Older cancer patients' information and communication needs: What they want is what they get?

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ABSTRACT

Objective: To evaluate what information and communication aspects older cancer patients (≤ 65) consider important in preparing for chemotherapy treatment (CT), the extent to which this corresponds with what oncology nurses consider important, and the extent to which nurses attend to these aspects during real-life educational visits in oncology.

Methods: The QUOTE[chemo] was used to have patients (n = 116) and nurses (n = 123) rate the importance of 66 aspects of patient education. Subsequently, the implementation of these 66 aspects during videotaped nursing visits (n = 155) with older cancer patients receiving CT for the first time was examined.

Results: Older cancer patients attached most importance to 'treatment-related information', 'rehabilitation information', 'affective communication' and discussing 'realistic expectations'. Nurses placed great importance to almost all aspects except to discussing 'realistic expectations'. Discrepancies were found between expressed importance and the actual performance during the videotaped consultations, particularly in discussing realistic expectations, coping information, interpersonal communication, and tailored communication.

Conclusion: Results pointed to aspects that need improvement to ensure high quality patient education tailored to the patients' needs.

Practice implications: To make sure older cancer patients' needs are met, more attention should be paid to the development of interventions supporting both needs assessment and fulfillment.

INTRODUCTION

Effective communication surrounding treatment is considered to be the key to good cancer care. However, health care professionals frequently lack the communication skills needed to identify patients' individual concerns and problems [1]. As a consequence, the information provided is often insufficiently tailored to the patients' information and communication needs, resulting in unmet needs (see Hack et al. [2], for a review). Cancer is frequently a disease of older adults and, due to population growth and aging, the number of new cancer patients is expected to double by the year 2050 [3,4]. Older cancer patients are physiologically, psychologically, socially, economically and culturally heterogeneous, which pose challenges to the care, including patient education, for this growing segment of the population [5]. Communication with older cancer patients can be complicated by various age-related barriers [6], such as cognitive decline [7], sensory impairments [8] and patients' beliefs, perceptions and knowledge about cancer [9]. Understanding older cancer patients' information and communication needs and the extent to which these needs are fulfilled is essential, because not being well informed may affect patient outcomes negatively. According to the Elaboration-Likelihood Model, personal relevant information, i.e. information that is tailored to the patients' needs, is processed more deeply and is therefore likely to improve knowledge and recall of information, i.e. remembering and reproduction [10–12]. This might, ultimately, contribute positively to patient satisfaction [13], treatment adherence [6,13–15], disease management, anxiety [16,17] and quality of life [18]. Although oncology patients in general continuously seem to have unmet needs [2] and unfulfilled information and communication needs influences quality of life more negatively in older compared to younger patients [18], little is known about the (unmet) information and communication needs of older cancer patients (_65 years). In a recent systematic review of unmet support needs, including information and communication needs, it was found that the level of unmet needs in newly diagnosed older cancer patients undergoing active treatment was high, and the most common unmet needs were information and psychological needs. However, in only three out of 30 studies included in this review, the mean age was in the 70s, and only one study focused on older adults exclusively [19]. In an earlier literature review, no study could be identified that specifically addressed older cancer patients' information and communication needs either [20]. Puts and colleagues [19] concluded that more research is needed that focuses on the needs of older adults specifically, as this is an understudied area. Since the level of unmet needs is highest after diagnosis and start of treatment [19,21], the current study focuses on needs fulfillment of older cancer patients in this particular stage of their disease. We choose to study chemotherapy treatment (CT), because CT is in the top-three of most used treatments for cancer [22]. Oncology nurses play an important role in patient education about CT by providing information about the treatment and (handling) potential side effects, especially at the beginning of CT. One of their tasks is to provide individualized instruction to patients newly diagnosed with cancer after a careful assessment of the patients' needs [23,24]. It can be assumed that the nurses' opinion on which aspects are, in general, important to discuss during educational sessions preceding CT will influence the content of the consultation. It is therefore striking that, as far as we are aware, no previous studies compared the patients'

perspective with the nurses' perspective and with actual patient education during consultations. To take all these perspectives into account, we built on an approach called QUOTE (QUality Of care Through the patients' Eyes) [25–29]. According to this approach, quality of care is a multidimensional concept, based on a relationship between needs (or 'expectations') and performance (or 'experiences'), in the current study being defined as the degree to which the providers' information and communication performance meets the patients' needs. To gain insight in unmet needs two indicators are used: 'importance', i.e. how significant a specific health care aspect is to patients, and 'performance', i.e. the actual experience of patients with that aspect. QUOTE questionnaires are standardized and validated surveys in which patients' experiences with quality of care are conceptualized according to these importance and performance dimensions. When combined, these dimensions reflect what people see as desired qualities in health care [28,29]. Generally, both dimensions are assessed by self-reported patient questionnaires. However, previous research indicates that the relationship between perceived information provision and actual information provision is weak [30]. As we were interested in what had actually been discussed during the consultation, we decided to make use of video observations to examine the performance dimension. To summarize, this research aims to understand the information and communication needs of older cancer patients at the start of CT, the needs as perceived by their nurses, and the extent to which these needs are actually met during educational nursing visits in oncology. The study was conducted among cancer patients aged 65 years or older, because this cut-off point is frequently used to define older age [31,32].

2. METHODS

2.1. Design

The current study is part of a larger study in which the specific information and communication needs that have to be addressed in health education preceding CT in older cancer patients were examined, in order to develop and evaluate an intervention to improve the communication with older patients. The study was performed in twelve wards of ten Dutch hospitals. The main study used a randomized pre- and post-test design with measurements (i.e., video observations and questionnaires) at baseline (pre-test) and directly after the implementation of the intervention (post-test), with randomization at ward level. The control group of nurses continued in giving standard information. For the current study, only data from the control group (pre- and post-test) and the experimental group at pre-test were used. The Medical Ethical Committee of the University Medical Centre Utrecht, the Netherlands, granted permission for the study (trial number 04/ 184), supplemented by local feasibility statements from all participating hospitals.

