

# Information Provision and Patient Reported Outcomes in Patients with Metastasized Colorectal Cancer: Results from the PROFILES Registry

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## Abstract

**Background:** Patients with metastasized colorectal cancer (mCRC) have different information needs compared with patients with nonmetastatic colorectal cancer (CRC). Appropriate information provision leads to better patient reported outcomes for patients with nonmetastatic disease.

**Objective:** To measure the perceived level of, and satisfaction with, information received by patients with mCRC as compared with those with nonmetastatic (stage I,II,III) CRC. Also, associations of information provision with health status, anxiety, depression, and illness perceptions were investigated.

**Methods:** A cross-sectional population-based survey was conducted. All CRC patients diagnosed between 2002 and 2007 according to the Eindhoven Cancer Registry (ECR) were selected. Response rate was 75% ( $n = 1159$ , of which 139 had mCRC). Participants completed questionnaires on information provision (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-INFO25), health status (Short Form-36), anxiety and depression (Hospital Anxiety and Depression Scale [HADS]), and illness perceptions (Brief Illness Perception Questionnaire [B-IPQ]).

**Results:** The perceived receipt of information was quite comparable between CRC patients with and without mCRC. Only perceived receipt of treatment information was higher for patients with mCRC (45 versus 37;  $p < 0.01$ ). Sixty percent of the patients with mCRC were satisfied with the amount of received information and almost 30% wanted to receive more information. The perceived receipt of more *disease* information and information about *other services* was associated with worse health outcomes, whereas *satisfaction* with the received information was not associated with health outcomes.

**Conclusion:** The findings of this study indicate that some improvements can be made in the provision of information to patients with mCRC. Adequate assessment of information needs of mCRC patients, as well as appropriate responses to these needs by providing the information in an appropriate way could possibly lead to improvements in patient satisfaction.

## Introduction

THE PROVISION OF INFORMATION to patients is one of the most important factors of supportive cancer care. Appropriate information provision can result in informed decision making, better treatment adherence, better health status, lower levels of distress, improved satisfaction with care, and a sense of control.<sup>1-5</sup> However, adequate information provision is a frequently reported unmet need among patients with

cancer across the whole cancer continuum.<sup>6</sup> There is a discrepancy between the actual information needs of cancer patients and the perception of health care providers (HCPs) about the needs of cancer patients.<sup>7,8</sup> Most cancer patients want as much information as possible; however, this varies by gender, age, cultural background, educational level, coping style, and stage of disease.<sup>5,9,10</sup>

About one-fifth of patients with colorectal cancer (CRC) will present with metastatic disease, and 20% to 30% of

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patients will develop metastatic CRC (mCRC) after successful curative treatment of the primary tumor.<sup>11</sup> Patients with mCRC are living longer due to earlier detection and effectiveness of treatments.<sup>12</sup> It is important to ensure patients' well-being during this phase of fighting against a potentially life-threatening disease. Patients with mCRC experience decline in health status,<sup>13</sup> report high levels of anxiety and depression,<sup>14</sup> and have problems with illness perception.<sup>15</sup> Furthermore, they are dealing with specific questions and uncertainties concerning end-of-life issues, symptom relief, and patterns of decline.<sup>16</sup> For patients with advanced disease, information about the course of the disease, prognosis, available (palliative) treatment options, how to manage disease symptoms, and how cancer will affect daily life are the most important informational needs.<sup>17</sup> Patients need to be aware of the nature and course of their disease to make informed medical decisions and to handle and plan this phase of their lives.<sup>7,8,16,18,19</sup> However, a recent study showed that oncologists are often unwilling, unable, or uncomfortable with honestly disclosing and discussing information regarding diagnosis and prognosis with patients with advanced disease.<sup>20</sup> In addition, many HCPs avoid discussing the topic or withhold information.<sup>21</sup> Furthermore, HCPs tend to underestimate patients' need for information and overestimate patients' understanding of their prognosis.<sup>7</sup>

Because a positive association has been found between satisfaction with received information and health outcomes among cancer patients with less advanced disease,<sup>1,22</sup> it is important to study these relations among patients with metastatic disease. Therefore, the objective of this study was to measure the perceived level of, and satisfaction with, information received by patients with mCRC (stage IV) as compared with those with nonmetastatic (stage I,II,III) CRC. Second, our objective was to investigate the association of information provision with health status, anxiety, depression, and illness perceptions among patients with mCRC.

## Methods

### Setting and participants

This study is part of a long-term follow-up assessment of CRC patients registered with the Eindhoven Cancer Registry (ECR). The ECR compiles data of all individuals newly diagnosed with cancer in southern Netherlands, an area with 10 hospitals serving 2.3 million inhabitants.<sup>23</sup> For this study, all patients identified from the ECR and diagnosed with CRC between 2002 and 2007 were eligible for participation. A local certified Medical Ethics Committee approved this study.

