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Quality of life in elderly patients with an ostomy – a study from the population-based PROFILES registry

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Abstract

Aim Ostomies are being placed frequently in surgically treated elderly patients with colorectal cancer (CRC). An insight into the (potential) impact of ostomies on quality of life (QoL) could be useful in patient counselling as well as in the challenging shared treatment decision-making.

Method Patients with CRC diagnosed between 2000 and 2009 and registered in the population-based Eindhoven Cancer Registry received a QoL questionnaire (EORTC QLQ-C30) in 2010. In addition, QoL was compared with an age- and sex-matched normative population.

Results The study included 2299 CRC patients, of whom 494 had an ostomy. No differences were found in reported ostomy-related problems between patients aged ≤65, 66–75 and ≥76 years. Ostomy patients aged 66–75 and ≥76 years reported significantly lower physical functioning compared with those without an ostomy. In the elderly (those aged ≥76 years) ostomates reported a worse physical and social functioning compared with the normative population. All these differences were of small clinical relevance. The impact of an ostomy seems to be more prominent in younger (≤75 years old) ostomates, as they experience more functional limitations and a decrease in global health status compared with younger nonostomy patients and the normative population.

Conclusion Although elderly (≥76 years old) patients with an ostomy report significantly more limitations in functioning compared with a normative population and elderly CRC patients without an ostomy, the clinical relevance of this finding is limited. In contrast, the impact of an ostomy is more prominent in younger patients. Thus, age itself is not a reason for withholding an ostomy.

Keywords Colorectal cancer, elderly patients, ostomy, quality of life

What does this paper add to the literature?
Decision-making regarding the treatment of colorectal cancer in elderly patients is challenging. One of the items that can aid this decision-making is having knowledge about the impact of ostomy placement in this generally frail patient group. This paper provides this necessary knowledge.

Introduction

As (temporary) ostomies are being placed in 35% of surgically treated older patients with colorectal cancer (CRC) [1], it is important to have an insight into the impact of an ostomy on the quality of life (QoL) in such patients. There are about 32 000 people with a permanent ostomy in the Netherlands (0.2% of the population) and approximately 7000 ostomies (temporary and permanent) are being placed each year [2]. Due to increasing life expectancy, aging of the population and CRC screening programmes, the number of older ostomy carriers is expected to rise even further in the coming years [3–8].

The heterogeneous elderly patient population generally have more comorbidities, functional impairments and a decreased physiological reserve [9]. They experience higher morbidity rates after cancer treatment and more (excess) mortality compared with their young

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(er) counterparts [10–12]. Having an ostomy is, in general, associated with a lower QoL and worse illness perception and leads to higher health-care consumption among CRC patients [13,14]. On the other hand, placing an ostomy should always be weighed against the risk of anastomotic leakage, which occurs in up to 7% of elderly patients [15]. Although a recent study on older ostomates found that they do not experience more limitations or a greater psychosocial impact due to the ostomy compared with their younger counterparts [16], there is little other evidence addressing this important topic. Moreover, no comparisons of QoL with CRC patients without an ostomy or with the normative (non-CRC) population have been made.

Decision-making regarding CRC surgery is challenging in this specific group of elderly patients. An insight into the (potential) impact of an ostomy could be useful in preoperative patient counselling as well as in the challenging shared treatment decision-making. Therefore, our aim was to compare the QoL, and to a lesser extent symptom scales, of CRC ostomates in different age categories and with CRC patients without an ostomy. In addition, QoL was compared with an age- and sex-matched normative population.

Materials and methods

Setting and participants

For this study, data from the first wave (December 2010) of a prospective, population-based, yearly survey among CRC survivors were used. Details of the data collection have previously been reported [17]. A brief summary relevant to the present analyses is provided here. Everyone diagnosed with CRC between the years 2000 and 2009, as registered in the Eindhoven Cancer Registry (ECR) in the Netherlands, was eligible for participation [18]. Those with unverifiable addresses, with cognitive impairment, who died prior to the start of the study or were terminally ill and those with carcinoma *in situ* or who were already included in another ECR study were excluded. Data collection was performed within PROFILES (Patient Reported Outcomes Following Initial Treatment and Long Term Evaluation of Survivorship), which is a registry for the physical and psychosocial impact of cancer and its treatment (https://www.profilesregistry.nl/) [19]. The data presented in this article are based on a questionnaire which was circulated in 2010. The Medical Ethics Committee of the Maxima Medical Centre Veldhoven, the Netherlands, approved this study. All patients signed an informed consent.