2.2. Subjects

 To be eligible for the study, patients had to meet the following inclusion criteria: (1) aged 65 years or older, (2) receiving CT for the first time or for the first time in 5 years, (3) not participating in a Phase III clinical trial, (4) sufficient mastery of the Dutch language, and (5) no non-age related cognitive impairment (according to the medical file). Eligible nurses had to meet the following criteria: (1) certified to

provide oncology care and (2) providing patient education about CT as part of their regular employment duties. Temporary staff and students were not eligible.

2.3. Procedure

Before the consultation, written informed consent to videotape the consultation was given by patients and nurses. The consultation was videotaped using an unmanned camera. Immediately after the consultation, patients were asked to complete a questionnaire on background characteristics. A researcher was available to read the questions aloud, if necessary. After the consultation, nurses were asked how they had experienced being videotaped. Although most of them reported to have experienced some anticipatory tension, the stress generally disappeared once the consultation had started. Thus, the majority of nurses reported that the consultation reflected the normal situation. Six weeks after the consultation, participating patients received a second questionnaire, including the QUOTE-Importance questionnaire, in which patients were asked to rate the extent to which specific aspects of information and communication were considered important during the educational nurse consultation at the beginning of CT. All nurses that fulfilled the inclusion criteria received the same QUOTE^{chemo}-Importance questionnaire at the beginning of the study. They were asked to attach importance to the same aspects of information and communication as older cancer patients (see Section 2.4.2).

2.4. Measurements

2.4.1. Background characteristics

The self-administered post-visit questionnaire for patients contained socio-demographic items inquiring about age, gender, education and living situation. Additional medical background characteristics (diagnosis, time since diagnosis and treatment goal) were obtained from the medical file. In addition, frailty was measured using the Groningen frailty indicator (GFI) [33,34]. The GFI contains 15 items and screens for the loss of functions and resources in four domains of functioning: physical (mobility functions, multiple health problems, physical fatigue, vision, hearing), cognitive (cognitive functioning), social (emotional isolation), and psychological (depressed mood and feelings of anxiety). A total score was counted (range 0–15). A score of 4 indicates moderate frailty and a higher score indicates more frailty [34].

2.4.2. Unmet needs

Needs fulfillment was measured by the QUOTE^{chemo}. As there were no validated questionnaires available for the purpose of this study, the QUOTE^{chemo} was developed [35], in conformity with the QUOTE (QUality Of care Through the patients' Eyes) methodology [27–29]. The QUOTE^{chemo} consists of two parts, i.e. the QUOTE-^{chemo}-Importance and the QUOTE^{chemo}-Performance. They each contain the same 67 items. One item of the original QUOTE^{chemo} (i.e., 'discussion of all possible side-effects of treatments') was removed, because the performance of this item could not reliable been assessed as there are many different kind of CTs and the observers had no knowledge of all possible side-effects of each CT. This resulted in 66 items in this study. The QUOTE^{chemo}-Importance was completed by older cancer patients to

get insight in their information and communication needs surrounding CT and by nurses to get insight in the congruence between patients and nurses. The extent to which patients and nurses considered the 66 specific aspects of information and communication important at the beginning of CT ('needs') was assessed on a 4-point Likert scale ('not important', 'fairly important', 'important', 'extremely important'). The extent to which the nurses implemented the same 66 communication aspects during the consultation was rated by trained observers on a 4-point Likert scale ('not at all', 'not really', 'on the whole, yes', 'yes') using the QUOTE^{chemo}-Performance. Nurses' performance was assessed by observing video recordings in order to have an objective rating. Five independent observers rated the video observations of the nursing encounters preceding chemotherapy. Interrater reliability (mean Cohen's Kappa) was 0.49, which can be considered as moderate [36]. The 66 items of the QUOTE^{chemo} were in a previous study [35] categorized in seven dimensions, i.e. three cancer-related categories: (1) treatment-related information (e.g., how treatment works, side-effects); (2) discussing realistic expectations/prognosis informa-tion (e.g., expected life span, discussing the future); (3) rehabilita-tion information (e.g., impact on activities of daily life, dealing with side effects at home) and four generic communication skills categories: (4) coping information (e.g., exploring the patients' feelings, how to get support); (5) interpersonal communication (e.g., being attentive to significant others, exploring their questions); (6) tailored communication (e.g., understanding the patients' personal circumstances and tailoring the information accordingly), and (7) affective communication (e.g., showing empathy, providing space for feelings and emotions). A validation study of the QUOTE^{chemo} in a different sample revealed good internal consistency, satisfactory item-total correlations and convergent validity. The development and psychometric properties of the QUOTE^{chemo} are extensively described elsewhere [35]. Table 1 gives an overview of the QUOTE^{chemo} categories, their content and the Cronbach's alpha's of the QUOTE^{chemo}–Importance and QUOTE^{chemo}–Performance in the present study.

2.5. Data analysis

A non-response analysis between participants and non-participants and between completers and non-completers of the QUOTE^{chemo}–Importance was conducted using t-tests and Chi-square tests, where appropriate. Importance and Performance scores on the seven categories of the QUOTE^{chemo} were calculated as the mean of the scores on the relevant items (range of the subscales 1–4).

[TABLE 1]
Differences between, on the one hand, patients' scores on the QUOTE^{chemo}–Importance and, on the other hand, nurses' scores on the QUOTE^{chemo}– Importance, and patients' performance scores were examined using ANOVAs. Quality impact indices (QIIs) were calculated, in line with earlier studies on QUOTE questionnaires, by multiplying the patients' importance score of the items with the fraction (%/100) of consultations in which there was a lack of performance on that item, i.e. the item was 'not at all' (score 1) or 'not really' (score 2) discussed (importance score _ proportion lack of performance) [26]. A QII of 0.30 or more indicates a need for improvement (based on the criterion of minimal 10% of the consultations with a lack of performance on an 'important item', i.e. importance score = 3), and a QII of 1.0 or

more shows a very clear need to be improved (based on the criterion of minimal one third of the consultations with a lack of performance on an 'important item', i.e. importance score = 3, or minimal 25% of the consultations with a lack of performance on a 'very important item', i.e. importance score = 4) [26].
All analyses were conducted in SPSS version 19. 3.