### Data collection

Data collection started in January 2009 within PROFILES (Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship). PROFILES is a registry for the study of the physical and psychosocial impact of cancer and its treatment from a dynamic, growing population-based cohort of both short- and long-term cancer survivors. PROFILES contains a large web-based component and is linked directly to clinical data from the ECR. CRC patients ( $n = 1542$ ) were informed of the study with a letter from their (ex-) attending surgeon. The letter explained that by completing and returning the enclosed questionnaire, patients consented to

participate in the study and agreed to the linkage of the questionnaire data with their disease history in the ECR. Details of the data collection method have been previously described.<sup>24</sup>

## Measures

**Sociodemographic and clinical characteristics.** Patients' sociodemographic and clinical information were available from the ECR. The ECR routinely collects data on tumor characteristics, including date of diagnosis, tumor grade,<sup>25</sup> clinical stage,<sup>25</sup> treatment, and patient background characteristics. Because the ECR only collects clinical disease stage at primary diagnosis, we conducted a chart review to identify the respondents who have developed metachronous metastasis between initial diagnosis and the start of our study. Questions on marital status, educational level, current occupation, and comorbidity at time of questionnaire were added to the questionnaire.

**Information provision.** To evaluate the information received by cancer patients, the internationally validated EORTC QLQ-INFO25 questionnaire was used.<sup>26</sup> The EORTC QLQ-INFO25 consists of 25 items, grouped into four information provision subscales: perceived receipt of information about the disease (four items regarding diagnosis, spread of disease, cause(s) of disease, and whether the disease is under control), medical tests (three items regarding purpose, procedures, and results of tests), treatment (six items regarding medical treatment, benefits, side-effects, effects on disease symptoms, social life, and sexual activity), and other care services (four items regarding additional help, rehabilitation options, managing illness at home, and psychological support). Additionally, it contains eight single items on, for instance, wanting to receive more or less information, and on the satisfaction with and helpfulness of the received information. Answer categories range from 1 (not at all) to 4 (very much), except for four items with a 2-point scale (yes/no). After linear transformation, all scales and the items range in scores from 0 to 100, with higher scores indicating better perceived information provision.

**Health status.** Health status was assessed with the validated Dutch version of the SF-36 questionnaire, which incorporates eight domains: physical function, role limitations due to physical health, bodily pain, general health perceptions, vitality, social function, role limitations due to emotional health, and general mental health.<sup>27</sup> According to standard scoring procedures, the subscales were linearly converted to a 0–100 scale, with higher scores indicating better functioning.

**Anxiety and depression.** Anxiety and depressive symptoms were assessed using the Hospital Anxiety and Depression Scale (HADS). The HADS is a self-report questionnaire comprising 14 items on a 4-point Likert scale; seven for depression and seven for anxiety.<sup>28</sup> We used a score of 8 as a cutoff value for both depression and anxiety.<sup>28,29</sup>

**Illness perceptions.** Illness perceptions were assessed using the Brief Illness Perception Questionnaire (B-IPQ), a nine-item instrument used to assess cognitive and emotional representations of the illness.<sup>30</sup> The B-IPQ uses a single-item scale approach to assess perceptions on a continuous linear 0

to 10 point scale. Five of the items assess cognitive illness representations (consequences, time line, personal control, treatment control, and identity), two items assess emotional representations (concern and emotion), and one item assesses illness comprehensibility (coherence).

**Statistical analyses**

Routinely collected data from the ECR on patient and tumor characteristics enabled us to compare the group of respondents, nonrespondents, and patients with unverifiable addresses, using analysis of variance (ANOVA) for continuous variables and  $\chi^2$  analyses for categorical variables. Furthermore, differences between patients with mCRC and nonmetastatic CRC in sociodemographic and clinical characteristics and on the subscales of the EORTC-INFO25, SF-36, HADS, and B-IPQ were also analyzed using ANOVA or Wilcoxon tests (when normality and homogeneity assumptions are violated) for continuous variables and  $\chi^2$  analyses for categorical variables.

Multivariate linear regression analyses were carried out to investigate the associations of the different information subscales (perceived receipt of disease information, medical test information, treatment information, information about other services, and satisfaction with received information) with the subscales of the SF-36, HADS, and B-IPQ for patients with mCRC only. We controlled for sociodemographic variables (age, gender) and clinical variables (primary treatment, years since diagnosis, and comorbidity).

All statistical tests were two-sided and considered significant if  $p < 0.05$ . All analyses were conducted using SPSS version 17.0 (Statistical Package for Social Sciences, Chicago, IL).

