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# Nurse-patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication

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## ABSTRACT

*Objective*: The aim is to investigate the relationship between nurses' cueresponding behaviour and patient satisfaction.

*Methods*: One hundred patient-nurse conversations about present concerns were videotaped and patients' expression of emotional cues and nurses' cue responses were coded using the Medical Interview Aural Rating Scale. Nurses (N=34) and patients (N=100) were recruited from seven oncology inpatient clinics from a University Medical Centre.

*Results*: A mixed-model analysis was conducted to examine whether cue responding was related with patient satisfaction with the conversation, after adjusting for confounding variables and correlation due to repeated measure of each nurse. Nurses' cue responding was independently related to patient satisfaction. Controlling for the level of cue responding, palliatively treated patients were more satisfied with the communication than curatively treated patients.

*Conclusions*: This study provides evidence that nurses' cue-responding behaviour is appreciated by the patients. Future studies might focus on the effect



of improved cueresponding skill on more distal outcome measures, such as identification of concerns, mood and coping behaviour.

#### INTRODUCTION

Patients seldom express their concerns and emotions directly and spontaneously, but instead express indirect cues that something is worrying them [1,2]. Studies indicate that psychological distress is negatively correlated with the explicit expression of concerns [3,4], but positively with the expression of cues [5]. This suggests that patients who need emotional support the most, i.e. anxious patients, do not express this need explicitly by mentioning their concerns, but implicitly through the expression of cues. A core skill for nurses is therefore to recognize cues of patients that are clinically relevant but not directly expressed [6]. Picking up cues of patients may lead to the recognition of patients who need emotional support. Leaving cues of patients undetected, on the other hand, may prevent patients from getting the care they require. It is frequently observed that nurses overlook patients' social and emotional needs [4,7–9].

Findings from a recent descriptive study showed that patients are dissatisfied with the tendency of oncologists and oncology nurses not to pay attention to the emotional consequences of cancer diagnosis and treatment [10]. These findings concur with studies [11–16] reporting that the emotional dimension of provider communication is an important factor in determining patient satisfaction.

However, since relatively little is known about the value patients specifically assigned to nurses' cueresponding behaviour, it is appropriate to investigate the relationship between nurses' cue-responding behaviour and patient satisfaction.

#### BACKGROUND

The concept 'cue' was originally described in the context of the conversational model of psychotherapy. This model was devised for teaching trainee psychiatrists the concepts and skills used during psychotherapy sessions. The emphasis of the model is on patient's feelings and on '*hearing' what the patient is 'saying*', see p. 574 of Goldberg's *et al.* paper [17]. Put another way, according to the model the provider needs to understand and express '*the meaning of messages conveyed by cues about the patients' feelings*', p. 568 of Goldberg *et al.* [17].

Subsequently, the concept cue responding was used to draw attention to skills of GPs, doctors and nurses in oncology care to detect psychological problems of patients. For instance, Davenport et al. [5] showed that doctors who are better able to detect psychiatric illness are more likely to allow patients to express verbal cues. Subsequent studies [18] examined which behaviours of doctors and nurses influence this altered rate of cue emission by the patient. It appeared that the use of open directive questions, eliciting of emotional concerns, clarification of emotional aspects, empathy, summarizing and screening questions like 'What else?' or 'Have you any other concerns or questions?' increases the rate of expression of cues that are indicative for emotional distress. In 2005, the European Association of Communication in Health Care reached consensus on the definitions of 'cue' and 'concern'. A cue has been defined as: 'a hint, which might be an expression or signal, mostly verbal but also nonverbal, which indirectly indicates an issue of presumed importance for the patient and implies an emotion, worry or uncertainty that the patient would like to bring up, or a move to another topic, that should demand an exploration from the provider'. A concern is described as: 'a verbal expression, which explicitly indicates an issue of importance for the patient' [19].

To our knowledge, only one study empirically examined the relation between cue responding and patient satisfaction. Butow *et al.* [1] in a study with medical and radiation oncologists found no correlation between cue responding and patient satisfaction.



