a 30 item, cancer-specific questionnaire designed for patient self-completion. It is organized into five functional scales (physical, role, cognitive, emotional and social), 3 symptom scales (fatigue, pain, and nausea and vomiting), and a global QL scale. The remaining single items assess additional symptoms commonly reported by cancer patients (dyspnea, appetite loss, sleep disturbance, constipation, and diarrhea), as well as the perceived financial impact of the disease and treatment. For the majority of the items, a 4-point Likert-type response scale is used. For ease of presentation and interpretation, all subscale and individual item responses are linearly converted to a 0 to 100 scale. For the functional and global QL scales, a higher score represents a better level of functioning. For the symptom scales and items, a higher score reflects a greater degree of symptomatology. The time-frame of the questionnaire encompasses the previous week.

Process and outcome measures

A research assistant monitored the patients as they completed the questionnaire, noting whether the patients were able to complete the questionnaire without assistance, the time required to complete it, and the time required to score and print the results.

The research assistant was present during the medical consultation. A checklist was employed to note which topics were discussed, and who took the initiative (the doctor or the patient) to raise a particular topic for discussion. This checklist of topics was designed to parallel the content areas of the QLQ-C30, and only those topics covered by the questionnaire were rated. The total duration of each medical consultation was also recorded.

Prior to the first (baseline) outpatient visit, the patients were asked to rate how important it was to them that their physician be well-informed about their level of both physical and psychosocial functioning. Following both the baseline and the third outpatient visit, both patients and physicians were asked to rate, on a 5-point scale, their overall satisfaction with their communication during the consultation. They were also asked to rate the physician's awareness of the patient's quality of life (i.e., 3 questions about awareness of physical functioning, emotional functioning, and functioning in daily life).

Additionally, after the third visit, the physicians and patients were asked whether: (1) the QL summary had had any effect on their communication and, if so, whether that effect was positive or negative; and (2) whether specific topics had been discussed as a direct consequence of the QL summary and, if so, which

topics. Finally, during a brief interview conducted at the end of the study, they were asked to provide an overall rating of the value of the QL summary as an aid in facilitating doctor-patient communication.

Statistics

Student's t-test was employed to test for changes over time in the frequency with which various QL topics were discussed, and the frequency with which the doctor versus the patient initiated such discussions. The Mann-Whitney test was employed to compare baseline versus follow-up ratings of the physicians' awareness levels, and of satisfaction with the quality of the communication during the consultations.

Results

Patient sample characteristics

During the study period 2 of the 20 patients discontinued their participation (one switched to another physician; the other was admitted to the hospital on an inpatient basis). The mean age of the participating patients was 58 years (range = 29 to 85 years). Eleven of the 18 patients were female. Ten of the patients had breast cancer, 5 head and neck cancer, and 3 cancer of the lymphatic system. Nine of the patients were receiving chemotherapy or hormonal therapy; 4 patients were undergoing radiotherapy and 5 patients were in follow-up.

Feasibility of the procedures

As planned, all 18 participating patients completed the QLQ-C30 at the second and third outpatient visits. The mean time elapsed between administrations was 5 weeks. All but one patient completed the questionnaires without assistance. This latter patient required help because of poor eyesight. Completion of the questionnaire required, on average, 5.5 minutes (range = 2.5 to 13 minutes), and could always be accomplished during the available waiting room time. Scoring and printing of the QL summary required approximately 3 minutes.

Quantitative aspects of doctor-patient communication

Introduction of the QL summary as a part of the medical consultation had no impact on the duration of contact between doctor and patient. At the baseline visit, where no QL summary was available, the mean duration of the consultations was 7.7 minutes (standard deviation = 3.8 minutes). The mean duration of the second and third visits, at which time the QL summary was provided, was 7.9 minutes (standard deviation = 4.1 minutes) and 7.7 minutes (standard deviation = 3.9 minutes), respectively.

The frequency with which various QL topics were discussed, and the initiator of these discussions (doctor or patient) are presented in Table 1. As the pattern of results for the second and third visits (during which the QL summary was available) was very similar, the comparisons presented are between the baseline and the third visits.

Table 1 Total number of topics discussed and the numbers initiated by physician and patient at baseline and second follow-up visit.

	baseline (N=18)			follow-up (N=18)		
	topics discussed		initiator	topics discussed		initiator
functioning	topics	physician	patient	topics	physician	patient
physical	5	2	3	8	7	1
emotional	4	0	4	3	1	2
role	4	1	3	4	3	1
social	3	1	2	4	3	1
cognitive	1	0	1	0	0	0
total functioning	17	4	13	19	14	5
symptoms						
fatigue	7	2	5	6	4	2
pain	7	2	5	9	5	4
nausea	4	0	4	4	3	1
gastro-intest	3	1	2	5	4	1
appetite-loss	7	4	3	9	8	1
insomnia	3	1	2	3	3	0
dyspnoea	0	0	0	3	3	0
total symptoms	31	10	21	39	30	9
total	48	14	34	58	44	14

There were no statistically significant differences observed in the frequency with which the functioning of the patient, in either physical or psychosocial terms, was addressed at the baseline versus the third visit (17 versus 19 times). Similarly, although a slight trend was observed toward increased discussion of physical symptoms at the third visit (39 times) as compared to the baseline visit (31 times), this difference did not reach conventional levels of statistical significance. At both the baseline and third visit, an approximate ratio of 2:1 was observed in the

frequency with which symptoms were discussed, as compared to the patients' level of functioning.

A significant shift was noted over time in the frequency with which the patient versus the physician initiated discussion of various issues relating to the patients' functioning and symptom experience. At baseline, it was primarily the patient who took the initiative to discuss these topics (in approximately 70% of the cases). At the third visit this pattern was reversed, with the physician taking the initiative in approximately 75% of the cases ($p < .05$). This trend was observed across virtually all topics discussed.

Physicians' awareness of the patients' QL

At the baseline visit, 16 of the 18 patients reported that they considered it important that their physician be aware of not only the physical aspects of their disease and its treatment, but also of the consequences for daily life and psychosocial functioning (data not shown in tabular form). As can be seen in Table 2, at baseline, the majority of the patients rated their physician as being well-informed about their symptom experience, but not about their level of psychosocial functioning or activities of daily living. At the third visit, an increase was observed in the number of patients who perceived their physician as being well-informed about these latter issues, although the differences were not statistically significant. Parallel ratings provided by the physicians themselves indicated a statistically significant increase in the perceived awareness from the baseline to the third visit of the patients' activities of daily living ($p < .05$).

Table 2 Patients' and physicians' ratings of the physicians' awareness of the patients' health status.

Health status	physician judged as well-informed by patient		physician judged as well-informed by physician	
	baseline	follow-up	baseline	follow-up
physical symptoms	17	18	14	13
activities daily living	6	9	1	9*
emotional functioning	2	7	6	5

* $p = .028$

N = 18

Perceived impact and value of the QL summary

Half of the patients believed that the QL summary had a positive influence on their communication with their doctor; that it made explicit the specific effects of the disease and treatment on their physical and psychosocial well-being. The other 9 patients did not perceive any change in the nature or quality of their communication as a result of the QL summary. Four of these latter patients expressed some disappointment that not all of the issues raised in the QL summary were actually discussed during the medical visit. All of the patients stated that they would be willing to complete the QLQ-C30 as a regular part of their outpatient clinic care, and all but one patient believed that the QL summary could be useful in facilitating communication with their doctor.

The physicians reported that the QL summary had a positive impact on communication in 13 of the 18 cases. In the remaining 5 cases, the summary was rated as having had no impact, either positive or negative. All 6 of the participating physicians believed that the QL summary provided a useful, overall impression of their patients' functional health and symptom experience. None of the physicians found the summary to be disruptive of their "normal" pattern of communication with their patients. Three of the physicians mentioned spontaneously that the QL summary increased the efficiency with which they were able to elicit relevant information from their patients. All physicians expressed interest in continued use of this procedure.

Discussion

The results of this small study support the feasibility of introducing standardized QL assessments into the daily routine of an outpatient oncology

clinic. The QL questionnaire employed in this study could be completed by the large majority of patients quickly and without assistance, and the results were available in a matter of minutes. Administration and scoring of the questionnaire could always be accomplished during the time that the patients were waiting to see their doctor.

One of the concerns raised by the participating physicians prior to the start of the study was that the introduction of the QL summary might lengthen the time required per patient, and thus would result in longer waiting times at the outpatient clinic. This did not prove to be the case. No increase was observed in the average time spent per patient after introduction of the procedure. To the contrary, several of the physicians indicated that the availability of the QL summary had increased their efficiency; that it enabled them to focus in quickly on issues that required further discussion with their patients.

While a small increase in the average number of quality of life issues discussed was noted after the introduction of the questionnaire, the most notable trend observed was the increased responsibility taken by the physicians in raising specific quality of life issues for discussion. When the QL summary was available, the physicians raised 3 times as many topics then was the case prior to its use.

A significant increase over time was observed in the physicians' perceived awareness of their patients' problems in daily living. In part, this might simply reflect the passage of time (i.e., the more often a physician has contact with a patient, the better he gets to know him). However, we would point out that all consultations, including the baseline consultation, were follow-up visits, and thus the physician-patient pairs had already had at least several previous contacts. Thus it seems unlikely that the observed change in perceived awareness reflects a time effect only, but rather is due to the availability of the QL summary as well.

We recognize that a simple count of the number of topics raised and by whom is insufficient for evaluating the nature and quality of doctor-patient communication. It would have been desirable to audiotape or videotape the medical consultations in order to analyze more thoroughly the effect of the QL summary information on both the content and style of communication (e.g., the use of open-ended versus closed-end questions). We chose not to do so in this pilot study because a primary aim of the study was to determine whether introduction of the QL summary might disrupt the "natural" interaction between physicians and their patients. We were concerned that the use of audio- or videotaping would, in and of itself, have had a disruptive effect. Although the presence of a research assistant might also have influenced the behaviour of the physicians and patients, we considered this influence to be of a lesser magnitude. The physicians and patients

were accustomed to having another person (e.g. a nurse or resident) present during their consultations, and neither was aware of the fact that the research assistant was noting the frequency with which QL topics were discussed.

The extant literature on doctor-patient communication suggests that the observed increase in initiative taken by the physicians in raising QL issues for discussion with their patients can be viewed in a positive light. In the absence of such prompting, patients may hesitate to "burden" their doctor with their problems, and thus will often leave things unsaid or will tend to raise psychosocial concerns at the end of the visit when there is little time left to discuss them.^{7,29,30} The research literature also suggests that increased initiative on the part of physicians in addressing the concerns and problems of their patients can have a salutary effect on patient and physician satisfaction with medical encounters. Patients' satisfaction with office visits has been found to be associated significantly with the perception that the doctor is interested and concerned about their problems.^{31,32} Similarly, patients appear to be most satisfied with interactions in which their point of view is actively elicited by their doctor.^{33,34} The potential value of the QL summary as used in the current study is that it signals to the patient that his or her doctor is interested in and prepared to talk about a wide range of health-related issues. Importantly, physicians also appear to be more satisfied with medical encounters when they are successful in eliciting important information from their patients.^{35,36} Of course, such a QL summary can never substitute for the natural dynamic of doctor-patient communication and interaction. It can, however, be viewed as a valuable tool for structuring the information-gathering process.

