

# Living with the physical and mental consequences of an ostomy: a study among 1–10-year rectal cancer survivors from the population-based PROFILES registry

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## Abstract

**Background:** This study examined the physical and mental consequences of an ostomy among 1–10-year rectal cancer survivors.

**Methods:** Patients with rectal cancer diagnosed from 2000 to 2009, as registered in the population-based Eindhoven Cancer Registry, received a questionnaire on quality of life (QOL; EORTC QLQ-C30), disease-specific health status (EORTC QLQ-CR38), depression and anxiety (HADS), illness perceptions (Brief Illness Perception Questionnaire), and health care utilization; 76% ( $n = 1019$ ) responded.

**Results:** A total of 408 (43%) rectal cancer survivors had an ostomy at survey and they reported a statistically significant and clinically relevant lower physical, role, and social functioning, and global health status/QOL but fewer problems with constipation and diarrhea compared with those without an ostomy. Also, they had a significantly worse body image, more male sexual problems, and fewer gastrointestinal problems although these differences were not clinically relevant. No differences regarding the prevalence of symptoms of anxiety and depression were found. Survivors with an ostomy believed that their illness have significantly more serious consequences, will last longer (clinically relevant), and were more concerned about their illness compared with those without an ostomy. Survivors with an ostomy visited their medical specialist, but not their general practitioner, significantly more often. Also, they more often received additional support after cancer treatment.

**Conclusions:** Rectal cancer survivors with an ostomy have a lower QOL, worse illness perceptions, and a higher health care consumption compared with those without an ostomy 1–10 years after diagnosis.

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Received: 20 August 2013

Revised: 12 February 2014

Accepted: 13 February 2014

## Introduction

Because of improvements in treatment, such as total mesorectal excision and neoadjuvant (chemo) radiotherapy, the survival of rectal cancer has improved [1]. These growing numbers of survivors have to live with the long-term consequences of rectal cancer and its treatment. One of those consequences can be the presence of an ostomy, which refers to the surgically created opening in the abdominal wall for the discharge of stool. An abdominoperineal resection is performed when the tumor is located in the lower part of the rectum. In this situation, the anal sphincter cannot be preserved, thus requiring an ostomy [2]. A low anterior resection is the treatment of choice if the tumor is located in a more upper part of the rectum [2] and then the anal sphincter can usually be preserved. However, patients often get an ostomy in order to minimize possible complications of an anastomotic leakage.

Having an ostomy can have a negative effect on body image [3–5] and sexual functioning [3–5] and can also

result in fewer problems with diarrhea [5] and constipation [3,4]. A review concluded that avoiding a permanent ostomy, when possible, is preferable in terms of quality of life (QOL) [6]. In contrast, a Cochrane review concluded that 10 trials showed no poorer QOL for ostomy patients, whereas 16 studies found some differences but not always in favor of those without an ostomy [7]. Findings on the consequences of living with an ostomy are thus mixed and most often only focus on QOL. Furthermore, most studies are relatively small, not population-based, and lack information on the clinical relevance of the results [7].

Therefore, our aim was to compare QOL, anxiety, depression, illness perceptions, and health care utilization of 1–10-year rectal cancer survivors with and without an ostomy. We hypothesize that those with an ostomy have a lower QOL because of the physical limitations that the ostomy brings. We do not expect differences regarding anxiety and depression because we expect that patients will adjust mentally to their ostomy. Furthermore, we hypothesize that those with an ostomy have more negative

illness perceptions because the ostomy serves as a constant reminder of their disease. Finally, we expect patients with an ostomy to have a higher health care consumption because of their ostomy and its possible complications.

## Methods

### Setting and participants

Data from the first wave (December 2010) of a prospective population-based yearly survey among colorectal cancer survivors were used. Data collection was carried out within PROFILES ([www.profilesregistry.nl](http://www.profilesregistry.nl)) [8]. Everyone diagnosed with colorectal cancer (CRC) from 2000 to 2009 as registered in the Eindhoven Cancer Registry (ECR) was eligible for participation. Those with unverifiable addresses, with cognitive impairment, who died prior to the start of study or were terminally ill, those of whom the tumor was not staged, and those already included in our 2009 study [9,10] or another study ( $n=169$ ) were excluded. This study was approved by a local certified Medical Ethics Committee.