Yet, patient satisfaction in their study was measured 7–10 days after the conversation where cue responding was displayed. This might have affected their outcome. So at this time it is too early to draw conclusions and besides results could be different for nurses' cue-responding behaviour. So far, no studies have been undertaken to analyse the relation between nurses' cue responding and patient satisfaction. The present study investigates the relationship between nurses cue-responding behaviour and patient satisfaction. We hypothesize that cue responding will be related to patient satisfaction with the conversation.

## METHODS

This explorative study was conducted in a University Medical Centre in The Netherlands with oncology nurses and patients with heterogeneous cancers. The data for this study were collected between February 2006 and February 2007 by videotaped conversations of nurses with cancer patients and questionnaires. The Regional Ethics Committee was informed about the study and had no objections to the study. The chief physicians and head nurses of the wards involved approved the study. Participation of nurses was voluntary.

#### **Participants**

A sample of 34 nurses and 100 patients was recruited from seven medical or surgical oncology inpatient clinics of a University Medical Centre in The Netherlands. Because communicative behaviour of nurses differs with age and gender [20], quota sampling was used to obtain a representative sample of nurses. Inclusion criteria required that nurses were employed as a Registered Oncology Nurse (a legal qualification in The Netherlands) or as a Registered Nurse with at least two years experience in oncology nursing, a 0.6–1.0 job assignment and gave informed consent. For each participating nurse, three patients were randomly drawn from eligible admitted patients. Inclusion criteria for patients required that they were at least 17 years of age, able to speak Dutch and gave written informed consent. Exclusion criteria were obvious psychopathology and tracheostoma.

#### Procedure

Each participating nurse performed three videotaped conversations. Each conversation with a different cancer patient. Prior to the day, on which participating nurses were scheduled for data collection, admitted patients were screened for study eligibility. From the eligible patients, the required number of patients was randomly selected.

Patients were then informed about the purpose and requirements of the study and written informed consent to participate in the study was obtained. Preceding the actual videotaped conversation with the nurse, patients completed two short questionnaires assessing patients present concerns and measuring anxiety and depression. These questionnaires were administered by either the researcher (RU) or a research assistant. Before each conversation, nurses were instructed to read the patient's chart. Subsequently, they were asked to discuss the patient's present concerns for approximately 20 min. They were informed that, after 20 min, videotaping would terminate. The video recording was performed in the absence of researcher and the conversation took place in a patient room at the ward. Immediately after termination of the videotaped conversation, a questionnaire was administered by the researcher to enquire whether concerns had been discussed by the nurse and whether patients were satisfied with the communication during this encounter.

#### Measures

#### Dependent variable

Patient satisfaction with nurses' cue responding was measured as the patient's judgement about the performance of the nurse with respect to care aspects that are felt to be important by the patient.

Under the assumption that patient concerns represent relevant care aspects for the patient, items of the Concerns Checklist were incorporated in the questionnaire. The Concerns



Checklist was originally developed by Devlen *et al.* [21] and has been used in a number of studies with patients with different cancer types and at various stages [4,7,8,22–24]. We extended the Heaven and Maguire version that was developed for the palliative care setting, from 18 to 32 items. Details of the questionnaire items are attached as Appendix A. For each item it was asked whether the concern or worry is present or not (for example: 'Are you worried about the illness?'). When present each item measures the performance of the nurse on this item immediately after the conversation ('Did the nurse pay attention to your worries about the illness').

Response options for perceived performances are 'no', 'not really', 'yes, more or less' and 'yes'.

## Independent variables

Trained observers (R. U. and E. D.) coded nurses' cue responding according to the Medical Interview Aural Rating Scale (MIARS). The MIARS was originally developed by Heaven and Green [25]. In the MIARS, the basic unit of observation is each turn of speech, for both nurse and patient. A turn is everything a current speaker says before the next speaker takes over [26]. The MIARS distinguishes three levels of disclosure of patients' feelings. The nurse's turn is coded in six categories of adequate cue-responding behaviour, six categories of inadequate cue responding and four categories that take the morphological aspects of the turn into account.