**Results**

**Patient characteristics**

Of the 1542 eligible CRC patients, 1159 (75%) returned a completed questionnaire. A comparison of respondents, nonrespondents, and patients with unverifiable addresses

indicated that respondents and patients with unverifiable addresses were younger and more often male compared with nonrespondents (Table 1). No differences were found in mean years after diagnosis, stage of disease, and treatment.

Patients with mCRC were significantly younger, were more recently diagnosed, were more often men, had a higher socioeconomic status, and more often received chemotherapy (in addition to surgery) as primary treatment compared with patients without metastasis (Table 2). No differences were found in the number of comorbidities, marital status, educational level, and employment between these two groups.

**Information provision and satisfaction: Differences between patients with nonmetastatic CRC and mCRC**

On the subscales of the EORTC-QLQ-INFO25, patients with mCRC indicated having received more information compared with patients with non-mCRC. However this was only significant for the subscale information about treatments (Table 3).

In-depth analyses of single items of the EORTC QLQ-INFO25 showed comparable results between both groups, 72% of the cancer patients with mCRC received (quite) a lot information about their diagnosis (versus 66% of the patients without metastasis). Seventeen percent (versus 15%) received (quite) a lot information about the causes of their disease. The perceived receipt of medical test information was high: 73% (versus 64%) received (quite) a lot information about the goals of the tests, 74% (versus 68%) about the course of the tests, and 79% (versus 74%) received information on the results of the tests. Most patients with mCRC received (quite) a lot treatment information (80% versus 64%), about the results of the treatment (51% versus 47%) and about the side effects of treatments (65% versus 35%). In contrast, less information was received on other services, for example rehabilitation options (14% versus 13%), dealing with cancer at home (21% versus 20%), and psychological help (12% versus 7%).

TABLE 1. DEMOGRAPHIC AND CLINICAL CHARACTERISTICS STRATIFIED BY RESPONSE STATUS

	Respondents (n=1159)	Nonrespondents (n=265)	Patients with unverifiable addresses (n=118)	P value
Mean age at time of survey (SD)	69.2 (9.7)	71.1 (10.2)	68.3 (11.4)	0.008
Mean years since diagnosis (SD)	3.5 (1.5)	3.6 (1.6)	3.7 (1.5)	0.530
Gender				0.003
Male	663 (57.2%)	121 (45.7%)	63 (53.4%)	
Female	496 (42.8%)	144 (54.3%)	55 (46.6%)	
Stage at diagnosis <sup>a</sup>				0.507
I	309 (26.7%)	71 (26.8%)	33 (28.0%)	
II	450 (38.8%)	108 (40.8%)	47 (39.8%)	
III	331 (28.6%)	78 (29.4%)	29 (24.6%)	
IV	69 (6.0%)	8 (3.0%)	9 (7.6%)	
Primary treatment				0.253
SU only	599 (51.7%)	162 (61.6%)	64 (54.2%)	
SU + RT	231 (19.9%)	38 (14.4%)	21 (17.8%)	
SU + CT	250 (21.6%)	48 (18.3%)	23 (19.5%)	
SU + RT + CT	68 (5.9%)	12 (4.6%)	9 (7.6%)	
CT only	11 (0.9%)	3 (1.1%)	1 (0.8%)	

<sup>a</sup>Disease stage at primary diagnosis. CT, chemotherapy; SD, standard deviation; SU, surgery; RT, radiotherapy.

TABLE 2. DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF RESPONDENTS STRATIFIED BY STAGE OF THE DISEASE

	Patients with metastasis at time of study (n=139)	Patients without metastasis at time of study (n=1020)	P value
Mean age at time of diagnosis (SD)	62.7 (9.2)	66.1 (9.7)	<0.001
Mean age at time of survey (SD)	65.9 (9.2)	69.7 (9.7)	<0.001
Mean years since initial diagnosis (SD)	3.2 (1.3)	3.6 (1.5)	0.01
Median years since diagnosis (25%–75%)	2.9 (2.2–4.0)	3.2 (2.4–4.5)	
Gender			0.02
Male	92 (66.2%)	571 (56.0%)	
Female	47 (33.8%)	449 (44.0%)	
Primary treatment			<0.001
SU only	38 (27.3%)	561 (55.0%)	
SU+RT	17 (12.2%)	214 (21.0%)	
SU+CT	61 (43.9%)	189 (18.5%)	
SU+RT+CT	12 (8.6%)	56 (5.5%)	
CT only	11 (7.9%)	-	
Comorbidity			0.92
0	34 (24.5%)	255 (25.0%)	
1	35 (25.2%)	270 (26.5%)	
2 or more	70 (50.4%)	495 (48.5%)	
Marital status			0.14
Partner	108 (80.6%)	733 (74.3%)	
No partner (single/divorced/widowed)	26 (19.4%)	254 (25.7%)	
Educational level			0.50
High	190 (19.5%)	24 (18.0%)	
Medium	336 (58.4%)	86 (64.6%)	
Low	215 (22.1%)	23 (17.3%)	
Employment status			0.90
Not working	112 (84.2%)	824 (84.6%)	
Working	21 (15.8%)	150 (15.4%)	
Socioeconomic status			0.04
Low	22 (16.8%)	222 (23.1%)	
Medium	49 (37.4%)	402 (41.9%)	
High	60 (45.8%)	336 (35.0%)	