### Data collection

Survivors were invited via a letter from their (former) attending specialist. Non-respondents were sent a reminder within 2 months.

### Demographic and clinical characteristics

Survivors' sociodemographic and clinical information was available from the ECR. Comorbidity was assessed with the adapted Self-administered Comorbidity Questionnaire (SCQ) [11]. Socioeconomic status was determined by an indicator developed by Statistics Netherlands [12]. Questions on marital status, educational level, body mass index, and employment status were added to the questionnaire.

### Quality of life

The EORTC QLQ-C30 was used to assess cancer-specific QOL [13]. It contains five functional scales, a global health status/QOL scale, three symptoms scales, and six single items. Each item is scored on a four-point Likert scale, except the global QOL scale, which has a seven-point Likert scale. Scores were linearly transformed to a 0–100 scale [14].

### Disease-specific health status

Disease-specific health status was assessed with EORTC QLQ-CR38 [15]. It consists of two multi-item and two single-item scales and seven symptom scales and an item on weight loss. Items were scored on a four-point Likert scale. All scales were linearly converted to a 0–100 scale.

### Depression and anxiety

The Hospital Anxiety and Depression Scale (HADS), comprising 14 items on a four-point Likert scale, was used

to assess symptoms of anxiety and depression. We used a score of 8 as a cut-off value for subthreshold depression and anxiety [16,17] and a cut-off of 11 for clinical depression and anxiety [18,19].

Depression was also assessed with the adapted SCQ, which lists 14 medical conditions including depression and allows patients to note if they have the condition, are treated for it, and if it hinders them [11].

### Illness perceptions

Illness perceptions were assessed using the Brief Illness Perception Questionnaire (BIPQ) [20], which uses an eight single-item scale approach to assess perceptions on a continuous linear 0–10 point scale.

### Health care utilization

Patients were asked to indicate the number of visits to a general practitioner and medical specialist (in relation to cancer) in the past 12 months. Also, they were asked whether they received additional support after cancer treatment (e.g., from a psychologist, social worker, pastor, physiotherapist, and oncology nurse).

### Statistical analyses

Patient and tumor characteristics of respondents, non-respondents, and patients with unverifiable addresses, were compared using *t*-tests for continuous and chi-square analyses for categorical variables. We used non-parametric equivalents, where appropriate. Similarly, differences between those with and without an ostomy were analyzed.

The EORTC QLQ-C30 and EORTC QLQ-CR38 mean scores, stratified by ostomy, were compared with analysis of covariance (ANCOVA). Clinically relevant differences for the EORTC QLQ-C30 were determined according to the guidelines by Cocks *et al.* [21]. Regarding the EORTC QLQ-CR38, clinically relevant differences were based on Norman's 'rule of thumb' [22]. These analyses were also carried out among those treated with low anterior resection, stratified by ostomy. Multivariate linear regression analyses were conducted to study the independent association between sociodemographic and clinical characteristics with the EORTC QLQ-C30 and EORTC QLQ-CR38 subscales.

The percentage of patients with a subthreshold or clinical depression and anxiety, stratified by ostomy, were compared with binary logistic regression analysis. Similar comparisons were made with respect to the presence of a depression as assessed with the SCQ, stratified by ostomy. Also, similar comparisons were made with regard to the treatment for depression and the amount of bother experienced by a depression.

The BIPQ mean scores, stratified by ostomy, were compared with ANCOVA. Clinically relevant differences were based on Norman's rule of thumb [22]. Similar analyses were performed when comparing those with a

permanent ostomy, temporary ostomy, and those who never had an ostomy.

Patients' health care utilization, stratified by ostomy, was compared with ANCOVA.

Confounding background variables included for adjustment in all ANCOVA analyses were determined a priori [23] and chosen to be age at diagnosis, years since diagnosis, cancer grade, initial treatment, comorbidity, marital status, and educational level. Because of multiple testing, statistical differences were indicated at  $p < 0.01$ . Reported  $p$ -values were two-sided. All statistical analyses were performed using SAS version 9.2 (SAS institute Inc., Cary, NC, USA).

