Cognitive coping style (monitoring and blunting) and the need for information, information satisfaction and shared decision making among patients with haematological malignancies

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Abstract

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Objective: A haematological malignancy is a serious, life-altering disease and may be characterised as an uncontrollable and unpredictable stress situation. In dealing with potentially threatening information, individuals generally utilise two main cognitive coping styles: monitoring (the tendency to seek threat-relevant information) and blunting (avoiding threatening information and seeking distraction). The aim of this study was to obtain insight into the association between cognitive coping style and (a) need for information, (b) satisfaction with information, (c) involvement in decision making, and (d) quality of life (QoL).

Methods: In this cross-sectional study, coping style was assessed among adult patients diagnosed with a haematological malignancy, using an adapted version of the Threatening Medical Situations Inventory. Information need, information satisfaction, decision-making preference and QoL were measured with validated questionnaires.

Results: In total, 458 patients returned the questionnaire (66%). A monitoring coping style was positively related to need for both general and specific information. Blunting was positively and QoL was negatively related to need for information. Monitoring was positively related to involvement in decision-making and negatively to information satisfaction. Using multivariate analysis, this relation between monitoring and information satisfaction disappeared, and for blunting, we found a negatively significant relation. QoL was not related to coping style.

Conclusions: Among patients with haematological malignancies, coping style is related to a need for information, information satisfaction, and involvement in treatment decision-making. Therefore, it is important for health care professionals to be aware of individual differences in cognitive coping style. Copyright © 2014 John Wiley & Sons, Ltd.

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Background

Providing timely and accurate information to patients diagnosed with a haematological malignancy is a challenge in clinical practice. In case of acute leukaemia, aggressive non-Hodgkin lymphoma or multiple myeloma treatment frequently has to start promptly, with little time to inform patients. Furthermore, it is particularly difficult to inform the patient on the diagnosis, prognosis and various intensive therapy options, which are all associated with serious and even fatal complications.

With regard to information provision, health care professionals generally advised to tailor the type and amount of information to patients' individual needs [1], but knowledge on the perceived need for information in patients with haematological malignancies is scarce [2]. At the same time, unfulfilled information need is a risk factor for the patient because it may cause several problems such as a reduced ability to cope with the disease [3], whereas satisfaction with information received is associated with better health outcomes [4–6].

Worldwide, more than 850 000 patients are diagnosed with a haematological malignancy each year [7]. A diagnosis of a haematological malignancy constitutes a serious uncontrollable and unpredictable medical stress situation. According to the literature, individuals dealing with potentially threatening information may use two main cognitive coping styles: monitoring (the tendency to seek threat-relevant information) and blunting (avoiding threatening information and actively seeking distraction under impending threat) [1]. Under impending medical threat, high monitors are highly concerned about their risks, scan for potentially threatening health information, increase the threatening cues and worry about these signals. Low monitors, however, refrain from engaging in this behaviour [8]. It has been shown that high monitors are less satisfied with the information provided than low monitors [8,9]. The blunting coping style has empirically been shown to be independent of monitoring [10]. High blunters avoid confrontation with potentially threatening information, minimise informational uptake and instead engage in distracting cognition and behaviours.

According to several studies, information is more effective, and patients adapt better to the situation if the provided information is tailored to their monitoring or blunting coping style [8,11]. Furthermore, cognitive coping style influences the involvement in the decisionmaking process [8,9,12–14]. Monitoring and blunting may therefore be useful concepts in clinical cancer care in order to tailor the information to the individual patient.

The aim of this study was to test the following hypotheses in patients with haematological malignancies: (a) monitoring is positively and blunting is negatively associated with the need for information regarding the disease, its treatment and related psychosocial issues; (b) monitoring is negatively related with information satisfaction, (c) monitoring is positively and blunting is negatively related with involvement in decision-making; and (d) monitoring is negatively related with quality of life (QoL).