RESULTS

3.1. Response

In total, 361 patients were informed about the study and asked to give written consent. Eighteen patients did not meet the inclusion criteria and had to be excluded afterwards, leaving 343 eligible patients. Of these, 115 patients (33.5%) refused to participate. They felt it was too much (n = 69), were too tired or too ill (n = 10), did not want to be videotaped (n = 16) or had other reasons (n = 20). Eighteen patients (5.2%) could not be included due to logistical reasons (e.g. the ward forgot to forward the patient's name to the researchers, time schedule changed, traffic delay). In total, 210 older cancer patients (61.2%) participated in the larger study and their consultations were videotaped. As we only used pre- and post-data of the control group and pre-test data of the experimental group, 55 (26.2%) patients were excluded from analysis, because they were randomized to the experimental group at post-test. Of the resulting 155 patients, 116 (74.8%) completed the QUOTE^{chemo}-Importance. The QUOTE^{chemo}-Performance could be assessed for all 155 videotaped consultations. A non-response analysis revealed that non-participating patients were older (M = 73.7, SD = 6.8) than participating patients (M = 72.2, SD = 4.8; p < .05). There were no differences in gender between participating and non-participating patients. Moreover, participating (videotaped) patients who did not complete the QUOTE^{chemo}-Importance were more frail (M = 3.6, SD = 1.7 vs M = 2.1, SD = 1.9; p < .001) and more often living alone (40.5% vs 15.7%; p < .05) than participating patients who fulfilled the QUOTE^{chemo}-Importance. The majority (75.7%) completed the questionnaire alone, 22.5% together with someone else. There were no other differences in background characteristics between non-completers and completers of the QUOTE^{chemo}-Importance (see Table 2). In total, 141 nurses participated in the study. 77 (54.6%) were videotaped as part of their regular employment duties. The QUOTE^{chemo}-Importance was filled out by 123 nurses, 59 of whom (48.0%) could be videotaped during one or more educational consultations preceding CT. Another 18 nurses were videotaped, but did not complete the QUOTE^{chemo}-Importance.

3.2. Background characteristics patients

The majority of included patients was male (68.4%) and lived with a partner (71.9%). The mean age was 72.1 years (SD = 4.5) and half of the respondents had a lower educational background (50.0%). The mean frailty score was 2.4 (SD = 1.9). Table 2 summarizes the socio-demographic and disease characteristics of included patients.

3.3. Background characteristics nurses

Table 3 shows the demographic characteristics of the nurses who completed the QUOTE^{chemo}-Importance. The majority of the nurses was female (93.4%) with an average age of 41.0 years (SD = 8.1). The average duration of the videotaped consultation was 55.3 min (SD = 15.7).

3.4. Unmet needs

Fig. 1 shows the percentage of patients and nurses that rated specific aspects of cancer-related information and communication needs at category level as 'important' or 'very important' (mean score _ 2.5). A large proportion of patients (82.3%) reported it is (very) important to receive 'treatment-related information'. Nurses endorsed this importance (81.4%). Also 'rehabilitation information', i.e. information on how patients can deal with the side effects at home, was considered (very) important by a large number of patients (78.8%). Nurses attached even greater importance to this category (95.9%; p < .001). A large difference between patients and nurses was found in the category 'realistic expectations'. Two thirds of the patients (67.7%) found it (very) important that topics that have to do with the prognosis and the future are discussed with the nurse, but nurses attached significantly lower importance to these aspects (16.8%). Results on the QUOTE^{chemo}-Performance show that patients' needs with respect to 'treatment related information' were on average quite properly met. However, aspects regarding 'rehabili-tation information', considered as important by both patients and nurses, were on average in less than forty percent (38.1%) of the consultations moderately or maximally discussed (score 3 or 4). For 'realistic expectations', this was the case in only 3.2% of the consultations. Fig. 2 shows the results in relation to the generic information and communication needs categories. All four categories were found (very) important by a large majority of nurses (range 81.1% for 'coping information' to 99.2% for 'affective communication'). Although a considerable amount of patients considered these categories also as (very) important (range 44.1% for 'coping information' to 79.1% for 'affective communication'), they attached significantly less value to these aspects than nurses. With regard to performance, or the extent to which aspects of the four categories were actually addressed during the consultations, the patients' needs for 'affective communication' were properly fulfilled (84.5%). However, there was on average little 'interpersonal communication with relatives' (20.6%), the con-sultations were hardly personally 'tailored to the patients' circumstances' (3.2%), and there was little attention for discussing how the patient can 'cope with the disease' (5.8%). The difference between patients' and nurses' mean importance scores on the one hand and performance scores on the other hand are statistically significant (p < .001). Table 4 shows the mean importance scores of nurses and patients as well as the mean performance scores for each category and individual items. As was already shown by Figs. 1 and 2, aspects from the categories 'treatment-related information', 'rehabilitation information', 'affective communication' and dis-cussing 'realistic expectations' were generally considered most important by patients. Nurses attached great importance to all categories, with the highest scores on 'affective communication', 'rehabilitation information', 'tailored communication' and 'inter-personal communication'.

[TABLE 2] [TABLE 3] [TABLE 4] [FIGURE 1] [FIGURE 2]

Quality impact indices (QII) were calculated by combining importance scores of patients (needs) with performance scores. All QUOTE^{chemo} categories, except for 'affective communication', showed a mean QII of 1.00 or higher, indicating a need for improvement. The biggest gap between needs and experience was found for discussing 'realistic expectations' (QII = 2.59). Further-more, 'coping information'

(QII = 1.79), 'interpersonal communication' (QII = 1.73) and 'tailored communication' (QII = 1.72) showed high potential for improvement. At item level, the biggest incongruence was found in the individual items 'what will happen if patient chooses not to start treatment' (QII = 2.98), 'asking how much information the patient would like to know' (QII = 2.74), 'explaining emotional reactions on CT' (QII = 2.71), 'checking whether the patient still wants to start CT after being educated' (QII = 2.65), 'sufficient information about what is going on' (QII = 2.48) and 'checking the patients' expectations' (QII = 2.46).