## Results

### Demographic and clinical characteristics

In total, 6446 CRC patients were diagnosed between January 2000 and June 2009 within the area of the ECR. Of those, 2219 CRC patients had been previously selected for a CRC study and were thus excluded. Also, one participating hospital excluded 169 rectal cancer patients due to other ongoing research. Of the remaining 4058 CRC patients, 327 CRC patients died prior to the start of study, 63 CRC patients had cognitive impairment or were terminally ill, and from 83 CRC patients, the tumor was not staged. Thus, 3585 CRC patients were eligible for participation and received a questionnaire. Of those, 2625 (73%) CRC patients completed the questionnaire, 619 (17%) patients actively refused or did not return the questionnaire, and 341 (10%) patients had unverifiable addresses. For this study, only data on rectal cancer patients were used, 1019 (76%).

No differences were found between respondents, non-respondents, and those with unverifiable addresses regarding years since diagnosis, gender, and TNM stage. However, respondents were younger compared with non-respondents and those with non-verified addresses (68.6, 71.9, 69.0 years;  $p = 0.0027$ ). Also, respondents were less often treated with surgery only and more often with a combination of surgery and radiotherapy ( $p = 0.0002$ ).

Four hundred and eight (43%) survivors had an ostomy (Table 1). Besides differences in treatment, they were significantly older and less often had a high educational level. Patients were also asked what situation described their ostomy best; never had one ( $n = 191$ ; 18.7%), a permanent one ( $n = 371$ ; 36.4%), temporary but now closed ( $n = 347$ ; 34%), temporary but will be closed soon ( $n = 5$ ; 0.5%), temporary but do not know if it ever will be closed ( $n = 1$ ; 0.01%), temporary but became permanent ( $n = 15$ ; 1.5%), and temporary, which has been closed but I have a new ostomy due to complications ( $n = 16$ ; 1.6%). The average time patients had a temporary ostomy before it was closed was 5 months (standard deviation, 3.9).

**Table 1.** Sociodemographic and clinical characteristics of rectal cancer survivors, stratified by ostomy

	No ostomy	Ostomy	p-value
	538 (56.9)	408 (43.1)	
Age at time of survey (median)	67.9	69.8	0.0609
Age at time of survey			0.0006
<60 years	206 (38.3)	152 (37.3)	
60–69 years	230 (42.8)	138 (33.8)	
70+ years	102 (19.0)	118 (28.8)	
Years since diagnosis (median)	5.4	4.5	0.0241
Years since diagnosis			0.0917
1–4 years	259 (48.1)	219 (53.7)	
5–10 years	279 (51.9)	189 (46.3)	
Gender			0.0582
Male	302 (56.1)	254 (62.3)	
Female	236 (43.9)	154 (37.8)	
TNM stage			0.9626
1	218 (40.5)	167 (40.9)	
2	144 (26.8)	107 (26.2)	
3	137 (25.5)	100 (24.5)	
4	20 (3.7)	16 (3.9)	
Unknown	19 (3.5)	18 (4.4)	
Treatment <sup>a</sup>			<0.0001
SU only	129 (24.1)	34 (8.4)	
RT + SU	274 (51.2)	273 (67.6)	
CT + RT + SU	82 (15.3)	90 (22.3)	
CT + SU	46 (8.6)	4 (1.0)	
CT or RT only	4 (0.8)	3 (0.7)	
Comorbidity <sup>b</sup>			0.0588
None	159 (31.4)	91 (24.2)	
1	139 (27.4)	119 (31.7)	
2+	209 (41.2)	166 (44.2)	
BMI			0.0289
<18.4 (Underweight)	6 (1.1)	6 (1.5)	
18.5–24.9 (Normal)	192 (36.1)	111 (27.5)	
25–29.9 (Overweight)	258 (48.5)	211 (52.2)	
≥30 (Obese)	76 (14.3)	76 (18.8)	
Marital status			0.2056
Married	431 (80.4)	321 (79.9)	
Single/divorced	53 (9.9)	33 (8.1)	
Widow/widower	52 (9.7)	53 (13.0)	
Education level <sup>c</sup>			0.0028
Low	84 (15.8)	83 (20.4)	
Medium	309 (58.1)	254 (62.4)	
High	139 (26.1)	70 (17.2)	
Current occupation status			0.1542
Employed	111 (21.4)	69 (17.6)	
Not employed/retired	409 (78.7)	324 (82.4)	
Socioeconomic status			0.1800
Low	82 (15.7)	79 (20.3)	
Medium	230 (43.0)	166 (42.7)	
High	211 (40.3)	144 (37.0)	

Some variables exceed 100% due to rounding off.