More details about theMIARS, including reliability data, are published elsewhere [27]. To ease coding procedures, the categories of the MIARS were incorporated into Observer Video Pro software [28].

To control for the potential influence of different nurse and patient variables, additional data were assessed. The nurse's age, gender and workplace characteristic (medical vs surgical) were derived from the nurse questionnaire.

Studies indicate that patient satisfaction is dependent on patient age, disease status and psychological distress [12,29–35]. The patient's age, gender, education (lower, medium, higher), cancer diagnosis, stage of disease (logoregional disease vs metastatic disease), current treatment (surgical, systemic, radiotherapy and miscellaneous) and aim of treatment (curative vs palliative) were retrieved from the Hospital Information System. Patients' feeling of distress was assessed by the Hospital Anxiety and Depression Scale (HADS) [36]. The HADS includes two subscales and consists of 14 items. Items are rated on a 4- point Likert scale ranging from 0 to 3. Higher scores indicate higher anxiety and depression. The HADS is well validated in assessing anxiety and depression in a cancer population.

#### Statistical analyses

The level of cue responding was calculated as ((the number of exploring+acknowledging behaviours) -(the number of distancing behaviours))/ total number of cue responses. This variable was used for subsequent analyses of nurse responses.

Those conversations where patients emitted less than three cues (n=5) were excluded from analyses of nurse responses.

We first obtained descriptive statistics on all study variables. We then examined the bivariate relations between the independent variables and the outcome variable, using Pearson and Spearman correlations. Independent variables were evaluated for potential inclusion in our model based on a statistical significant association (criteria for significance p<0.05) with the outcome variable, i.e.

patient satisfaction with nurses' cue responding. We used a linear mixed-model approach in SPSS 14.0 software to evaluate the relation of cue responding with patient satisfaction adjusting for confounding variables and correlation due to the repeated observation of each nurse. This produces coefficients that measure the amount of change in patient satisfaction for a unit of change in cue responding.



#### RESULTS

The patient sample consists of 45 females and 55 males, with an average age of 54 years. Thirty-eight percent of patients had completed university or some other form of tertiary education. The sample was heterogeneous for primary site of the cancer and disease stage. Seventeen percent of the patients having haematological cancer, 16% having a gastro-intestinal cancer and 16% having lung cancer, the remainder distributed evenly across other sites. Chemotherapy was the current treatment for 58% of the patients. Patient sociodemographic and disease characteristics are displayed in Table 1. The nurse sample consists of 28 females and six males, with an average age of 38 years ranging from 23 to 59 years of age. A majority of nurses (65%) was employed at medical wards (Medical Oncology, Hematology, Lung Diseases) and 35% at surgical wards (Breast/Gastrointestinal, Urology/Gynaecology, Orthopaedy).

# [TABLE 1]

## Patients' cue expression

The mean number of patient turns per conversation was 56.3. The mean number of cues per conversation was 14.2 (95% CI: 12.7–15.7), with a minimum of one to maximum 30 cues per conversation. Per conversation 25% of the patient turns contained cues, while 75% contained neutral expressions. The mean numbers of different cue levels are displayed in Table 2. The largest part of the cues (70%) were expressions that signalled worry or concern (level 1), while only 24% of the cues mentioned worry or concern (level 2) and 6% clearly expressed unpleasant emotion (level 3).

#### Nurses' cue responding

Per conversation 21% of the cues were explored, 24% were acknowledged and 55% were responded to with distancing behaviours (see Table 2). The mean level of cue responding per conversation was -0.18 (SD=0.43, range -1.0 to 0.87 and 95% CI: -0.27 to -0.09). The level of cue responding was calculated as ((the number of exploring+acknowledging behaviours)-(the number of distancing behaviours))/total number of cue responses. Cueresponding levels higher than 0.0 were found in about 36% of the conversations. In these conversations more cues were acknowledged or explored than responded to with distancing behaviours. The extracts shown in Figure 1 illustrate the exploring and acknowledging responses of nurses to patients' cues on the one hand and distancing responses on the other.