Methods

Patients

Patients, 18 years and older, were asked to participate in the study if they were visiting the outpatient haematology clinic at the VU University Medical Center (VUmc), Amsterdam, or the Medical Centre Alkmaar, Alkmaar, the Netherlands, between April and December 2010. Participation was restricted to those diagnosed with a haematological malignancy: acute and chronic myeloid or lymphatic leukaemia, Hodgkin and non-Hodgkin lymphoma or multiple myeloma. Exclusion criteria were concurrent treatment of another malignancy, terminal phase of the disease, mental or physical inability to participate in the study, and lack of basic fluency in Dutch. No restrictions were made regarding treatment modality or time since diagnosis.

Measurements

Coping style was measured with an adapted version of the Threatening Medical Situations Inventory (TMSI), devised to measure two cognitive coping styles in the domain of threatening medical situations [1,10]. We used the psychometrically tested abbreviated version, which comprises two of the original four threatening situational descriptions [10,12], and added a third situation, that is, receiving the diagnosis of a haematological malignancy, in order to improve the relevance of the questionnaire for our patients. The TMSI is devised to measure two cognitive coping styles in the domain of threatening medical situations: monitoring and blunting [1]. Each threatening description is followed by six items, three monitoring and three blunting, in a random order, to be answered on a five-point Likert scale. Total monitoring and blunting scale scores were analysed as continues variables (for detailed description, refer to addendum).

To measure the perceived need for information, we compiled a questionnaire using existing validated and reliable instruments with complementary subscales: the Toronto Information Needs Questionnaire (TINQ)-Breast Cancer [15], the Patient Information Needs Questionnaire (PINQ) [16] and the Patient Learning Needs Scale (PLNS) [17]. From these instruments, duplicated items and irrelevant items (for instance, on mammography) were removed, resulting in a 92-item questionnaire. The English items were translated into Dutch back and forth by both a native English and Dutch speaker. Satisfaction with the current information provision was measured using the Information Satisfaction Questionnaire [18]. QoL was assessed using the European Organization for Research and Treatment of Cancer QoL Questionnaire C30 (version 3.0, Dutch version) [19].

Sociodemographic information was collected via a short study-specific questionnaire. Co-morbidity was measured using the Adult Co-morbidity Evaluation-27 [20] (for details of the various instruments, refer to the addendum). To evaluate possible participant bias, we also collected sociodemographic data and clinical parameters from the medical records of non-participants. For more information on the used questionnaires, refer to Supporting Information.

Informed consent and procedure

This study was approved by the Medical Ethical Committee of the VUmc. Written informed consent was obtained from all patients. After hospital visit, patients could fill out the questionnaires online or on paper. After 3 weeks, patients who had not responded were contacted once again.

Statistical analysis

Based on a 95% confidence level and an accuracy value of 0.05, the required sample size was at least 384 patients. Moreover, at least 30 patients per diagnosis were desirable for subgroup analysis. All continuous variables were tested for normality with Kolmogorov–Smirnov tests, and Cronbach's alpha was used to assess the internal consistencies of all subscales.

Associations between need for information and information satisfaction with coping style were tested with Spearman correlation coefficients.

Mann–Whitney tests were used to test differences in information satisfaction versus coping style. The Kruskal–Wallis test was used to test differences in decision-making preference between coping styles. Chi-square tests and Mann–Whitney tests were used to test differences in respectively ordinal and continuous demographic and clinical variables between participants and non-participants and between missing values and non-missing values [21].

Linear regression was used as a multivariate technique to test the relation between the need for information as a dependent variable (total scores of the TINQ, PINQ and PLNS) and the independent clinical and demographic variables. Logistic regression analysis was used as a multivariate technique to test the relation between, first, information satisfaction and, second, treatment decisionmaking and the clinical and demographic variables, coping style and QoL. For the second analysis, we combined the two last answer options into one variable 'limited information'.

Univariate variables with a significance of p < 0.10 were entered into the multivariate regression analysis. For all the other statistical analyses, a p < 0.05 was considered to indicate a statistically significant difference. For each analysis, we used the statistical software package SPSS, version 19.0.

Results

Study population

In total, 458 patients returned the questionnaire (66% response rate). A minority (7%) completed the questionnaire online. The mean age was 60.2 years and 55% were male patients. The majority of the patients was diagnosed with a lymphoma (45%), and most were diagnosed more than 2 years ago (61%). For an overview of all sociodemographic and clinical data, refer to an earlier published article [21].

