

The association of having a monitoring or blunting coping style with psychological distress, health-related quality of life and satisfaction with healthcare in gastrointestinal stromal tumour (GIST) patients

Deborah van de Wal^a, Britt van Doorn^a, Dide den Hollander^b, Ingrid M. E. Desar^b, Hans Gelderblom^c, Astrid W. Oosten^d, Anna K. L. Reyners^e, Neeltje Steeghs^{a,f}, Winette T. A. van der Graaf^{a,d} and Olga Husson^{a,g,h}

^aDepartment of Medical Oncology, The Netherlands Cancer Institute, Amsterdam, The Netherlands; ^bDepartment of Medical Oncology, Radboud University Medical Center, Nijmegen, The Netherlands; ^cDepartment of Medical Oncology, Leiden University Medical Center, Leiden, The Netherlands; ^dDepartment of Medical Oncology, Erasmus MC Cancer Institute, Erasmus University Medical Center, Rotterdam, The Netherlands; ^eDepartment of Medical Oncology, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands; ^fDepartment of Clinical Pharmacology, The Netherlands Cancer Institute, The Netherlands; ^gDepartment of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, The Netherlands; ^hDepartment of Surgical Oncology, Erasmus MC Cancer Institute, Erasmus University Medical Center, The Netherlands

ABSTRACT

Background: There are two main coping styles regarding information seeking under medical threat; monitoring (information-seeking) and blunting (information-avoiding). The aim of this study is to (1) determine factors associated with a monitoring or blunting coping style in gastro-intestinal stromal tumour (GIST) patients and (2) investigate its association with psychological distress, cancer-related concerns, health-related quality of life and satisfaction with healthcare.

Methods: In a cross-sectional study, Dutch GIST patients completed the shortened version of the Threatening Medical Situations Inventory to determine their coping style, the Hospital Anxiety and Depression Scale, Cancer Worry Scale, EORTC QLQ-C30 and part of the EORTC QLQ-INFO25.

Results: A total of 307 patients were classified as blunters ($n = 175$, 57%) or monitors ($n = 132$, 43%). Coping style was not associated with tumour or treatment variables, but being a female (OR 2.5; 95%CI 1.5–4.1; $p = <.001$) and higher educated (OR 5.5; 95%CI 2.5–11.9, $p = <.001$) were associated with higher odds of being a monitor. Monitors scored significantly lower on emotional functioning ($mean = 86.8$ vs $mean = 90.9$, $p = .044$), which is considered a trivial difference, more often experienced severe fear of cancer recurrence or progression (53.0% vs 37.7%, $p = .007$), and had more concerns about dying from GIST in the future (60.6% vs 47.4%, $p = .025$). Compared to blunters, monitors were less satisfied with the received healthcare and information, and would have liked to receive more information.

Conclusion: GIST patients with a monitoring coping style experience a higher emotional burden. Additionally, monitors exhibit a greater need for information. Although this need for information could potentially result in fears and concerns, recognising it may also create an opening for tailored communication and information.

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Background

Gastrointestinal stromal tumours (GISTs) are the most common mesenchymal tumours of the gastrointestinal tract, predominantly located in the stomach and small intestine [1,2]. However, GIST is relatively rare with an annual incidence in the Netherlands of 8 per million person-years [3]. The mainstay of treatment for localised GIST is surgical resection [4], combined with (neo-)adjuvant imatinib in patients at high risk of recurrence after their resection or with locally advanced, sometimes large tumours at diagnosis [4,5]. For

patients with metastatic GIST, primary surgery is not the treatment of choice, and they often depend on life-long treatment with tyrosine kinase inhibitors (TKIs) [6]. TKIs were introduced in 2001 and drastically improved the median overall survival of metastatic GIST patients up to 68 months [7].

These advancements in life-prolonging treatment enable a shift in focus to a more chronic perspective for GIST patients, which might have important implications for how patients deal with their disease including their coping. Coping can be

CONTACT Olga Husson  o.husson@erasmusmc.nl  Department of Surgical Oncology, Erasmus MC Cancer Institute, Erasmus University Medical Center, The Netherlands; Department of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, The Netherlands; Department of Surgical Oncology, Erasmus MC Cancer Institute, Erasmus University Medical Center, The Netherlands

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defined as the sum of – constantly adapting – cognitive and behavioural efforts, to seek and apply solutions to stressful situations that emerge because of stressors [8]. Previous research by Miller et al. [9], focusing on styles of information seeking under threat, described two main opposite coping styles: monitoring, which involves actively obtaining information about the stressful situation, and blunting, which involves seeking distraction from the stressful situation. Studies conducted in patients undergoing cancer screening and patients with cancers other than GIST found that an information-seeking coping style was associated with reduced health-related quality of life (HRQoL) [10–12]. Patients having a high-monitoring coping style were found to report higher levels of worries and concerns compared to patients applying a low-monitoring coping style [10,11]. In addition, monitors experienced more and longer-lasting physical symptoms while receiving chemotherapy compared to patients having a blunting coping style [11]. Given these findings in other types of cancer, GIST patients' coping style may also affect their psychological well-being and HRQoL.