Data collection

CRC survivors were informed of the study through a letter from their (ex-)attending specialist. This letter contained a link to a secure website with a login name and password, so that patients could provide informed consent and complete the questionnaire online. Those without Internet access, or those who preferred to complete the questionnaire on paper, could return a postcard by mail after which the respondent received a paper-and-pencil version of the informed consent and the questionnaire. Nonrespondents were sent a reminder letter and paper-and-pencil questionnaire within 2 months.

Socio-demographics and clinical characteristics

Survivor's socio-demographics (i.e. age, sex) and clinical information (e.g. date of diagnosis, tumour stage and treatment) was available from the ECR. Comorbidity at the time of the study was assessed with the adapted Self-administered Comorbidity Questionnaire [20]. In addition, questions on marital status and educational level were added to the questionnaire.

Ostomy status

Respondents were asked to report what situation described their ostomy best. Patients were then subdivided into two different groups. The first consisted of nonostomy carriers who never had an ostomy or who had had a temporary ostomy which had been closed. Patients with a permanent ostomy or those who had a temporary ostomy for over a year were classified as ostomates. We excluded those who reported that their temporary ostomy was going to be closed soon, as it was likely that these patients would view their ostomy in a different light with regard to QoL.

Quality of life

The European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ) C30 (version 3.0) was used to assess health-related quality of life [21]. It contains five functional scales, a global health status/QoL scale, three symptom scales and six single items (fatigue, nausea/vomiting, pain, dyspnoea, insomnia, appetite loss, constipation, diarrhoea, financial impact). Scoring of the QoL data was done according to the EORTC QLQ-C30 scoring manual [22]: each item was scored on a four-point Likert scale ranging from 1 ('Not at all') to 4 ('Very much'), except for the global health status/

QoL scale, which ranged from 1 ('Very poor') to 7 ('Excellent'). Regarding missing items, if at least half of the items in a scale had been completed it was assumed that the missing item(s) would have had values equal to the average of the items that were present. All scores were transformed to a 0–100 scale, where higher scores indicate a better level of functioning and more symptoms.

Ostomy-related problems

Ostomy-related problems were assessed with the EORTC QLQ-CR38 [23]. The questions on the ostomy-related problems scale include psychological impact (fear for noise and smell of the ostomy, concern about possible leakage, embarrassment and feeling less complete owing to the ostomy), physical (irritation of the skin around the ostomy) and care problems. All items are scored on a four-point Likert scale ranging from 1 ('Not at all') to 4 ('Very much').

Normative population

Socio-demographic (e.g. age, sex, marital status and comorbidity) and QoL (EORTC QLQ-C30) data for the normative population were obtained from CentERpanel, an online household panel representative of the Dutch-speaking population in the Netherlands [24]. Details of the annual data collection have been described elsewhere [25]. In total, data from 1883 cancer-free respondents ≥18 years, were available. Of this sample, a random age- and sex-matched normative sample was selected for this study, reflecting the distribution of the clinical sample. This resulted in a final normative sample of 239 respondents who we categorized into three age groups (≤65 years, 66–75 years, ≥76 years).

Statistical analyses

Baseline characteristics of respondents, nonrespondents and patients with unverifiable addresses were compared using analyses of variance for continuous variables and chi-square analyses for categorical variables. Baseline characteristics of the normative population, CRC patients with an ostomy and CRC patients without an ostomy, stratified for the three age groups, were also compared using chi-square tests for categorical variables and either independent samples *t*-tests or analyses of variance for continuous variables. Furthermore, among CRC patients with an ostomy, baseline characteristics between those aged ≤ 65 years, 66–75 years and ≥76 years were analyzed similarly. The responses (*n* (%)) on the seven items included in the ostomy-related problems scale were also compared between the three age groups using chi-square tests. In the present study, Cronbach's alpha between the seven items was 0.85.