Education levels included low: no/primary school, medium: lower general secondary education/vocational training, or high: preuniversity education/high vocational training/university.

CT, chemotherapy; SD, standard deviation; SU, surgery; RT, radiotherapy.

There were no significant differences between the two groups on satisfaction with and usefulness of the received information (Table 3). More than half (60% versus 55%) of the patients with metastasis were (quite) satisfied with the received information and 68% (versus 63%) perceived the received information as (quite) useful. Patients with mCRC wanted to receive more information (29% versus 24%), especially about the course of the disease (prognosis, future), side effects of treatment(s), and supportive care (open field question).

#### **Health status, anxiety and depression, illness perception: Differences between patients with metastatic and nonmetastatic CRC**

Patients with mCRC reported worse health status except for mental health (all  $p < 0.01$ ), higher levels of anxiety ( $p = 0.02$ ), and quite similar levels of depression ( $p = 0.24$ ) (Table 3). Patients with mCRC perceived their illness as worse (belief that their life is more affected, their disease is of longer duration, have less treatment and personal control, have more symptoms, and are more concerned and emotionally affected) compared with patients without metastasis, which is in accordance with their disease severity (all  $p < 0.01$ ). Patients with mCRC had a better understanding of their illness compared

with patients without mCRC ( $p = 0.01$ ). No differences in health outcomes were found between patients with synchronous ( $n = 69$ ) and metachronous metastasis ( $n = 70$ ; data not shown).

#### **Association of information provision and information satisfaction with health status, anxiety and depression, and illness perceptions among patients with mCRC**

Among patients with mCRC more information about the disease was associated with worse general health, social functioning and bodily pain, whereas more information about the treatment was associated with less role limitations due to emotional problems when corrected for covariates (Table 4). More information about other services was associated with worse functioning on all domains (except social functioning and general health), higher levels of depression, and more symptoms attributed to their illness.

Among patients without metastatic disease, higher satisfaction with the received information was associated with better health status, lower levels of anxiety and depression, and better illness perceptions, whereas more perceived receipt of information about other services was negatively associated with these outcomes (data not shown).



TABLE 3. INFORMATION PROVISION, HEALTH STATUS, ANXIETY AND DEPRESSION, AND ILLNESS PERCEPTIONS STRATIFIED BY STAGE OF THE DISEASE (MEAN [SD])

	<i>Patients with metastasis at time of study (n=139)</i>	<i>Patients without metastasis at time of diagnosis study (n=1020)</i>	<i>P value</i>
<b>Information provision<sup>a</sup></b>			
Information about the disease	49.7 (21.2)	48.2 (20.4)	0.44
Information about medical tests	64.6 (21.9)	61.4 (23.3)	0.14
Information about treatments	45.2 (19.8)	36.6 (23.4)	<0.01
Information about other services	19.9 (21.9)	19.0 (21.1)	0.65
Satisfaction with information	55.2 (26.3)	53.9 (25.7)	0.60
Usefulness of information	62.0 (26.0)	58.7 (26.1)	0.18
Want more information, <i>n</i> (%)	38 (28.6%)	220 (23.5%)	0.20
Want less information, <i>n</i> (%)	2 (1.5%)	27 (3.0%)	0.57
<b>Health status (SF-36)<sup>b</sup></b>			
General health	44.4 (24.3)	63.6 (21.0)	<0.01
Physical functioning	60.7 (30.8)	70.1 (27.2)	<0.01
Role limitations physical health	44.3 (43.9)	66.4 (41.9)	<0.01
Bodily pain	70.6 (28.6)	76.9 (24.2)	<0.01
Vitality	58.4 (23.1)	65.9 (20.4)	<0.01
Social functioning	71.8 (27.4)	82.2 (21.0)	<0.01
Role limitations emotional problems	70.9 (41.3)	81.9 (34.7)	<0.01
Mental health	75.0 (18.0)	77.7 (17.3)	0.09
<b>Anxiety<sup>c</sup></b>			
Anxiety dichotomized <sup>e</sup>			0.02
0–7, <i>n</i> (%)	95 (72.5%)	759 (79.3%)	0.09
8–21, <i>n</i> (%)	36 (27.5%)	198 (20.7%)	
<b>Depression<sup>c</sup></b>			
Depression dichotomized <sup>e</sup>			0.24
0–7, <i>n</i> (%)	91 (71.7%)	722 (76.4%)	0.27
8–21, <i>n</i> (%)	36 (28.3%)	223 (23.6%)	
<b>Illness perceptions<sup>d</sup></b>			
1 Consequences	6.1 (2.8)	4.0 (2.5)	<0.01
2 Time line	7.6 (2.8)	4.2 (3.3)	<0.01
3 Personal control	6.8 (2.9)	6.0 (3.1)	<0.01
4 Treatment control	5.1 (2.8)	3.5 (2.6)	<0.01
5 Identity	5.0 (2.6)	3.5 (2.6)	<0.01
6 Concern	6.5 (2.7)	4.0 (2.5)	<0.01
7 Coherence	3.7 (2.9)	4.4 (3.0)	0.01
8 Emotional representation	5.0 (2.7)	3.6 (2.5)	<0.01