Patients who participated in the study did not differ from non-participants in terms of sociodemographic or clinical characteristics, except for treatment intent (Pearson $\chi^2 = 24.36$, p < 0.001). For detailed description and psychometric findings of the used questionnaires, refer to addendum.

Coping style and the need for information

Monitoring was significantly and positively related to the need for information for all total scores on the three questionnaires (TINQ, PLNS and PINQ) and for all subscales, with moderate correlations around 0.25–0.30 (Table 1). Also, blunting was significantly and positively related with need for information regarding the total scores of

 Table 1. Overview of Spearman correlations between coping style

 and information need subscales

		Mo	nitoring	Blunting		
	Subscale	r	p-value	r	p-value	
TINQ	Total	0.32	< 0.00	0.11	0.145	
	Disease	0.30	< 0.00	0.18	0.001	
	Investigative tests	0.27	< 0.00	0.16	0.003	
	Treatment	0.30	< 0.00	0.09	0.204	
	Physical	0.24	< 0.00	0.24	< 0.00	
	Psychosocial	0.23	< 0.00	0.14	0.009	
PLNS	Total	0.29	< 0.00	0.17	0.003	
	Support and care in the community	0.26	< 0.00	0.14	0.008	
	Medication	0.22	< 0.00	0.14	0.009	
	Treatment and activities of living	0.27	< 0.00	0.16	0.002	
	Illness-related factors	0.27	< 0.00	0.17	0.001	
	Complications and symptoms	0.17	0.002	0.13	0.016	
PINQ	Total	0.31	< 0.00	0.14	0.013	
	Disease	0.34	< 0.00	0.13	0.018	
	Active	0.25	< 0.00 I	0.10	0.05	

Significant correlations are shown in italics.

 ${\sf TINQ},$ Toronto Information Needs Questionnaire; PLNS, Patient Learning Needs Scale; PINQ, Patient Information Needs Questionnaire.

two of the three questionnaires (PLNS and PINQ) and for all subscales, except for TINQ treatment and PINQ active. However, the correlations were low (mostly between 0.10 and 0.20).

Multivariate regression analysis revealed that monitoring had a significant positive relation with need for information on all three questionnaires (TINQ, PLNS and PINQ). On two of the three total scales (PLNS and PINQ), blunting was positively related and QoL negatively related with the need for information. Demographic and clinical variables were not related with the need for information (Table 2).

Coping style and satisfaction with information

Monitoring was related with the perception that the information provision could have been improved (Mann–Whitney U=10728.0, Z-2.37; p=0.018). With respect to blunting, no significant difference was found (Mann– Whitney U=11260.0, Z-1.83; p=0.067). There were no significant associations between coping style and information satisfaction questions (ISQ 3 to 8 together (ISQ total)) for either monitoring (r=-0.074, p=0.156) or blunting (r=-0.036, p=0.492).

Using multivariate logistic regression analysis, the relation between the monitoring coping style and information satisfaction disappeared (B = -0.015, p = 0.398). For blunting, we found a slightly negative relation between a high-blunting coping style and information satisfaction (B = -0.038, p = 0.048). Other demographic and clinical variables were not related with information satisfaction (Table 3).

Table 2. Overview of the relations between the need for information (total scores) on TINQ, PLNS and PINQ and sociodemographic andclinical variables, quality of life (global quality of life on European Organization for Research and Treatment of Cancer QoL QuestionnaireC30) and coping style (TMSI)