The EORTC QLQ-C30 mean scores of CRC patients with and without an ostomy, stratified for the three age groups, were compared using analysis of covariance (ANCOVA). As the CRC patients in this study were diagnosed 1–11 years ago, an interaction term was added between ostomy (yes/no) and years since cancer diagnosis to examine the influence of years since diagnosis on the effect of an ostomy on QoL. When the interaction term was significant, we stratified the ANCOVAs for time since diagnosis: 1–4 years *vs* ≥5 years. When the interaction term was not significant, the interaction term was removed, allowing interpretation of the main effect of an ostomy. Confounding background variables included for adjustment were determined *a priori* and chosen to be sex, age at diagnosis, years since diagnosis, comorbidity, treatment type (surgery *vs* surgery plus (neo)adjuvant therapy), partner status, educational level and cancer stage. In addition, ANCOVAs were also used to examine differences in EORTC QLQ-C30 mean scores between the age- and sex-matched normative population and (1) CRC patients with an ostomy, and (2) CRC patients without an ostomy. Confounding background variables included for adjustment in these analyses were also determined *a priori*, and were chosen to be sex, age, partner status, comorbidity and educational level. For all ANCOVA analyses, clinically relevant differences on the EORTC QLQ-C30 functioning scales were determined using the evidence-based EORTC QLQ-C30 guidelines by Cocks *et al.* [26]. In short, a large difference was defined as one that represented clear clinical relevance. A medium difference was defined as likely to be clinically relevant but to a lesser extent, while a small difference was believed to be a subtle but nonclinically relevant difference. For example, for the 'physical functioning' scale, a mean difference of 5–14 points was considered a small clinically relevant difference, a difference of 14–22 points was considered to be a medium clinical relevant difference, whilst a mean difference of >22 points was considered a large clinically relevant difference.

Because of multiple testing, statistical differences were indicated at $P < 0.01$. Reported *P*-values were two-sided. All statistical analyses were performed using SPSS 22 (IBM SPSS Statistics for Windows, Version 22.0, IBM Corps USA, Armonk, New York, USA).

Results

Socio-demographics and clinical characteristics

A total of 3585 patients were eligible for participation and received the questionnaire. There were 2625

respondents (73%), 619 (17%) actively refused or did not return the questionnaire and 341 (10%) patients had unverifiable addresses. After exclusion of six patients with a temporary ostomy which was 'going to be closed soon', the final sample consisted of 2299 CRC patients.

No differences were found between respondents, nonrespondents and those with unverifiable addresses regarding years since diagnosis or tumour stage. However, respondents were less often female ($P = 0.001$), and were less often treated with surgery alone ($P < 0.001$). Respondents were younger than nonrespondents (69.4 *vs* 72.4 years; $P < 0.001$).

A total of 494 patients (21%) had an ostomy [167 patients aged ≤65 years (34%), 183 patients aged 66–75 years (37%), 144 patients aged ≥76 years (29%)]. Socio-demographic data for ostomy and nonostomy patients did not differ significantly, except that educational levels in ostomates aged 66–75 years was lower than in those without an ostomy ($P = 0.001$; Table 1). Among all age groups, those with an ostomy were more often diagnosed with rectal cancer ($P < 0.001$) and consequently were treated more often with a combination of surgery and (neo)adjuvant radiotherapy and/or chemotherapy ($P < 0.001$).

Normative population

The normative population consisted of 239 participants (79 were ≤65 years, 91 were 66–75 years, 69 were ≥76 years). Socio-demographic characteristics of the age- and sex-matched normative population are also presented in Table 1. In those aged 66–75 years and ≥76 years, the normative group more often had a high educational level compared than CRC patients with an ostomy or those without an ostomy. In addition, among those with aged ≤65 years, the normative sample was younger than for CRC patients without an ostomy, whereas the age difference between the normative population and CRC patients with an ostomy was not significant.

Ostomy-related problems

No differences were found in reported ostomy-related problems between the three age groups (Table 2). Overall, 50% reported being 'a little', 'quite a bit' or 'very much' afraid that other people would be able to hear the ostomy, while 59% reported being afraid that other people would be able to smell the stools. In general, a total of 68% reported being worried about possible leakage, 16% experienced problems with caring for the ostomy, 36% had irritation of the skin around the ostomy, 44% felt embarrassed and 50% felt less complete.

Quality of life: comparing CRC patients with and without an ostomy

Overall, missing data on the C30 scales were relatively uncommon. Among those without an ostomy, C30 scales were not completed by 10–33 patients (0.6–1.8%), depending on the scale. Specifically, the constipation scale was completed least often. Among patients with an ostomy, 3–15 (0.6–3.0%) did not have complete data on the C30 scales. In this scale, the diarrhoea question was completed least often. Finally, there were no missing data on the C30 scales for the normative population.