<sup>a</sup>SU, surgery; RT, radiotherapy; CT, chemotherapy.

<sup>b</sup>Adapted Self-administered Comorbidity Questionnaire [25].

<sup>c</sup>Education: low (no or primary school); medium (lower general secondary education or vocational training); high (pre-university education, high vocational training, university).

### Quality of life

Those with an ostomy reported a statistically significant and clinically relevant worse physical, role, and social functioning, and global health status/QOL but fewer

symptoms of constipation and diarrhea compared with those without an ostomy (Table 2). Furthermore, they reported a statistically significant worse body image, more male sexual problems, and fewer gastrointestinal problems.

Multivariate linear regression analyses showed that the presence of an ostomy was negatively associated with physical, role, and social functioning and with global health status/QOL (indicating lower functioning and health status; Table 3). Also, having an ostomy was negatively associated with constipation and diarrhea indicating fewer symptoms. Furthermore, having an ostomy was negatively associated with body image (indicating worse body image) and gastrointestinal problems (indicating fewer problems) but positively with micturition problems,

chemotherapy side effects, and male sexual problems (indicating more problems).

Subanalyses showed that 58.3% ( $n=593$ ) of patients were treated with low anterior resection and 20.5% of them ( $n=112$ ) had an ostomy. They reported a statistically significant and clinically relevant worse physical (72.5 vs. 84.4;  $p < 0.0001$ ), role (72.5 vs. 84.3;  $p < 0.0001$ ), and social functioning (76.5 vs. 87.8;  $p < 0.0001$ ) and global health status/QOL (69.3 vs. 79.5;  $p < 0.0001$ ), and more fatigue (27.1 vs. 18.9;  $p=0.0051$ ) but less constipation (2.4 vs. 12.3;  $p < 0.0001$ ) compared with those without an ostomy. In addition, they reported worse body image (71.5 vs. 84.4;  $p < 0.0001$ ), more male sexual problems (66.9 vs. 48.0;  $p=0.0048$ ), and fewer gastrointestinal problems (13.6 vs. 18.2;  $p=0.0033$ , not clinically relevant).

**Table 2.** Mean EORTC QLQ-C30 and EORTC QLQ-CR38 scores, stratified by ostomy

EORTC QLQ-C30	Mean ( $\pm$ SD)		<i>p</i> -value
	No ostomy ( $n=534$ )	Ostomy ( $n=407$ )	
Physical functioning	84.0 (18.5)	75.7 (21.5)	<0.0001 <sup>a</sup>
Role functioning	83.1 (24.8)	75.7 (29.6)	0.0009 <sup>a</sup>
Emotional functioning	86.6 (18.6)	85.2 (20.0)	0.6465
Cognitive function	86.6 (19.2)	84.7 (20.2)	0.4500
Social function	87.6 (20.8)	82.1 (25.0)	0.0031 <sup>a</sup>
Global health status/QOL	79.2 (18.7)	74.1 (20.5)	0.0020 <sup>a</sup>
Fatigue	19.6 (22.9)	24.0 (24.4)	0.3101
Nausea and vomiting	3.2 (10.5)	3.9 (12.2)	0.5374
Pain	14.2 (22.7)	17.9 (25.6)	0.2902
Dyspnea	12.0 (22.4)	15.8 (26.1)	0.2889
Insomnia	19.5 (27.0)	21.0 (30.1)	0.9888
Loss of appetite	5.7 (16.6)	5.5 (17.6)	0.0754
Constipation	12.2 (21.5)	4.4 (15.1)	<0.0001 <sup>a</sup>
Diarrhea	12.6 (22.1)	9.0 (20.8)	0.0005 <sup>a</sup>
Financial impact	6.5 (19.3)	9.9 (21.2)	0.0954
<b>EORTC QLQ-CR38</b>			
Body image	85.1 (21.0)	73.8 (26.5)	<0.0001
Future perspective	73.1 (27.2)	69.6 (29.4)	0.2733
Sexual function	23.0 (22.2)	21.9 (23.0)	0.5386
Sexual enjoyment	57.3 (27.4)	53.4 (30.2)	0.6783
Micturition problems	21.3 (17.8)	24.7 (18.9)	0.0753
Chemotherapy side effects	9.1 (14.6)	12.3 (17.5)	0.0440
Gastrointestinal problems	17.7 (14.9)	13.4 (13.8)	<0.0001
Male sexual problems	44.9 (37.3)	62.1 (37.5)	<0.0001
Female sexual problems	28.4 (26.7)	27.8 (27.8)	0.5652
Defecation problems	18.8 (14.0)	-	
Stoma-related problems	-	22.5 (20.5)	
Weight loss	4.9 (15.0)	5.4 (15.1)	0.5566