<sup>a</sup>Higher score indicates more perceived receipt of information.

<sup>b</sup>Higher score indicates better functioning.

<sup>c</sup>Higher score indicates higher levels of anxiety/depression.

<sup>d</sup>Higher score indicates worse illness perceptions. <sup>e</sup>Based on their sum score, participants can be divided into two categories (<8 no anxiety/depression; ≥8 anxiety/depression).<sup>28,29</sup>

SD, standard deviation.

## Discussion

The present study showed that the perceived receipt of information was quite comparable between patients with and without mCRC. Patients with mCRC perceived receiving more treatment-related information compared with patients with non-mCRC. However, both groups perceived having received little information about other services and indicated to want more information. Issues related to disease course and supportive care were mentioned most frequently as topics that patients with mCRC wanted to receive more information about. Only 60% of the patients with mCRC were (quite) satisfied with the received information.

Despite the severity of their disease, the majority of cancer patients with metastasis want to be fully informed.<sup>31</sup> However, 40% of the patients with mCRC in our study were not satisfied with the received information and almost 30%

wanted to receive more information. This possibly indicates that not all informational needs were met. This is confirmed by our finding that patients with mCRC reported receiving only a little information about other services, and wanted more information about these topics. Other studies showed that the perceived need for additional help was very high among patients with advanced cancer, but HCPs are often unaware of this need.<sup>32</sup> HCPs are inclined to give routine medical/technical information (diagnosis, type of treatment) and avoid emotional and quality-of-life issues.<sup>33</sup> Furthermore, patients with mCRC possibly want (and expect) more direct emotional support from their HCP instead of only a referral to more formal organized support.<sup>32</sup>

Our results do not show differences in the perceived level of received information between patients with or without mCRC. This could indicate that the information HCPs provide is very general and routinely given, and not tailored to

TABLE 4. STANDARDIZED BETAS OF MULTIVARIATE LINEAR REGRESSION ANALYSES EVALUATING THE ASSOCIATION OF INFORMATION PROVISION SUBSCALES WITH HEALTH STATUS, ANXIETY AND DEPRESSION, AND ILLNESS PERCEPTIONS

	<i>Information about the disease</i>	<i>Information about medical tests</i>	<i>Information about treatment</i>	<i>Information about other services</i>	<i>Satisfaction with information</i>
Health status <sup>a</sup>					
General health	−0.24*	ns	ns	ns	ns
Physical functioning	ns	ns	ns	−0.36**	ns
Role limitations physical health	ns	ns	0.32*	−0.32**	ns
Bodily pain	−0.24*	ns	ns	−0.26*	ns
Vitality	ns	ns	ns	−0.37*	ns
Social functioning	−0.26*	ns	ns	ns	ns
Role limitations emotional problems	ns	ns	ns	−0.25*	ns
Mental health	ns	ns	ns	−0.32**	ns
Anxiety and depression <sup>b</sup>					
Anxiety	ns	ns	ns	ns	ns
Depression	ns	ns	ns	0.29**	ns
Illness perceptions <sup>c</sup>					
B-IPQ1 consequences	ns	ns	ns	ns	ns
B-IPQ2 time line	ns	ns	ns	ns	ns
B-IPQ3 personal control	ns	ns	ns	ns	ns
B-IPQ4 treatment control	ns	ns	ns	ns	ns
B-IPQ5 identity	ns	ns	ns	0.27*	ns
B-IPQ6 concern	ns	ns	ns	ns	ns
B-IPQ7 coherence	ns	ns	ns	ns	ns
B-IPQ8 emotional representation	ns	ns	ns	ns	ns

\* <0.05; \*\* <0.01

<sup>a</sup>Higher score indicates better functioning.