GIST is a rare type of cancer and therefore often unknown to family, friends, and colleagues, which can potentially lead to a more monitoring coping style. Furthermore, the coping style of patients with GIST may be influenced by the time since diagnosis and their treatment setting [13]. It could be hypothesised that GIST patients treated in a metastatic setting depending on TKIs, of whom most will eventually succumb to their disease, have a more information-seeking coping style, in an attempt to gain control. Meanwhile, patients with a localised GIST, who solely underwent surgery in a curative setting, may use a more information-avoiding coping style, as they might have less worries and concerns about their future. Besides, GIST patients with contrasting coping styles may have different expectations of the provided healthcare, possibly influencing their satisfaction with care. Up until this point, coping style in GIST patients and the effect of this coping style on HRQoL has not been investigated. Therefore, the aim of this study was to (1) determine the sociodemographic, clinical, and HRQoL factors associated with a monitoring or blunting coping style, and (2) investigate its association with HRQoL, psychological distress, and satisfaction with healthcare and information provision.

Methods

Study design, patients and data collection

The 'Life with GIST' study is a cross-sectional population-based study, conducted among GIST patients diagnosed between January 2008 and December 2018, registered in the Netherlands Cancer Registry (NCR). Patients were included if they had a confirmed GIST diagnosis, a minimum age of 18 years at diagnosis, and were treated within one of the participating GIST reference centres (Radboud University Medical Centre [Nijmegen], Erasmus Medical Centre [Rotterdam], Leiden University Medical Centre, Netherlands Cancer Institute [Amsterdam], and University Medical Centre Groningen). Patients were not eligible when they had a cognitive impairment or were too ill at the time of the study

based on the advice of their (former) treating specialist. After patients provided informed consent, including permission to link their study data to data from the NCR, patients completed the survey online or on paper. Data were collected within the Patient-Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship (PROFILES) registry [14] from September 2020 through June 2021. Ethical approval was obtained from the medical ethical committee of the Radboud University Medical Centre (2019-5888). According to the medical ethical regulations, the approval of one ethical committee for survey research is valid for all participating centres.

Sociodemographic and clinical characteristics

Sociodemographic (age, marital status, educational level) and clinical characteristics (age at diagnosis, tumour localisation, treatment phase, and type of treatment) were patient-reported. The Self-administered Co-morbidity Questionnaire (SCQ) [15] was used to obtain the type and number of co-morbidities. Additional data (gender and socio-economic status) and missing data were derived from the NCR database, if available. The socio-economic status was based on the median household income within a postal code level.

Coping style

To determine the information-seeking or avoiding coping style we used the shortened version of the Threatening Medical Situations Inventory (TMSI) [16]. This validated questionnaire describes two hypothetical situations, the first is about experiencing vague, suspicious headache and dizziness, and the second is about whether or not to undergo an uncertain heart surgery. Six items on how patients could cope with this, including three blunting and three monitoring items follow each situation. Items were scored on a Likert scale ranging from 1 (*not at all applicable to me*) to 5 (*strongly applicable to me*). To determine the coping style of each patient, a sum score was computed by subtracting the blunter score from the monitor score [9]. Those with sum scores equal to or below the median were classified as blunters, and those with scores above the median were classified as monitors [9].

Psychological distress

The Hospital Anxiety and Depression Scale (HADS) [17] was used to assess psychological distress in terms of symptoms of anxiety and depression. The HADS consists of 14 items, whereof seven items on anxiety and seven items on depression. Each item was scored on a Likert scale ranging from 0 to 3. A score of 8 or higher indicated possible symptoms of anxiety or depression, and symptoms were classified as 'present' (>11), 'mild' (8–10), or 'no symptoms' (0–7), for both subscales [17].

Cancer-related concerns

The Cancer Worry Scale (CWS) [18] was used to identify cancer-related concerns. This scale consists of eight items assessing concerns about the recurrence or progression of cancer. Responses to these items were rated on a four-point Likert scale ranging from 'never' (1) to 'almost always' (4). The item scores were added up to create a total score on fear of recurrence or progression, after which patients were classified as having 'low fear' (≤ 13) or 'severe fear' (≥ 14) [19]. In addition, three GIST-specific items of own design were added assessing concerns of needing TKIs in the future, dying from GIST in the near future, and in the long-term future. These items were also rated on a four-point Likert scale, and classified as either having concerns 'yes' (2–4) or 'no' (1).

