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# QUOTE<sup>chemo</sup>: A patient-centred instrument to measure quality of communication preceding chemotherapy treatment through the patient's eyes

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## ABSTRACT

**Background:** Knowing patients' needs is a prerequisite to ensure high quality cancer care. This study describes the development and psychometric properties of a patient-centred instrument to measure needs and actual experiences with communication preceding chemotherapy treatment: QUOTE<sup>chemo</sup>. QUOTE-questionnaires (Quality Of care Through the patients' Eyes) are widely used to gain insight into unmet needs, but no validated, standardised questionnaire combining patients' needs and experiences surrounding chemotherapy treatment is available yet.

**Methods:** To evaluate the psychometric properties of the QUOTE<sup>chemo</sup>, content validity, internal structure and convergent validity were investigated amongst 345 cancer patients, new to chemotherapy, from 10 different hospitals.

**Results:** Literature study, focus group discussions and a categorisation procedure of 67 relevant topics revealed seven main themes: Treatment-related information, Prognosis information, Rehabilitation information, Coping information, Interpersonal communication, Tailored communication and Affective communication. Confirmatory factor analysis using structural equation modelling indicated that the measurement model provided good fit to the data with factor loadings ranging from .43 to .77. The seven QUOTE<sup>chemo</sup> dimensions captured relevant issues of concern with good internal consistency ( $\alpha$  .72–.92), satisfactory item-total correlations (.35–.79) and satisfactory convergent validity. Affective communication, Treatment-related information and Rehabilitation information were perceived most important by patients. The instrument also appeared to be able to determine which aspects need improvement to ensure high quality care. The highest need for improvement was found for communicating Prognosis information and Rehabilitation information and for Interpersonal communication.

**Conclusions:** These findings provide preliminary evidence of the reliability and validity of the QUOTE<sup>chemo</sup> for use in cancer care surrounding chemotherapy treatment. Researchers

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and health care providers can use the instrument to measure patients' needs and experiences with communication to identify aspects that need improvement.

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## 1. Introduction

As the global burden of cancer is expected to grow to 27 million new cancer cases and 17.5 million cancer deaths in 2050, cancer treatments remain needed to curtail these high mortality statistics. Chemotherapy is a common treatment for cancer, alone or in combination with other treatments, such as radiotherapy or surgery.<sup>1</sup> Effective communication surrounding treatment is known to be the key to optimal health outcomes<sup>2</sup> and leads to a greater satisfaction, improved ability to cope with treatment, reductions in anxiety and mood disturbances and improved communication with family members (see Rutten and colleagues, for a review).<sup>3</sup> However, communication is often insufficiently tailored to the patients' individual needs, and as a result patients continuously seem to have unmet needs (see Hack and colleagues, for a review).<sup>4</sup> Research in this area has been generally compromised by a lack of validated, standardised measures.<sup>4</sup> Rutten and colleagues, therefore recommended to strive for continuity by developing new instruments based on the previous research.<sup>3</sup> Two widely used indicators to gain insight into unmet needs are '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. Quality of care can subsequently be defined as the degree to which perceived performance meets the patients' needs. A family of standardised and validated surveys using this approach is called QUOTE (Quality Of care Through the patients' Eyes).<sup>5–9</sup> QUOTE-questionnaires conceptualise patients' experiences with quality of care according to an importance and performance dimension. When combined, these dimensions reflect what people see as desired qualities in health care.<sup>8,9</sup> To our knowledge, no validated questionnaires are available which measure patients' needs and preferences in combination with experiences surrounding Chemotherapy Treatment (CT). Therefore, in the present study, a QUOTE instrument was developed that explicitly involved the input of cancer patients' with CT communication needs and experiences (QUOTE<sup>chemo</sup>). The aim of this study is to describe the development and psychometric properties of the QUOTE<sup>chemo</sup>-questionnaire. We describe (a) the importance that cancer patients assign to various dimensions of communication and different types of information surrounding their first CT; (b) the content validity and internal structure of these dimensions; (c) aspects of communication that need improvement to ensure high quality care, by combining importance scores ('needs') with performance scores ('experience') and (d) the convergent validity of the QUOTE<sup>chemo</sup> by examining whether the issues patients perceive as important are supported by measures of their information preferences, coping style and cancer-related stress reactions. Based on the previous research, we hypothesised that a high information need and a monitoring coping style are related to an increased preference for cancer-specific information and

sensitive communication.<sup>7,10</sup> Cancer-related stress reactions are expected to be associated with an increased need for emotional support as well as information, particularly concerning the emotional aspects and meaning of treatment.<sup>7</sup>

## 2. Methods

### 2.1. Subjects

Eligible patients were identified through the hospital records of 10 hospitals in the Netherlands. The QUOTE<sup>chemo</sup> was sent to the 60 most recent patients of each hospital that had started CT. Patients were eligible if they were (a) new to CT; (b) aged 18 years or older and (c) able to read Dutch. The current study is part of an intervention study on communication preceding CT. The study was approved by the Medical Ethical Committee of the University Medical Centre Utrecht, The Netherlands, supplemented by local feasibility statements from all participating hospitals.