<sup>b</sup>Higher score indicates higher levels of anxiety/depression.

<sup>c</sup>Higher score indicates worse illness perceptions.

Corrected for gender, age, time since diagnosis, chemotherapy, and comorbidity. These analyses only include patients with metastasized disease at time of diagnosis.  
ns, not significant.

the individual patient. Further complicating the interpretation of our results is that cancer patients tend to forget a substantial amount of information that has been given to them, because they may be emotionally overwhelmed,<sup>34</sup> impaired in their cognitive capability, may not understand the medical terminology used, or in the case of metastasized disease deny the “terminal” nature of their illness as a coping strategy to retain hope.<sup>16,35</sup> HCPs may have provided the required information but patients do not recall having received this information. Because satisfaction with information provision is in part determined by the amount of information received, it is important that HCPs constantly check what the patient has understood and whether the information was helpful.<sup>36</sup> When necessary, the HCP must repeat the information several times, both between and within consultations.<sup>7</sup>

The perceived receipt of more *disease* information and information about *other services* was associated with worse health outcomes among patients with mCRC. Part of this result could be influenced by confounding. Information provision about metastasis and *other services* may cause negative feelings on its own, because it is often emotionally loaded, whereas information about *treatment* options possibly gives the patient new hope. Hope is an important factor for a person’s well-being and quality of life.<sup>37</sup> Also, treatment information could empower the patient to anticipate and react to expected toxicities with a clear action plan. Furthermore, information provision about *other services* was too limited for most patients, possibly leading to more uncertainty or confusion.

Although satisfaction with the received information was associated with better health outcomes among patients with curable cancer,<sup>1</sup> we did not find this association in our study among patients with mCRC. A possible explanation for the absence of this association is that next to the amount of information, the content of information and the way the information is provided are at least equally important for the satisfaction levels of patients with mCRC.<sup>38</sup> Furthermore, patient satisfaction is associated with supportive HCP behaviors<sup>33</sup>; the way information is provided (although not assessed in this study) could influence the way information will be perceived.<sup>16</sup> Patients with advanced cancer want the HCP to be honest, to convey hope, to speak plain language instead of difficult medical terminology, to be empathic, to give enough time during discussion, and to pace the amount of information to what they can assimilate.<sup>16</sup> Another study reported that 100% of the respondents wanted HCPs to be honest, whereas 91% also wanted HCPs to be optimistic. However, it is difficult for HCPs to remain optimistic while being honest about a poor prognosis.<sup>39</sup>

Further, our results showed that patients with mCRC had worse illness perceptions compared with CRC patients without metastasis. Patients with mCRC were aware of the severity of their disease and also reported a better understanding of their illness compared with patients without mCRC. This indicates that HCPs did a good job in informing patients about their disease severity. However, we did not find an association between information provision and illness perceptions for patients with mCRC. In comparison, a recent

study showed that patient awareness of incurable disease was associated with improvements in health status,<sup>40</sup> because they were better able to understand and manage their symptoms.

Our results indicate that the delivery of information to patients with mCRC can be improved. Adequate assessment of patients' individual information needs as well as appropriate responses to these needs might lead to higher levels of satisfaction. HCPs can start a conversation by giving general information per topic and then ask whether or not a patient wants to discuss this topic in more detail.<sup>41</sup> In particular, providing information about other services can be bettered as both metastatic and non-mCRC survivors perceived receiving little information on this topic. HCPs need to become aware of the supportive care needs and provide the patient with more emotional and quality-of-life information when necessary. However, HCPs might not feel competent to provide patients with information about advanced disease.<sup>42</sup> Because satisfaction levels of mCRC patients might be related not only to the amount of information received, but also to the way the information is provided it seems important to pay attention to the communication skills of HCPs by developing and implementing education and training programs.<sup>43</sup>

The study has limitations. First, patients with mCRC included in our study were long-term survivors, which could have biased our results. Relative survival for stage IV colon and rectal cancer was respectively 7% and 6% in the period 2004–2006.<sup>44</sup> Multiagent chemotherapy has enabled previously unresectable mCRCs to be resected,<sup>11</sup> and 5-year relative survival for patients undergoing hepatic resection has increased to 45%.<sup>45</sup> It is therefore possible that some of the patients with mCRC were cured at the time of our study. Because we aimed to compare the levels of received information between patients whose cancer is curable (non-mCRC) and those whose cancer is not curable (mCRC), the potential curability of mCRC could have confounded our results. Unfortunately, we did not have data about the exact rates of cure in our study sample. Future research is needed to determine differences over time in health outcomes between patients with mCRC who are actually cured and those with incurable mCRC. Second, the cross-sectional design of the study limits the determination of causal associations between information provision and health outcomes. Third, because all participants were patients with CRC, we can only generalize our results to this group of patients. Finally, the EORTC QLQ-INFO25 does not measure who provided the information and when the information was provided exactly. It would be interesting to assess which aspects of information patients receive from different HCPs or other sources and at what point in their disease trajectory they receive the information. Prospective research is needed to overcome part of the recall bias.