A higher score on the EORTC QLQ-C30 and EORTC QLQ-CR38 functional scales and the EORTC QLQ-C30 global QOL scale means better functioning and QOL. A higher score on the EORTC QLQ-C30 and EORTC QLQ-CR38 symptom scales and the EORTC QLQ-CR38 single item on weight loss mean more complaints.

Confounding background variables included for adjustment in these analyses were determined a priori [23] and chosen to be age at diagnosis, years since diagnosis, cancer grade, initial treatment, comorbidity, marital status, and educational level.

<sup>a</sup>Clinically relevant differences for the EORTC QLQ-C30 were determined according to guidelines by Cocks et al. [21]. Differences found were all of small clinical relevance. Clinically relevant differences for the EORTC QLQ-CR38 were based on Norman's rule of thumb [22]. None were found.

**Depression and anxiety**

No differences regarding the prevalence of subthreshold anxiety (20.6 vs. 19.2;  $p=0.9675$ ) and depression (18.4 vs. 16.4;  $p=0.9486$ ) were found between those with and without an ostomy as assessed with the HADS. Also, no differences were found regarding the prevalence of clinical anxiety (7.0 vs. 6.7;  $p=0.7566$ ) and depression (8.4 vs. 6.5;  $p=0.6190$ ) as assessed with this questionnaire. Furthermore, no differences were found with respect to the presence of a depression in the past 12 months (6.1 vs. 5.9;  $p=0.9006$ ), whether those patients received treatment for this depression (88.9 vs. 66.7;  $p=0.2286$ ) and whether patients felt hindrance by their depression (61.1 vs. 55.2;  $p=0.5836$ ) as assessed with the SCQ.

**Illness perception**

Those with an ostomy believed that their illness had significantly more serious consequences (4.9 vs. 3.9;  $p < 0.0001$ ), will last longer (6.6 vs. 4.5;  $p < 0.0001$ ; clinically relevant), and were more concerned about their illness (4.5 vs. 3.8;  $p=0.0086$ ) compared with those without an ostomy.

Subanalyses showed that those who never had an ostomy believed that their illness had significantly less serious consequences (3.3 vs. 4.9 vs. 4.3, respectively;  $p < 0.0001$ ), have a shorter duration (3.9 vs. 6.6 vs. 4.9;  $p < 0.0001$ ), experienced fewer symptoms (3.1 vs. 4.0 vs. 4.1;  $p=0.0016$ ), and were less concerned about their illness (3.5 vs. 4.5 vs. 4.1;  $p=0.0078$ ) compared with those with a permanent or temporary ostomy. The difference between those who never had an ostomy and those with a permanent ostomy was clinically relevant for the subscales consequences and timeline [22].

**Health care utilization**

Those with and without an ostomy visited their general practitioner equally often in the past 12 months (4.2 vs. 3.9;  $p=0.6908$ ). However, the difference in visits in relation to cancer was nearly significant (1.9 vs. 1.0;  $p=0.0227$ ).

**Table 3.** Standardized betas of multivariate linear regression analyses evaluating the association of independent variables with EORTC QLQ-C30 subscales.