## [TABLE 2]

## Perceived performance of the nurse

Performance scores of the Likert-type scale were transformed into standardized scores, ranging from 0 to 1. The mean perceived performance of the nurse per conversation was 0.50 (SD=0.16, range 0.05–0.79 and 95% CI: 0.46–0.53).

#### **Correlational analyses**

To examine relations between perceived performance and cue responding, a series of correlations were calculated between the perceived performance scores, cue responding and possible confounders.

The correlation results involving perceived performance as well as intercorrelations among the other variables are demonstrated in Table 3. Perceived performance was positively correlated with cue responding and aim of treatment, at the p<0.01 level of significance. Perceived performance was also positively correlated with the number of cues and patients' age, at the p<0.05 level of significance.

The size of the correlations varied from r=0.23 for patients' age to r=0.33 for aim of treatment. The correlations with current treatment, anxiety or depression scores failed to meet criteria for significance. Exploratory analyses examining other patient and nurse



characteristics demonstrated no particular correlations with perceived performance. Although anxiety and depression scores (HADS) were not directly related with perceived performance, HADS scores did correlate with the number of cues and aim of treatment (see Table 3). In summary, those patients who reported higher performance scores also were of older age and had palliative treatment.

# [FIGURE 1]

## Mixed-model analyses

Mixed-model analyses were performed to examine whether cue responding remained related with perceived performance, after controlling for patients' age and aim of treatment, while adjusting for correlation due to repeated observation of each nurse. Number of cues, although significantly correlated with perceived performance, was not included in the model because of collinearity with cue responding (see Table 3). The mixed-model results are demonstrated in Table 4. Cue responding and palliative treatment independently contributed to perceived performance of the nurse.

Patient age was not a significant contributor.

The resulting equation of the model to predict patient satisfaction with communication is presented as follows: perceived performance (0-1)=0.47+0.09 [cue responding (-1 to +1)] - 0.09 [curative treatment (0.1)]. The residual component estimate of the model=0.02 with a standard error of estimate=0.004 (p<0.0001), which indicates that there are virtually no systematic differences between the nurses. In other words, the effect of clustering from observations at the nurse level was not significant. Consequently, we also applied a normal regression model to the data, this gave an R2 of 19%.

[TABLE 3]

[TABLE 4]

## DISCUSSION

The present study is the first that empirically confirms that oncology nurses' cue responding is independently related to patient satisfaction with communication. The only study with which our findings may be compared involves physicians' cue responding [1], which found no correlation between physicians' cue responding and patient satisfaction with the conversation. Our finding in comparison to Butow's *et al.* [1] study may be explained by the timing of the assessment of patient satisfaction with communication. In the current study, patient satisfaction was assessed immediately after the conversation, while Butow *et al.* [1] assessed patient satisfaction 7–10 days after the conversation. Yet, when measured not close to the moment of the actual performance, satisfaction tends to reflect improvement in functioning rather than satisfaction with particular health-care provider behaviour [30,36]. In the broader context of the emotional dimension of communication, our finding is in line with previous work [11–14,16,37] that showed that the emotional dimension of provider communication is valued by patients.

Our data also showed that patients who are palliatively treated were more satisfied with the communication of nurses than curatively treated patients, and this was true after controlling for the level of cue responding and patient age. This finding is at odds with findings from other studies [30,32,33,38], which reported that poor health status is associated with low satisfaction scores.

Our finding suggests that curatively treated patients in comparison with palliatively treated patients have a different perception of attention that is paid to their cues of worries and concerns.



Perhaps the emotional needs of palliatively treated patients, and the associated phenomenon of cognitive dissonance, renders them to value the emotional dimension of communication and thus have a clearer perception of cue-responding behaviour even when not supported by the observational data. In other words, curatively treated patients may be less receptive to cue-responding behaviour when displayed by the nurse. This is an indication that curatively treated patients expect less in terms of emotional communication. To substantiate this we used data (not shown) on the importance that patients assigned to the attention nurses pay to their worries and concerns. Post-hoc analyses on these data confirmed that curatively treated patients find it less important that nurses pay attention to their worries and concerns (p < 0.05).