### 2.2. Measurements

#### 2.2.1. Socio-demographic and medical background characteristics

The self-administrated questionnaire contained socio-demographic items on age, gender, living situation, education, ethnical background and medical background information on date of start chemotherapy, other treatments and the way chemotherapy was administered. Additional medical background characteristics (e.g. diagnosis) were obtained from the medical file.

#### 2.2.2. QUOTE<sup>chemo</sup>-questionnaire

The development of the QUOTE<sup>chemo</sup> was based on three different sources. First, the QUOTE<sup>communication</sup>.<sup>5</sup> Four of the 16 items in this questionnaire were not applicable to our study purposes of measuring needs and experiences regarding CT. Five items (Q5, Q7, Q31, Q47, Q51; see Table 4) were slightly rephrased to adapt them to CT. Next, to gain a thorough insight into specific aspects that are important to patients who undergo cancer treatment, a literature review was conducted.<sup>11</sup> Additionally, the Treatment Guide Chemotherapy, a patient booklet that is often used to aid education preceding chemotherapy, was studied extensively.<sup>12</sup> Last, five focus group interviews were conducted ( $n = 33$ ) as well as one-to-one interviews with cancer patients ( $n = 5$ ).<sup>13</sup>

Following the QUOTE methodology, the QUOTE<sup>chemo</sup> consists of two questionnaires, i.e. the QUOTE<sup>chemo</sup>-Importance and the QUOTE<sup>chemo</sup>-Performance. Based on the above-described three steps, 69 items were developed. The Importance questionnaire asks patients to rate the extent to which the 69 specific aspects of information and communication were considered important at the beginning of CT ('needs'), measured

by a 4-point Likert scale ('not important', 'fairly important', 'important', 'very important'). In the Performance questionnaire patients are asked to report whether these 69 aspects were covered during the actual communication ('experience'), measured by 2-point response categories ('yes', 'no').

The 69 items of the QUOTE<sup>chemo</sup> were categorised by two researchers (J.J. and J.N.) according to the typology developed by Rutten and colleagues.<sup>3</sup> This typology serves as a framework for crafting more comprehensive and standardised assessment tools for evaluating cancer patients' information needs. They both categorised 47 of the 69 items in the same five categories, indicating an inter-rater reliability of 68.1% agreement. The majority of the remaining items (20) did not fit well in the original typology. The categorisation was therefore discussed with a third researcher (J.W.). Incongruencies were solved and two new categories were developed (see below). Table 1 gives an overview of the categories and their content. The five dimensions from the typology that were found to be applicable are: (1) Treatment-related information; (2) Prognosis information; (3) Rehabilitation information; (4) Coping information and (5) Interpersonal communication. Results from the literature study and the focus group discussions revealed that tailored communication is necessary to provide personalised information and to tailor the information to the patients' individual needs.<sup>4,13</sup> Affective communication is needed to establish a trusting relationship between provider and patient.<sup>14</sup> These dimensions were not covered in the original framework, which mainly focussed on the content of information. We therefore added the two dimensions: (1) Tailored communication and (2) Affective communication.

Content validity of the categorisation, i.e. a subjective judgment by one or more experts indicating whether the dimensions sample relevant content,<sup>15</sup> was tested by 10 coders, who were asked to categorise each of the 69 QUOTE<sup>chemo</sup> into one of the seven above-described dimensions. Fifty six of 69 items were categorised by all of them in the intended category (100% agreement). Thirteen items were placed in a different category by some coders, but still the majority coded these items in the intended category. Therefore, the initial categorisation was considered valid.

### 2.2.3. Information preference

Information preference was assessed using an adapted item of the Information Satisfaction Questionnaire,<sup>16</sup> measuring the amount of information patients wish: (a) as much information as possible, both positive and negative; (b) as much as possible information, both positive and negative, but bit by bit (i.e. not all information at once); (c) do not need much information and (d) only want positive information. As the distribution of scores was skewed (5% did not need much information; 10% only wanted positive information), (c) and (d) were combined into a new variable 'does not want as much information as possible'.