Among all CRC patients with an ostomy, no significant differences were observed between the three age groups in any of the QoL scales (data not shown). When examining the differences in functioning and global health status, several differences were found between CRC patients with and without an ostomy (Fig. 1). In patients aged ≤65 years, those with an ostomy compared with CRC patients without an ostomy reported a significantly lower global health status [mean (M) = 72.0, standard deviation (SD) = 22.2 *vs* M = 78.3, SD = 17.8) and lower physical (M = 77.6, SD = 20.8 *vs* M = 86.7, SD=16.9), role (M = 71.6, SD = 33.1 *vs* M = 81.3, SD = 27.1) and social functioning (M = 77.0, SD = 26.9 *vs* M = 86.9, SD = 77.0), all $P < 0.001$ (Fig. 1). Furthermore, two groups, ostomy patients aged 66–75 (M = 76.0, SD = 21.8 *vs* M = 83.5, SD = 18.6; $P < 0.001$) and those aged ≥76 years (M = 69.8, SD = 22.5 *vs* M = 74.8, SD = 21.3; $P = 0.009$) reported significantly lower physical functioning compared with their counterparts without an ostomy. All the differences were of small clinical relevance.

Regarding the symptom scales, ostomy patients aged ≤65 years compared to those without an ostomy, reported more nausea/vomiting (M = 5.5, SD = 16 *vs* *M* = 3.0, SD = 9.9; $P = 0.003$) and more financial difficulties (M = 20.1, SD = 29.8 *vs* M = 10.7, SD = 24; $P < 0.001$). Moreover, a significant interaction between having an ostomy and the number of years since diagnosis was found for constipation, indicating that the impact of an ostomy on constipation depended on the number of years since diagnosis (and therefore ostomy placement). Specifically, ostomy patients aged ≤65 years that were diagnosed 1–4 years ago, reported less constipation than patients without an ostomy (M = 2, SD = 9.3 *vs* M = 9.8, SD = 21.6; $P < 0.001$), while there was no significant difference found among those diagnosed 5–11 years ago (M = 8.1, SD = 21.9 *vs* M = 7.4, SD = 16.9; $P = 0.66$). The differences in constipation and financial difficulties were of small clinical

Table 1 Characteristics of the study population.

	Age ≤ 65 years			*P*-value ostomy *vs* no ostomy	Age 66–75 years			*P*-value ostomy *vs* no ostomy	Age ≥ 76 years			*P*-value ostomy *vs* no ostomy
	Norm (*n* = 79)	Ostomy (*n* = 167)	No ostomy (*n* = 599)		Norm (*n* = 91)	Ostomy (*n* = 183)	No ostomy (*n* = 690)		Norm (*n* = 69)	Ostomy (*n* = 144)	No ostomy (*n* = 516)	
Socio-demographics												
Male gender	44 (56)	106 (64)	318 (53)	0.02	52 (57)	114 (62)	389 (56)	0.15	37 (54)	84 (59)	269 (52)	0.19
Age (mean ± SD)	55.9 ± 9.7	58.1 ± 6.2	58.1 ± 6.5†	0.96	70.1 ± 2.8	70.6 ± 2.9	70.2 ± 2.9	0.11	79.5 ± 2.8	79.8 ± 2.9	79.3 ± 2.9	0.06
Partner (yes)	60 (76)	138 (83)	514 (86)	0.31	70 (77)	156 (85)	540 (79)	0.06	49 (73)	93 (65)	346 (68)	0.53
Educational level*				0.05				**<0.001**				0.62
Low	3 (4)	19 (11)	48 (8)		5 (6)	45 (25)†	112 (16)†		6 (9)	38 (26)†	150 (30)†	
Medium	52 (6)	113 (68)	370 (62)		52 (58)	117 (64)	421 (62)		37 (54)	81 (56)	285 (56)	
High	24 (30)	35 (21)	177 (30)		33 (37)	20 (11)	150 (22)		26 (38)	25 (17)	74 (15)	
Comorbidity				0.96				0.20				0.88
0	39 (49)	56 (35)	200 (35)		24 (26)	29 (18)	157 (24)		16 (23)	23 (18)	89 (18)	
1	20 (25)	48 (30)	172 (30)		29 (32)	54 (33)	194 (30)		15 (22)	37 (29)	127 (26)	
≥2	20 (25)	55 (35)	208 (36)		38 (42)	83 (50)	302 (46)		38 (55)	70 (54)	268 (55)	
Cancer characteristics												
Malignancy				**<0.001**				**<0.001**				**<0.001**
Colon cancer		20 (12)	397 (66)			36 (20)	473 (69)			35 (24)	397 (77)	
Rectal cancer		147 (88)	202 (34)			147 (80)	217 (31)			109 (76)	119 (23)	
Years since diagnosis (mean ± SD)		4.5 ± 2.3	5.0 ± .8	0.02		5.2 ± 2.7	5.3 ± 2.9	0.73		4.9 ± 2.7	5.5 ± 2.9	0.03
Years since diagnosis				0.36				0.88				0.15
1–4		100 (60)	335 (56)			98 (54)	365 (53)			83 (58)	262 (51)	
5–11		67 (40)	264 (44)			85 (46)	325 (47)			61 (42)	254 (49)	
Tumour stage				0.02				0.03				0.03
I		63 (40)	161 (28)			62 (35)	195 (29)			58 (41)	147 (29)	
II		42 (26)	204 (35)			54 (31)	263 (39)			44 (31)	216 (43)	
III		47 (30)	180 (31)			47 (27)	198 (29)			34 (24)	129 (25)	
IV		7 (4)	8 (7)			12 (7)	23 (3)			4 (3)	19 (4)	
Treatment				**<0.001**				**<0.001**				**<0.001**
Surgery only		20 (12)	263 (44)			33 (19)	362 (53)			40 (28)	171 (33)	
Surgery and RTx and/or CHT		144 (88)	330 (56)			145 (82)	321 (47)			101 (72)	343 (67)	