Although patient age correlated with patient satisfaction with communication it did not independently contribute to patient satisfaction with communication. It appears that the correlation of patient age with patient satisfaction is included in aim of treatment, i.e. palliative treatment is associated with older age.

The low estimate of the residual term in the model suggests that only few differences in the performance score cannot be effectively explained by variables in the model, i.e. cue responding and aim of treatment.

Another striking finding of our study is that patients are indeed implicit in their expression of concerns, i.e. 70% of the patients' cues were hints at worry or concern (level 1 cue). This result highlights the potential benefit of nurses' responsiveness to patients' cues, which may lead to a better identification of patient concerns. In view of the finding that more than half of the patients' cues were responded to with distancing behaviours, it seems appropriate to make an effort to improve the cue-responding skills of oncology nurses.

The modest correlation of cue responsiveness with patient satisfaction was slightly disappointing.

We have no clear explanation for this finding. We expected a stronger correlation because nurses' responsiveness to patients' cues is exemplary for patient-provider fit, which is correlated with increased patient satisfaction [39,40]. A possible explanation may have to do with the coding of cues, which does not accurately distinguish cues that signal a need to express emotions from cues that signal a preference to conceal and control emotions. Consequently, the (mis)match of nurses' behaviour to cues that signal a preference to conceal emotions cannot be coded, which may have had an influence on the correlation of cue responsiveness with patient satisfaction. We recommend future research to examine if the MIARS can be extended with a behavioural element to code cues that 'signal a need to conceal worries or concerns'. A second possible explanation, also related to the coding of cues, is that coding of cues in the current study was limited to emotional cues and that coding of informational cues was ignored. This could potentially have influenced the correlation of cue responsiveness with patient satisfaction. For instance, when numerous informational cues were emitted and adequately responded to by the nurse this could have translated into a high satisfaction score while the actual level of responding to emotional cues could have been low. Future studies that examine cue responding in relation to patient satisfaction should consider extending the MIARS with a separate category denoting 'cues that signal a need for information'.

A final explanation may be that in the current study really good conversations in terms of cue responsiveness are under represented in the sample.

Only 13 of 95 conversations are rated with a cueresponsiveness score of 0.30 or higher. Some study limitations should be considered.

Firstly, patient satisfaction is a self-report measure that may have introduced recall bias and rendered patients to answer in a social desirable manner.

This could have influenced the strength of the correlation with cue responsiveness. We do however think that the chance that this actually occurred is small, since the timing of measurement was close to the moment of the actual conversation.



Secondly, although we included the known patient and nurse characteristics that potentially influence patient satisfaction, there may have been unmeasured characteristics of patients and nurses that influenced patients' report of satisfaction with communication. If these unmeasured variables account for the moderate association observed in these data, we would erroneously infer that cue responding is only marginally appreciated by patients. A final limitation has to do with the patient sample, i.e. nearly all patients in the current study were Caucasian. As ethnicity and culture can possibly influence patient satisfaction with communication, future studies are needed that use more culturally diverse patient samples. Yet, the strength of this study is built on several facts. Firstly, we used observational data of patient-nurse interaction to investigate the relation of cue responding with patient satisfaction. Secondly, we conceptualized patient satisfaction as the patient's judgement about the responsiveness of nurses for care aspects that are felt to be important by patient. This makes it less sensitive for the phenomenon of cognitive dissonance and subsequent positively skewed data, in comparison with overall global satisfaction rating. A final strong feature of the current study is the random selection of both nurses and patients, limiting the risk of selection bias.

Our results indicate that patient satisfaction is related with the level of nurses' cue responding and can satisfactory be predicted in a model containing level of cue responding and aim of treatment (palliative vs curative). Since, we do not share a deontological view of communication as an end-initself, we recommend future research to focus on the relation of cue responding with more distal outcome measures, for instance, identification of concerns, mood and coping behaviour.