In summary, the results of this pilot study indicate that the introduction of individual quality of life assessments into an outpatient oncology clinic is feasible, and appears to facilitate communication between patients and their physicians. At the same time, the methodological limitations of this study (small sample size, short follow-up period, absence of a control group, and the lack of more qualitative data on doctor-patient interactions) underscore the need for cautious interpretation of the results. Nevertheless, the findings are sufficiently encouraging to warrant further research. Toward this end, we have recently initiated a prospective, randomized study to investigate in a more rigorous manner the value of standardized QL information in daily clinical practice. The study sample includes 10 medical oncologists, and 200 of their patients who are receiving outpatient palliative treatment. The two primary outcomes are: (1) the content and quality of doctor-patient communication, and (2) physicians' awareness of their patients' level of physical and psychosocial functioning. To evaluate doctor-patient

communication, audiotapes are made of all of the medical visits. The taped consultations will be submitted to an in-depth analysis, using the Roter Interaction Analysis System (RIAS).³⁷ To evaluate physicians' awareness, comparisons will be made between physicians' and patients' ratings on the COOP/WONCA Functional Health Assessment Charts.²⁶ Additional outcome parameters include patients' and physicians' satisfaction with their medical interactions, physicians' medical chart notations, and patients' QL over time. If demonstrated to be effective, the relative simplicity of the intervention would recommend its use in a wide range of treatment settings, including both academic and community-based practice settings.

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Chapter 6

A randomized study of the value of health-related quality of life assessments in daily clinical oncology practice

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Abstract

Background. There has been increasing interest in the use of health-related quality of life (HRQL) assessments in daily clinical practice. This study evaluated the efficacy of incorporating standardized HRQL assessments as a routine part of the outpatient palliative treatment of cancer patients in terms of two primary outcomes: 1) facilitating doctor-patient communication, and 2) increasing physicians' awareness of patients' physical and psychosocial health problems. Additional outcome parameters included patient management, patients' and physicians' satisfaction with their medical interactions, and patients' HRQL over time.

Methods. A prospective, randomized (cross-over) study was employed, including 10 medical oncologists and 214 of their patients treated with palliative chemotherapy. For each patient, four follow-up consultations were observed. Audiotapes of the consultations were used to evaluate doctor-patient communication by means of a substantive content checklist. To evaluate physicians' awareness, comparisons were made between physicians' and patients' ratings on the COOP/WONCA charts.

Results. The results showed that patients' level of physical and psychosocial functioning, and their symptom experience was discussed significantly more frequently in the intervention than in the control group. Physicians in the intervention condition tended to identify successfully a greater percentage of patients with moderate to severe problems in several HRQL domains than did those in the control condition. A minimal effect on patient management and patients' HRQL over time and no significant effect on patients' and physicians' satisfaction was found. All of the physicians and 75% of the patients in the intervention condition believed that the intervention facilitated communication and expressed interest in continued use of the procedure.

Conclusions. Incorporating standardized HRQL assessments in daily clinical oncology practice facilitates the discussion of HRQL issues, and can heighten physicians' awareness of their patients' problems.

Introduction

During the past several decades there has been increasing interest in the use of health-related quality of life (HRQL) assessments in clinical oncology. The most common application of such assessments has been in observational studies and clinical trials aimed at characterizing the effect of cancer and its treatment on patients' symptom experience, functioning, and sense of well-being.^{1,2} More recently, interest has been expressed in the use of HRQL assessments with individual patients in daily clinical practice.^{3,4} It has been suggested that routine, standardized assessment of patients' HRQL could serve as a useful aid in detecting physical or psychosocial problems that otherwise might be overlooked, in monitoring the course of the disease and treatment benefits over time, and in improving the delivery of care.^{5,6}

While numerous articles have appeared in the professional literature enumerating the putative benefits of routine assessment of patients' HRQL in clinical practice⁵⁻⁸, relatively few empirical studies have actually investigated the effect of such a procedure. These studies can be broadly organized into those focusing on the feasibility of clinical practice-based HRQL assessment, and those investigating the impact of such assessments on the process and outcome of patient care.

The results of the feasibility studies are consistent and encouraging. Administration of self-report HRQL questionnaires in outpatient clinic settings requires only a modest investment in material and personnel, and is acceptable to patients and staff alike.⁹⁻¹³ The randomized studies that have investigated the value of routine HRQL assessments for patient management and outcomes, most of which were conducted in primary care or mental health settings, have yielded less consistent, and generally less favorable results.^{9,11;14-20} While several studies have reported improved detection of patients' problems (e.g., depression)^{16;20}, others have not.^{14;21} No studies have found a salutary effect on patient satisfaction or health status.

There are several possible explanations for the relative paucity of positive findings. In some studies, the HRQL assessments were made at fixed time intervals, regardless of whether they coincided with specific medical visits.^{14;19} In other studies the assessments were made at a single point in time, thus precluding the possibility of monitoring changes in patients' HRQL over time.^{9;11;18;20} None of the studies provided the patients themselves with summaries of their responses to the HRQL questionnaires that they had completed.

Most notable, however, is the lack of attention that has been paid to the effect of HRQL assessments on the nature or content of doctor-patient

communication. Although, in several of the studies, the participating physicians reported that the availability of the HRQL data facilitated communication with their patients,^{11;11;14;14;17} such self-reports need to be confirmed by direct behavioral measures.²² In only one study which, to our knowledge, is also the only efficacy study conducted in an oncology setting, were patients asked to rate the role of standardized HRQL assessments in facilitating communication with their physician.¹⁵ Although the results were positive, again, they were based solely on self-reported communication behavior. Given that effective communication is the first step in the care process,²³ it seems only logical that doctor-patient communication be included as the most proximal outcome in studies evaluating the effect of the routine use of standardized HRQL assessments in daily clinical practice, and that communication behavior be rigorously measured with appropriate observational techniques. If no effect on communication is found, it is very unlikely that any effect on more distal outcomes, such as patient satisfaction or HRQL will be observed.

The current, randomized study was undertaken to investigate the potential value of providing oncologists and their patients with timely, structured feedback on the patients' HRQL during palliative chemotherapy treatment as a means of: (1) facilitating doctor-patient communication; and (2) increasing physicians' awareness of their patients' physical and psychosocial health problems. Additional outcome parameters included clinical management activities, patients' and physicians' satisfaction with their medical interactions, and patients' self-reported HRQL over time.

Methods

Study site and subjects

The study was conducted at The Netherlands Cancer Institute/Antoni van Leeuwenhoek Hospital, a specialized cancer treatment center in Amsterdam. The physician sample consisted of the medical oncologists working in the Department of Medical Oncology. The patient sample was composed of a consecutive series of patients with incurable cancer who were receiving outpatient palliative chemotherapy, and who were under the care of one of the participating physicians. Patients were excluded if they lacked basic proficiency in the Dutch language, were younger than 18 years of age, or were participating in a concurrent HRQL study.

Study design

Eligible patients were invited to participate in the study after they had received two cycles of chemotherapy. This point in time was chosen in consultation with the participating physicians, who preferred that patients first have the opportunity to adjust to the new treatment setting before being approached for the study. Additionally, it was believed that the effects of the chemotherapy on HRQL would begin to emerge only after several cycles of treatment. Patients were provided with both oral and written information about the study prior to obtaining their informed consent. The study was approved by the institutional review board of the hospital. Patients who declined to participate were asked to respond to a brief questionnaire by telephone.

The study employed a longitudinal, randomized, cross-over design. The participating physicians were initially assigned, at random, to either the intervention condition or to the control condition. For each physician, a minimum cohort of 10 consecutive patients was subsequently recruited into the study. The 1st on-study medical visit served as a baseline assessment for both the intervention group and the control group. The intervention was introduced at the second on-study medical visit and continued through the 4th on-study visit.

Midway through the study, a crossover took place. The physicians originally assigned to the control arm of the study were switched to the intervention arm, and those originally assigned to the intervention arm were switched to the control arm. A second cohort of at least 10 patients per physician was recruited and followed in a manner identical to that in the first phase of the study. To minimize the risk of a carry-over effect, (i.e., that physicians first exposed to the intervention would remain sensitized to HRQL issues during the period in which they were in the control condition), a "buffer" period of approximately two months was introduced before starting recruitment of the second cohort of patients. This cross-over design was deemed the most appropriate means of testing the effect of the intervention, given the relatively limited number of participating physicians. That is, with each physician serving as his or her own control, the potential influence of between-physician differences in sociodemographic characteristics, professional experience, and in attitudes and behavior on key study outcomes could be neutralized.

Description of the intervention

Patients in both the intervention and the control group had standard, follow-up consultations with their physician prior to the start of each cycle of chemotherapy. During these consultations, disease symptoms and treatment side-effects, test results, possible changes in the treatment (e.g., the chemotherapy dose

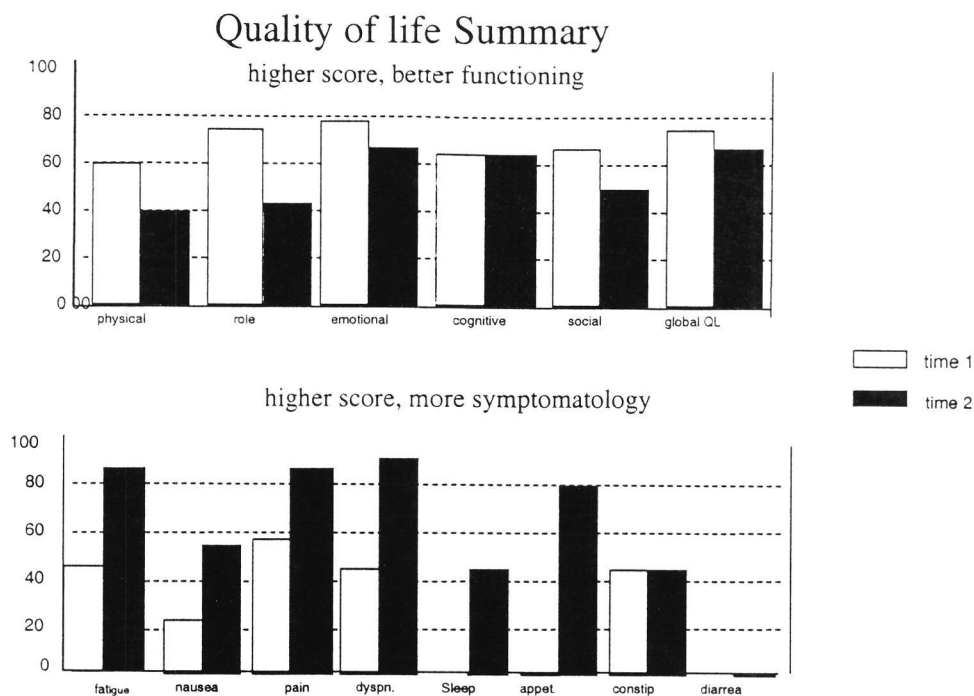
or schedule, concomitant medications, etc.) and, where applicable, tumor response were topics of discussion.

Patients in the intervention arm were asked to complete a standardized HRQL questionnaire, the EORTC QLQ-C30, in the waiting room immediately prior to each outpatient visit with their treating physician. The EORTC-QLQ-C30 is a standardized, cancer-specific HRQL questionnaire used extensively in oncology settings in Europe and North America. It has been translated and validated for use in a large number of countries, including the Netherlands.^{24,25} The QLQ-C30, version 3.0, includes 30 questions organized into five functional scales (physical, role, cognitive, emotional and social), three symptom scales (fatigue, pain, and nausea and vomiting), and a global HRQL scale. The remaining single items assess additional symptoms commonly reported by cancer patients (dyspnea, appetite loss, sleep disturbance, constipation and diarrhea). The questions are posed in terms of the previous week.

For the majority of the QLQ-C30 items, a 4-point Likert-type response scale is used (ranging from “not at all” to “very much”). For ease of presentation and interpretation, all subscale and individual item responses are linearly converted to a 0 to 100-scale. For the functional and global QL scales, a higher score represents a better level of functioning. For the symptom scales and items, a higher score reflects more severe symptomatology.

The patients’ paper-and-pencil responses to the QLQ-C30 were optically scanned into a desktop computer, scored, and printed in the form of a graphic summary profile. Copies of this graphic summary were given to both the patient and the treating physician immediately prior to the medical consultation. Additionally, a copy of the summary was placed in the patients’ medical record. At the two subsequent outpatient medical visits, the QLQ-C30 summary included both the patients’ current scores and those elicited at the previous visit(s). Figure 1 provides an example of such a graphic summary profile.