			TI	NQ		PLNS				PINQ				
		Univariate		Multiv	Multivariate		Univariate		Multivariate		Univariate		Multivariate	
Variable		$Z/\chi^2/r$	p-value	В	p-value	$Z/\chi^2/r$	p-value	В	p-value	$Z/\chi^2/r$	p-value	В	p-value	
Gender	Female	-2.18	0.029	4.435	0.305 0.305	-2.20	0.045	-0.349	0.901 0.901	-1.60	0.110			
	Male			0	0.303			0	0.701					
Age		-1.99	0.007	-0.255	0.174	-1.41	0.001	-0.239	0.056	-1.43	0.006	-0.164	0.237	
Marital Sta	atus	— I.89	0.059		0.460	-0.75	0.454			-0.58	0.565			
	Alone			-3.675	0.460									
	Together			0										
Education	level	2.75	0.252			2.21	0.332			1.12	0.572			
	Primary Secondary													
	Higher													
Diagnosis		6.73	0.082		0.757	6.27	0.099		0.123	8.84	0.032		0.239	
	Acute leukaemia			6.31	0.418			4.925	0.365			8.249	0.218	
	Chronic leukaemia			-3.599	0.621			-6.045	0.096			1.186	0.842	
	Multiple myeloma			2.553	0.642			3.297	0.429			8.443	0.085	
	Lymphoma			0				0				0		
Time since	e diagnosis	2.98	0.562			0.38	0.984			2.76	0.599			
Co-morbio	•	7.17	0.067		0.842	12.44	0.006		0.130	5.59	0.133			
00 110101	No	,,	0.007	7.400	0.513		0.000	0.029	0.997	0.07	01100			
	Mild			5.237	0.653			4.272	0.553					
	Moderate			9.098	0.436			8.881	0.220					
	Severe			0	0.150			0.001	0.220					
Stom coll t	transplantation	-1.32	0.187	0		-2.35	0.019	0	0.767	-1.75	0.081		0.663	
Sterri Cerri	Not transplanted	-1.52	0.107			-2.55	0.017	29.251	0.218	-1.75	0.001	20.829	0.003	
	Autologous							30.611	0.218			19.231	0.231	
	*							27.892	0.203			14.952	0.277	
	Allogenic							27.408						
	Autologous and allogenic Matched unrelated donor							27.408 0	0.263			14.788 0	0.420	
Treatment	t intent	8.49	0.037		0.191	3.59	0.310			3.85	0.037		0.189	
	Active surveillance			-9.836	0.549							-19.427	0.070	
	Curative			-12.617	0.521							-7.554	0.637	
	Maintenance			-26.766	0.154							-26.832	0.033	
	Palliative			0								0		
Treatment	t response	8.11	0.044		0.852	6.07	0.108			6.83	0.077		0.300	
	Complete remission			12.605	0.517							9.128	0.555	
	Partial remission			11.591	0.486							19.416	0.062	
	Stable disease			12.712	0.420							16.182	0.104	
	Progressive disease			0								0		
Hospital	0	-0.71	0.478			-1.96	0.049		0.433	-1.77	0.077		0.333	
	Medical Center Alkmaar							2.735	0.433			4.23	0.333	
	VU University Medical Cen	nter					0					0		
Member c	patient association	— I.38	0.169			-2.29	0.022		0.274	-3.06	0.002		0.070	
· P	Yes							4.159	0.274			7.705	0.070	
	No							0				0	/ -	
Total mon		0.32	< 0.001	0.981	< 0.001	0.29	< 0.001	0.694	< 0.001	0.31	< 0.001	0.867	<0.001	
Total blunt	0	0.11	0.145	5.701	20.001	0.17	0.003	0.493	0.015	0.14	0.013	0.487	0.034	
. o car orann	ality of life	-0.05	0.535			-0.16	0.004	-0.222	0.001	-0.15	0.004	-0.204	0.009	

Significant relations are showed in italics.

TINQ, Toronto Information Needs Questionnaire; PLNS, Patient Learning Needs Scale; PINQ, Patient Information Needs Questionnaire. Univariate variables with a p-value <0.10 were entered in the multivariate regression analysis.

Coping style and decision-making preference

In response to the ISQ on how much information patients desire and the preferred involvement in decision-making,

high monitors showed a stronger desire for more information and more involvement in decision-making than low monitors (p < 0.001). For blunting, no differences were found (p = 0.350; table 4).