4. DISCUSSION AND CONCLUSION

4.1. Discussion

Older cancer patients attached the most importance to 'treatment-related information', 'rehabilitation information' (i.e., the impact of treatment on daily life and how to deal with side effects at home), 'affective communication' and discussing 'realistic expectations'. Nurses highly valued almost all aspects except discussing 'realistic expectations'. Although both patients and nurses placed great importance to certain aspects, results pointed to impressive discrepancies between perceived importance and performance during actual consultations. The highest need for improvement was found for discussing 'realistic expectations', 'coping information', 'interpersonal communication' and 'tailored communication'. The results regarding needs are in line with other studies using the QUOTE[chemo] among a heterogeneous sample of 345 cancer patients with a mean age of 55.7 years (range 20–84) [35] resp. 960 cancer patients with a mean age of 57.0 (range 18– 100) [37]. In both studies, 'treatment-related information', 'affective communication' and 'rehabilitation information' were perceived most important by patients [36,37], and in the study of Bolle et al. [37] discussing 'realistic expectations' was also one of the most prevalent needs. In the latter study, no differences were found between younger (<65) and older (≤ 65) patients, except for 'affective communication', which was found to be even more important for older than for younger patients [37]. The literature demonstrates that a patient-centred approach to communicating with older cancer patients should take place in the context of a caring, continuous relationship [6]. Also, a good atmosphere during the consultation, emotional support, the feeling there is a bond of trust and a safe environment have earlier been described as a prerequisite for older patients to be able to reflect on the information and to process the information cognitively [38]. In both of these previous studies, the highest need for improvement was found for discussing 'realistic expectations', 'rehabilitation information' and 'interpersonal communication' [36,37]. However, in the current study 'coping information' and 'tailored communication' needs were more often unmet than 'rehabilitation information' and 'affective communication'. Also, all quality impact indices were (much) higher in the present study. The previous studies both assessed performance by self-reported measurements, while in the current study video observations of actual consultations were used, which might explain the difference. For instance, independent observers might judge the extent to which the communication was tailored to individual characteristics of the patient as minimal, while the patients might experience the same consultation as sufficiently tailored to their situation. In previous research it was also concluded that the assessment of actual communication by independent observers not fully reflects the patients'

perceived experience. Patients probably judge the information and communication during consultations on other factors than what actually has been discussed, such as their relation with the caregiver, comprehensiveness of the information and communication expectations in general [30]. Thus, it is important to be aware of differences between perceived performance and actual performance, before deciding which measurement is most appropriate concerning the study goals. In the current study, we choose for objective video observations as older adults are expected to underreport their unmet needs [19]. Another explanation might be found in the time at which the survey was conducted. In the current study, patients fulfilled the questionnaire six weeks after the start of treatment, while in the previous studies CT started on average 6.7 months [36] resp. 5.7 years [37] ago. This means that there was a different time lag between the start of CT and patients filling out the questionnaire. It is known that needs change across the cancer care continuum [2,19], but it might also be possible that memories change when the event, i.e. the educational consultation at the start of CT, was longer ago. The results of these retrospective studies might be dissimilar from the immediate outcomes when directly assessed before, after or during the consultation [38]. Future studies should initiate measurement of patients' needs at the time of diagnosis and follow patients throughout their cancer journey to ascertain important changes in information needs over time [36,41]. In the current study, the QII was especially high for discussing 'realistic expectations'. It is known that health care professionals seem to experience difficulties in discussing topics that have to do with prognosis, especially when it concerns bad news [39,40]. However, it is particularly noticeable that most nurses placed very little importance to discussing topics regarding the future, prognosis and realistic expectations, while two thirds of the patients attached (much) value to talking about these topics with their nurse. Apparently, oncology nurses do not consider discussing these aspects as their task. The role of the caregiver in prognosis communication has not been well studied [42], and as far as we are aware, hardly any research focused on task definition of physicians and nurses in communicating 'realistic expectations' at the start of treatment. We know from research on end-of-life decisions that increased clarity about the role of nurses is needed [43], and this might also count for the start of treatment. The difference between nurses and physicians is that physicians are legally responsible for making decisions [43] and it is their formal task to communicate the exact prognosis. However, this does not mean that nurses cannot play a significant role in discussing topics that have to do with the prognosis, such as talking about the future, checking the patients' expectations or giving advice. Although guidelines have been developed to assist physicians in prognosis communication [44], it is recommended to develop additional guidelines describing the role of nurses, including how and to which extent to communicate prognosis information and realistic expectations sensitively and effectively. Not talking at all about the prognosis might be a missed opportunity, as has been stated by Mills and Sullivan [45, p. 633]: ''Without nursing involvement, many patients will not truly understand their illness, prognosis, or treatment options, and this could seriously hinder, and indeed adversely affect, their recovery''. The other categories in which high QIIs were found, were all generic communication skills categories, i.e. 'coping information', 'interpersonal communication' and 'tailored communication'. This indicates that there seems to be more room for improvement in generic communication skills than in providing cancer-specific