Figure 1 Example of the graphic summary profile



Prior to the start of the intervention period, each physician received a single, half-hour educational session during which an explanation was provided of how to read and interpret the QLQ-C30 summary scores. Patients in the intervention group received a similar explanation in a pamphlet mailed to their home. If so desired, a research assistant provided patients with an additional verbal explanation of the QLQ-summary at the time of the first, on-study medical consultation. Neither the physicians nor the patients were provided with any specific guidelines or recommendations as to how they should use the summary during the medical consultations. Such proscriptive advice was avoided in order to minimize the possibility of resistance on the part of the physicians²⁶, and to allow the doctor-patient communication to proceed in a natural way. Thus, each physician and patient had complete freedom to discuss the QLQ-C30 summary or to disregard it during the medical consultation.

Study measures

Patients' sociodemographic and clinical characteristics

At the time of the baseline medical visit, the patients were asked to complete a brief sociodemographic questionnaire (i.e., age, gender, education, marital status), and the physicians were asked to rate their patients' performance status by means of the ECOG performance status scale.²⁷ Information regarding patients' diagnosis, treatment history, and current chemotherapy treatment was extracted from the medical records. Subsequently, one of the co-authors (JS), an experienced medical oncologist, rated the various chemotherapy regimens in terms of known side-effects (i.e., "mild", "moderate" or "severe").

Doctor-patient communication

All of the medical consultations were audiotaped for purposes of subsequent content analysis. A checklist was used to extract information from the audiotapes regarding the HRQL topics that were discussed. This checklist included all HRQL topics included in the QLQ-C30. Coding was carried out directly from audiotape by three raters. The level of agreement between raters in determining whether a topic had been discussed was assessed for 10 consultations recorded during the early part of the study. Although the agreement was nearly 100%, weekly meetings were held throughout the course of the study to identify any problems in carrying out the ratings, and to achieve consensus where uncertainty existed. The audiotapes were also employed to document whether the effect of the treatment, in terms of tumor response, had been discussed, and to record the total length of the consultations.

Physicians' awareness of patients' HRQL

At the 1st and 4th on-study visits, the physicians and patients in both the intervention and control group were asked to complete the COOP/WONCA Charts.²⁸ These charts assess a core set of physical and psychosocial health domains, including physical fitness, feelings, daily and social activities, pain, and overall health. An additional chart assessing fatigue was also included. Each chart contains one question with a 5-point response scale. The response categories are illustrated by drawings depicting the corresponding level of functioning or well-being. The COOP/WONCA charts have been shown to be valid and reliable when employed in a range of clinical settings, including oncology.²⁹ The charts were used for two purposes: (1) to determine the physicians' awareness of their patients HRQL; and (2) to identify patients with serious HRQL impairments (see below).

Patient management

The patients' medical records and the audiotapes were used to abstract notations and comments made by the participating physicians with regard to the management of the patients' physical and psychosocial health problems. Categories of HRQL-related patient management activities included: prescription of medication, ordering of tests, referrals to other health care providers, and counseling. The counseling category included any advice directed at a specific HRQL-related problem (e.g., in the case of fatigue, statements such as "You should try to rest more during the day"). A composite patient management score was calculated by summing all HRQL-related actions taken by the physicians per patient.

Patient and physician satisfaction

Following the 1st and the 4th on-study visits, patients were asked to rate their satisfaction with that specific medical visit by means of the Patient Satisfaction Questionnaire- C (PSQ-C) developed by Blanchard et al.³⁰ The PSQ-C consists of five items, assessing patients' satisfaction with needs addressed, active involvement during the visit, doctor-patient interaction in general, information received, and emotional support received. Each question has a 5-point response scale, ranging from "not at all satisfied" to "completely satisfied." An overall satisfaction score was calculated by averaging the responses to the 5 individual items.

At the same time points, the physicians were asked to rate their global satisfaction by means of a single question: "How satisfied were you with the communication with your patient during this visit?" Five response choices were available, ranging from "not at all satisfied" to "completely satisfied."

Patients' self-reported HRQL

At the 1st and 4th visits, the MOS 36-Item Short-Form Health Survey (SF-36)³¹ was employed as an additional measure of the HRQL of patients in both the intervention and control groups. The SF-36 is a generic health status/HRQL questionnaire that has been translated and validated for use in a wide range of countries and patient populations, including cancer patients in the Netherlands.³² The SF-36 is composed of 36 questions organized into 8 multi-item scales: physical functioning, role limitations due to physical health problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and general mental health. On the basis of previous work, it was decided not to field the questions referring to general health perceptions because they proved to be too confronting and/or upsetting to patients with advanced cancer.³²

Patient and physician evaluation of the intervention

Following the 4th on-study visit, patients in the intervention group were asked to complete a questionnaire and to undergo a brief telephone interview to elicit their opinions regarding: (1) whether the graphic summary had been used during the medical consultations and, if so, whether it had any effect, positive or negative, on communication during the consultations; (2) suggestions for revising either the procedures employed or the content of the intervention; and (3) the overall usefulness of the intervention, including whether they would like to see its use continued beyond the period of the study. Similarly, all of the participating physicians underwent a semi-structured interview to obtain their views on the same set of issues.

Statistical analysis

To evaluate the effectiveness of the randomization procedures, differences in the background characteristics of the patients in the intervention and control groups were tested using the χ^2 statistic for categorical data, and Student's t-test for interval-level data.

All statistical analyses relating to the effectiveness of the intervention were based on data obtained from the 4th on-study visit. For all analyses, gender was employed as a covariate. This was considered appropriate because of an overrepresentation, albeit non-significant, of female patients in the intervention group, and because the literature suggests that gender can influence significantly the nature and content of doctor-patient communication.^{33;34} Additionally, where possible, data from the 1st (baseline) visit were used as covariates in the analysis. This could be done for those between-group comparisons based on the entire study sample, but not for those based on various subgroups (see below).

The effect of the intervention on the *verbal content* of the medical consultations was evaluated by comparing the percentage of consultations in the intervention versus control group in which the specific HRQL topics covered by the QLQ-C30 were discussed. This was done for the entire study sample (controlling statistically for both gender and baseline values), as well as for subgroups formed on the basis of: (1) the severity of HRQL impairments (based on dichotomized COOP/WONCA chart ratings of 1 and 2 versus 3 to 5); and (2) whether tumor response was discussed during the consultation (labeled as an "evaluative" consultation). For these latter two analyses, it was not possible to control statistically for baseline values because the patients with moderate/severe HRQL impairment and/or for whom the consultation was evaluative in nature were not necessarily the same at the 1st and at the 4th visit.

Physicians' awareness of patients' HRQL problems at the 4th visit was assessed by calculating the percentage of exact and global agreement between patient and physician ratings for each of the COOP/WONCA charts. Exact agreement was defined as identical patient and physician ratings, while global agreement was defined as agreement within one response category in either direction. Between-group differences for the total sample were tested by means of logistic regression analysis, with gender and baseline values used as covariates. Additional between-group analyses were performed for the subgroup of patients experiencing moderate to severe problems (COOP/WONCA chart ratings of 3 to 5) at the 4th visit. For these latter analyses, agreement was defined as agreement within one response category within the restricted COOP/WONCA score range (i.e., ratings of 3-5). Because the patients with moderate/severe problems at the 4th visit were not necessarily the same as those at the 1st visit, baseline values could not be used as covariates in these analyses. Finally, *within-group* change over time in physician awareness of patients with moderate/severe problems was examined, although no formal statistical testing could be performed for the same reason as noted above (i.e., non-identical subgroup composition at the two assessment points). Rather, a within-group shift over time of at least 10% in the percentage of cases in which there was agreement between the physicians' and patients' COOP/WONCA chart ratings was taken as an indication, albeit informal, of improved physician recognition of these patients' problems.

Linear regression analysis, with gender and baseline values as covariates, was performed to test for between-group differences at the 4th visit in the mean scores on the measures of patient management, patient and physician satisfaction, and patients' self-reported HRQL as measured by the SF-36. In addition, between-group comparisons were made of the percentage of patients whose SF-36 scores improved significantly (i.e., by at least 0.5 standard deviation units) from the 1st to the 4th visit. The significance level for all statistical tests was set at $p = 0.05$.

Results

Patient and physician recruitment and sample description

All 12 physicians from the Department of Medical Oncology were asked to participate in the study; 10 agreed to do so. The two oncologists who declined to participate objected to having their consultations audiotaped. Four of the 10 participating physicians were female. Their mean age was 44 years (range 35-53 years) with, on average, 11 years of working experience in oncology (range 2-24 years).

During a two-year recruitment period, a total of 382 patients were invited to participate in the study, of whom 273 agreed (71% response rate). Of the 109 non-respondents, 50 declined to participate due to very poor physical or emotional condition, 43 indicated insufficient interest or lack of time, and 16 patients had difficulty with the audiotaping. A non-respondent analysis indicated that patients who declined to participate in the study were significantly less well-educated than those who agreed to participate ($p < .001$). No statistically significant differences were found between the respondents and non-respondents with respect to age, sex, marital status, tumor site or scores on the COOP/WONCA charts.

During the course of the study, 31 patients in the intervention group and 28 patients in the control group were lost to follow-up. Of these patients, 33% died, 30% had changed physician, and 37% had transferred to another hospital. There were no statistically significant differences between the intervention and control group with regard to reasons for loss to follow-up.

The sociodemographic and clinical characteristics, and the self-reported HRQL of the remaining 214 patients are presented in Table 1. The intervention and control groups were well-balanced with regard to age, marital status and education. The two groups were also highly comparable with regard to disease stage, severity of the chemotherapeutic treatment, number of previous courses of chemotherapy, ECOG performance status, and self-rated HRQL as assessed by the COOP/WONCA Charts. The control group included proportionally more breast cancer patients than the intervention group (41% vs 62% $p < 0.05$) reflecting, in part, the greater percentage of female patients in the control group (81% vs 73%, NS).

Table 1 Characteristics of the patient sample (N=214)*

	control group n = 100	intervention group n = 114	p-value
Gender			0.15
Female	81	73	
male	19	27	
Age (mean)	55	58	0.24
Education			0.56
lower level high school	18	25	
middle level high school	45	55	
advanced/university	37	25	
Marital status			0.37
single	27	21	
married	73	79	
Diagnosis			0.03
breast	62	41	
colorectal	16	18	
gynaecological	3	9	
lymphoma	9	14	
other	10	18	
Chemotherapy			0.94
mild	48	46	
severe	52	54	
Course nr. (median)	3	3	0.44
COOP/WONCA mean scores (SD)			
physical fitness	3.2 (1.1)	3.3 (1.1)	0.64
daily activities	2.8 (1.2)	2.9 (1.1)	0.64
feelings	2.3 (1.2)	2.2 (1.0)	0.36
social activities	2.2 (1.2)	2.2 (1.2)	0.72
overall health	3.4 (0.8)	3.3 (1.0)	0.42
pain	2.3 (1.0)	2.3 (1.0)	0.75
fatigue	2.9 (1.0)	2.9 (1.0)	0.73

* Data are presented as percentage of patients unless otherwise indicated.

Communication about the patients' HRQL

Table 2 reports the frequency with which various HRQL topics were discussed during the 1st and the 4th visit in the intervention and control group. As can be seen, 10 of the 12 HRQL issues were discussed more frequently in the intervention group as compared to the control group. These differences reached

statistically significant levels for the discussion of social functioning (22% vs 11%), fatigue (54% vs 37%) and dyspnea (23% vs 13%). Additional analyses were undertaken to determine whether between-group differences in the frequency with which HRQL topics were discussed varied significantly as a function of the severity of the patients' self-reported problems (mild versus severe), as assessed by the COOP/WONCA charts. This proved not to be the case (data not presented in tabular form).