### 2.2.4. Coping style

Monitoring coping style was measured using a short, adapted version of the Threatening Medical Situation Inventory (TMSI).<sup>17,18</sup> The scale pertains three questions with a 5-point Likert scale (1 = 'not at all applicable to me', 5 = 'strongly applicable to me'): (a) bury on the situation by reading about

**Table 1 – Categories of the QUOTE<sup>chemo</sup> and internal consistency of QUOTE<sup>chemo</sup>-Importance and QUOTE<sup>chemo</sup>-Performance dimensions.**

Category	Number of items	Content	Cronbach's $\alpha$ QUOTE <sup>chemo</sup> -Importance	Cronbach's $\alpha$ QUOTE <sup>chemo</sup> -Performance
<i>Cancer-specific issues</i>				
Treatment-related information	20	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; preventing, reducing and reporting side effects, where to get information about treatment	.90	.92
Prognosis information	3	Realistic expectations: life span or survival rate; effect on life plan or long term goals in the future; outcome if no treatment	.76	.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 behaviour and promotion	.86	.87
<i>Generic issues</i>				
Coping information	7	Emotional reactions, coping with cancer and treatment; community counselling or support; support from other patients or support groups	.81	.78
Interpersonal communication	6	Effect of treatment on significant others, i.e. family members or friends; attention to significant others	.90	.89
Tailored communication	10	Communication skills; knowledge of and adaptation to the patients personal situation and preferences	.81	.86
Affective communication	10	Empathising, giving attention and emotional support, listening	.88	.91

cancer; (b) going as deeply as possible into information on treatment and (c) getting information from the medical specialist. Total monitoring scores were calculated as the total scores on the items (range 0–12). Cronbach's  $\alpha$  was .78.

#### 2.2.5. Cancer-related stress reactions

Cancer-related stress reactions were assessed with the Dutch version of the Impact of Event Scale (IES).<sup>7,19</sup> The scale consists of an intrusion subscale (7 items;  $\alpha$  = .85) and an avoidance subscale (8 items;  $\alpha$  = .79), assessing the patients' level of intrusive and avoidant thinking in context of experiences with a stressful event, in this study 'being treated for cancer', on a 4-point Likert scale (0 = 'not at all', 1 = 'rarely', 3 = 'sometimes', 5 = 'often'). Total intrusion and avoidance scores were rated (range 0–35 and 0–40, respectively).

### 2.3. Analysis

Missing values on items that were part of a (sub)scale were substituted according to the 'mean value of valid sub-tests principle' (only if 25% or less of the items of the (sub)scale had missing values): The missing value was replaced by the mean value calculated from the valid items scores of the (sub)scale obtained for the same case.

A non-response analysis was conducted using t-tests to examine differences in age and  $\chi^2$  tests to examine differences in gender and diagnosis. Descriptive statistics were obtained on the demographic characteristics of subjects.

In this study, construct validity is considered as a unitary concept testing the degree to which a score can be interpreted as representing the intended underlying construct.<sup>20</sup> We used content validity (discussed above), internal structure (factor analysis, internal consistency, item-total correlations) and convergent validity as sources of construct validity evidence.<sup>20</sup>

To examine the factor structure of the seven dimensions of the QUOTE<sup>chemo</sup>, confirmatory factor analysis was performed with Structural Equation Modelling (SEM) using AMOS Software Version 4.0. The Normed Fit Index (NFI), Comparative Fit Index (CFI), Root Mean Square of Error Approximation (RMSEA) and the Akaike Information Criterion (AIC) were used as additional fit measures. The loading of the first indicator for each latent construct was set to 1 in order to create its metric.<sup>21</sup>

Cronbach's  $\alpha$  was rated to assess the internal consistency of QUOTE-categories. Internal consistency measures how well the scores for individual items on the instrument correlate with each other.<sup>20</sup> In addition, the item-total correlations (ITCs) correcting for item overlap were calculated.<sup>9</sup> ITC should preferably be larger than .40.<sup>22</sup> Factor analysis and internal consistency are generally considered evidence for internal structure.<sup>20</sup>

Convergent validity (also known as 'Relations to other variables'), i.e. the extent to which the new instrument is related to other instruments or outcomes for which correlation would be expected,<sup>15,20</sup> was measured by computing Pearson's correlations. We assessed the relationship between the seven QUOTE<sup>chemo</sup>-Importance dimensions and the validating measures 'information preferences', 'coping style' and 'cancer-related stress reactions'. The magnitude of the ef-

fect size was used as an informational source following Cohen's guidelines: effect sizes are small when  $r$  is equal to or larger than .10, medium when  $r$  is between .30 and .50, and large when  $r$  equals or exceeds .50.<sup>23</sup>