Health-related quality of life

HRQoL was assessed by the European Organisation for Research and Treatment for Cancer Quality of Life Questionnaire C30 version 3.0 (EORTC QLQ-C30) [20]. This measure consists of 30 items assessing physical, role, cognitive, emotional, and social functioning, the financial impact, global quality of life, and specific symptoms (fatigue, nausea, vomiting, pain, dyspnoea, insomnia, appetite loss, constipation, diarrhoea). Each item was scored on a Likert scale ranging from 1 (*not at all*) to 4 (*very much*), except for the items regarding global health and quality of life, which were scored from 1 (*very poor*) to 7 (*excellent*). A linear transformation was conducted to standardise the raw scores of the scales, hence scores ranged from 0 to 100. Higher scores indicate a better global quality of life and functioning, whereas a higher symptom score indicates a higher symptom burden [20].

Satisfaction with healthcare

Satisfaction with the received healthcare and with the amount of information was assessed using four items, three from EORTC QLQ-INFO25 [21] and one of our own design. The item of own design was about general satisfaction with the received healthcare and scored on a five-point Likert scale ranging from 'very dissatisfied' (1) to 'very satisfied' (5). The first item of the EORTC QLQ-INFO25 was about satisfaction with the amount of received information scored on a four-point Likert scale, followed by two items to indicate whether patients would have liked to receive more or less information from their healthcare providers, and if so, on what specific topic. The answers to these open-ended questions were analysed using a thematic approach [22].

Statistical analyses

All statistical analyses were performed using SPSS Statistics (IBM Corporation, version 29.0, Armonk, NY, USA). Two-sided p -values of $<.05$ were considered statistically significant. Categorical data were described as frequencies and percentages, continuous data were described as mean and standard

deviation (SD). Chi-square tests (categorical data) and independent samples t -tests (continuous data) were conducted to compare HRQoL, psychological distress, cancer-related concerns, and healthcare satisfaction among GIST patients with different coping styles; monitors versus blunters. We performed univariable logistic regression analyses to examine the association between coping style and sociodemographic and clinical characteristics, psychological distress and cancer-related concerns. For the multivariable logistic regression analyses, only variables with a p -value of $<.1$ in our univariate logistic regression were included, except for those with high multi-collinearity as indicated by a variance inflation factor >10 and variance proportions of $>.90$. Additionally, we performed a uni- and multivariable linear regression analyses to evaluate variables associated with satisfaction with healthcare. In our multivariable analyses, all variables with a p -value of $<.1$ in the univariate analysis were included.

Results

Sample characteristics

A total of 328 GIST patients (response rate 63%) participated in this study of whom 307 completed the TMSI, resulting in 132 patients (43%) being classified as monitors and 175 patients (57%) as blunters. More than half of the monitors were females (55.3%), while the majority of blunters were males (61.1%). In comparison to monitors, blunters were of a slightly older age ($mean = 67.6$ vs $mean = 64.7$, $p = .015$) and had a significantly lower educational level ($p = <.001$). Monitors and blunters did not differ significantly in terms of comorbidities, tumour and treatment characteristics. An overview of the sample characteristics can be found in Table 1.

Factors associated with coping style

Results of the logistic regression analysis are shown in Table 2. Being female (OR 2.5; 95%CI 1.5–4.1; $p = <.001$) and being higher educated (OR 5.5; 95%CI 2.5–11.9, $p = <.001$) were associated with higher odds of being a monitor, while tumour or treatment characteristics were not associated with coping style.

Comparison of HRQoL

As shown in Figure 1, global quality of life was comparable between blunters and monitors ($mean = 80.9$ vs $mean = 79.0$, $p = .336$). However, monitors scored significantly lower on emotional functioning in comparison to blunters ($mean = 86.8$ vs $mean = 90.9$, $p = .044$), which was considered a trivial difference [23]. When comparing symptom scales, there were no significant differences between monitors and blunters except for dyspnoea, which was significantly higher in blunters ($mean = 13.9$ vs $mean = 8.4$, $p = .014$) and considered a small difference.

Table 1. Coping scores, sociodemographic- and clinical characteristics of included patients.