Table 2 Percentage of consultations in which patients' HRQL was discussed

	Consultations (%) in which a HRQL topic was discussed	
	control (n = 95)¹	intervention (n=104)¹
physical functioning	32	28
role functioning	57	66
emotional functioning	43	51
social functioning	11	22 *
cognitive functioning	5	10
pain	58	70
fatigue	37	54 *
dyspnea	13	23 *
sleep problems	20	24
nausea/vomiting	26	29
appetite loss	41	38
constipation/diarrhea	28	32

¹ = total number of patients is less than 214 due to missing data

* = $p < 0.05$, based on logistic regression analysis controlled for baseline visit and patients' gender

Table 3 presents the percentage of consultations in which various HRQL topics were discussed in the intervention versus control group, broken down by type of consultation: "evaluative" (i.e., tumor response was evaluated) versus "non-evaluative." As can be seen, during the evaluative consultations, daily functioning (72% vs 53%), emotional functioning (63% vs 43%), fatigue (61% vs 33%), appetite loss (42% vs 30%) and constipation or diarrhea (30% vs 17%) were

discussed significantly more frequently in the intervention group than in the control group. During the non-evaluative consultations, no such differences favoring the intervention group were observed. In fact, the only statistically significant group difference, the discussion of appetite loss, favored the control group (54% versus 30%).

Table 3 Percentage of evaluative and non-evaluative consultations in which patients' HRQL was discussed

	evaluative consultations		non-evaluative consultations	
	control (n = 53) ¹	intervention (n=57) ¹	control (n=42) ¹	intervention (n=47) ¹
physical functioning	34	31	31	30
daily functioning	53	72*	64	62
emotional functioning	43	63*	43	37
social functioning	8	18	19	24
cognitive functioning	8	9	2	13
pain	55	68	62	64
fatigue	33	61*	41	47
dyspnea	19	23	7	23
sleep problems	15	28	21	26
nausea/vomiting	32	35	21	23
appetite loss	30	42*	54 *	30
constipation/diarrhea	17	30*	41	28

¹ = total number of patients is less than 214 due to missing data

*= $p < 0.05$, based on logistic regression analysis, with an interaction between intervention and type of consultation, controlled for patients' gender

Physicians' awareness

There were no statistically significant differences observed at the 4th consultation between the intervention and the control group with regard to exact or global agreement between the physicians' and patients' ratings on the COOP-WONCA charts (data not shown in tabular form). Exact agreement varied between 28% and 52% in the control condition, and between 30% and 52% in the intervention condition; global agreement varied between 88% and 96% in the control condition, and between 86% and 92% in the intervention condition.

Similar results were noted when limiting the analysis to those patients who reported moderate to severe problems on one or more of the COOP/WONCA charts. The only statistically significant group difference was observed in ratings of social functioning, where agreement was reached in 83% of the intervention group versus 65% of the control group ($p < 0.05$).

Table 4 displays the percentages of doctor-patient agreement at the 1st versus the 4th visit for the intervention and control groups separately. Within the intervention group, an increase over time of at least 10% in physician recognition of moderate to severe problems was observed for five of the COOP/WONCA charts: daily activities, feelings, social activities, pain and fatigue. Within the control group, this was the case for only two of the COOP/WONCA charts: daily activities and pain.

Table 4 Physicians' recognition (%) of patients' problems for patients who reported moderate to severe problems on the COOP/WONCA charts

	control group		intervention group	
	1 st visit	4 th visit	1 st visit	4 th visit
physical fitness	86	83	79	88
daily activities	66	83 #	68	81 #
feelings	63	59	51	64 #
social activities	63	65	41	83 #
overall health	83	86	78	82
pain	58	78 #	56	72 #
fatigue	61	63	49	70 #

= at least 10% improvement *within* groups from 1st visit to fourth visit

Patient management

The mean number of HRQL-related patient management actions taken per patient was very similar for the intervention and control group (0.6 and 0.5, respectively, $p > 0.05$). No statistically significant between-group differences were observed in the prescription of medications, ordering of tests, or referrals to other health care providers. However, a significantly greater percentage of patients in the intervention group than in the control group received counseling or advice from

their physician on how to manage their physical or psychosocial health problems (23% v 16%, $p < .05$).

Patient and physician satisfaction

Overall patient satisfaction with the 4th medical visit was high in both the intervention and control group (mean total score of 4.4 and 4.3, respectively, $p > 0.05$). At the individual item level, the only statistically significant between-group difference was with regard to the degree of emotional support received during the consultation (mean = 4.3 versus 4.0 for the intervention and control groups, respectively, $p < 0.05$). The level of physician satisfaction with the medical encounter was similarly high in both the intervention and control conditions (mean score = 4.5 in both groups).

Patients' HRQL

Table 5 displays the mean SF-36 scale scores for the two groups at the 1st and 4th visit. Controlling for baseline values, no statistically significant between-group differences were noted at the 4th visit for any of the SF-36 scales. However, a significantly greater percentage of patients in the intervention group as compared to the control group exhibited improvement over time (defined as a 0.5 standard deviation unit or greater change) in mental health and role functioning-emotional (43% versus 30% and 22% versus 11%, respectively, $p < 0.05$, data not shown in tabular form).

Table 5 Mean scores (SD) of SF-36¹

	1 st visit		4 th visit	
	control group (n=95)	intervention group (n=104)	control group (n=95)	intervention group (n=104)
physical functioning	57 (25)	55 (28)	52 (26)	53 (28)
role-physical	35 (42)	35 (42)	31 (41)	36 (42)
bodily pain	68 (25)	68 (25)	66 (28)	68 (28)
vitality	53 (22)	54 (19)	49 (25)	51 (25)
social functioning	70 (25)	72 (24)	63 (29)	65 (30)
role-emotional	74 (38)	73 (41)	60 (44)	69 (44)
mental health	73 (21)	73 (16)	68 (21)	70 (19)

¹ higher scores indicate better functioning and fewer complaints

Consultation duration and evaluation of the intervention

No statistically significant between-group difference was found in the mean duration of the medical visits: 19.8 minutes versus 20.4 minutes for the intervention and control groups, respectively ($p > 0.05$).

As shown in Table 6, 78% of the patients in the intervention group reported that the HRQL summary profile provided a very accurate picture of their functioning and well-being, 19% reported that it was moderately accurate and 3% thought that it was not accurate. The large majority of the patients in the latter group had other chronic health problems, and were uncertain whether they should report a particular symptom or functional limitation if they believed that it had nothing to do with their cancer.

The majority of patients (57%) reported that the HRQL summary profile was used explicitly during the medical visits, although most of these patients indicated that they waited for their physician to initiate a discussion of the results. The majority of the patients (79%) believed that the summary enhanced their doctor's awareness of their symptoms and functional problems.

Table 6 Patients' evaluation of the intervention (%)

	not at all	somewhat	quite a bit / very much
accurate picture of HRQL	3	19	78
actually used	43	39	18
improves physicians' awareness	21	51	28
useful as standard procedure	13	50	37

Finally, the large majority of the patients (87%) believed that it would be useful to introduce the intervention as a standard part of the outpatient clinic procedure. When asked to elaborate, the most common response was that the HRQL summary profile provided the physician with useful information, and helped the patient to structure the discussion of his or her problems and concerns. Interestingly, approximately one-quarter of the patients indicated that they had discussed the HRQL summary profile with family members or close friends, and 6% had shared it with their family physician. The majority of the patients who rated the intervention less positively reported that they already had optimal communication with their doctor, and thus the HRQL summary had little or no added value.

All physicians reported that the summary profile provided a useful, overall impression of their patients' symptom experience and functional health, and indicated that it facilitated communication, especially with regard to psychosocial topics and "unexpected" symptoms (e.g. sleep disturbances). Although all of the physicians indicated that they would like to continue use of the HRQL summary profile in their daily practice, several suggested that the information provided would be more useful if it included more tailored information about the problems common in specific patient groups (e.g., site of pain and use of pain medication for patients with bone metastases).

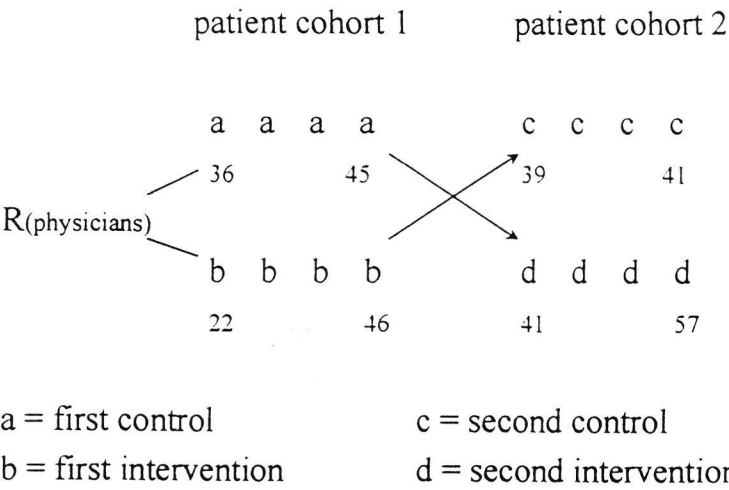
Possible carry-over effect of the intervention

Given the nature of the intervention, we expected that its effect would be limited primarily to the medical consultations during which the HRQL summary profile was actually available. However, we recognized that the intervention might also have a more general impact; that it might sensitize physicians to a range of HRQL issues, and thus could result in an increased discussion of such issues even during the control consultations where the HRQL summary was not available. More specifically, we recognized the possibility of a carry-over effect for those physicians who were first exposed to the intervention, and then switched to the control condition midway through the study. We attempted to limit the likelihood of this happening by building in a two-month buffer period before the switch in conditions occurred.

Nevertheless, our data suggest that a carry-over effect may indeed have been present. This can be illustrated by the pattern of results pertaining to the discussion of patients' emotional functioning at the 1st and the 4th medical visit for both the intervention and control group during the first phase (prior to the cross-over) and the second phase (following the cross-over) of the study (Figure 2). In principle, the data obtained at the time of the 1st medical visit, both prior to and following the cross-over, represented baseline assessments. That is, they were intended to reflect the "natural" pattern of doctor-patient communication when the HRQL summary profile was not available. In the absence of a carry-over effect, one would expect that, at baseline, the percentage of consultations in which patients' emotional functioning was discussed would be very similar for the groups that included the same physicians (in Figure 2, groups a and d, and groups b and c). This was, in fact, the case for groups a and d (i.e., the two baseline visits for those physicians who first were in the control condition and then were exposed to the intervention; 36% and 41%, respectively). However, as can be seen, the percentage of baseline consultations in which emotional functioning was discussed was considerably higher in group c than group b (i.e., where physicians were first

exposed to the intervention, and then crossed-over to the control condition; 39% and 22%, respectively). The hypothesis that this was due to a carry-over effect is further supported by the finding that, during the first phase of the study, a substantial increase over time was observed in group b in the percentage of consultations in which patients' emotional functioning was discussed. A similar pattern of results was noted when exploring other HRQL outcomes.

Figure 2 Percentage of consultations in which patients' emotional functioning was discussed.



Discussion

This prospective, randomized (cross-over) study evaluated the efficacy of incorporating standardized HRQL assessments as a routine part of the outpatient palliative treatment of cancer patients. The two primary outcomes of interest were: (1) doctor-patient communication regarding HRQL-related issues; and (2) physicians' recognition of their patients' level of functioning and well-being. More distal outcomes were also evaluated, including patient management activities, patient and physician satisfaction, and patients' self-reported HRQL over time.