RTx, radiotherapy; CHT, chemotherapy.

Some variables exceed 100% due to rounding off.

*Education: low (no or primary school); medium (lower general secondary education or vocational training); high (pre-university education, high vocational training, university).

†Significant difference ($P < 0.01$) from the normative sample.

Values in bold are statistically significant ($P < 0.01$).

relevance, while the difference in nausea/vomiting was not clinically relevant. Among those aged 66–75 years, no significant differences between patients with and without an ostomy were found for any of the symptom scales. Among patients aged ≥76 years, ostomy patients did report less constipation than their counterparts without an ostomy (M = 3.2, SD = 12.1 *vs* M = 12.4, SD = 22.8; $P < 0.001$). This difference was of small clinical relevance. Subanalyses of patients aged ≥81 years showed no differences in any of the QoL scales when comparing ostomates with patients without an ostomy (data not shown).

Quality of life: comparing CRC patients with the normative population

With regard to functioning and global health status, ostomy patients aged ≤65 years reported significantly worse physical (M = 77.6, SD = 20.8 *vs* M = 92.6, SD = 11.1; $P < 0.001$), role (M = 71.6, SD = 33.1 *vs* M = 90.3, SD = 18.4; $P < 0.001$), cognitive (M = 82.6, SD = 23.7 *vs* M = 92.4, SD = 14.6; $P = 0.002$) and social (M = 77.0, SD = 26.9 *vs* M = 94.9, SD = 14.7; $P < 0.001$) functioning compared with the normative population (Fig. 1). Differences in role and cognitive functioning were of small clinical relevance, the difference in physical functioning was of medium clinical relevance, and the difference in social functioning was of large clinical relevance. Comparisons between patients without an ostomy and the normative population showed that patients without an ostomy reported worse cognitive (M = 84.5, SD = 21.5 *vs* M = 92.4, SD = 14.6) and social (M = 86.9, SD = 21.7 *vs* M = 94.9, SD = 14.7) functioning (both $P = 0.002$). Both differences were of small clinical relevance. Differences in functioning between the normative population and CRC patients with an ostomy were also found among those aged 66–75 years. Specifically, ostomy patients reported worse physical (M = 76.0, SD = 21.8 *vs* M = 88.9, SD = 13.6; $P < 0.001$), role (M = 76.8, SD = 29.7 *vs* M = 88.5, SD = 19.7; $P = 0.003$) and social (M = 84.5, SD = 23.6 *vs* M = 95.8, SD = 10.7; $P < 0.001$) functioning. The difference in social functioning was of medium clinical relevance, the other two differences were found to be of small clinical relevance. Patients without an ostomy also reported worse social functioning compared with the normative population (M = 89.4, SD = 20.0 *vs* M = 95.8, SD = 10.7; $P < 0.001$). This difference was of small clinical relevance. Finally, among those aged ≥76 years, patients with an ostomy reported worse physical (M = 69.8, SD = 22.5 *vs* M = 77.9, SD = 19.7; $P = 0.004$) and social (M = 82.9, SD = 26.0 *vs* M = 90.8, SD = 16.6; $P = 0.006$) functioning. These differences were also of small clinical relevance. No differences were found between CRC patients without an ostomy and the normative population.