	Total (n = 307)	Blunters (n = 175, 57%)	Monitors (n = 132, 43%)	p-value
TMSI sum score ^a Mean ± SD	-1.6 (6.3)	-5.8 (4.2)	4.1 (3.6)	<.001
Blunter score Mean ± SD		20.5 (4.1)	15.9 (4.1)	
Monitor score Mean ± SD		14.7 (4.3)	20.0 (4.6)	
Sex n (%)				
Male	166 (54.1)	107 (61.1)	59 (44.7)	.004
Female	141 (45.9)	68 (38.9)	73 (55.3)	
Age in years at moment of questionnaire Mean ± SD	66.4 ± 10.3	67.6 ± 9.8	64.7 ± 10.7	.015
Socioeconomic status n (%)				
Low	106 (34.5)	58 (33.1)	48 (36.4)	.636
Intermediate	102 (33.2)	62 (35.4)	40 (30.3)	
High	99 (32.2)	55 (31.4)	44 (33.3)	
Marital status n (%)				
Married / Living with partner	235 (76.5)	129 (73.7)	106 (80.3)	.274
Not living with a partner	69 (22.5)	43 (24.6)	26 (19.7)	
Missing	3	3	-	
Educational level ^b n (%)				
Low	64 (20.8)	51 (29.1)	13 (9.8)	<.001
Intermediate	125 (40.7)	64 (36.6)	61 (46.2)	
High	112 (36.5)	54 (30.9)	58 (43.9)	
Missing	6	6	-	
Comorbidity n (%)				
None	104 (33.9)	62 (35.4)	42 (31.8)	.807
1	65 (21.2)	36 (20.6)	29 (22.0)	
≥2	136 (44.3)	76 (43.4)	60 (45.5)	
Missing	2	1	1	
Time since diagnosis in years Mean ± SD	5.9 ± 2.8	5.9 ± 2.8	5.8 ± 2.7	.593
Location primary GIST n (%)				
Stomach	194 (63.2)	114 (65.1)	80 (60.6)	.769 ^c
Small intestine	75 (24.4)	42 (24.0)	33 (25.0)	
Rectum	19 (6.2)	10 (5.7)	9 (6.8)	
Other	19 (6.2)	9 (5.1)	10 (7.6)	
Current phase of treatment n (%)				
Declared cured, no follow up	53 (17.5)	33 (19.3)	20 (15.2)	.457
Not receiving active treatment, in follow up	143 (47.2)	75 (43.9)	68 (51.5)	
Receiving active treatment with curative intent	44 (14.5)	28 (16.4)	16 (12.1)	
Receiving active treatment with palliative intent	63 (20.8)	35 (20.5)	28 (21.2)	
Missing	4	4	-	
Treatment setting n (%)				
Curative setting	244 (79.5)	140 (80.0)	104 (78.8)	.795
Palliative setting	63 (20.5)	35 (20.0)	28 (21.2)	
Current or past TKI treatment n (%)	204 (66.4)	114 (65.1)	90 (68.2)	.854
Curative setting	141 (45.9)	79 (45.1)	62 (47.0)	
Palliative setting	63 (20.5)	35 (20.0)	28 (21.2)	
Had surgery for GIST n (%)	279 (91.8)	157 (90.8)	122 (93.1)	.455

^aTo determine the coping style of each patient, a sum score was computed by subtracting the blunter score from the monitor score. Those with sum scores equal to or below the median (median = -1) were classified as blunters, and those with scores above the median were classified as monitors.

^bLow (primary and secondary education), intermediate ((secondary) vocational education), and high (higher vocational education and academic education) educational level.

^cFisher's exact test or likelihood ratio.

Table 2. Logistic regression models evaluating factors associated with a monitoring coping style.

	Univariable logistic regression ^a		Multivariable logistic regression	
	OR (95%CI)	p-value	OR (95%CI)	p-value
Sex				
Male	Reference		Reference	
Female	1.95 (1.23-3.08)	.004	2.49 (1.50-4.15)	<.001
Age at moment of questionnaire	0.97 (0.95-1.00)	.016	0.99 (0.96-1.01)	.269
Educational level				
Low	Reference		Reference	
Intermediate	3.74 (1.85-7.55)	<.001	5.03 (2.34-10.84)	<.001
High	4.21 (2.07-8.60)	<.001	5.49 (2.51-12.01)	<.001
Fear of recurrence or progression				
Low	Reference		Reference	
Severe	1.88 (1.19-2.98)	.007	1.47 (0.83-2.63)	.190
Concerns about dying from GIST in the long term future				
No concerns	Reference	.025	Reference	.186
Having concerns	1.69 (1.07-2.67)		1.48 (0.83-2.65)	

^aThe results of the full univariable logistic regression analysis are available as [Supplementary Material 1](#), here we only report the variables included in the multivariable logistic regression.