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## [APPENDIX A]

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#### TABLES ,FIGURE AND APPENDIX

Table I. Sample characteristics

		Mean ( $\pm$ SD),
	%	range
Patient sociodemographic and medical of	har	acteristics (N = 100)
Male gender	55	_
Age (yrs)	_	54.4 (±  6. ),  7-85
Civil status		
Single	9	_
Married, cohabiting or living apart together	91	
Education		
High	38	_
Medium	31	
Low	31	_
Caucasian race	97	
Cancer diagnostic group		
Hematological	17	
Lung	16	
Gastrointestinal	16	
Bone and soft tissue	10	_
Female reproduction organs	9	
Urinary tract	8	_
Breast	8	
Male reproduction organs	7	_
Skin	4	
Head and neck	2	
Undifferentiated carcinoma	2	
Central nervous system		
Time since diagnoses (months)		2.4 (±3 .9), 0–24
Metastases		
No metastases	45	
Mestastasis	38	
Not applicable (hematological cancer)	17	
Current treatment		
Chemotherapy	58	
Surgery	33	
Miscellaneous	9	
Aim of treatment		
Curative	55	
Palliative	45	
HADS-Anxiety (0–21)		6.0 (±4.0), 0-17
HADS-Depression (0–21)	_	5.4 (±4.0), 0–19



Table 2.	Patients'	cue expr	ession	and	nurses'	cue	responding
in videota	ped conv	ersations	(N = 1)	00)			

	Mean number per conversation (range)	95% Confi- dence inter- val
Cue expression		
Cues level 1: expression that	10 (1-27)	8.9-11.1
hints at worry or concern		
Cues level 2: expression that	3.4 (0–11)	2.8-4.0
mentions worry or concern		
Cues level 3: clear expres-	0.8 (0-15)	0.31-1.29
sion of unpleasant emotion		
Cue responding		
Exploring	3.0 (0-16)	2.4-3.6
Acknowledging	3.4 (0-12)	2.8-4.0
Distancing	7.9 (1-20)	7.1–8.8

**Table 3**. Correlations for primary study measures (N = 95)

		I.	2	3	4	5	6	7
١.	Perceived performance							
2.	Cue responding	0.27						
	p-Value	0.007						
3.	Number of cues	0.24	0.38					
	p-Value	0.021	0.000					
4.	Age patient	0.23	0.05	-0.03				
	p-Value	0.025	ns	ns				
5.	Aim of treatment ( $0 = curative$ , $  = palliative$ )	0.33	0.10	0.23	0.21			
	p-Value	0.001	ns	0.024	0.043			
6.	Current treatment ( $0 =$ surgery, $  =$ chemotherapy and miscellaneous)	0.10	0.22	0.07	-0.02	0.33		
	p-Value	ns	0.034	ns	ns	0.001		
7.	HADS anxiety	0.07	0.05	0.36	0.05	0.27	-0.16	
	p-Value	ns	ns	0.000	ns	0.009	ns	
8.	HADS depression	0.09	-0.5	0.30	0.12	0.22	0.13	0.49
	p-Value	ns	ns	0.004	ns	0.032	ns	0.000

ns = not statistically significant.

Table 4. Results mixed model approach adjusting for age and aim of treatment (N = 95)

		Perceived performance (0–1)					
	<b>B</b> ata		p-Value	95% Confidence interval			
	Beta	(SE beta)		Lower	Upper		
Intercept	0.47	0.06	< 0.000	0.35	0.59		
Cue responding $(-1 \text{ to } +1)$	0.09	(0.03)	< 0.05	0.02	0.16		
Aim of treatment (curative vs palliative)	-0.09	(0.03)	< 0.0	-0.15	-0.03		
Patient age			NS	_	_		