Importance scores on the seven categories were rated as the mean of the scores on the relevant items (range of the subscales 1–4). Quality Impact Indices (QIIs) were calculated, in line with earlier studies on QUOTE questionnaires, by multiplying the importance score of the items with the fraction (%/100) of patients that experienced shortcomings in the performance on that item (i.e. proportion negative experience \* importance score).<sup>6</sup>

## 3. Results

### 3.1. Response

Patient (597) addresses were gathered from the medical files. Nine patients had passed away, three moved to an unknown address and three were of the opinion that they had not received CT, resulting in 582 eligible subjects. Patients (345) (59.3%) returned the questionnaire. They all completed the entire questionnaire. A non-response analysis revealed no significant differences between those who responded and those who did not with regard to age ( $F(560, 540) = 5546$ ,  $p > .05$ ), gender ( $\chi^2(1) = 0.007$ ,  $p > .05$ ) and diagnosis ( $\chi^2(6) = 6896$ ,  $p > .05$ ).

### 3.2. Background characteristics

Table 2 summarises the socio-demographic characteristics for subjects. The majority of respondents was female (67.0%) and lived with a partner (79.0%). The mean age was 55.7 years ( $SD = 11.0$ ) and almost half of the respondent had a low education (47.2%).

The disease characteristics are shown in Table 3. Almost half of the respondents had been diagnosed with breast cancer (47.2%). Two-thirds (74.5%) underwent a surgery, in addition to CT, and 45.5% radiotherapy. For the majority of patients, the aim of treatment was curative (74.8%).

### 3.3. Internal structure

Confirmatory factor analysis showed that the initial measurement model, in which all indicators were allowed to load on their respective latent construct, provided good fit to the data,  $\chi^2 = 5246.44$  ( $df = 2256$ ),  $p < .001$ , NFI = .93, CFI = .96, RMSEA = .06, AIC = 5702.44. However, this revealed two items with a factor loading  $< .40$  (i.e. Q3 and Q4). Deletion of these items and re-estimating the model provided good fit to the data,  $\chi^2 = 5008.30$  ( $df = 2123$ ),  $p < .001$ , NFI = .93, CFI = .94, RMSEA = .06, AIC = 5452.30, with all factor loadings  $> .40$  ( $p < .001$ ). The final instrument therefore consists of 67 items. Factor loadings for this overall measurement model are shown in Table 4.

Table 1 shows that satisfactory to good Cronbach's  $\alpha$  were found for the seven QUOTE<sup>chemo</sup>-Importance categories (range .76–.90) as well as the QUOTE<sup>chemo</sup>-Performance categories (range .72–.92). All item-total correlations (ITCs) corrected for overlap were higher than the threshold of .40



**Table 2 – Demographic characteristics of the sample (N = 345).**

Characteristic	n <sup>a</sup>	Valid %
Gender		
Male	114	33.0
Female	231	67.0
Age		
M (SD)	55.7 (11.0)	
Range	20–84	
Educational level		
Low	162	47.2
Middle	85	24.8
High	96	28.0
Living arrangements		
Alone	55	16.0
With partner	173	50.4
With partner and child(ren)	98	28.6
With child(ren)	12	3.5
Other	5	1.5
Children		
Yes	268	78.1
No	75	21.9
Employed		
Yes	181	52.8
No	162	47.2
Ethnicity		
Dutch	336	98.2
Other	6	1.8
Religious		
Yes	195	56.9
No	148	43.1

a n Varies slightly due to missing data.

(ranging to .79), except for Q56 (ITC = .36), Q60 (ITC = .39) and Q65 (ITC = .35). We decided to retain these items in the scales, because the ITCs were close to .40 and the items were considered of importance within the subscales.

### 3.4. Importance, performance and quality impact indices (QIIs)

Table 4 shows the number of patients who rated specific aspects important (score 3) or very important (score 4). Affective communication (84.1%), Treatment-related information (83.4%) and Rehabilitation information (83.3%) are generally considered most important. Specific items that were listed as (very) important by more than 95% of the respondents were 'listening carefully to my questions' and information regarding: 'possible side effects of treatment', 'risk of infections during treatment', 'preventing or reducing side effects at home', and 'when you should contact the hospital'. The only item mentioned by less than 50% of the subjects to be (very) important is 'support from other patients or support groups'.