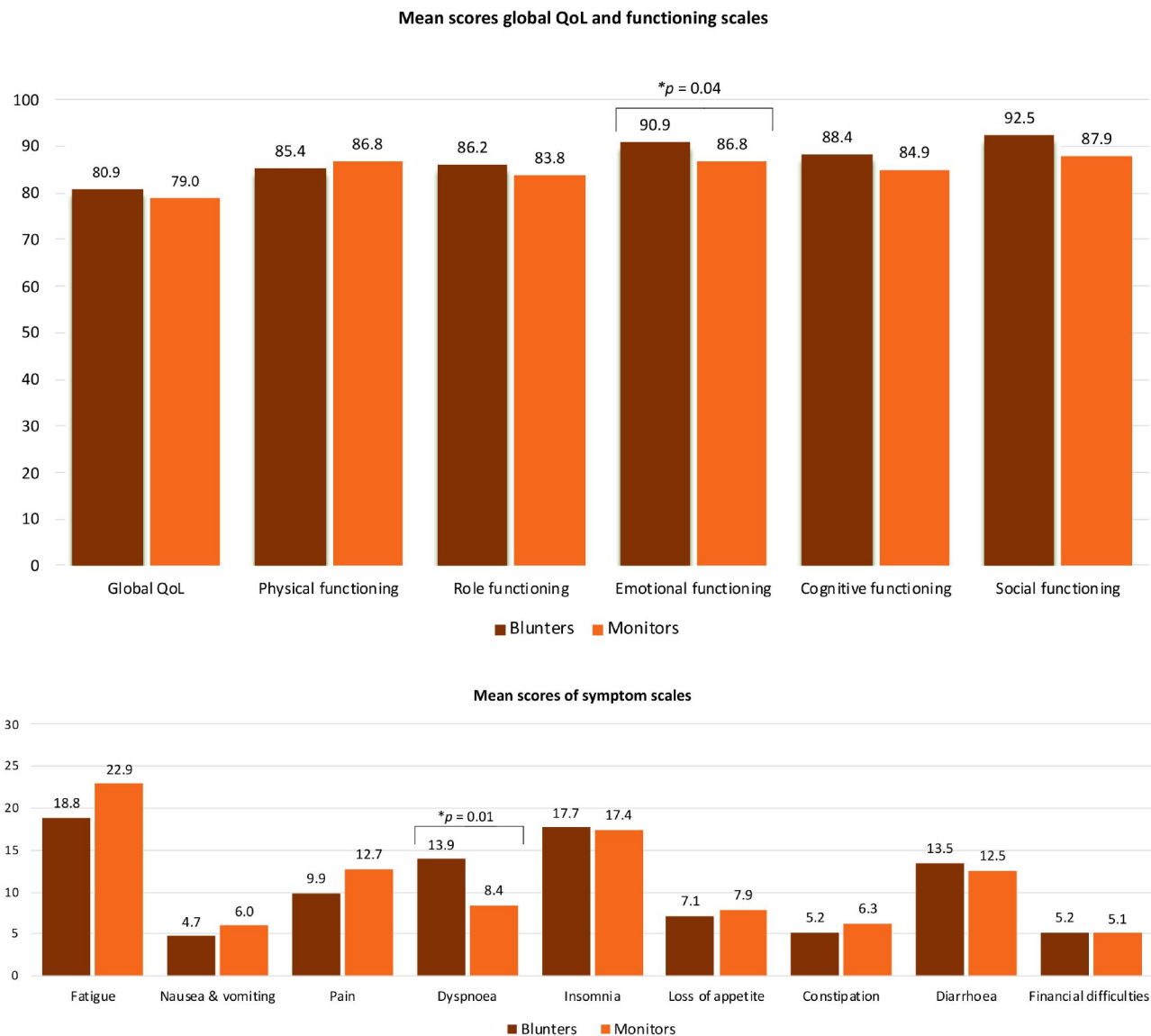


Figure 1. Comparison of mean scores on global QoL, functioning scales and symptoms scales of the EORTC QLQ-C30 among blunters and monitors. On global QoL and functioning scales, higher scores indicate a better global quality of life and functioning, whereas a higher symptom score indicates a higher symptom burden.

Psychological distress and cancer-related concerns

The proportion of patients who experienced severe fear of recurrence or progression of GIST was found to be higher among monitors compared to blunters (53.0% vs 37.7%, $p=.007$). In addition, monitors more often experienced concerns about dying from GIST in the future in comparison to blunters (60.6% vs 47.4%, $p=.025$). No significant association was found between coping style and symptoms of anxiety nor depression, as is shown in Table 3.

Satisfaction with healthcare and informational needs

Blunters were significantly more satisfied with the received healthcare compared to monitors ($mean=78.5$ vs $mean=70.9$, $p=.005$) as is shown in Table 3. The overall regression was statistically significant ($R^2=.125$, $F(14, 243)=2.490$, $p=.003$). It was found that being female ($B=-5.8$, $p=.040$) and having a monitoring rather than a blunting coping style (B

$=-5.6$, $p=.048$) significantly predicted dissatisfaction with received care (Table 4).

In addition, monitors would have liked to receive more information, whereas blunters were more often satisfied with the received amount of information (25.2% vs 11.0%, $p=.001$). The 52 patients, 19 blunters and 33 monitors, who would have liked to receive more information from their healthcare providers, also specified the topics they wished to receive more information on. Based on their answers we identified seven themes within their information needs (Figure 2), including the disease itself ($n=8$), course of the disease ($n=11$), diagnostics ($n=2$), treatment ($n=21$), GIST-related care ($n=8$), information provision ($n=6$), and supportive care ($n=6$).

Discussion

This cross-sectional study was the first to investigate the impact of a monitoring or blunting coping style on HRQoL,

Table 3. Psychological distress, cancer-related concerns, and patient satisfaction with provided healthcare and information among blunters and monitors.