EORTC QLQ-C30 subscales	Independent variables										
	Age <sup>a</sup>	Years since diagnosis <sup>a</sup>	Male versus female	Married versus not married	Ostomy versus no ostomy	Comorbidity <sup>a</sup>	CT or RT versus SU	SU + RT versus SU	SU + RT + CT versus SU	Grades 1, 3, 9 versus 2	Grades 2, 3, 9 versus 1
EORTC QLQ-C30											
Physical functioning	-0.14***	0.09**	0.09*	0.10**	-0.15**						
Role functioning		0.08*		0.09*	-0.11*	-0.22***					
Emotional functioning	0.12**					-0.24***					
Cognitive functioning		0.09*		0.10*		-0.19***					
Social functioning					-0.11*	-0.13***					
Global health status/QOL		0.11**			-0.11***	-0.29***					-0.11**
Fatigue				-0.09*		0.28***	0.09*				
Nausea and vomiting											
Pain			-0.11**			0.26***					
Dyspnea			-0.20***	-0.14***		0.22***					
Insomnia						0.15***					
Loss of appetite					-0.19***						
Constipation					-0.09*			0.21***			
Diarrhea											
Financial impact	-0.23***										
EORTC QLQ-CR38											
Body image	0.11*	0.11*									
Future perspective	0.10*	0.14***									
Sexual function	-0.22***		0.10*								
Sexual enjoyment	-0.20**		0.17**	0.08*							
Micturition problems	0.17***										
Chemotherapy side effects		-0.10*	-0.15***								
Gastrointestinal problems	-0.16***		-0.15***						0.11**		
Male sexual problems	0.19***										
Female sexual problems											
Defecation problems <sup>b</sup>									0.17***		
Stoma-related problems <sup>c</sup>										0.23***	0.17***
Weight loss				-0.19***							

A higher score on the EORTC QLQ-C30 and EORTC QLQ-CR38 functional scales and the EORTC QLQ-C30 global QOL scale means better functioning and QOL. A higher score on the EORTC QLQ-C30 and EORTC QLQ-CR38 symptom scales and the EORTC QLQ-CR38 single item on weight loss mean more complaints.

CT, chemotherapy; RT, radiotherapy; SU, surgery; N/A, not applicable.  
<sup>a</sup>Age, years since diagnosis, and comorbidity: continuous variables.  
<sup>b</sup>Only filled out by survivors without an ostomy.  
<sup>c</sup>Only filled out by survivors with an ostomy.  
 \*p < 0.01. \*\*p < 0.001. \*\*\*p < 0.0001.

Furthermore, those with an ostomy visited their medical specialist significantly more often (4.6 vs. 3.3;  $p=0.0003$ ), also in relation to cancer (4.0 vs. 2.5;  $p<0.0001$ ).

Both ostomy and non-ostomy patients indicated that they received follow-up care (80 vs. 79%;  $p=0.5402$ ) and were comfortable with their follow-up control scheme (87 vs. 87%;  $p=0.7764$ ). The receipt of additional support after cancer treatment was higher in those with an ostomy (44 vs. 25%;  $p<0.0001$ ).

## Discussion

Ostomy patients had a clinically relevant worse physical, role, and social functioning, and global health status/QOL, even after controlling for important variables that are known to have an influence such as age and initial treatment. This confirms the results from an Italian study among sixty-two 5-year rectal cancer survivors, which also showed that those with an ostomy had lower physical and role functioning as well as global health status/QOL [24]. In addition, it confirms results from a UK study showing that those with an ostomy had a worse social functioning [25] and a German study reporting that they had worse role and social functioning [26]. In contrast, a Dutch study reported no differences on the function scales except for social functioning, which was better in those with an ostomy [27]. Also, in contrast, another Dutch study showed that ostomy patients reported a better global health status/QOL and they did not find differences in physical, role, and social functioning [28]. However, both Dutch studies were relatively small, and the median follow-up of the second study was relatively short compared with ours (36 vs. 67 months).