Regarding performance, more than a quarter of the respondents felt that there are shortcomings in discussing Prognosis information (27.2%) and Interpersonal communication (25.2%) (see Table 3). Quality Impact Indices (QIIs) were

**Table 3 – Disease characteristics of the sample (N = 345).**

Characteristic	n <sup>a</sup>	Valid %
Primary tumour site		
Breast	160	47.2
Digestive-gastrointestinal	73	21.5
Haematologic	36	10.6
Lung	33	9.7
Gynaecological	21	6.2
Urologic	10	2.9
Other	6	1.8
Time since diagnosis (months)		
M (SD)	11.5 (13.8)	
Time since start chemotherapy (months)		
M (SD)	6.7 (13.8)	
Treatment intent		
Curative	234	74.8
Palliative	79	25.2
Method of administering CT		
Intravenous	266	78.0
Oral	2	.6
Combined	73	21.4
Suffering from side effects		
More than expected	108	32.0
Same as expected	78	23.1
Less than expected	152	45.0
Other treatments		
No other treatments (only CT)	56	16.2
Other treatments (in addition to CT)	289	83.3
Namely:		
Surgery	254	74.5
Radiotherapy	155	45.5
Hormone replacement therapy	72	21.1
Immunotherapy	21	6.2
CT currently finished		
Yes	208	61.4
No	131	38.6
Global health status/QoL (0–100 <sup>b</sup> )		
M (SD)	68.8 (20.7)	
Information preferences		
As much information as possible	193	56.9
As much as possible, but bit by bit	95	28.0
Not as much information as possible	51	15.0
Coping style		
Monitoring (0–12 <sup>c</sup> ); M (SD)	9.8 (3.0)	
Cancer-related stress reactions		
Intrusion (0–35 <sup>d</sup> ); M (SD)	13.5 (7.9)	
Avoidance (0–40 <sup>e</sup> ); M (SD)	13.6 (8.7)	

a n Varies slightly due to missing data.

b A higher score indicates better health status/QoL.

c A higher score indicates a more monitoring coping style.

d A higher score indicates more intrusive reactions.

e A higher score indicates more avoidant reactions.

calculated by combining importance (needs) and performance (experience) scores (range .17–.99). All seven QUOTE-chemo-categories showed a mean QII between .30 and 1.0. A QII of .30 or more indicates a need for improvement (based on the criterion of minimal 10% of the respondents having a

**Table 4 – Factor loadings of the 67 items. Number (%) of patients' perceived importance and performance responses. Mean Quality Impact Indices (QIIs).**

Number	Item description	Factor loading <sup>a</sup>	% (Very) important (score 3–4)	% Lack of performance	Mean QII <sup>b</sup>	(SD)
<i>Cancer-specific issues</i>						
F1	Treatment-related information		83.4	18.3	.56	(.08)
Q1	Aim of treatment	.44	94.5	13.4	.45	(.09)
Q2	Discussion of possible side effects of treatment	.51	97.1	20.9	.71	(.12)
Q9	Risk of infections during treatment	.61	95.6	26.6	.92	(.16)
Q11	Low white blood cell count	.57	88.6	21.1	.67	(.15)
Q12	Number of blood tests needed	.64	91.3	21.3	.69	(.14)
Q13	Hospital procedures and logistical information	.66	80.2	16.7	.49	(.14)
Q14	Sufficient information about what is going on	.61	87.8	17.6	.58	(.14)
Q15	Increased risk of getting bruises and nose bleeds	.65	83.3	26.8	.80	(.18)
Q18	Influence of treatment on the development of cancer cells	.60	81.1	32.8	.99	(.26)
Q19	How often you need to come to the hospital	.64	72.9	10.9	.30	(.09)
Q20	When you should contact the hospital	.54	95.3	14.4	.50	(.08)
Q25	Order in which medicines are administered	.54	67.6	10.6	.29	(.10)
Q44	How the medicines spread through the bloodstream	.54	62.6	28.2	.74	(.26)
Q51	Sufficient information about chemotherapy treatment	.58	93.6	13.5	.44	(.08)
Q52	Length of chemotherapy treatment	.67	84.8	9.4	.28	(.06)
Q56	Influence on sexuality	.43	60.5	18.4	.46	(.17)
Q59	How chemotherapy is administered	.56	70.5	10.0	.28	(.08)
Q60	Which members of hospital team can answer questions	.46	92.1	8.1	.26	(.05)
Q64	Treatments that can reduce side effects	.68	93.0	25.0	.82	(.16)
Q69	Discussion of all possible side effects of treatment	.59	76.0	21.0	.61	(.18)
<i>Prognosis information</i>						
F2	Prognosis information		72.3	27.2	.77	(.22)
Q22	What will happen if patient chooses not to start treatment	.65	78.7	27.6	.84	(.26)
Q24	Expected survival	.76	74.1	25.5	.74	(.27)
Q50	Discussing the future	.76	64.0	28.5	.74	(.29)
<i>Rehabilitation information/dealing with treatment at home</i>						
F3	Rehabilitation information/dealing with treatment at home		83.3	21.5	.65	(.10)
Q5	Preventing or reducing side effects at home	.51	95.6	26.9	.91	(.16)
Q10	Impact of treatment on activities of daily living	.66	87.1	25.9	.82	(.18)
Q23	Necessity of home care during treatment	.62	72.1	20.7	.58	(.16)
Q27	Prevention of mouth ulcers	.67	88.6	18.8	.59	(.12)
Q30	Possibilities to do pleasant things during treatment period	.57	79.9	22.6	.56	(.21)
Q32	Dietary advice during treatment	.58	81.0	24.2	.72	(.19)
Q33	Managing fatigue	.69	81.9	28.3	.84	(.20)
Q39	Consequences of treatment for patients' daily life	.68	85.4	25.2	.77	(.16)
Q42	How to deal with diarrhoea or constipation	.64	87.4	19.4	.61	(.13)
Q61	How to deal with urine, faeces and vomit	.57	89.5	9.7	.31	(.07)
Q66	Possibilities to continue work life or leisure during treatment	.47	69.3	14.8	.40	(.12)
<i>Generic issues</i>						
F4	Coping information		65.1	17.6	.47	(.10)
Q26	Exploring the patients' feelings about treatment	.66	83.2	14.2	.42	(.10)
Q28	Explaining emotional reactions on chemotherapy treatment	.58	82.6	29.6	.88	(.20)
Q38	Support from other patients or support groups	.46	43.3	12.8	.28	(.12)
Q47	Psychosocial care	.63	64.7	14.6	.38	(.12)
Q48	Exploring the patients' worries and anxieties	.72	73.1	20.0	.57	(.16)
Q55	Alternative or complementary therapies	.59	54.7	19.1	.46	(.17)
Q58	How to get emotional support from others	.68	54.1	12.8	.31	(.12)