		Total (n = 306)	Blunters (n = 174)	Monitors (n = 132)	p-value
Psychological distress					
Total psychological distress score	Mean ± SD	6.7 ± 6.5	6.2 ± 6.1	7.5 ± 7.0	.078
Total anxiety score	Mean ± SD	3.6 ± 3.8	3.1 ± 3.6	4.1 ± 4.1	.030
Symptoms of anxiety n (%)	Present	20 (6.5)	9 (5.1)	11 (8.3)	.489
	Mild	23 (7.5)	12 (6.9)	11 (8.3)	
Total depression score	No	261 (85.0)	151 (86.3)	110 (83.3)	
	Mean ± SD	3.2 ± 3.2	3.0 ± 3.1	3.4 ± 3.4	.316
Symptoms of depression n (%)	Present	7 (2.3)	3 (1.7)	4 (3.0)	.448
	Mild	33 (10.7)	16 (9.1)	17 (12.9)	
	No	264 (86.0)	153 (87.4)	111 (84.1)	
Cancer-related concerns					
Fear of cancer recurrence or progression n (%)	High	136 (44.3)	66 (37.7)	70 (53.0)	.007
	Low	169 (55.0)	108 (61.7)	61 (46.2)	
Concerns about the need for TKI treatment in the future n (%)	Yes	123 (40.6)	70 (40.7)	53 (40.5)	.966
	No	180 (59.4)	102 (59.3)	78 (59.5)	
Concerns about dying from GIST in the near future n (%)	Yes	119 (38.8)	64 (36.6)	55 (41.7)	.407
	No	186 (60.6)	109 (62.3)	77 (58.3)	
Concerns about dying from GIST in the long term future n (%)	Yes	163 (53.1)	83 (47.4)	80 (60.6)	.025
	No	143 (46.6)	91 (52.0)	52 (39.4)	
Satisfaction with healthcare and information					
General satisfaction with the received healthcare	Mean ± SD	75.2 ± 22.2	78.5 ± 21.6	70.9 ± 22.4	.005
Satisfaction with the received information	Mean ± SD	72.3 ± 26.4	74.4 ± 25.5	69.7 ± 27.5	.126
Would have liked to receive more information n (%)	Yes	52 (17.1)	19 (11.0)	33 (25.2)	.001
	No	252 (82.9)	154 (89.0)	98 (74.8)	
Would have liked to receive less information n (%)	Yes	4 (1.3)	2 (1.2)	2 (1.5)	.785
	No	301 (98.7)	171 (98.8)	130 (98.5)	

Table 4. Linear regression analysis to evaluate factors associated with satisfaction with care.

	Simple linear regression ¹			Multiple linear regression		
	Beta	B (95% CI)	p-value	Beta	B (95% CI)	p-value
Coping style						
Blunter		Reference			Reference	
Monitor	-0.17	-7.7 (-13.0; -2.3)	.005	-0.13	-5.6 (-11.2; -0.1)	.047
Sex						
Male		Reference			Reference	
Female	-0.19	-8.3 (-13.6; -3.0)	.002	-0.13	-5.8 (-11.4; -0.2)	.041
Number of comorbidities						
Range 0 - 12	-0.18	-2.6 (-4.3; -0.9)	.003	-0.10	-1.4 (-3.3; .5)	.154
Symptoms of anxiety						
No		Reference			Reference	
Present	-0.11	-6.6 (-14.0; .7)	.078	.03	1.5 (-8.4; 11.6)	.758
Symptoms of depression						
No		Reference			Reference	
Present	-0.15	-9.5 (-17.1; -1.8)	.015	-0.08	-5.0 (-15.0; 5.0)	.323
Fear of progression or recurrence						
Low		Reference			Reference	
Severe	-0.13	-5.7 (-11.1; -0.3)	.038	.00	.2 (-5.8; 6.1)	.956
Global QoL						
Range 0 - 100	.21	.3 (.1; .4)	<.001	.05	.1 (-0.2; .3)	.621
Physical functioning						
Range 0 - 100	.19	.2 (.1; .4)	.003	.07	.1 (-0.2; .3)	.478
Role functioning						
Range 0 - 100	.20	.2 (.1; .3)	.001	.05	.1 (-0.1; .2)	.623
Emotional functioning						
Range 0 - 100	.12	.2 (-0.0; .3)	.055	-0.04	-0.1 (-0.3; .2)	.627
Cognitive functioning						
Range 0 - 100	.14	.2 (.0; .3)	.024	.05	.1 (-0.1; .2)	.470
Pain						
Range 0 - 100	-0.15	-0.2 (-0.3; -0.0)	.013	.02	.0 (-0.1; .2)	.780
Diarrhoea						
Range 0 - 100	-0.16	-0.1 (-0.3; -0.0)	.010	-0.09	-0.1 (-0.2; .0)	.203

^aThe results of the full simple linear regression analysis are available as [supplementary material 2](#), here we only report the variables included in the multiple linear regression.