			Information s	atisfaction		Treatment decision-making					
Variable		Univariate		Multivariate		Univariate		Multivariate			
		χ ² /U	p-value	В	p-value	χ ² /U	p-value	В	p-value		
Gender		0.08	0.776			5.925	0.052	0.156	0.635		
	Female Male										
Age Marital status		13 294.500 0.012	0.016 0.912	0.013	0.193	11.966 2.285	0.003 0.319	0.004	0.755		
	Alone Together										
Education level	Primary	11.806	0.003		0.057	10.054	0.040		0.351		
	Secondary			-0.119	0.761			0.150	0.707		
	Higher			-0.718	0.077			-0.430	0.369		
Diagnosis		9.507	0.023		0.243	2.007	0.919				
	Acute leukaemia				0.0/5						
	Chronic leukaemia			0.952 0.700	0.065 0.174						
	Multiple myeloma Lymphoma			0.700	0.174						
Time since diag	/ /	5.417	0.247	0.401	0.525	8.689	0.369				
Co-morbidity	10313	5.581	0.134			10.850	0.093		0.174		
	No	515 51	01101			101000	0107.5		0.1.7		
	Mild							0.010	0.981		
	Moderate							0.327	0.468		
	Severe							1.358	0.031		
Stem cell transp	lantation	0.022	0.882			1.277	0.528				
Treatment inter	ıt	2.180	0.536			10.115	0.120				
Treatment respo	onse	5.001	0.172			6.224	0.399				
Hospital		1.222	0.269			17.151	< 0.00 l	-0.404	0.240		
	MCA										
	VUmc										
Member patient	t association Yes	4.619	0.032	0.451	0.163	9.168	0.010	0.357	0.503		
	No										
Total monitoring	g	10 728.000	0.018	-0.015	0.398	55.214	<0.001	-0.174	< 0.001		
Total blunting		11 260.000	0.067	-0.038	0.048	2.099	0.350				
Quality of life		13 081.000	0.041	0.173	0.097	5.199	0.074	0.135	0.310		

Table 3. Overview of the relations between information satisfaction (ISQ2), treatment decision-making (ISQ1) and sociodemographic and clinical variables, quality of life (European Organization for Research and Treatment of Cancer global) and coping style (TMSI)

Significant relations are showed in italics.

Univariate variables with a p-value <0.10 were entered in the multivariate regression analysis.

Multivariate regression analysis revealed that this relation between a high-monitoring coping style and treatment decision-making persisted (B = -0.174, p < 0.001). Other demographic and clinical variables were not related with treatment decision-making (Table 3).

Coping style and quality of life

No significant relation was found between coping style and QoL (monitoring r=0.065, p=0.204, blunting r=0.042, p=0.409).

Discussion

The finding that a monitoring coping style was positively related with the need for information (hypothesis 1) is consistent with our hypothesis and confirms the results of previous studies in patients with cancer and during gastrointestinal endoscopy [8,12,13,22]. More precisely, they are in line with previous research, which found a higher need for medical as well as psychosocial information in patients with a monitoring coping style [13]. However, it should be mentioned that in all these studies, the correlations found were moderate, indicating that other factors may also influence the need for information. However, using linear regression analysis, only coping style and global QoL were related with the need for information.

In the present study, contrary to our expectations, patients with a blunting cognitive coping style also had a high need for information, which is in contrast to previous studies investigating coping style during gastroscopy, before an electric shock, and during palliative and curative radiotherapy consultations, and it is also in contrast with the original theory, in which high blunting was associated with a lower need for information [1,13,22]. An explanation for the absence of a

	l would like all available information and be involved in decisions about my illness		I would only like positive information about my illness		l would only like l information and would doctor to make the			
-	Median (IQR)	N	Median (IQR)	N	Median (IQR)	N	χ ²	p-value
Monitoring Blunting	29.00 (10.00) 29.00 (9.00)	314 314	21.50 (10.00) 24.00 (17.00)	2 3	19.00 (9.25) 29.00 (9.00)	54 53	55.21 2.10	<0.001 0.350

Table 4. Associations between decision-making (ISQ 1) and coping style (total monitoring and blunting) with Kruskal–Wallis test

Significant associations are showed in italics.

IQR, interquartile range

negative relation in the present study might be that most patients were included more than 2 years after diagnosis, when their lives were no longer dominated by dealing with potentially threatening circumstances as at the time of the overwhelming diagnosis. In this new situation, information might be welcomed anyway as a form of distraction, for high as well as for low blunters. This is also in accordance with the study of Baker, in which high-monitoring patients prefer information later on in their disease [23]. Furthermore, we studied coping style among patients with a treatment intent of palliation, curation, maintenance and active surveillance, which might also mean that this patient group was in a less threatening situation than the participants of the study of Timmermans et al. where a relation was found only in the case of palliative radiotherapy [13]. In any case, when possible during the whole disease process, it is important to match the amount of information to each patient's cognitive coping style, as this can reduce the patient's level of stress [8].