(continued on next page)

Table 4 – (continued)

Number	Item description	Factor loading <sup>a</sup>	% (Very) important (score 3–4)	% Lack of performance	Mean QII <sup>b</sup>	(SD)
F5	Interpersonal communication		68.4	25.2	.64	(.16)
Q34	Being attentive to significant others	.75	74.1	24.6	.71	(.21)
Q45	Exploring questions of significant others	.77	71.7	25.0	.70	(.20)
Q49	Discussing how patient and significant others can cope with treatment together	.65	70.0	26.1	.74	(.21)
Q53	Exploring support needs of significant others	.80	74.6	26.0	.69	(.22)
Q62	Adapting to the needs and wishes of significant others	.84	58.8	15.0	.39	(.13)
Q67	Discussing how significant others might provide emotional support	.71	61.1	24.5	.63	(.21)
F6	Tailored communication		72.6	17.3	.48	(.09)
Q6	Asking how much information the patient would like to know	.42	78.7	20.2	.59	(.15)
Q8	Checking what information the patient already knows	.48	77.6	17.1	.49	(.14)
Q16	Understanding the patients' personal circumstances	.66	74.6	15.3	.44	(.12)
Q17	Checking the patients' expectations	.60	70.2	25.2	.69	(.20)
Q29	Checking patients' preferences for treatment	.50	60.8	18.5	.47	(.19)
Q31	Checking whether the patient still wants to start CT after being educated	.50	67.3	19.6	.53	(.20)
Q35	Considering the patients' current capabilities	.68	74.1	14.2	.40	(.10)
Q37	Checking the patients' knowledge about chemotherapy	.59	60.1	16.7	.42	(.15)
Q41	Tailoring the information to the patients' personal circumstances	.58	71.1	15.7	.44	(.13)
Q65	Checking the patients' understanding of information	.53	91.8	10.3	.34	(.06)
F7	Affective communication		84.1	9.8	.31	(.05)
Q7	Listening carefully to questions	.53	96.2	13.7	.48	(.08)
Q21	Being attentive to how the patient is doing	.69	90.1	13.0	.41	(.08)
Q36	Paying attention to the patient	.72	82.5	10.3	.30	(.07)
Q40	Showing empathy	.62	58.5	6.9	.17	(.05)
Q43	Being kind	.54	91.8	6.0	.20	(.04)
Q46	Lending a listening ear	.78	86.8	9.7	.30	(.06)
Q54	Being open	.52	93.3	9.7	.33	(.06)
Q57	Providing space for feelings and emotions	.69	76.3	10.3	.30	(.08)
Q63	Tailoring information to the patient's situation	.74	77.2	10.0	.29	(.08)
Q68	Taking time	.73	88.3	8.5	.27	(.05)

a  $p < .001$  for all variables.

b QIIs = Quality Impact Indices (scores  $\geq .30$  indicate a need for improvement; the higher the score, the more discrepancies between Importance and Performance).