As hypothesized, the intervention resulted in a significant increase in the frequency with which HRQL issues were discussed. Specifically, patients' social functioning, fatigue and dyspnea were discussed significantly more often during consultations in which the HRQL summary profile was available. An even greater number of significant differences favoring the intervention group were observed during consultations in which tumor status was evaluated. This latter finding is of particular importance in that previous research has found that HRQL considerations typically contribute modestly, at least in an explicit sense, to the evaluation of treatment efficacy in daily clinical oncology practice.³⁵

The observed, salutary effect of the intervention on physician-patient communication is particularly encouraging in that the most notable increase was in the discussion of HRQL issues that are less observable (i.e., social functioning), or are of a more diffuse and chronic nature (i.e., fatigue), and thus often are not addressed by health care providers.^{36;37}

No statistically significant between-group differences were observed in physicians' awareness of the level of functioning or symptom experience of their patients. However, a series of within-group analyses indicated that, over time, physicians in the intervention group improved (by more than 10%) in their recognition of patients' with moderate or severe problems in 5 of the 7 HRQL domains covered by the COOP/WONCA charts. Again, it is noteworthy that substantial improvement was observed in the recognition of emotional and social problems (13% and 42% improvement, respectively), fatigue (21% improvement) and pain (16% improvement); problems that tend to be underestimated by health care providers. Within the control group, similar improvement in problem recognition was found for only 2 domains (daily activities and pain).

The intervention was found to have only a modest effect on patient management activities, primarily in terms of increased levels of patient counseling. No significant impact was observed on medication prescription, ordering of tests, or referral patterns. This may be due to several factors. First, the intervention was of a relatively short duration – lasting for only 3 consecutive medical visits. This

may not have been a sufficient period of time for physicians to incorporate the additional information regarding their patients' HRQL into treatment and care decisions.

Second, although the physicians received basic instruction in the interpretation of the HRQL summary profiles, no guidelines were provided as to how to proceed when patients' reported that their level of functioning or symptoms worsened over time. We chose not to do so not only because we wanted to observe how the additional information would be used spontaneously by the physicians, but also because the questionnaire employed to generate the HRQL summary profiles, the EORTC QLQ-C30, was not designed for such purposes. As with all currently available HRQL instruments, the QLQ-C30 was originally developed for use in clinical research rather than daily clinical practice. Its reliability is more than adequate for group-level comparisons, but does not meet the criterion for measurement precision typically applied to instruments intended for screening purposes. Relatedly, until quite recently, little information was available for defining changes in QLQ-C30 scores over time that are of sufficient magnitude to be considered (by patients) to be of importance³⁸. Thus the HRQL summary profile was intended primarily to facilitate communication, rather than to define "cases" for whom practice guidelines could be developed and applied. As more experience is gained with the use of HRQL questionnaires in routine practice settings, we expect that the clinical interpretation of scores will become clearer, as will the implications of such scores for case management.

The only statistically significant difference between the intervention and control groups in patient satisfaction with the medical encounter was in the perceived emotional support received from the physician. This is not unimportant, in that previous research has indicated that patients are significantly more likely to disclose information about their psychosocial functioning when their doctor exhibits such supportive behavior.³⁹ The failure to detect significant between-group differences in other aspects of patient satisfaction, and in physician satisfaction, may be due to the fact that levels of satisfaction tended to be high, in general, leaving little room for improvement. Such a "ceiling" effect has been reported in other studies.^{10;15;40}

The large majority of the patients exposed to the intervention, and all of the physicians reported that the HRQL summary profile was useful in facilitating communication and in enhancing physician awareness of patients' problems. They also favored continued use of the intervention as a standard part of the outpatient clinic procedure. An additional, unanticipated finding was that

approximately one-quarter of the patients shared the results of the summary profile with family members or with their general practitioner. We consider this to be a positive spin-off, in that numerous studies have shown that patients' partners and formal caregivers are often less than fully informed about the patients' HRQL.⁴¹

The intervention appeared to have only a modest impact on patients' self-reported HRQL over time, as assessed by the SF-36. This was not unanticipated, given the complex array of factors that can affect patients' functional health, symptom experience, and sense of well-being. Nevertheless, the finding that significantly more patients in the intervention than the control group improved by more than half a standard deviation on the two SF-36 indicators of emotional health (the mental health and role-functioning-emotional scales) is encouraging.

We are cognizant of a number of limitations of our study. First, although the patient sample was large, the physician sample was limited. This led us to select a study design that incorporated a cross-over element, enabling us to largely neutralize any effect that might be attributed to physicians' background characteristics. However, it also carried with it the risk of a carry-over or contamination effect. The pattern of results, as described previously, suggests that such a carry-over effect may, in fact, have occurred. Physicians who began in the experimental condition, and midway through the study shifted to the control condition, may have been sensitized to HRQL issues, in general, and thus may have changed their behavior during the period in which they were no longer exposed explicitly to the intervention. Importantly, however, any such carry-over effect would tend to have a conservative effect, as it would suppress between-group differences in the principal study outcomes.

Second, the HRQL summary profiles were generated with the use of a paper-and-pencil version of the EORTC QLQ-C30. This required the presence of a research assistant for purposes of scanning, computer-scoring and printing of the profiles. Although this was accomplished at minimal costs, and without disruption of normal clinic routine, recent studies have supported the feasibility, reliability and validity of touchscreen versions of the QLQ-C30 and similar HRQL instruments.^{13;42;43} Such technology can further simplify and increase the efficiency of procedures for assessing patients' HRQL on a routine basis.

Third, as previously indicated, the QLQ-C30 (and other fixed-length HRQL questionnaires) was not originally developed for use at the level of the individual patient. While we considered its use appropriate, given the specific objectives of the study, recent developments in measurement theory and practice advocate the use of computer-adaptive or dynamic testing, based on the principles

item-response theory, in order to increase the flexibility and precision with which individualized HRQL profile scores can be generated.⁴⁴⁻⁴⁷

Finally, the study was conducted in a single hospital, specialized in the treatment of patients with cancer. Future studies are needed to evaluate the efficacy of the intervention in more diverse treatment settings and with more diverse physician and patient populations.

In conclusion, our results support the use of standardized HRQL assessments in the palliative cancer treatment setting as a means of facilitating the discussion of HRQL issues, and of heightening physicians' awareness of their patients' problems. Future efforts should be directed at improving the flexibility and precision of HRQL assessments, and at linking patients' HRQL (change) scores to specific treatment and care strategies.

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Chapter 7

Summary and discussion

In this chapter, the principal results reported in chapters 2 to 6 are summarized and placed in perspective. A number of methodological issues are discussed, the clinical implications of the most important findings are outlined, and directions for future research are given.

Introduction

The primary objective of this thesis was to investigate the effect of individual health-related quality of life (HRQL) assessments on doctor-patient communication in a palliative outpatient cancer clinic. Before examining the effectiveness of such HRQL assessments on communication, we investigated the communication preferences of, and the 'natural' communication between patients and physicians regarding HRQL issues. Additionally, the role of HRQL considerations in treatment decisions in the palliative treatment setting was investigated.

Summary of the results

Chapter 2 described the attitudes of cancer patients towards discussing HRQL issues, the association between such attitudes and patients' characteristics, and oncologists' attitudes and self-reported behavior regarding these same issues. A total of 240 patients and 10 physicians were asked to complete a series of questionnaires. The results showed that almost all patients wanted to discuss their physical symptoms and physical functioning, and were also willing to address their emotional functioning and daily activities. However, 25% of the patients were only willing to discuss these latter two issues at the initiative of their physician. Patients varied most in their willingness to discuss their family and social life, with 20% reporting no interest at all in discussing these issues. Female patients were more reluctant to discuss various HRQL issues than male patients. Older and less well-educated patients were more likely to prefer that their physician initiate discussion of HRQL issues. All physicians considered it to be primarily their task to discuss the physical aspects of their patients' health, while 4 physicians indicated that discussion of psychosocial issues was a task to be shared with other healthcare providers. All physicians indicated that they generally defer to their patients in initiating discussion of psychosocial issues.

It was concluded that both patients and oncologists appear willing to discuss a wide range of HRQL issues. Nevertheless, communication regarding psychosocial issues may be hampered by competing expectations as to who should take the lead in initiating such discussions.

Chapter 3 presented an observational study of doctor-patient communication regarding HRQL issues during the period of palliative treatment. The content of communication regarding HRQL issues between oncologists and their patients was investigated, and patient-, physician- and visit-specific factors associated significantly with the discussion of such issues were identified. Discussions between 240 patients and 10 physicians were audiotaped and content-analyzed using the Roter Interactional Analysis System and a substantive content checklist. In addition, patients and physicians were asked to complete a number of questionnaires. Physicians devoted approximately two-third of their conversation to medical/technical issues and one-quarter to HRQL issues. Patients' communication behavior was divided more equally between medical/technical issues (41%) and HRQL topics (48%). Of the independent variables investigated, patients' self-reported HRQL was the most powerful predictor of discussing HRQL issues. Nevertheless, in between 20% and 54% of the consultations in which patients were experiencing serious HRQL problems, no time was devoted to the discussion of those problems. In particular, patients' emotional functioning and fatigue were often left un-addressed. The discussion of HRQL issues was not found to be related significantly to patients' preferences for discussing these topics. In addition, the evaluation of tumor progression was not related to the discussion of HRQL topics.

The main conclusion to be drawn from this study was that, despite increasing recognition of the importance of maintaining patients' HRQL as a goal of palliative treatment, the amount of doctor-patient communication devoted to such issues remains limited, and does not appear to contribute, at least in an explicit sense, to the evaluation of treatment efficacy in daily clinical practice.

Chapter 4 described a study to determine the relative importance of HRQL considerations in treatment decisions in palliative chemotherapy by investigating: (1) the frequency with which HRQL considerations are the primary reason to modify or discontinue palliative chemotherapy, based on actual discussions between physicians and their patients; and (2) the relationship between physicians' formal ratings of their patients' HRQL and such treatment decisions. A total of 203 patients and 10 physicians participated in this study. Four consecutive outpatient consultations between patient and physician were audiotaped and content-analyzed to determine how often and for which reasons treatment alterations were made. Additionally, physicians rated their patients' HRQL using the COOP/WONCA Charts. Data on tumor response and treatment toxicity were obtained from the audiotapes and, where necessary, were confirmed by medical chart audits. Of the 203 patients, the

treatment was modified in 54 (26%) cases and discontinued in 40 (20%) cases. The primary reason for *modifying* treatment, as discussed during the consultations, was toxicity (22 cases), followed by HRQL considerations (18 cases) and tumor progression (14 cases). The primary reason for *discontinuation* of treatment was tumor progression (23 cases), followed by HRQL considerations (6 cases) and treatment toxicity (3 cases). For 8 patients, a combination of tumor progression and HRQL considerations led to the decision to discontinue the treatment. Treatment decisions were significantly associated with physicians' global ratings of their patients' HRQL, but not with the more specific HRQL domains assessed by the COOP/WONCA charts. In the presence of either tumor progression or serious treatment toxicity, HRQL considerations played little or no role in treatment decisions. Further, approximately 70% of those patients without evidence of tumor progression or treatment toxicity, but with seriously impaired HRQL, continued to receive their treatment as planned. It was concluded that, contrary to previous findings based on physicians' self-reported attitudes and behavior, HRQL considerations appear to play a relatively minor role in decisions regarding modification or discontinuation of palliative chemotherapy.

Chapter 5 presented the results of a pilot-study investigating the feasibility of introducing individual quality of life assessments into the daily routine of an outpatient oncology clinic, and the potential impact of such assessments on doctor-patient communication. The study sample included 6 physicians and 18 of their patients. For each patient, three follow-up consultations were observed. The first visit was employed for purposes of a baseline measurement. At the two subsequent visits, the patients were asked to complete the EORTC QLQ-C30, a standardized, cancer-specific QL questionnaire. The patients' responses were computer-scored and transformed into a graphic summary. The summary included current scores as well those elicited at the previous visit. Both the physicians and the patients received a copy of the summary just prior to the medical consultation.

Completing, scoring and printing the HRQL data could be done during waiting room time. The availability of the summary did not lengthen the average consultation time. A small increase was noted in the average number of HRQL issues discussed per consultation. However, the most notable trend was the increased responsibility taken by the physicians in raising specific HRQL issues for discussion. When the HRQL summary was available, the physicians raised 3 times as many topics compared to when it was not available. All of the physicians and the majority of the patients believed that the HRQL summary facilitated communication, and expressed interest in continued use of the procedure.

The conclusion was that the introduction of individual HRQL assessments in routine outpatient oncology practice is feasible and appears to stimulate physicians to inquire into specific aspects of the health and well-being of their patients.