## Conclusion

The findings of this study indicate that some improvements can be made in the provision of information to patients with mCRC. Patients especially wanted more information about supportive care. Our results with regard to the associations between perceived receipt of more *disease* information and information about *other services* with worse health outcomes should be interpreted with care, because the way the information was provided and the content of the information are probably more important for patient satisfaction than the

amount of received information. This can possibly also explain the lack of a relation between satisfaction with the received information and health outcomes.

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## References

- Husson O, Mols F, van de Poll-Franse LV: The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: A systematic review. *Ann Oncol* 2011;22:761–772.
- Mallinger JB, Griggs JJ, Shields CG: Patient-centered care and breast cancer survivors' satisfaction with information. *Patient Educ Couns* 2005;57:342–349.
- Mesters I, van den Borne B, De Boer M, Pruynt J: Measuring information needs among cancer patients. *Patient Educ Couns* 2001;43:253–262.
- Arraras JI, Kuljanic-Vlasic K, Bjordal K, et al.: EORTC QLQ-INFO26: A questionnaire to assess information given to cancer patients a preliminary analysis in eight countries. *Psychooncology* 2007;16:249–254.
- Mills ME, Sullivan K: The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *J Clin Nurs*. 1999;8(6):631–642.
- Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ: What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer* 2009;17:1117–1128.
- Hancock K, Clayton JM, Parker SM, et al.: Discrepant perceptions about end-of-life communication: A systematic review. *J Pain Symptom Manage* 2007;34:190–200.
- Elkin EB, Kim SH, Casper ES, Kissane DW, Schrag D: Desire for information and involvement in treatment decisions: Elderly cancer patients' preferences and their physicians' perceptions. *J Clin Oncol* 2007;25:5275–5280.
- Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J: Information needs and sources of information among cancer patients: A systematic review of research (1980–2003). *Patient Educ Couns* 2005;57:250–261.
- Miller SM: Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer* 1995;76:167–177.
- Eadens MJ, Grothey A: Curable metastatic colorectal cancer. *Curr Oncol Rep* 2011;13:168–176.
- Meulenbeld HJ, van Steenberghe LN, Janssen-Heijnen ML, Lemmens VE, Creemers GJ: Significant improvement in survival of patients presenting with metastatic colon cancer in the south of The Netherlands from 1990 to 2004. *Ann Oncol* 2008;19:1600–1604.