content information, which might also apply to other fields than cancer care. Results regarding 'interpersonal communication' and 'tailored communication' are in line with previous studies. Although the need for interpersonal communication has hardly been assessed in older cancer patients, family members of breast cancer patients in general are found to have substantial needs for information (see Rees and Bath, [46] for a review), informal caregivers of cancer patients would like more professional attention [47], and spouses of breast cancer patients were not content with available information [48]. In the latter study, age was not associated with a perception of sufficient information [48]. The need for 'tailored communication' has been recognized in older cancer patients [6,18]. Especially eliciting the patients' expectations is considered vital to attaining concordance between older cancer patients and physicians [6]. Results regarding 'coping information' suggest room for improvement for older cancer patients. However, the need for 'coping information' by older cancer patients requires more research. Although Puts et al. [19] reported psychological care as one of the highest unmet needs in older cancer patients, several studies suggest that cancer and its treatment has a greater psychological impact on younger than on older patients, indicating that older cancer patients are better able to cope with serious illness than younger ones [49–52]. As well informed older (_65 years) cancer patients showed a better ability to cope with psychological and emotional assumptions of their disease and treatments [53], this topic is worth additional research. The present study has been conducted in a sample of nurses. It would be interesting to know whether the results can be transferred to other professionals such as physicians. A previous study comparing the information priorities of prostate cancer patients to those of their health-care professionals (nurses, physicians and radiation therapy technologists) concluded that each professional groups significantly more agreed with the other professional groups than they agreed with patients [54,55]. The findings of the current study confirm that professionals cannot assume that their own information and communication priorities are the same as those of their patients [54]. However, despite the between-group similarity between professional groups in previous research, opinions varied widely within each profession [55,56] in two different countries [56]. Although these studies suggest that the nurses' opinions in the current study might in general be comparable with those of physicians, professionals in general seem to vary substantially in the information that they deem essential to discuss, which has important implications for patients. It seems therefore important to develop strategies for improving the equity of information provision [55]. It must be noted that the mean frailty score of participants in this study was 2.4. Considering patients with a frailty score of 4 or higher as moderately frail [34], we can conclude that the majority of included patients was not or only a little frail. As we used a convenient sample from ten hospitals, we have no indications that our sample was biased. The frailty scores suggest that CT was offered to a relatively 'healthy population'. This idea is supported by literature, particularly regarding curative CT. For instance, while a large majority of younger patients with stage III colon cancer receives adjuvant CT, many older patients with the same stage of cancer do not get this treatment. The most common motives for withholding CT are a combination of high age, co-morbidity and poor performance status [57], all indicators for frailty. In the current study, the patients who did not complete the QUOTE^{chemo}- Importance were more frail (M = 3.6) than completers (M = 2.1), although they still were only moderately frail (i.e.

below the cut-off point of 4.0). It might therefore be possible that information and communication needs of older cancer patients who are more frail differ from the needs that are reported in the current study.

4.2. Conclusion

Increasing insight into individual (unmet) needs may help health care providers to better tailor their communication to cancer patients' needs. 'Treatment-related information', 'rehabilitation information', 'affective communication' and discussing 'realistic expectations' were most highly valued by patients. Discrepancies between importance and actual performance during educational nursing consultations were especially found in discussing 'realistic expectations', 'coping information', 'interpersonal communication' and 'tailored communication'.

4.3. Practice implications

The results of this study provide tools for the development of interventions supporting both needs assessment and fulfillment to make sure older cancer patients' needs are properly met. Unmet needs assessment is recommended in addition to needs assessement by distinguishing how well needs have been met and identifying those that remains unmet [21]. Specific attention should be paid to role definition between physicians and nurses on communicating prognosis information and realistic expectations. Moreover, generic communication skills could be improved by communication skills training in which attention is paid to better tailoring communication to older cancer patients' needs, interpersonal communication with significant others and providing coping information, ultimately resulting in increased quality of care.

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TABLES AND FIGURES

Table 1
Categories of the QUOTE[chemo] and internal consistency of importance and performance categories.

Category	Number of items	Content	Cronbach's α QUOTE[chemo] Importance (questionnaires)[a]	Cronbach's α QUOTE[chemo] Performance (video observations)
Cancer-specific categories				
Treatment-related information	19	Purpose of treatment; how treatment works; treatment plan, description, logistic information, tests and procedures, hospital routines; side effects and physical effects of treatment; influence of treatment on sexuality; where to get information about treatment	0.92	0.92
Realistic expectations	3	Expected life span or survival rate; discussing the future (e.g. effect on life plan or long term goals); what will happen if patient chooses not to start CT treatment	0.70	0.72
Rehabilitation information	11	Self-care issues during treatment and recovery; dealing with side effects at home; nutrition, effects on social life, leisure, employment or work life, health behavior and promotion	0.85	0.87
Generic communication skills categories				
Coping information	7	Coping with cancer and treatment; exploring the patients' feelings and emotions; community counseling or support; support from other patients	0.85	0.82
Interpersonal communication	6	Effect of treatment on significant others, i.e. family members or friends; attention to significant others; exploring support needs of significant others	0.89	0.72
Tailored communication	10	Communication skills to provide personalized information and tailor the information to the patients' individual needs; knowledge of and adaptation to the patients personal situation and preferences	0.83	0.71
Affective communication	10	Establishing a trusting relationship between provider and patient, e.g. by empathizing, giving attention and emotional support, listening	0.89	0.88

[a] Based on patient questionnaires (n=116).

Table 2
Characteristics of the total group of participating patients (N = 155) and completers of the QUOTE[chemo]-Importance (n = 116).

	Total group (N = 155)		Completers QUOTE[chemo]-Importance (n = 116)		p[a]
	n[b]	%	n[b]	%	
Gender					0.506
Male	106	68.4	81	69.8	
Female	49	31.6	35	30.2	
Age					0.408
M (SD)	72.1 (4.5)		71.9 (4.4)		
Range	(65.0–85.7)		(65.0–85.0)		
Educational level					0.139
Low	76	50.0	54	47.3	
Middle	27	17.8	24	21.1	
High	49	32.2	36	31.6	
Living arrangements					0.020
Alone	33	21.7	18	15.7	
With partner	108	71.9	89	77.4	
With partner and child(ren)	6	3.9	4	3.5	
With child(ren)	3	2.0	2	1.7	
Other	2	1.3	2	1.7	
Primary tumor site					0.264
Breast	12	7.7	9	7.9	
Digestive-gastrointestinal	60	38.7	47	41.2	
Hematologic	15	9.7	14	12.3	
Lung	42	27.1	26	22.8	
Gynecological	6	3.9	4	3.5	
Genitourinar	16	10.3	12	10.5	
Other	2	1.3	2	1.8	
Time since diagnosis (months)					0.458
M (SD)	3.8 (10.1)		3.4 (8.2)		
Treatment intent					0.107
Curative	39	25.2	32	27.6	
Palliative	88	56.8	60	51.7	
Unknown	28	18.1	24	20.7	
Frailty (GFI; 0–15)[c]					0.001
M (SD)	2.4 (1.9)		2.1 (1.9)		

[a] Difference between completers and non-completers of QUOTE[chemo]-Importance questionnaire.
[b] n varies slightly due to missing data.
[c] The underlined score indicates the most favourable score (least frailty) for the scale.