Chapter 6 described a prospective, randomized (cross-over) study evaluating the efficacy of incorporating standardized HRQL assessments as a routine part of the outpatient palliative treatment of cancer patients. The two primary outcomes were: 1) doctor-patient communication, and 2) physicians' awareness of patients' physical and psychosocial health problems. Additional outcome parameters included patient management, patients' and physicians' satisfaction with their medical interactions, and patients' HRQL over time. The study sample included 10 medical oncologists and 214 of their patients treated with palliative chemotherapy. For each patient, four follow-up consultations were observed. Audiotapes of the consultations were used to evaluate doctor-patient communication by means of a substantive content checklist. To evaluate physicians' awareness, comparisons were made between physicians' and patients' ratings on the COOP/WONCA charts. The results showed that patients' level of physical and psychosocial functioning, and their symptom experience, was discussed significantly more frequently in the intervention than in the control group. Physicians in the intervention condition tended to successfully identify a greater percentage of patients with moderate to severe problems in several HRQL domains than did those in the control condition. No significant effect on patients' and physicians' satisfaction and a minimal effect on patients' management and patients' HRQL over time was found. All of the physicians and 75% of the patients in the intervention condition believed that the intervention facilitated communication and expressed interest in continued use of the procedure. It was concluded that incorporating HRQL assessments in daily clinical practice facilitates the discussion of HRQL issues, and heightens physicians' awareness of their patients' problems.

Discussion

In this thesis we have reported a number of related studies of the role of HRQL in clinical practice. Chapters 2 to 4 provided descriptive data regarding patients' and physicians' attitudes, preferences and observed behavior regarding HRQL issues during a palliative treatment period. Chapter 5 described a pilot study testing the feasibility of introducing HRQL assessments into clinical practice, while chapter 6 presented the results of a randomized study on the effect of HRQL

assessments on doctor-patient communication and physicians' awareness of their patients HRQL.

Methodological reflections

Study Design

The limited number of participating physicians (N=10) led to two methodological concerns. The first was related to the hierarchical structure of the data, consisting of patients nested within physicians. This was of particular concern in the observational study reported in chapter 3. It might be expected that communication during consultations of one particular physician is more consistent than communication during consultations of different physicians. In other words, the consultations cannot be regarded as completely independent. One possible way of dealing with such correlated data would be to aggregate the data at the physician level, using the average scores on the communication variables per physician. A disadvantage of this method is that, as a result of this aggregation, information is lost about variance at the patient level. Another approach to analyse such nested data, is the use of multi-level models. However, sample size limitations ultimately recommended against their use. A minimum of approximately 30 cases in the highest level is needed to make use of such multi-level statistical techniques.¹ With only 10 physicians, (our sample in the highest level) the use of such methods is likely to yield unstable parameter estimates. To examine possible differences in communication behavior between physicians, intraclass correlations for the selected HRQL issues were computed. The intraclass correlations were very small (below 0.05), indicating that the variance between physicians was limited. Under such conditions, we considered the use of traditional regression models as appropriate.

A second point of concern was the choice of a proper study design for the intervention study (chapter 6). The most preferable design would be to randomize physicians between the intervention and control condition; a group of physicians with their patients would receive the intervention, and another group of physicians with their patients would function as the control condition. However, given the relatively limited number of physicians, having presumably some variability in communication style, this design was considered problematic. A number of alternative designs were considered, of which the first was to randomize patients within physicians to either the intervention condition or to a standard treatment control condition (i.e. patients of each participating physician would receive either the intervention or standard care). A disadvantage of this design is the potential contamination effect due to randomizing patients *within* physicians. The

intervention might sensitize physicians to HRQL issues, in general, and thus might affect their communication with patients both in the experimental and in the control conditions. Another possible design, attractive for its simplicity, was the before-after design; all physicians would start in the control condition and, after a period of time, switch to the intervention condition. However, any possible history effect can not be detected with this design. Finally, we considered a randomized, cross-over design to be the most appropriate considering the available number of physicians. The participating physicians were initially assigned at random to either the intervention or control condition. During the first phase of the study, a cohort of over 100 patients was recruited (minimally 10 patients per physician). Following a baseline medical consultation, all patients were followed for 3 consecutive medical consultations. Midway through the data collection period, a cross-over took place. Those physicians originally in the control condition were exposed to the intervention; those originally in the intervention arm were switched to the control condition. A second cohort of at least 100 patients was recruited and followed in a manner identical to that in the first study phase. To minimize any potential carry-over effect, a 'buffer' period of approximately 2 months was introduced before starting recruitment of the second cohort of patients. Nevertheless, the results of the study suggest that a carry-over effect did occur for those physicians who started in the intervention condition and switched to the control condition in the second part of the study. During these consultations HRQL issues were more frequently discussed than was expected. Nevertheless, any such carry-over effect would work in the conservative manner, tending to suppress any real difference between the intervention and control conditions. Importantly, a number of significant effects of the intervention were detected, despite the conservative method of the study design.

Generalizability

All patients included in the studies reported in this thesis were treated in a specialized cancer center. These patients may have been younger, or more highly educated than cancer patients treated in general hospitals, and these patient characteristics might have influenced their communication behavior. In addition, patients who choose to be treated in a specialized cancer center may have different treatment preferences and might be more willing to accept limitations in their HRQL than patients treated elsewhere. Although our findings indicate that most patients prefer to discuss a range of HRQL issues with their physician (chapter 2), the role of HRQL issues in treatment decisions seems to be limited (chapter 4). In this respect, it is difficult to determine the extent to which the results can be

generalized to all cancer patients receiving palliative treatment. Another point of concern regarding the generalizability of the findings relates to the participating oncologists. These were all experienced medical oncologists, working in the same hospital and with a heavy caseload. As physicians' communication patterns vary as a function of their experience with specific patients,² it remains an empirical question as to whether similar results would be obtained with physicians working in other settings.

Analysis of physician-patient communication

Communication about HRQL issues was one of the primary foci of this thesis. Thus, it was important to obtain detailed information about physician-patient interactions. We considered using either videotapes or audiotapes to collect these data. An advantage of videotapes is that both verbal and non-verbal behavior can be observed. Videotaping has been used in physician training and assessment of communication skills, as well as to analyse consultations in general practice settings.³ However, we were concerned about the feasibility of employing videotaping in the palliative cancer treatment setting, particularly given the need to record four consecutive visits for each patient. In addition, although videotapes record both verbal and non-verbal communication behavior, the emphasis of our research was on the former, i.e. the frequency with which various specific HRQL issues were discussed. For these reasons, we chose to make use of audiotapes. Although several of the participating physicians had initially voiced concern (either for themselves or for their patients) about the potential intrusiveness of these recordings, this proved not to be a problem during the course of the study.

In total, more than 700 consultations were audiotaped. One may wonder whether the presence of a tape recorder inhibited or otherwise affected the nature and content of the doctor-patient communication. Results of previous studies^{4,5} and of our own study indicate this not to be the case. Both patients and physicians reported forgetting about the tape recorder soon after the visit began, and few indicated that the audiotaping changed their behavior in any way. The fact that the audiotaping was carried out successfully over a relatively long period of time attests to the feasibility and acceptability of such data collection methods, even in studies of patient with serious, life-threatening illness.

Instrument used to assess patients' HRQL

The EORTC-QLQ-C30 was selected to measure patients' HRQL, because it has been designed specifically for cancer patients, measures a wide range of HRQL domains, and can be completed within 10 minutes.⁶ However, as with all currently available HRQL instruments, the QLQ-C-30 was developed for use in clinical research rather than daily clinical practice. As is the case with other

available measures, the majority of the subscales of the QLQ-C-30 meet the 0.70 reliability criterion commonly accepted for group level comparisons, but not the 0.90 criterion advocated for interpretation of scores at the level of the individual patient.⁷ It is important to emphasize, however, that this stringent criterion is intended primarily for those situations in which test scores are to be used as the basis for overt decision-making (e.g., whether or not an individual patient should receive a given treatment). In our study the QLQ scores were not intended to be used for the purpose of making clinical decisions. Rather, the patients' HRQL ratings were intended to facilitate doctor-patient communication by identifying problem areas that needed further attention and discussion with the patient. In such a situation, somewhat more liberal reliability criteria can be accepted.⁸ Nevertheless, in recent years new scaling methods have been developed, that seem promising in fulfilling the higher precision levels recommended in individual patient care. In the next section this will be discussed further.

Implications for clinical practice and research

The main conclusions from the descriptive parts of our research were that patients and physicians had competing expectations as to who should initiate HRQL issues (chapter 2), actual discussion of HRQL issues was limited (chapter 3) and HRQL considerations did not appear to play a prominent role in treatment decisions (chapter 4). Together, these results indicate that, although enhancing patients' HRQL is an important goal of a palliative treatment, the explicit role of HRQL during treatment is rather limited. These results are consistent with findings in other medical settings, indicating that there is no substantial difference in communication between palliative treatment settings and other treatment settings, such as primary care and curative treatment.

As expected, physicians' and patients' attitudes were related to these findings. The attitude of the physician was of particular importance for the discussion of psychosocial issues. This suggests the need for an increased emphasis in medical school curricula on training communication skills and on stimulating a positive attitude towards psychosocial issues as an integral part of the communication process.

In addition, patients themselves infrequently ask questions or initiate discussion of HRQL issues. Rather, a considerable percentage of patients prefer that their physician initiate discussions. Apparently, despite the increased role of patients as active consumers of health care, for many patients being a "good" patient means not asking many questions, and not attempting to raise problems or

concerns.⁹ Therefore, more effort should be placed on encouraging patients to take an active part in their care by raising questions and discussing issues that are important to them. Of course, changing attitudes is not simple, because they are part of established social roles, learned in childhood and reinforced by a wide variety of social stimuli. Therefore, the efforts should be extensive and should be continued over a considerable period of time.

Our study results confirm the findings of previous studies: discussing HRQL issues, in particular psychosocial issues, does not automatically increase consultation time.¹⁰⁻¹² Physicians should be made more aware of this, particularly because many physicians are still anxious that discussing HRQL issues will significantly increase the duration of their consultations.

The use of HRQL assessment for individual patients in routine clinical practice has proven to be feasible and to facilitate communication between physicians and their patients. Feasibility of a procedure is of importance for further implementation. In our study, paper-and-pencil questionnaires were filled in and, with the use of an optical scanner, software applications, a high-speed desktop computer and a printer, a graphic summary was made available in about two minutes. Although all this could be done within waiting room time, special forms were required and verification and examination of the scanning process was necessary. A more efficient method would be to use electronic methods of data collection, such as a (touch-screen) computer. Some of the problems with the process of data entry may be overcome. Furthermore, there is increasing evidence that these methods are easy, quick, reliable and acceptable to patients.^{13;14}

The observed effect of routine HRQL assessments on doctor-patient communication is particularly encouraging, because the most notable increase in the discussion of HRQL topics was for psychosocial problems and non-specific symptoms, such as fatigue. Many patients consider fatigue to be one of the most important problems during (and after) their treatment.¹⁵ Given the relevance of HRQL issues for cancer patients¹⁶⁻¹⁸ and considering that communication about the range of problems that affect patients is in itself an important goal of the medical visit, the recommendation to incorporate standardized HRQL assessments as a routine part of clinical oncology practice would seem to be justified.

In addition, the positive effect of the intervention on the discussion of HRQL topics indicates that it might be realistic to expect any effect on more distal aspects of patient care, such as patient management and patient outcomes. It seems likely that effective communication will lead to increased recognition of patients' problems, that, in turn, will lead to appropriate medical actions (e.g. referrals, medication prescriptions), and ultimately to an improvement in patients' HRQL over time.