negative experience 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 respondents having a negative experience on an 'important item', i.e. importance score = 3, or minimal 25% of the respondents having a negative experience on a 'very important item', i.e. importance score = 4).<sup>6</sup> According to these criteria, the results indicate room for improvement in all categories. No extremely unmet needs (QII > 1.0) were found. The biggest gap between needs and experience was found for Prognosis information (i.e. realistic expectations) (QII = .77). In particular, the need to discuss 'what will happen if patient chooses not to start CT' was often unmet (QII = .84). Furthermore, Rehabilitation information (QII = .65) and Interpersonal communication (QII = .64) showed potential for

improvement. Regarding Rehabilitation information, the biggest incongruence was found in talking about 'preventing or reducing side effects at home' (QII = .91), 'dealing with fatigue' (QII = .84) and 'impact of treatment on activities of daily living' (QII = .82). The biggest gap within Interpersonal communication concerned 'discussing how patient and significant others can cope with treatment together' (QII = .74), 'being attentive to significant others' (QII = .71) and 'exploring questions of significant others' (QII = .70).

### 3.5. Convergent validity

Table 5 shows the correlations between QUOTE<sup>chemo</sup>-Importance categories and the validating measures 'information preferences', 'monitoring coping style', 'intrusion' and 'avoid-



**Table 5 – Correlations between background characteristics, information preferences, monitoring, intrusive and avoidant thinking and QUOTE<sup>chemo</sup>-Importance Scores (N = 345).**

	Cancer-specific issues			
	Treatment-related information	Prognosis information	Rehabilitation information	
<i>Validating measures</i>				
Information preferences <sup>a</sup>	-.26**	-.19*	-.18*	
Monitoring <sup>b</sup>	.26**	.16**	.20**	
Intrusion <sup>c</sup>	.20**	.25**	.15**	
Avoidance <sup>d</sup>	.11*	.16**	.09	
	Generic issues			
	Coping	Interpersonal communication	Tailored communication	Affective communication
Information preferences <sup>a</sup>	-.19**	-.17**	-.15**	-.09
Monitoring <sup>b</sup>	.23**	.09	.17**	.17**
Intrusion <sup>c</sup>	.23**	.13*	.17**	.17**
Avoidance <sup>d</sup>	.11*	.13*	.14*	.07

\*  $p < .05$ .  
 \*\*  $p < .01$ .  
 a 0;1 Variable (0 = wants as much information as possible (at once or bit by bit); 1 = 'does not want as much information as possible').  
 b A higher score indicates a more monitoring coping style.  
 c A higher score indicates more intrusive reactions.  
 d A higher score indicates more avoidant reactions.

ance'. Patients who did not want to receive as much information as possible indicated a lower need on all seven categories than those who reported a preference for receiving all possible information, except for the need for Affective communication. A higher score on monitoring coping style, and a higher score on cancer-related stress reactions (intrusion and avoidance) correlated significantly with a higher perceived importance score on all seven categories, except for Interpersonal communication, which was not related to monitoring, and Rehabilitation information and Affective communication, which was not related to avoidance.

Effect sizes for the correlations between the QUOTE<sup>chemo</sup>-Importance categories and the validating measures are small. To establish convergent validity, the scores need to correlate, but we do not want the scales to be too highly correlated as this would indicate that the new scale is measuring the same thing.<sup>15</sup> Convergent validity is therefore considered satisfactory.

#### 4. Discussion

In this study, we developed the QUOTE<sup>chemo</sup> for measuring information and communication needs and experiences preceding chemotherapy treatment. The following seven categories could be reliably confirmed: Treatment-related information, Prognosis information, Rehabilitation information, Coping information, Interpersonal communication, Tailored communication and Affective communication. Psychometric properties of the questionnaire were good. Internal consistency ranged from .72 to .92 and all item-total correlations were higher than the threshold of .40<sup>22</sup>, except for three (although these three items all had ITC > .35). Convergent validity was investigated by exploring the relationship between the QUOTE<sup>chemo</sup>-Importance scale and other frequently used

instruments, i.e. an adapted item of the Information Satisfaction Questionnaire, an adapted version of the Threatening Medical Situation Inventory (measuring a monitoring coping style), and the Impact of Event Scale (measuring cancer-related stress reactions). Most of the QUOTE<sup>chemo</sup> categories showed the hypothesised relations with the validating measures, indicating satisfactory convergent validity. Results of this analysis demonstrated that patients who did not want to receive as much information as possible expressed a lower need for information and communication on all categories than those who reported maximal information preferences, except for the need for Affective communication. Affective communication has been valued as a useful tool to centre on 'the patient that has a disease' instead of on the 'disease of the patient'.<sup>24</sup> Apparently, patients with different levels of information needs have the same need to establish a trusting relationship with health care providers. The results of this study confirm that patients who do not want to be extensively informed, still want to receive attention and emotional support. Because meeting the full range of psychosocial needs is likely to contribute significantly to the well-being of cancer patients, health care providers should not only consider disease and treatment topics, but also be aware of socio-emotional or affective communication during patient education sessions.<sup>4</sup>