Consistent with the literature and with our second hypothesis, we found with a univariate analysis that monitoring was related to lower satisfaction with the information received [8,13,24]. Timmermans et al. found that in palliative radiotherapy consultations, high-monitoring patients were less satisfied with the information received concerning treatment procedures, side effects and physical impact of the treatment. Also, in curative radiotherapy consultations, high-monitoring patients were less satisfied with the information received on treatment procedures and on the emotional impact of the treatment [13]. Furthermore, high-monitoring survivors and patients with breast cancer and healthy women were less satisfied with the prognostic information [24]. In the present study, using multivariate analysis, this relation disappeared, which is consistent with the absent relation between information satisfaction and monitoring coping style described in recent literature on information satisfaction in patients with a history of cancer and undergoing chemotherapy as a result of cancer [14,25]. It should be noted that none of the previous authors, except van Vliet et al., performed a multivariate analysis of the information satisfaction and therapy decision-making; only univariate analysis were performed. Regarding the coping style blunting, we found just a negative relation with satisfaction

with the information received. Previous studies disagree with each other on the relation between a blunting coping style and satisfaction with the information received [8,13,14,24]. Timmermans *et al.* found a higher satisfaction among only palliative high-blunting patients [13]. In addition, Elf and colleagues found, as did our present study, that high blunters were more dissatisfied with the information received [14]. van Vliet *et al.* did not find a relation between information satisfaction and high blunting [24]. A possible interpretation would be that in accordance with the theory of the blunting coping style, high blunters are not interested in information and do not seek information and might therefore not receive enough information [11].

As expected, and in line with the results of Timmermans et al. [13] and Ong et al. [12], monitoring was associated with the preference to be more involved in decision-making (hypothesis 3). In contrast, Miller found a more passive role in decision-making in high monitors, possibly because these monitoring patients tended to give the decisional control to a more competent individual, such as a physician [8]. Other research has shown that blunting was related to a more passive way of decision-making, except in palliative radiotherapy consultations [13]. The absence of a relation between blunting and decision-making found in the present study may support the idea that a patient with a haematological malignancy is already in a further phase of the threatening situation, and therefore, the need for information and involvement in decisionmaking is present in the same degree in both lower and higher blunting.

In the present study, coping style was not related to QoL (hypothesis 4). There are no previous studies on the relationship between coping style and QoL, except a recent study of Michel *et al.* on survivors of cancer, where QoL was studied as generic QoL (physical and mental) and survivor-specific QoL (psychological problems and social problems) [25]. According to this study, only a relation between high monitors and more psychological problems was found; the other three QoL sections were not related, as was the case in the current study [25]. It should be noted that they used the TMSI in a different way, by means of the calculation of a combined monitoring scale by subtracting the blunting score from the monitoring score [25].

To our knowledge, this is the first study investigating the cognitive coping styles of patients with a haematological malignancy in relation to the need for information, satisfaction with the information received, and preferences regarding shared decision-making. Some limitations should be mentioned. The inclusion of outpatients impeded the generalisability of the results to all patients diagnosed with a haematological malignancy. Most importantly, the cross-sectional design of the study, in which patients participated at various stages in their disease and treatment, does not reflect the development of information satisfaction and need for information throughout the disease process. Future prospective studies should focus on inpatients and outpatients with a haematological malignancy during their entire disease trajectory.

Our results have important implications for clinical practice. It is important for health care professionals to be aware of individual differences in cognitive coping style and the associated need for information, satisfaction with information and the wish to be involved in

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decision-making among patients with haematological malignancies.

Conclusion

Among patients with haematological malignancies, cognitive coping style is related to a need for information, information satisfaction and the wish to be involved in shared decision-making. Moreover, high blunting does not imply a reduced need for information in this patient group. Therefore, it is important for health care professionals to be aware of individual differences in cognitive coping style. Further research is needed to develop and evaluate assessment tools for quick recognition of coping styles that can be used in clinical practice.

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