However, the effect will gradually decrease and it will take a considerable amount of time and effort to establish effect on these outcomes. A general recommendation for future research would be to intensify the assessments; both increasing the number of patients per physician and lengthening the assessment period per patient. Additionally, a number of specific points can be taken into account to increase the effect on patient management. One of the results of the intervention study (chapter 6) was that, although patients and physicians were positive about the use of HRQL assessments, some concern remained about the precision and flexibility of the measurement instrument. In particular, a number of the physicians expressed a need for more 'patient-tailored' information. There are several possible ways to achieve this goal. The first is to consider the use of individualized HRQL instruments instead of a standardized instrument, as was employed in this study. Individualized measures, such as the Patient Generated Index or the SEIQoL, allow patients first to select the most important areas of life affected by their medical condition and then to rate how strongly affected they are in each area.^{19;20} There is a need for further experience with these types of measures but they would seem to hold promise for use at the individual patient level.

A second proposal for achieving more precision and flexibility in HRQL assessments is to use computer- adaptive testing based on item response theory.^{21;22} Computer-adaptive testing uses the subject's responses to an initial set of questions to determine which questions need to be posed subsequently in order to achieve the desired level of measurement precision. Fayers and Machin²³ describe the use of computer-assisted questionnaires, in which questions of appropriate difficulty are selected on the basis of earlier responses. This can result in more precise grading of ability, while at the same time reducing the number of questions each person needs to answer. Item response theory is the underlying psychometric model used to generate the individualized computer algorithms. The rapid development of such modern information technology will facilitate efficient and precise estimation of the HRQL of individual patients.

Third, one could consider including additional information in the HRQL summary. For example, in case of the assessment of pain, one could include information on the pain site, its frequency, severity and duration, the nature and effectiveness of analgesic use, and eventually management guidelines.

Furthermore, we would recommend evaluating the use of HRQL assessments in other settings and with more diverse populations. For example, survivors of cancer may have continuing problems long after their treatment is completed.²⁴ These late and sometimes unexpected problems may be easily

overlooked if they are not routinely assessed. It would also be of interest to investigate whether standardized HRQL assessments are particularly useful in a clinical setting where patients do not see the same physician at each visit. In such group practices, the HRQL assessments could contribute to ensuring the continuity of care. Relatedly, it is necessary to investigate the value of standardized HRQL assessments for other health care workers, including primary care physicians, mental health professionals, nurses, physiotherapists, etc.

In conclusion, the results of our research indicate that routine, standardized HRQL assessment is a simple, efficient, effective and acceptable means of increasing communication between oncologists and their patients. Moreover, our results suggest that such assessments have the potential of improving the quality of patient care through timely recognition of the nature and severity of patients' physical and psychosocial health problems.

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Samenvatting

De rol van kwaliteit van leven in de dagelijkse klinische oncologische praktijk

Kanker is een levensbedreigende ziekte; een aanzienlijk deel van de patiënten met kanker kan niet genezen en ondergaat daarom een palliatieve behandeling. De belangrijkste doelstellingen van zo'n behandeling zijn het verlengen van de levensduur en het voorkomen en verlichten van hinderlijke klachten. Hierbij spelen kwaliteit van leven overwegingen, in het algemeen gedefinieerd als het fysiek, psychisch en sociaal functioneren en welbevinden van de patiënt, een belangrijke rol, zowel in de keus voor een behandeling als in het evalueren van het effect van een behandeling. En hoewel in klinisch onderzoek kwaliteit van leven steeds belangrijker wordt om het effect van een therapie te evalueren, is er nog weinig bekend over de rol van kwaliteit van leven in de dagelijkse klinische praktijk.

De belangrijkste doelstelling van dit proefschrift was te onderzoeken in hoeverre het meten van kwaliteit van leven en het presenteren van de resultaten hiervan een gunstig effect heeft op de communicatie tussen arts en patiënt. Voordat deze vraagstelling beantwoord is, hebben we eerst onderzocht in hoeverre artsen en patiënten bereid zijn te spreken over kwaliteit van leven onderwerpen, in hoeverre deze onderwerpen in het algemeen besproken worden en in hoeverre kwaliteit van leven overwegingen expliciet een rol spelen tijdens beslissingen om de therapie te wijzigen of te staken.

Hoofdstuk 2 beschrijft de houding van kankerpatiënten ten aanzien van het bespreken van kwaliteit van leven onderwerpen en de houding en het zelfgerapporteerde gedrag van de artsen ten aanzien van het bespreken van deze onderwerpen. Daarnaast is onderzocht in hoeverre er een relatie is tussen de houding van patiënten en hun sociodemografische en klinische kenmerken. Aan 240 patiënten en 10 artsen is gevraagd een aantal vragenlijsten in te vullen.

De resultaten lieten zien dat bijna alle patiënten bereid waren hun fysieke klachten en functioneren ten gevolge van de ziekte en behandeling te bespreken met hun arts. Tevens waren bijna alle patiënten bereid om te spreken over de invloed die de ziekte en de behandeling heeft op hun psychisch functioneren en op hun dagelijkse activiteiten; echter ongeveer 25% van de patiënten wilde deze onderwerpen alleen bespreken op initiatief van hun arts. De patiënten waren het meest verdeeld in hun bereidheid om te spreken over de invloed van de ziekte en behandeling op hun familierelaties en op hun sociale leven. 20% van de patiënten wilde deze onderwerpen helemaal niet bespreken en ongeveer 50% prefereerde dat de arts deze onderwerpen initieerde. Vrouwen toonden zich minder bereid dan

mannen om bovenstaande kwaliteit van leven onderwerpen te bespreken met hun arts. Oudere en relatief lager opgeleide patiënten gaven er vaker de voorkeur aan dat de arts kwaliteit van leven onderwerpen initieerde. Opmerkelijk was dat alle artsen aangaven dat ze vaak het initiatief namen om over fysieke klachten van hun patiënten te praten, maar dat ze het aan hun patiënten overlieten om psychosociale klachten ter sprake te brengen. Bovendien werd door 4 van de 10 artsen het bespreken van psychosociale klachten beschouwd als een verantwoordelijkheid die gedeeld diende te worden met andere hulpverleners.

Geconcludeerd is dat zowel artsen als patiënten weliswaar bereid zijn om over kwaliteit van leven onderwerpen te praten, maar dat het bespreken van psychosociale onderwerpen belemmerd wordt door tegengestelde verwachtingen over wie het initiatief moet nemen.

In hoofdstuk 3 is de daadwerkelijke communicatie omtrent kwaliteit van leven tussen arts en patiënt beschreven. Er is onderzocht of en in welke mate kwaliteit van leven onderwerpen besproken werden en in hoeverre er een relatie was tussen patiënt, arts en consultkenmerken enerzijds en het bespreken van een aantal belangrijke kwaliteit van leven onderwerpen (dagelijks functioneren, psychisch functioneren, pijn en moeheid) anderzijds. Hiervoor werden gesprekken tussen 240 patiënten en 10 artsen met een cassette recorder opgenomen en geanalyseerd met behulp van het Roter Interactie Analyse Systeem en een uitgebreide checklist. Daarnaast werden artsen en patiënten gevraagd een aantal vragenlijsten in te vullen.

De resultaten lieten zien dat de artsen ongeveer tweederde van het inhoudelijke deel van de communicatie besteedden aan medisch technische onderwerpen en een kwart aan kwaliteit van leven onderwerpen. De inhoud van de communicatie van patiënten was meer gelijkwaardig verdeeld over medisch technische onderwerpen (41%) en kwaliteit van leven onderwerpen (48%). De mate waarin de patiënt beperkt was in een van de kwaliteit van leven onderwerpen bleek het beste te voorspellen of dit onderwerp besproken werd. Hoe ernstiger het probleem, hoe vaker dit werd besproken. Echter, tevens werd gevonden dat in 20 tot 54% van de consulten kwaliteit van leven onderwerpen helemaal niet besproken werden, ondanks dat de patiënt aangaf hier ernstige problemen in te ondervinden. Met name het psychisch functioneren van de patiënt en moeheid kwamen vaak niet ter sprake. Er werd geen relatie gevonden tussen de voorkeuren van patiënten om kwaliteit van leven onderwerpen te bespreken (zoals aangegeven in hoofdstuk 2) en het daadwerkelijk bespreken hiervan. Tevens bleek dat kwaliteit van leven

onderwerpen niet vaker besproken werden tijdens consulten waarin het effect van de behandeling op tumorprogressie geëvalueerd werd.

De belangrijkste conclusie van dit hoofdstuk is dat ondanks een toenemend besef dat een palliatieve behandeling het in stand houden en zo mogelijk verbeteren van de kwaliteit van leven van patiënten beoogt, de communicatie tussen artsen en patiënten over kwaliteit van leven onderwerpen beperkt is en weinig bijdraagt (in expliciete zin) aan de evaluatie van het effect van de behandeling.

In hoofdstuk 4 is verder ingegaan op het belang van kwaliteit van leven overwegingen bij het nemen van beslissingen omtrent de therapie. Naast tumor progressie en toxiciteit van de behandeling speelt kwaliteit van leven een rol bij beslissingen om een palliatieve behandeling te wijzigen of te staken. Hoe groot die rol is, is onduidelijk. Weliswaar wordt in de literatuur aangegeven dat kwaliteit van leven de belangrijkste overweging is om een palliatieve therapie te wijzigen of te staken, echter dit is op basis van de mening van artsen omtrent beslissingen en niet op basis van daadwerkelijke beslissingen. In deze studie hebben we ten eerste onderzocht hoe vaak kwaliteit van leven overwegingen als belangrijkste reden genoemd werden om de therapie te wijzigen of te stoppen (op basis van gesprekken tussen artsen en patiënten). Ten tweede is onderzocht in hoeverre er een relatie was tussen de kwaliteit van leven van de patiënt (zoals deze ingeschat werd door de arts) en therapie beslissingen. Aan deze studie namen 203 patiënten en 10 artsen deel. Van iedere patiënt werden 4 opeenvolgende consulten opgenomen en geanalyseerd met behulp van een checklist. Op basis hiervan kon worden bepaald hoe vaak en om welke reden de therapie gewijzigd of gestaakt werd. Bovendien werd de artsen gevraagd de kwaliteit van leven van hun patiënten in te schatten met behulp van een vragenlijst. Hiermee kon onderzocht worden in hoeverre er een relatie was tussen de kwaliteit van leven en therapiebeslissingen. Gegevens over tumor respons en toxiciteit van behandeling werden verkregen via de bandopnames en zonodig geverifieerd door status onderzoek.

De resultaten lieten zien dat bij 54 patiënten (26%) de behandeling gewijzigd en bij 40 patiënten (20%) de behandeling voortijdig gestaakt werd. De belangrijkste reden om de therapie te wijzigen was toxiciteit van de behandeling (22 patiënten), gevolgd door kwaliteit van leven overwegingen (18 patiënten) en tumor progressie (14 patiënten). Bij het staken van de therapie was de belangrijkste reden tumor progressie (23 patiënten), gevolgd door kwaliteit van leven overwegingen (6 patiënten) en toxiciteit van de behandeling (3 patiënten). Bij 8 patiënten was de combinatie van tumor progressie en kwaliteit van leven de reden om de therapie te stoppen. Alhoewel er een relatie gevonden werd tussen het globale oordeel van de

arts over de kwaliteit van leven van de patiënt enerzijds en beslissingen omtrent de therapie anderzijds, werd er geen verband gevonden tussen enig specifiek kwaliteit van leven onderwerp en therapie beslissingen. Wanneer er sprake was van tumor progressie of van toxiciteit van behandeling bleken kwaliteit van leven overwegingen geen rol te spelen. Bovendien bleek dat bij 70% van de patiënten waarbij geen sprake was van tumor progressie of van toxiciteit van behandeling, maar wel van ernstige problemen in hun kwaliteit van leven, de behandeling noch gewijzigd, noch gestaakt werd.

Geconcludeerd is dat expliciete kwaliteit van leven overwegingen een relatief onbelangrijke rol spelen in beslissingen rondom het wijzigen of staken van palliatieve chemotherapie.