Table 3
Characteristics of nurses who completed the QUOTE^{chemo}-Importance (n = 123).

	n^a	%
Gender		
Female	114	93.4
Male	8	6.6
Age		
M (SD)	41.0 (8.1)	
Experience as a nurse (years)		
M (SD)	17.1 (8.2)	
Experience in oncology		
M (SD)	11.8 (7.5)	
Employed on this ward (years)		
M (SD)	10.1 (7.7)	
Position		
Nurse	13	10.7
Nurse being educated for oncology nurse	7	5.7
Oncology nurse	66	54.1
Specialized oncology nurse	13	10.7
Nurse practioner or research nurse	6	4.9
Other	17	14.0

[a] n varies slightly due to missing data.

Figure 1. percentages of cancer-specific categories scored as (very) important by patients and nurses resp. discussed during consultation (mean score >2.5)
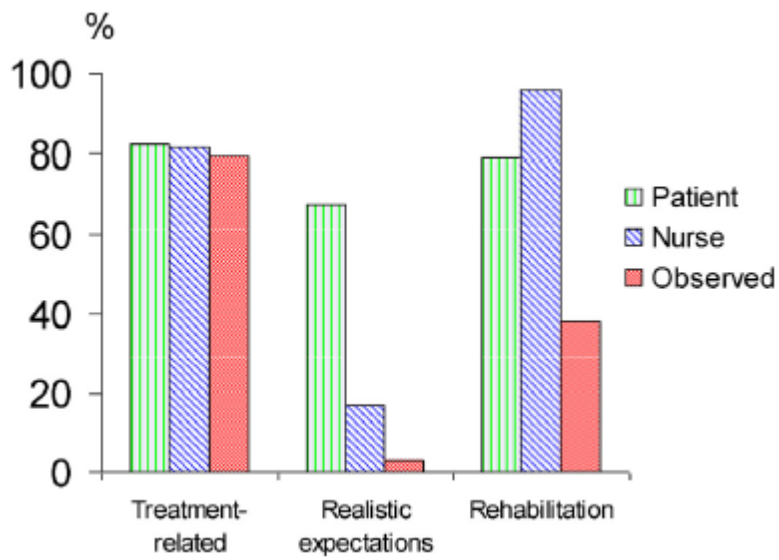
Table 4
Mean Importance scores of nurses and patients, mean Performance scores and mean quality impact indices (QIIs).