psychological distress, and healthcare satisfaction in Dutch GIST patients. Using the TMSI, we identified 132 (43%) monitors and 175 (57%) blunters. To distinguish between monitors and blunters, we used the median to classify patients, a frequently used method in research regarding information-

seeking and avoiding coping styles [10,24,25]. At the same time, this method makes a comparison with the existing literature not possible, because both groups will be more or less equal. In the introduction, we hypothesised that time since diagnosis and the treatment setting might influence

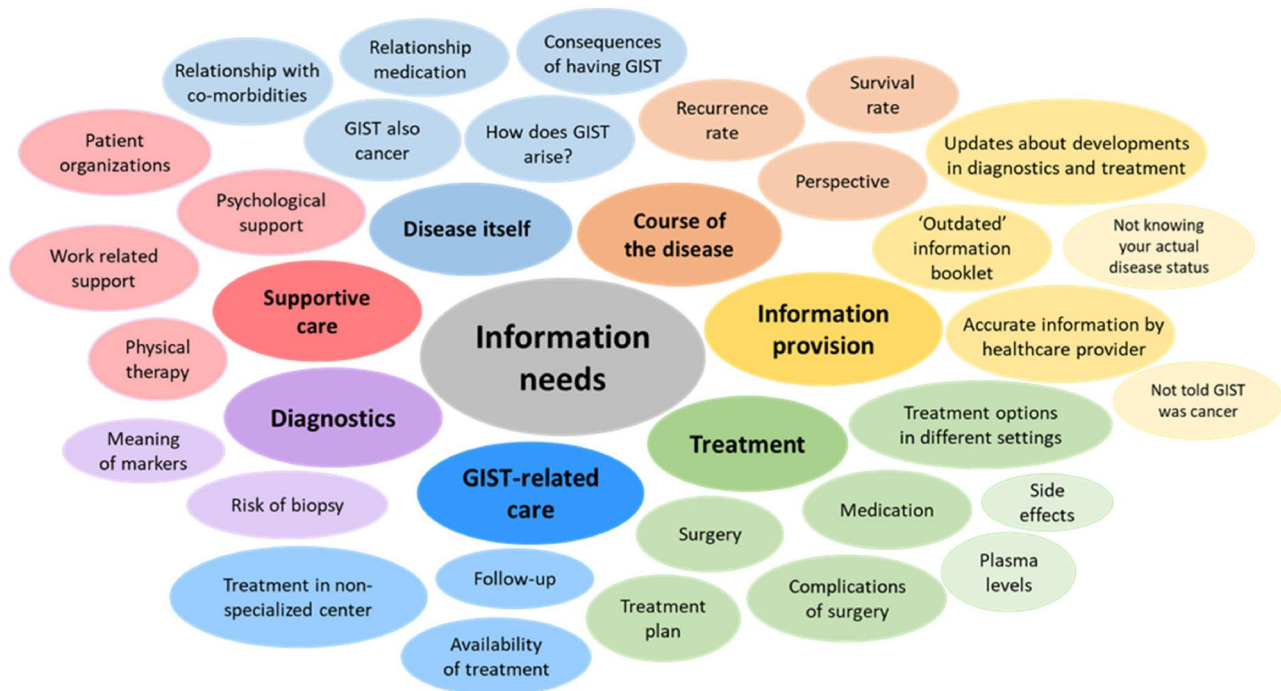


Figure 2. Topics patients ($n = 52$) would have liked to receive more information on – darker coloured circles present the main themes; more specific information needs about the main themes are shown in the lighter coloured circles.

the type of coping style of a GIST patient. However, our logistic regression analyses showed that none of the tumour and treatment characteristics, including time since diagnosis, were associated with a certain coping style. This supports the theory that an information-seeking or avoiding coping style is trait-oriented [26], rather than state-oriented, which suggests that patients will not change or adapt this coping style. Despite that, a nuance must be added, as the coping strategy can differ within a patient depending on personal and environmental factors [30], for example, being alone versus having a lot of social support from family and friends.

Aligning with previous studies, being female and higher educated were associated with higher odds of having a monitoring coping style [13–16,27–30], leading to the question of why monitors are more likely to possess these characteristics? Women, as a general tendency, tend to engage in ruminating and worrying more frequently than men [31–33]. Next to that, being higher educated may equal having more holistic thinking abilities. The tendency to ruminate, worry and think holistically could lead to more comprehensive thinking and potentially explain the increased levels of fear about recurrence or progression and concerns about dying from GIST observed in monitors. Consequently, the question arises: does an individual engage in monitoring behaviour due to their increased levels of fears and concerns, or does the act of being a monitor give rise to these increased levels? On one hand, the greater levels of fear regarding cancer recurrence or progression and concerns about dying from GIST among monitors could be attributed to their tendency to engage in information-seeking behaviour. For example, searching the internet may expose them to potentially unreliable or worrisome information regarding recurrence risks and chances of survival. On the other hand, due to their

increased concerns about the disease, monitors experience increased thinking about GIST. This in turn leads to a higher frequency of distressing thoughts, and consequently, the tendency to search for answers.