	Distancing responses to patients'cues:	MIARS coding
Ρ	Because this (points at her amputated shoulder)this is most	Cue-level 2
	horrifyingthat this is flattenedso thin it is even difficult for me	
	to look at it right now	
Ν	Okayit seems that you and your husband can handle the	Distancing
	situation you are able to talk about it?	
Ρ	Yeswith different people	
Ρ	They first thought it was an infectionthey can detect it in the	Cue evel 2
	bloodand when uhnothing of an infection could be foundsoit	
	is a <b>ll</b> so strangeI am worriedbut yeah <b></b>	
Ν	And how are things going at home?	Distancing, open
		directive question
	I de la constant d'a sinte a d'a service. Marchene de la constant de la constant	Conclusion 1
٢	adon t want to die sick and in agony, you know what I meanthe	Cue level 1
	have to find a way for this	
N	Has any emotional support been offered?	Distancing
	has any emotional support seen onerca.	Distancing
Р	It drags on too longlike riding in an old car, waiting for it to break	Cue level 1
	downyou say goodbye to them and that's it	
Ν	Wellit is a good thing that, while you were undergoing treatment,	Distancing
	you could still make plansso I believe that you should look back	
	positively	
	Adequate responses to cues of patients:	
Ρ	My husbandhe is very tired at the momentit is the stress you	Cue level 1
	know and he is upset of coursehe gives me as much support as he	
	can, but he cannot cure meand I have to keep asking for	
	everythingof course my friend is a big help but	
Ν	Is that difficult for you to have to ask for help for almost everything?	Exploring
Р	Awful, terrible   am still not used to it to be so dependent	Cue level 2
	makes me depressed	
Р	And then they said they were going to do a caesarean section and	Cue level 2
	yes, because I had to undergo general anaesthesia, I thought I'd	
	never wake up againthat was a really frightening idea yestruly	
N	can imagine, how did that idea came about?	Exploring, open
		directive question
Р	Because things were going very bad at that timeI was in my worst	Cue level 2
	nadir (lowest blood cell counts during period after stem cell	
	transplant) so I really had the ideaeverybody had told me that a	
	caesarean section would be dangerous, especially because of my	
	condition, the nadir $\ldots$ it frightened me $\ldots they \ would \ give \ me \ general$	
	anaesthesia to get her ( <i>the baby</i> ) and thenyes thenwhat wi <b>ll</b>	
	happen to me thenyes that was truly distressing	

Figure I. Examples of distancing and adequate responses to patients' emotional cues



#### Appendix A

#### The concerns checklist

Are you worried about ... (response options are 'no' or 'yes')

- 1. The illness itself
- 2. The treatment of your illness
- 3. The impact of disease and treatment on the emotions of your family<sup>1</sup>
- 4. The impact of disease and treatment on the functioning of your family  $^{\rm I}$
- 5. Any of the following physical complaints or symptoms: #

a. Pain

- b. Low energy level
- c. Breathlessness
- d. Appetite<sup>2</sup>
- e. Weight loss<sup>2</sup>
- f. Weight gain<sup>3</sup>
- g. Nausea and vomiting
- h. Diamhea or constipation
- i. Pressure ulcers<sup>3</sup>
- j. Excessive sweating<sup>3</sup>
- k. Fever<sup>3</sup>
- I. Infection<sup>3</sup>
- i. Intection
- m. Dizziness<sup>3</sup>
- n. Other symptoms, namely.....
- 6. The way you handle your emotions
- 7. Loosing your independence<sup>4</sup>
- 8. The professional support you receive<sup>3</sup>
- 9. The professional support you may need in the future<sup>3</sup>
- 10. The impact of disease and treatment on your future

# Original items that are related to physical complaints or symptoms are placed under one heading. <sup>1</sup>The original item 'family' was splitted into two separate items.

- 'The original item 'family' was splitted into two separate items. <sup>2</sup>The original item 'appetite and weight loss' was splitted into two separate items.
- <sup>3</sup>New item added to the present list.
- <sup>4</sup>The original item 'independence' was splitted into five separate items.

- 11. The impact of disease and treatment on your concentration<sup>3</sup>
- 12. The impact of disease and treatment on daily social activities<sup>4</sup>
- 13. The impact of disease and treatment on your appearance
- 14. The impact of disease and treatment on basic self-care activities<sup>4</sup>
- 15. The impact of disease and treatment on daily house-hold activities<sup>4</sup>
- 16. The impact of disease and treatment on work<sup>4</sup>
- 17. The impact of disease and treatment on your finances<sup>3</sup>
- 18. The impact of disease and treatment on the relationship with your  $\mathsf{partner}^3$

19. Any other concerns, which have not been mentioned already, namely.....