Furthermore, ostomy patients reported fewer symptoms of constipation and diarrhea and this was clinically relevant and confirmed by two other studies [3,28]. However, constipation and diarrhea differ widely between those with and without an ostomy, so comparison is difficult. For example, it is a possibility that ostomy patients interpret their watery stool in the ostomy bag as diarrhea. Also, the current study showed that those with an ostomy reported a worse body image, more male sexual problems, and fewer gastrointestinal problems. Although these differences were statistically significant, they were not clinically relevant. This might explain the fact why most other studies did not find these differences which in turn might also be explained by the small number of included patients in those studies. Nevertheless, an Italian and Danish study also reported a worse body image and worse sexual functioning [3,24], whereas fewer gastrointestinal problems were confirmed by a Dutch and Danish study [3,28].

No differences regarding anxiety and depression between those with and without an ostomy were found in the current study, which thereby confirmed the results of a Dutch study [27]. However, a Danish study did report higher depression scores on the HADS for those with an ostomy, but the follow-up was much shorter (i.e., 2 years) [3]. This finding

confirms our hypotheses that most patients are able to adjust mentally to their situation.

To our knowledge, this is the first study that investigated illness perceptions among rectal cancer survivors, and our results cannot therefore be compared with other studies. However, they do confirm our hypothesis that those with an ostomy have more negative illness perceptions, especially regarding the consequences of their disease, possibly because the ostomy serves as a constant reminder of their disease.

Survivors with an ostomy visited their medical specialist and numerous other health care providers more often after cancer treatment. Although the exact reasons for visiting the medical specialist and other health care providers are unknown, this higher frequency of visits is not unexpected because of the differences in follow-up time, the risk of ostomy-related complications [29], the challenges for self-care [30], and the fact that living with an ostomy requires multiple adaptations to daily life [31]. Another explanation for these differences might be that patients without an ostomy seek less help than they actually need because they might feel ashamed of their fecal problems.

The present study has some limitations. It remains unknown whether non-respondents declined to participate because of poor mental or physical health status. In addition, because of the cross-sectional nature of the data, it is not possible to draw conclusions on the direction of the relationship between ostomies and physical and mental health status. Furthermore, the ostomy group is quite heterogeneous, which makes it difficult to draw firm conclusions for the individual ostomy patient. Nevertheless, the present study provides an important contribution to the limited data available on the physical and mental consequences of having an ostomy among 1–10 year rectal cancer survivors. The results are especially important in view of the increasing number of temporary and permanent ostomies, which were recently observed in our region (unpublished data), probably as a result of focusing at minimization of possible complications of an anastomotic leakage.

Prospective longitudinal studies that assess the true influence of an ostomy on QOL, anxiety, depression, illness perceptions, and health care utilization among short-term and long-term rectal cancer survivors are necessary. Also, information on the clinical relevance of statistically significant differences would be helpful in understanding the true impact of an ostomy on a patient's life. With respect to the clinical care of CRC patients, clinicians should be aware that the aforementioned physical and mental consequences of an ostomy exist. Therefore, asking about these issues should be a routine part of clinical care so that patients can be referred to the appropriate aftercare if necessary.

## Acknowledgements

We would like to thank all patients and their doctors for their participation in the study. Special thanks go to Dr. M. van Bommel, who was

willing to function as an independent advisor and to answer questions of patients. In addition, we would like to thank the following hospitals for their cooperation: Amphia Hospital, Breda; Bernhoven Hospital, Veghel and Oss; Catharina Hospital, Eindhoven; Elkerliek Hospital, Helmond; Jeroen Bosch Hospital 's-Hertogenbosch; Maxima Medical Centre, Eindhoven and Veldhoven; Sint Anna Hospital, Geldrop; St. Elisabeth Hospital, Tilburg; Twee Steden Hospital, Tilburg and Waalwijk; VieCury Hospital, Venlo and Venray, all in the Netherlands.

The present research was supported by a VENI grant (#451-10-041) from the Netherlands Organization for Scientific Research (The Hague, The Netherlands) awarded to Floortje Mols and a Social Psychology Fellowship from the Dutch Cancer Society to Melissa Thong (#UVT2011-4960). Data collection of this study

was funded by the Comprehensive Cancer Centre South, Eindhoven, the Netherlands; and an Investment Subsidy (#480-08-009) of the Netherlands Organization for Scientific Research (The Hague, The Netherlands). These funding agencies had no further role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report, and in the decision to submit the paper for publication.

## Conflict of Interest

The authors have declared no conflicts of interest.

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