A higher score on intrusion correlated significantly with a higher perceived importance score on all seven QUOTE<sup>chemo</sup>-Importance categories, and a higher score on avoidance was significantly related with higher expressed needs in five of the seven categories. An earlier study on seeking genetic counselling for hereditary cancer also reported significant correlations of intrusion and avoidance with cancer-specific issues as well as generic issues.<sup>7</sup> Avoidance has been described as a maladaptive strategy of dealing with intrusive

thoughts and might mediate the relation between intrusive thoughts and later psychological distress in patients with advanced stages of cancer.<sup>25</sup> It is therefore important for health care providers to explore the level and content of cancer-related stress reactions amongst cancer patients.

The QUOTE<sup>chemo</sup> appeared to be able to detect issues that needed improvement to ensure high quality care by calculating Quality Impact Indices. QII-scores of categories ranged from .31 to .77. The highest need for improvement was found for the dimensions Prognosis information, Rehabilitation information and Interpersonal communication. These results are in line with previous research. Health care professionals seem to experience difficulties in discussing prognosis with cancer patients, especially when it concerns bad news.<sup>26,27</sup> It must be noted that not all patients want to receive complete Prognosis information.<sup>4</sup> Percentages of patients desiring a quantitative prognosis range from 50% to 61%, but only 28% to 50% receive this information.<sup>28,29</sup> Explicit discussion of preferred information in order to inform patients and their families to the level they wish may decrease gaps and improve medical encounters.<sup>4</sup> Especially in palliative care, it remains a challenge to find the balance between communicating hope while at the same time providing honest and clear information.<sup>27</sup> Recently, guidelines have been prepared to assist physicians with this difficult but important task.<sup>30</sup> It is recommended to develop additionally guidelines for other health care providers on how and to which extent to communicate Prognosis information both sensitively and effectively.

Our results confirm that attention to ADL (Activities of Daily Living) has been limited in the area of cancer rehabilitation. Cancer patients seem to experience a disruption in daily life during the whole trajectory of care<sup>31</sup> and are often dissatisfied with the help they receive in managing their disease and treatment at home.<sup>32</sup> Since a recent shift to home chemotherapy has been observed, this may become even more crucial in the future. Oncology nurses are the key point of contact between the patient and the physician and have increasing responsibilities in coaching patients how to deal with CT at home, including day-to-day management of patients in their care.<sup>33</sup> Until recently, the needs of cancer patients' family members, who often are informal caregivers, were rarely assessed. In line with our findings, Osse and colleagues found that informal caregivers of cancer patients would like more professional attention.<sup>34</sup> It is recommended to systematically explore and identify difficulties that the patients experience in their daily life as well as the needs of family members and/or individual caregivers for information and support.

This study has some limitations. Measurements were conducted retrospectively, so there was a time lag between patients filling out the questionnaire and the actual start of CT. Therefore, the results might be dissimilar from the immediate outcomes when directly assessed before, after or during the consultation.<sup>4</sup> Moreover, it is known that needs change across the cancer care continuum,<sup>3</sup> although information needs are expected to be especially high at the beginning of the treatment. 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<sup>3</sup> and ultimately,

complement this information with the assessment of patient-provider interaction during real-time consultations.<sup>35</sup> Another limitation is the length of the QUOTE<sup>chemo</sup>-questionnaire (67 items). We collected no information regarding feasibility, for instance the time it took for patients to complete the questionnaire and whether they thought completing the questionnaire was easy or difficult. However, the response rate was good and all responders, almost half of whom were low educated, completed the entire questionnaire. Of the 124 respondents who made a comment, only one mentioned that the questionnaire was 'extensive'. The other comments mainly considered experiences with treatment and care.

## 5. Conclusion

The use of the QUOTE<sup>chemo</sup> seems to allow for a reliable assessment of patients' needs and experiences with information and communication preceding chemotherapy treatment. Further, it highlights aspects that need improvement in order to fulfil cancer patients' communication needs. The instrument can be used by researchers as well as health care providers. Increasing insight into individual (unmet) needs may help health care providers to better tailor their communication to cancer patients' needs, ultimately resulting in increased quality of care.

## Conflict of interest statement

None declared.

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