13. Hwang SS, Chang VT, Fairclough DL, Cogswell J, Kasimis B: Longitudinal quality of life in advanced cancer patients: Pilot study results from a VA medical cancer center. *J Pain Symptom Manage* 2003;25:225–235.
14. Wilson KG, Chochinov HM, Skirko MG, et al.: Depression and anxiety disorders in palliative cancer care. *J Pain Symptom Manage* 2007;33(2):118–129.
15. Corli O, Apolone G, Pizzuto M, et al.: Illness awareness in terminal cancer patients: An Italian study. *Palliat Med* 2009;23:354–359.
16. Strohbuecker B, Gaertner J, Stock S: Informing severely ill patients: Needs, shortcomings and strategies for improvement. *Breast Care (Basel)* 2011;6:8–13.
17. Wong RK, Franssen E, Szumacher E, et al.: What do patients living with advanced cancer and their carers want to know? A needs assessment. *Support Care Cancer* 2002;10:408–415.
18. Weeks JC, Cook EF, O'Day SJ, et al.: Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 1998;279:1709–1714.
19. Butow PN, Dowsett S, Hagerty R, Tattersall MH: Communicating prognosis to patients with metastatic disease: What do they really want to know? *Support Care Cancer* 2002;10:161–168.
20. Cherny NI: Factors influencing the attitudes and behaviors of oncologists regarding the truthful disclosure of information to patients with advanced and incurable cancer. *Psychooncology* 2011; 20:1269–1281.
21. Hancock K, Clayton JM, Parker SM, et al.: Truth-telling in discussing prognosis in advanced life-limiting illnesses: A systematic review. *Palliat Med* 2007;21:507–517.
22. Husson O, Thong MS, Mols F, Oerlemans S, Kaptein AA, van de Poll-Franse LV: Illness perceptions in cancer survivors: What is the role of information provision? *Psychooncology* 2012 Feb 6 [Epub ahead of print].
23. Janssen-Heijnen MLG, Louwman WJ, Van de Poll-Franse LV, Coebergh JWW: *Results of 50 Years Cancer Registry in the South of the Netherlands: 1955–2004*. Eindhoven: Eindhoven Cancer Registry, 2005.
24. van de Poll-Franse LV, Horevoorts N, van Eenbergen M, et al.: The Patient Reported Outcomes Following Initial Treatment and Long-term Evaluation of Survivorship Registry: Scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. *Eur J Cancer* 2011;47:2188–2194.
25. UICC: *TNM Atlas Illustrated Guide to the TNM/pTNM Classification of Malignant Tumors, 4th ed, 2nd rev. ed.* Berlin: Springer-Verlag, 1992, pp. 141–144.
26. Arraras JL, Greimel E, Sezer O, et al.: An international validation study of the EORTC QLQ-INFO25 questionnaire: An instrument to assess the information given to cancer patients. *Eur J Cancer* 2010;46:2726–2738.
27. Aaronson NK, Muller M, Cohen PD, et al.: Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *J Clin Epidemiol* 1998;51:1055–1068.
28. Zigmond AS, Snaith RP: The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983;67:361–370.
29. Olsson I, Mykletun A, Dahl AA: The Hospital Anxiety and Depression Rating Scale: A cross-sectional study of psychometrics and case finding abilities in general practice. *BMC Psychiatry* 2005;5:46.
30. Broadbent E, Petrie KJ, Main J, Weinman J: The Brief Illness Perception Questionnaire. *J Psychosom Res* 2006;60:631–637.
31. Pardon K, Deschepper R, Vander Stichele R, et al.: Are patients' preferences for information and participation in medical decision-making being met? Interview study with lung cancer patients. *Palliat Med* 2011;25:62–70.
32. Hagerty RG, Butow PN, Ellis PM, et al.: Communicating with realism and hope: Incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol* 2005;23:1278–1288.
33. Fine E, Reid MC, Shengelia R, Adelman RD: Directly observed patient-physician discussions in palliative and end-of-life care: A systematic review of the literature. *J Palliat Med* 2010;13:595–603.
34. van der Molen B: Relating information needs to the cancer experience. 2. Themes from six cancer narratives. *Eur J Cancer Care (Engl)* 2000;9:48–54.
35. Galfin JM, Watkins ER, Harlow T: A brief guided self-help intervention for psychological distress in palliative care patients: A randomised controlled trial. *Palliat Med* 2012; 26:197–205.
36. Rose KE: A qualitative analysis of the information needs of informal carers of terminally ill cancer patients. *J Clin Nurs* 1999;8:81–88.
37. Rustoen T: Hope and quality of life, two central issues for cancer patients: A theoretical analysis. *Cancer Nurs* 1995;18: 355–361.
38. Clayton JM, Hancock K, Parker S, et al.: Sustaining hope when communicating with terminally ill patients and their families: A systematic review. *Psychooncology* 2008;17: 641–659.
39. Kutner JS, Steiner JF, Corbett KK, Jahnigen DW, Barton PL: Information needs in terminal illness. *Soc Sci Med* 1999;48: 1341–1352.
40. Lee MK, Baek SK, Kim SY, et al.: Awareness of incurable cancer status and health-related quality of life among advanced cancer patients: A prospective cohort study. *Palliat Med* 2011 Dec. 5 [Epub ahead of print].
41. van Vliet L, Francke A, Tomson S, Plum N, van der Wall E, Bensing J: When cure is no option: How explicit and hopeful can information be given? A qualitative study in breast cancer. *Patient Educ Couns* 2011 May 7 [Epub ahead of print].
42. Rainbird K, Perkins J, Sanson-Fisher R, Rolfe I, Anseline P: The needs of patients with advanced, incurable cancer. *Br J Cancer* 2009;101:759–764.
43. Back AL, Arnold RM, Baile WF, et al.: Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med* 2007;167: 453–460.
44. Lemmens V, van Steenberghe L, Janssen-Heijnen M, Martijn H, Rutten H, Coebergh JW: Trends in colorectal cancer in the south of the Netherlands 1975–2007: Rectal cancer survival levels with colon cancer survival. *Acta Oncol* 2010; 49:784–796.
45. Dols LF, Verhoef C, Eskens FA, et al.: [Improvement of 5 year survival rate after liver resection for colorectal metastases between 1984–2006]. *Ned Tijdschr Geneesk* 2009;153: 490–495.

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