Given the previously described association between information-seeking coping style and HRQoL [10–12], we also studied this in our GIST population and found a worse emotional functioning among GIST monitors in comparison to GIST blunters. Both the increased fear of recurrence and progression and the higher prevalence of concerns about dying from GIST in our monitor group, might have contributed to worse emotional functioning. Comparing symptom scales, we found that blunters scored significantly higher on dyspnoea, which was considered a small mean difference [23]. It could be hypothesised that blunters find other ways to cope with the stressful situation, such as smoking, eventually resulting in more dyspnoea. However, we lack the data to support this.

As expected, blunters and monitors generally tend to differ in healthcare- and information preferences. Monitors prefer more detailed information, more participation in medical decision-making, and tend to ask more questions during their consultations compared to blunters [27,–34]. In addition, previous studies have shown that higher educated individuals have a preference for being told the truth and for the use of medical language by their healthcare providers, which is consistent with our study results regarding the greater likelihood for monitors to be high educated [35,36]. By gaining insight into the coping styles of GIST patients and therewith their personal needs, tailored healthcare, and in particular tailored information provision, can be provided. According to previous research, tailored healthcare based on coping style will give healthcare providers the potential to

decrease stress-, anxiety-, and depression levels in patients [25,37], and increase healthcare satisfaction [24]. Additionally, as patients in our study indicated on what topics they would like to receive more information, these topics can be used for implementing a broader information supply for monitors according to their needs. For blunters, a more efficient and specific information provision could be considered, as high blunting does not imply a reduced need for information [34]. Therefore, we propose a more specific information provision based on individual preferences, instead of solely reducing the amount of information. For both monitors and blunters information provision needs to be accompanied by tailored healthcare provider-patient communication, and, if necessary, support in how to deal with uncertainties must be provided. When improving the information facilities for GIST patients, there is also an important role for the patient organisation. Since 2003, we have a patient advocacy platform in the Netherlands for patients with GIST and their relatives [38]. They provide up-to-date information about the GIST diagnosis and treatment, as well as information on GIST related developments in research, and ensure peer contact by organising patient contact days.

This study was the first to investigate monitoring and blunting coping styles among GIST patients. The survey design and use of a variety of patient-reported outcome measures were unique in our study. Most studies in GIST patients focus on objective and physician reported outcomes, and the perspective of the patient is not taken into account. Our relatively high response rate (63%) underlines the importance and willingness of GIST patients to participate in this type of studies. The observed willingness to participate in a study could have led to some degree of non-response bias. However, it is to be expected that monitors are more likely to participate than blunters, therefore the fact that our study consist of more blunters makes us assume that the non-response bias is limited. Another strength of this study is the diverse groups of patients included, ranging from patients no longer in follow-up after curative treatment to patients in a metastatic setting. Although the study sample did contain a relatively high percentage of patients that were not receiving any treatment, we focussed on all GIST patients and not solely patients on TKIs, resulting in a diverse and corresponding representation of clinical practice.

Our study has several limitations that should be acknowledged. Firstly, the cross-sectional design of the study, which makes it difficult to establish causal relationships and not possible to investigate if coping style possibly changes over time. Future research would benefit from longitudinal and between-subjects methods to further investigate this. Secondly, we included only Dutch patients, which could impede the generalisability as the Dutch healthcare system differs from those in other countries. For instance, the absence of private clinics for GIST patients and the broad coverage of insured health care in the Netherlands in comparison to other countries could result in contrasting experiences among patients from other countries. Thirdly, we solely included patients treated in specialised GIST centres, which could potentially influence patients' perspectives

and experiences on satisfaction with care, distress and concerns, and HRQoL compared to patients treated in non-specialised GIST centres, since healthcare providers in non-specialised GIST centres most likely have less knowledge on rare cancers like GIST.

Conclusion

In conclusion, GIST patients in general are satisfied with the healthcare and information they received from their healthcare providers. However, GIST patients with a monitoring coping style experience a higher emotional burden, exhibit lower satisfaction levels and a greater need for information in comparison to blunters. The current lack of adjustment to their needs may give rise to fear of cancer recurrence or progression and concerns about long-term mortality related to GIST. Tailored communication and information may serve as a potential solution to address these fears and concerns, and increase healthcare satisfaction.

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Ethical approval

Ethical approval was obtained from the medical ethical committee of the Radboud University Medical Centre (2019-5888). According to the medical ethical regulations, approval of one ethical committee for survey research is valid for all participating centres.

Consent to participate

Written informed consent was obtained from all individual patients included in the study.

Disclosure statement

No potential conflict of interest was reported by the author(s)

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Data availability statement

The data that support the findings of this study are available from the corresponding author, OH, upon reasonable request.

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