Number	Item description	Mean Importance score nurses	Mean Importance score patients	Mean Performance score	% lack of Performance (score 1 or 2)	Mean QII[a]	(SD)
Cancer-specific issues							
F1	**Treatment-related information**	**2.79 (0.41)**[b,*]	**2.97 (0.48)**[A,*]	**2.83 (0.35)**	**36.1**	**1.07**	**(0.17)**
Q1	Aim of treatment	2.90 (0.89)[c,*]	3.17 (0.65)[f]	2.62 (0.96)[A,*,b]	42.6	1.35	(0.28)
Q2	Discussion of possible side effects of treatment	3.01 (0.78)	3.18 (0.71)	3.02 (0.71)	20.0	0.64	(0.14)
Q9	Risk of infections during treatment	3.48 (0.55)	3.31 (0.64)	3.47 (0.83)	11.6	0.38	(0.07)
Q11	Low white blood cell count	2.95 (0.80)	3.06 (0.76)	3.08 (0.90)	21.1	0.71	(0.18)
Q12	Number of blood tests needed	3.12 (0.67)	3.20 (0.65)	3.21 (0.89)	18.1	0.58	(0.12)
Q13	Hospital procedures and logistical information	2.85 (0.77)[c,*]	2.69 (0.82)	2.54 (0.90)[A,*]	46.5	1.25	(0.38)
Q14	Sufficient information about what is going on	2.33 (0.95)[b,c]	3.16 (0.73)[A,c]	1.76 (0.93)[A,b]	78.7	2.48	(0.57)
Q15	Increased risk of getting bruises and nose bleeds	3.11 (0.69)[c,*]	2.99 (0.67)	2.81 (1.19)[A,*]	35.5	1.06	(0.24)
Q18	Influence of treatment on the development of cancer cells	2.09 (0.91)[b,c]	3.08 (0.85)[A,c]	2.51 (1.03)[A,b]	46.5	1.43	(0.39)
Q19	How often you need to come to the hospital	2.20 (0.81)[b]	2.78 (0.79)[A,c]	2.29 (0.85)[b]	60.0	1.67	(0.47)
Q20	When you should contact the hospital	3.84 (0.39)[b,c]	3.52 (0.60)[f]	3.46 (0.74)[f]	11.7	0.41	(0.07)
Q25	Order in which medicines are administered	1.90 (0.90)[b,c]	2.83 (0.90)[f]	2.89 (1.12)[a]	33.5	0.95	(0.30)
Q44	How the medicines spread through the bloodstream	1.93 (0.89)[b]	2.56 (0.91)[A,c]	1.68 (0.87)[b]	85.2	2.18	(0.78)
Q51	Sufficient information about chemotherapy treatment	3.25 (0.73)[c]	3.19 (0.62)[f]	2.72 (0.58)[A,b]	31.6	1.01	(0.20)
Q52	Length of chemotherapy treatment	2.58 (0.89)[b,c]	3.11 (0.69)[f]	3.19 (0.84)[f]	18.3	0.57	(0.13)
Q56	Influence on sexuality	2.65 (0.68)[b,c]	1.85 (0.93)[A,c,**]	2.23 (1.14)[A,b,**]	53.5	0.99	(0.50)
Q59	How chemotherapy is administered	2.34 (0.91)[f]	2.53 (1.00)[f]	2.96 (0.93)[A,b]	29.2	0.74	(0.29)
Q60	Which members of hospital team can answer questions	3.43 (0.63)[b]	3.05 (0.82)[A,c]	3.50 (0.82)[f]	10.5	.32	(0.09)
Q64	Treatments that can reduce side effects	3.02 (0.65)[c,**]	3.16 (0.65)[f]	2.75 (0.74)[A,**,b]	31.6	1.00	(0.20)
F3	**Realistic expectations/prognosis information**	**1.76 (0.63)**[b,c]	**2.83 (0.78)**[A,c]	**1.25 (0.48)**[A,b]	**91.4**	**2.59**	**(0.71)**
Q22	What will happen if patient chooses not to start treatment	1.83 (0.86)[b,c]	3.21 (0.88)[A,c]	1.20 (0.66)[A,b]	92.9	2.98	(0.81)
Q24	Expected survival	1.39 (0.60)[b]	2.76 (1.09)[A,c]	1.30 (0.71)[f]	88.4	2.44	(0.96)
Q50	Discussing the future	2.10 (0.83)[A,**,c]	2.46 (1.03)[A,**,c]	1.24 (0.57)[A,b]	92.9	2.29	(0.96)
F2	**Rehabilitation information/dealing with treatment at home**	**3.12 (0.40)**[b,c]	**2.87 (0.45)**[A,c]	**2.33 (0.49)**[A,b]	**51.9**	**1.49**	**(0.23)**
Q5	Preventing or reducing side-effects at home	3.63 (0.52)[b,c]	3.31 (0.58)[A,c]	2.70 (0.65)[A,b]	32.7	1.08	(0.19)
Q10	Impact of treatment on activities of daily living	3.28 (0.53)[A,b,c]	3.04 (0.57)[f,*,c]	1.91 (0.94)[A,b]	67.1	2.04	(0.38)
Q23	Necessity of home care during treatment	3.09 (0.68)[b,c]	2.45 (0.82)[A,c]	1.65 (1.01)[A,b]	78.7	1.93	(0.64)
Q27	Prevention of mouth ulcers	3.42 (0.56)[A,**,c]	3.09 (0.62)[A,**]	3.12 (1.04)[A,**]	25.3	0.78	(0.16)
Q30	Possibilities to do pleasant things during treatment period	2.72 (0.73)[A,*,c]	2.41 (0.92)[A,*,c]	1.75 (1.02)[A,b]	73.5	1.77	(0.68)
Q32	Dietary advice during treatment	2.68 (0.84)[A,*]	3.02 (0.73)[A,*]	2.92 (0.97)	29.7	0.90	(0.22)
Q33	Managing fatigue	3.16 (0.59)[b,c]	2.85 (0.70)[A,*]	2.60 (1.13)[f]	43.2	1.23	(0.30)
Q39	Consequences of treatment for patients' daily life	2.99 (0.56)[c]	2.76 (0.68)[f]	1.79 (0.89)[A,b]	72.7	2.01	(0.49)
Q42	How to deal with diarrhea or constipation	3.23 (0.64)[c]	3.19 (0.59)[f]	2.36 (1.05)[A,b]	50.0	1.60	(0.30)
Q61	How to deal with urine, feces and vomit	3.23 (0.57)	3.11 (0.74)	3.30 (0.99)	14.8	0.46	(0.11)
Q66	Possibilities to continue work life or leisure during treatment	2.78 (0.68)[b,c]	2.27 (0.88)[A,c]	1.49 (0.89)[A,b]	83.2	1.89	(0.73)
Generic issues							
F6	**Coping information**	**2.90 (0.46)**[b,c]	**2.34 (0.63)**[A,c]	**1.75 (0.48)**[A,b]	**76.5**	**1.79**	**(0.48)**
Q26	Exploring the patients' feelings about treatment	3.38 (0.58)[b,c]	2.72 (0.74)[A,c]	1.96 (1.07)[A,b]	72.3	1.96	(0.54)
Q28	Explaining emotional reactions on chemotherapy treatment	2.53 (0.76)[b,c]	2.78 (0.85)[A,*,c]	1.12 (0.39)[A,b]	97.4	2.71	(0.83)
Q38	Support from other patients or support groups	2.66 (0.70)[b,c]	1.80 (0.86)[A,c]	1.50 (1.05)[A,b,*]	82.6	1.48	(0.71)
Q47	Psychosocial care	2.97 (0.69)[b,c]	2.38 (0.90)[f]	2.27 (1.40)[f]	55.8	1.33	(0.50)
Q48	Exploring the patients' worries and anxieties	3.30 (0.58)[b,c]	2.40 (0.93)[A,c]	2.02 (0.84)[A,b]	70.3	1.69	(0.65)
Q55	Alternative or complementary therapies	2.53 (0.77)[b,c]	2.11 (0.92)[f,c]	1.17 (0.59)[A,b]	94.8	2.00	(0.87)
Q58	How to get emotional support from others	2.97 (0.62)[b,c]	2.13 (0.90)[f]	2.19 (1.01)[f]	62.6	1.33	(0.56)
F5	**Interpersonal communication**	**2.96 (0.47)**[A,**,c]	**2.55 (0.78)**[A,**,c]	**2.06 (0.56)**[A,b]	**64.7**	**1.73**	**(0.46)**
Q34	Being attentive to significant others	3.26 (0.58)[b]	2.66 (0.94)[A,c]	3.45 (1.75)[b]	27.5	0.73	(0.26)
Q45	Exploring questions of significant others	2.94 (0.64)	2.70 (0.90)	3.05 (1.97)	47.4	1.28	(0.43)
Q49	Discussing how patient and significant others can cope with treatment together	2.96 (0.62)[c]	2.71 (0.88)[f]	2.46 (0.98)[A,b]	75.0	2.03	(0.66)
Q53	Exploring support needs of significant others	3.00 (0.65)[c,*]	2.53 (0.96)	2.34 (2.23)[A,*]	76.8	1.94	(0.74)
Q62	Adapting to the needs and wishes of significant others	2.83 (0.70)	2.58 (0.92)	2.65 (2.09)	75.9	1.96	(0.69)
Q67	Discussing how significant others might provide emotional support	2.76 (0.63)[c,*]	2.35 (0.94)	2.22 (2.23)[A,*]	85.4	2.00	(0.80)
F4	**Tailored communication**	**3.07 (0.35)**[b,c]	**2.69 (0.54)**[A,c]	**1.90 (0.33)**[A,b]	**63.9**	**1.72**	**(0.34)**
Q6	Asking how much information the patient would like to know	3.15 (0.78)[A,**,c]	2.85 (0.75)[A,**,c]	1.15 (0.49)[A,b]	96.1	2.74	(0.72)
Q8	Checking what information the patient already knows	3.24 (0.64)[b,c]	2.76 (0.86)[A,c]	2.40 (1.10)[A,b,**]	55.8	1.54	(0.48)
Q16	Understanding the patients' personal circumstances	3.15 (0.63)[b,c]	2.74 (0.81)[A,c]	1.71 (0.69)[A,b]	87.7	2.40	(0.71)
Q17	Checking the patients' expectations	3.10 (0.61)[A,**,c]	2.78 (0.89)[A,**,c]	1.43 (0.77)[A,b]	88.4	2.46	(0.78)
Q29	Checking patients' preferences for treatment	2.24 (0.76)[c]	2.19 (0.96)[f]	1.55 (0.98)[A,b]	80.0	1.75	(0.77)
Q31	Checking whether the patient still wants to start CT after being educated	2.15 (0.93)[b,c]	2.74 (1.00)[A,c]	1.10 (0.43)[A,b]	96.8	2.65	(0.97)
Q35	Considering the patients' current capabilities	3.27 (0.58)[b,c]	2.57 (0.81)[f]	2.63 (0.79)[f]	32.3	0.83	(0.26)
Q37	Checking the patients' knowledge about chemotherapy	3.18 (0.60)[b,c]	2.37 (0.86)[A,c,**]	1.99 (1.14)[A,b,**]	67.1	1.59	(0.58)
Q41	Tailoring the information to the patients' personal circumstances	3.42 (0.57)[b,c]	2.68 (0.82)[f]	2.61 (0.79)[f]	40.0	1.07	(0.33)
Q65	Checking the patients' understanding of information	3.73 (0.45)[b,c]	3.16 (0.66)[A,c]	2.46 (0.96)[A,b]	52.3	1.65	(0.34)