In hoofdstuk 5 zijn de resultaten beschreven van een pilotstudy waarin de haalbaarheid van het meten van kwaliteit van leven in de dagelijkse praktijk werd onderzocht. Aan deze pilotstudy werd door 6 arts en 18 patiënten deelgenomen. Van iedere patiënt werden 3 opeenvolgende consulten geobserveerd. Het eerste consult werd gebruikt als een baseline meting. Voor de 2 daaropvolgende consulten werd de patiënten gevraagd om de EORTC QLQ-C30, een korte kanker specifieke kwaliteit van leven vragenlijst, in te vullen. De ingevulde vragenlijst werd met behulp van de computer gescoord en omgezet in een grafische samenvatting. Op deze samenvatting stonden zowel de huidige scores als de scores verkregen bij het voorgaande consult. Voor aanvang van het consult kregen de arts en de patiënt een kopie van deze samenvatting.

In de praktijk bleek het mogelijk om de vragenlijst te laten invullen, de antwoorden te scoren en de samenvatting te printen in de tijd dat de patiënt zat te wachten op het consult. De aanwezigheid van de samenvatting had geen effect op de duur van het consult. Er werd een geringe toename gevonden in het aantal kwaliteit van leven onderwerpen dat besproken werd gedurende het consult. Het meest opmerkelijke resultaat echter was een stijging van het aantal onderwerpen dat door de arts geïnitieerd werd. Bij de aanwezigheid van de samenvatting brachten de artsen 3 keer zoveel kwaliteit van leven onderwerpen ter sprake dan wanneer deze niet aanwezig was. Alle artsen en de meeste patiënten waren van mening dat de kwaliteit van leven samenvatting een positief effect had op de communicatie.

De conclusie van deze studie luidt dat het haalbaar is om kwaliteit van leven metingen te introduceren in de klinische praktijk en dat de kwaliteit van

leven samenvatting artsen stimuleert om specifieke aspecten van de kwaliteit van leven van hun patiënten ter sprake te brengen.

De resultaten van de pilotstudy zijn de aanleiding geweest tot nader onderzoek, waarover gerapporteerd wordt in hoofdstuk 6. Dit hoofdstuk beschrijft de resultaten van een prospectief, gerandomiseerd (cross-over) onderzoek over de bruikbaarheid van kwaliteit van leven metingen tijdens een palliatieve behandeling van kanker patiënten. De belangrijkste doelstellingen van dit onderzoek waren om na te gaan of er een toename was in de frequentie waarmee kwaliteit van leven onderwerpen besproken worden en in de kennis van de arts over de kwaliteit van leven van zijn/haar patiënt. Daarnaast werd het effect van de kwaliteit van leven metingen op de zorgverlening aan de patiënt, de tevredenheid van de patiënt en de arts met het medisch consult, en de gezondheidstoestand van de patiënt gemeten. Aan dit onderzoek namen 10 artsen en 214 patiënten die behandeld werden met palliatieve chemotherapie, deel. Iedere patiënt werd gedurende 4 opeenvolgende consulten gevolgd. Het eerste consult werd gebruikt als een baseline meting. Voor de 3 daaropvolgende consulten werd de helft van de patiënten (interventie-groep) gevraagd om, net als in de pilotstudy, de EORTC QLQ-C30 in te vullen. De ingevulde vragenlijst werd gescoord en omgezet in een grafische samenvatting. Op deze samenvatting stonden zowel de huidige scores als de scores verkregen bij de voorgaande consulten. Voor aanvang van het consult kregen de arts en de patiënt een kopie van deze samenvatting. De andere helft van de patiënten (controle-groep) kreeg de standaard zorg.

Om inzicht in de communicatie tussen arts en patiënt te krijgen, werden alle consulten op cassetteband opgenomen en geanalyseerd met behulp van een checklist. Om inzicht te verkrijgen in de kennis van de arts omtrent de kwaliteit van leven van zijn of haar patiënt werd de mate van overeenstemming bepaald tussen gerapporteerde kwaliteit van leven door de patiënt zelf en door de arts. Hiervoor werden patiënten en artsen gevraagd een korte kwaliteit van leven vragenlijst (COOP/WONCA charts) in te vullen. Er werden vragenlijsten gebruikt om de tevredenheid met het medisch consult en de gezondheidstoestand te bepalen.

De resultaten wezen uit dat er een toename was in het bespreken van kwaliteit van leven onderwerpen; zowel het functioneren van de patiënt als klachten werden vaker besproken in de interventie-groep dan in de controle groep. Met name het psychosociale functioneren van de patiënt en a-specifieke klachten (zoals moeheid) werden significant vaker besproken. Tevens bleken de artsen beter in staat om matige tot ernstige problemen in verschillende kwaliteit van leven domeinen van patiënten in de interventie-groep te herkennen dan van patiënten in

de controle-groep. Er werd geen effect gevonden op de tevredenheid met het consult en er werd een minimaal effect gevonden op de zorgverlening aan patiënten en op de gezondheidstoestand van de patiënten. Alle arts en 75% van de patiënten waren van mening dat de interventie een gunstig effect had op hun communicatie en wilden graag dat de procedure een vervolg zou krijgen.

Geconcludeerd kan worden dat het invoeren van kwaliteit van leven metingen in de klinische praktijk zorgt voor een toename van het aantal kwaliteit van leven onderwerpen dat besproken wordt en de kennis van de arts vergroot omtrent problemen in kwaliteit van leven domeinen van de patiënt.

In hoofdstuk 7 zijn de belangrijkste conclusies samengevat, en worden aanbevelingen gedaan voor de klinische praktijk en voor verder onderzoek. De belangrijkste conclusie van de beschrijvende hoofdstukken (2,3,4) is dat, ondanks toenemende interesse voor kwaliteit van leven als uitkomstmaat, de expliciete rol van kwaliteit van leven in de klinische praktijk beperkt is. Zowel de houding van de arts als van de patiënt blijken hierbij een belangrijke rol te spelen. Er wordt derhalve aanbevolen om meer aandacht aan communicatie vaardigheden en aan het aanleren van een positieve houding t.o.v. psychosociale onderwerpen te besteden tijdens de medische opleiding.

Ook patiënten zouden aangemoedigd moeten worden om een actieve rol te vervullen tijdens het consult door vragen te stellen en problemen ter sprake te brengen die belangrijk voor hen zijn.

Uit het onderzoek is gebleken dat het meten van kwaliteit van leven en het presenteren van de resultaten ervan, haalbaar is in de klinische praktijk. De haalbaarheid van een procedure is van belang voor verdere implementatie. In ons onderzoek is gebruik gemaakt van schriftelijke vragenlijsten, waarvan de antwoorden met behulp van een scanner en de nodige software omgezet werden in een samenvatting binnen een tijdsbestek van 2 minuten. Alhoewel dit haalbaar bleek te zijn, kan de procedure efficiënter worden door het gebruik van elektronische vragenlijsten, bijvoorbeeld met behulp van een touch-screen computer.

Het waargenomen effect van de interventie op de arts-patiënt communicatie is bemoedigend, vooral omdat het effect het grootste was bij het bespreken van psychosociale onderwerpen en niet-specifieke klachten, zoals bijvoorbeeld moeheid. Gezien het belang van deze onderwerpen voor patiënten met kanker en het belang van een effectieve communicatie tijdens een behandeling, is het aan te bevelen het meten van kwaliteit van leven in de klinische praktijk verder

toe te passen. Bovendien maken deze onderzoeksresultaten het aannemelijk dat op de langere duur tevens een effect te vinden zal zijn op de zorg aan patiënten en uiteindelijk op de gezondheidstoestand van patiënten. Het bespreken van specifieke problemen van patiënten leidt tot een betere kennis van de arts omtrent deze problemen, wat er voor kan zorgen dat er acties ondernomen worden (voorschrijven van medicatie, doorverwijzen naar een andere hulpverlener, geven van advies), hetgeen uiteindelijk zal resulteren in een betere gezondheidstoestand van de patiënt. Het kost echter veel tijd en inspanning om deze uiteindelijke doelstellingen te bereiken. Hier ontbreekt het in onderzoeksprojecten vaak aan. We zouden dan ook in het algemeen willen aanbevelen om deze inspanning te vergroten (meer patiënten per arts en een langere follow-up periode per patiënt). Ook kunnen een aantal aanvullende maatregelen genomen worden om het effect op de patiëntenzorg te vergroten; getracht kan worden om de gepresenteerde informatie flexibeler en preciezer te laten zijn. Dit kan bijvoorbeeld door gebruik te maken van geïndividualiseerde vragenlijsten en/of van computer-adaptive testing.

Concluderend kan gesteld worden dat de resultaten van ons onderzoek aantonen dat kwaliteit van leven metingen in de klinische praktijk simpel en doeltreffend zijn om de communicatie omtrent kwaliteit van leven onderwerpen te bevorderen.

Alhoewel het me tevreden stemt dat dit proefschrift afgerond is, besef ik dat hiermee tevens een leuke en leerzame periode is afgesloten. Zo denk ik met veel plezier terug aan de samenwerking met Lidwina Wever, Caroline van Tuyl, Martin Muller en Kommer Sneeuw. Zij hebben er niet alleen aan bijgedragen dat het onderzoek goed is verlopen en de gegevens op de juiste manier zijn verwerkt, maar zij hebben tevens gezorgd voor de nodige humor tijdens het werk. We hebben het werk zo vaak gerelativeerd, dat het opmerkelijk is dat het onderzoek toch nog redelijk vlot is afgerond. Misschien is dit wel deels te danken aan alle andere medewerkers van de afdeling Psychosociaal Onderzoek en Epidemiologie, die altijd hebben gezorgd voor een prettige en stimulerende werksfeer.

Ook in het ziekenhuis heb ik veel medewerking bij het onderzoek ervaren. Er was een prettige samenwerking met de artsen die bereid waren een aanzienlijk aantal van hun gesprekken met patiënten op te laten nemen.

Jan Schornagel was altijd bereid om opgewekt advies te geven op klinisch gebied. Daarnaast hebben vele medewerkers van het ziekenhuis assistentie verleend bij de badmintonselectie.

Na de drukke periode van het verrichten van het onderzoek, is het opschrijven van de resultaten toch een solistisch gebeuren. Desalniettemin heeft mijn promotor Neil Aaronson er voor gezorgd dat het schrijfproces een niet al te eenzaam bestaan was. Zijn immer kritisch en waakzame oog was niet alleen aanleiding voor intensieve discussies (en soms tot ongewenste vertraging), maar heeft er uiteindelijk ook voor gezorgd dat de kwaliteit van het proefschrift en van mijn Engels aanzienlijk is verbeterd (Neil, thanks.....).

Rest mij nog om veel dank te betuigen aan alle patiënten. Uiteindelijk hebben zij de belangrijkste bijdrage aan dit proefschrift geleverd door belangeloos aan dit onderzoek mee te werken.

Symone Detmar werd op 6 maart 1961 geboren te Bakhuizen (Friesland). In 1979 behaalde zij het eindexamen Gymnasium aan het Stedelijk Gymnasium te Leeuwarden. Een jaar later is zij de opleiding tot verpleegkundige A gaan volgen in het Leyenburg Ziekenhuis te Den Haag. In 1983 haalde zij hiervoor het diploma. Vanaf 1984 heeft zij antropologie gestudeerd aan de UVA in Amsterdam. In 1990 behaalde ze haar doctoraal examen, met als afstudeerrichting medische antropologie.

Van 1991 tot 2001 heeft zij gewerkt op de afdeling Psychosociaal Onderzoek en Epidemiologie van het Nederlands Kanker Instituut. Gedurende de laatste jaren werd het onderzoek verricht waarvan de resultaten in dit proefschrift beschreven zijn.

Sinds februari 2001 is zij werkzaam als wetenschappelijk medewerker op de afdeling kwaliteit van leven bij TNO Preventie en Gezondheid te Leiden.

Zij is getrouwd met Andre Schoorl en samen hebben zij 3 kinderen, Sake (1987), Rosanna (1989) en Sarah (1998).