Table 4 (*Continued*)

Number	Item description	Mean Importance score nurses	Mean Importance score patients	Mean Performance score	% lack of Performance (score 1 or 2)	Mean QII[a]	(SD)
F7	**Affective communication**	**3.42 (0.36)[b,c]**	**2.85 (0.50)[a,c] ****	**3.07 (0.55)[a,b] ****	**22.5**	**0.64**	**(0.11)**
Q7	Listening carefully to questions	3.78 (0.41)[b,c]	3.21 (0.60)[a,c]	3.49 (0.60)[a,b]	5.2	0.17	(0.03)
Q21	Being attentive to how the patient is doing	3.60 (0.52)[b,c]	2.79 (0.64)[a]	2.97 (0.86)[a]	25.2	0.70	(0.16)
Q36	Paying attention to the patient	3.48 (0.55)[b,c]	2.62 (0.78)[a]	2.82 (0.73)[a]	34.2	0.90	(0.27)
Q40	Showing empathy	3.19 (0.61)[b,c]	2.37 (0.76)[a,c]	2.84 (0.83)[a,b]	32.3	0.76	(0.25)
Q43	Being kind	3.44 (0.56)[b]	3.17 (0.68)[a,c]	3.51 (0.60)[b]	5.2	0.17	(0.04)
Q46	Lending a listening ear	3.48 (0.55)[b,c]	2.85 (0.66)[a]	3.01 (0.86)[a]	26.5	0.76	(0.17)
Q54	Being open	3.30 (0.59)[c]	3.24 (0.72)[c]	2.87 (0.72)[a,b]	26.5	0.86	(0.19)
Q57	Providing space for feelings and emotions	3.47 (0.53)[b,c]	2.50 (0.84)[a]	2.70 (0.88)[a]	39.4	0.98	(0.33)
Q63	Tailoring information to the patient's situation	3.10 (0.59)[b]	2.70 (0.74)[a,c]	3.14 (0.77)[b]	20.1	0.54	(0.15)
Q68	Taking time	3.37 (0.53)[b]	3.01 (0.67)[a,c]	3.37 (0.67)[b]	10.3	0.31	(0.07)

QII = quality impact indices based on patients' importance score and performance score (scores ≥ 1.00 indicate a clear need for improvement; the higher the score, the more discrepancies between Importance and Performance).

[a] Significant different from mean importance score of nurses ($p < 0.001$ unless otherwise stated directly after.
[b] Significant different from mean importance score of patients ($p < 0.001$ unless otherwise stated directly after.
[c] Significant different from mean performance score ($p < 0.001$ unless otherwise stated directly after.
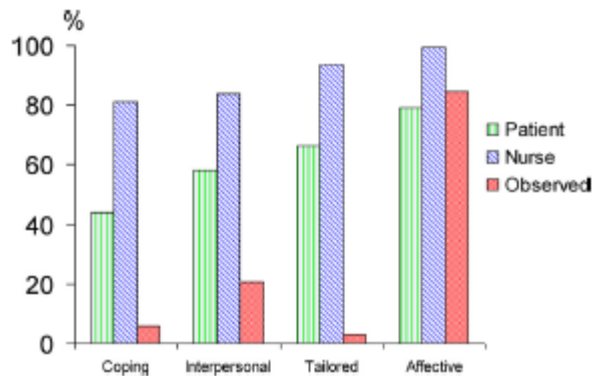* $p < 0.05$.
** $p < 0.01$.

Fig. 2. Percentages of generic categories scored as (very) important by patients and nurses resp. discussed during consultation (mean score ≥ 2.5).