Regarding the symptom scales, among those aged ≤65 years, both ostomy patients and those without an ostomy reported, compared with the normative population, more dyspnoea (M = 22.1, SD = 12.1 *vs* M = 3.0, SD = 9.5; $P = 0.007$ and M = 10.3, SD = 21.3 *vs* M = 3.0, SD = 9.5; $P = 0.008$, respectively), diarrhoea ($M = 12.3$, SD = 24.1 *vs* I = 3.8, SD = 11.9; $P = 0.007$ and M = 12.3, SD = 23.5 *vs* M = 3.8, SD = 11.9; $P = 0.003$, respectively) and financial difficulties (M = 20.1, SD = 29.8 *vs* M = 3.4, SD = 15.6; $P < 0.001$ and M = 10.7, SD = 24 *vs* M = 3.4, SD = 15.6; $P = 0.005$). Moreover, ostomy carriers reported more fatigue than their nonostomy counterparts (M = 26.5, SD = 27.3 *vs* M = 15.3, SD = 17.1; $P = 0.001$). For the differences between ostomy patients and the normative population, the difference in fatigue was of small clinical relevance while the other three differences were of medium clinical relevance. The difference in diarrhoea between those without an ostomy and the normative population was of medium clinical relevance, the other two differences were of small clinical relevance. Among those aged 66–75 years, ostomy patients and patients without an ostomy both reported more diarrhoea than the normative population (M = 8.4, SD = 20.7 *vs* M = 1.1, SD = 6; $P = 0.008$ and M = 10, SD = 20.2 *vs* M = 1.1, SD = 6; $P < 0.001$, respectively). Also, ostomy patients reported more fatigue (M = 23.5, SD = 23.8 *vs* M = 13,7, SD = 16.4; $P = 0.008$) and patients without an ostomy reported more constipation (M = 8.6, SD = 18.6 *vs* M = 3.3, SD = 12.2; $P = 0.003$) compared with the normative population. Both differences in diarrhoea were of medium clinical relevance, while the other two differences were of small clinical relevance. Finally, among those aged ≥76 years, ostomy patients reported more insomnia than the normative population (M = 24.1, SD = 30.2 *vs* M = 14.5, SD = 20.2; $P = 0.003$). This difference was found to be of small clinical relevance. No differences were found in any of the symptom scales when comparing CRC patients without an 'ostomy with the normative population.

Discussion

In this population-based analysis of 2299 CRC survivors, of whom 494 had an ostomy, we found that elderly ostomy patients (≥76 years) experienced more limitations in physical functioning than the nonostomy elderly with CRC, although this difference was of small clinical relevance. The impact due to the ostomy was less pronounced in the elderly compared with the

Table 2 Responses on the questions on ostomy-related problems, comparing patients of the three age groups.

During the past week:	Total (n = 494)	Age ≤ 65 years (n = 167)	Age 66–75 years (n = 183)	Age ≥ 75 years (n = 144)	P-value
Afraid that other people would be able to *hear* the ostomy					
Not at all	242 (50%)	77 (46%)	90 (50%)	75 (54%)	0.40
A little	153 (32%)	59 (35%)	59 (33%)	35 (25%)	
Quite a bit	58 (12%)	20 (12%)	17 (10%)	21 (15%)	
Very much	31 (6%)	11 (7%)	13 (7%)	7 (5%)	
Afraid that other people would be able to *smell* the stools					
Not at all	197 (41%)	72 (43%)	69 (39%)	56 (28%)	0.25
A little	181 (3%)	66 (40%)	73 (41%)	42 (30%)	
Quite a bit	60 (12%)	16 (10%)	18 (10%)	26 (19%)	
Very much	47 (10%)	13 (8%)	19 (11%)	15 (11%)	
Worried about possible *leakage* from the ostomy bag					
Not at all	154 (32%)	54 (32%)	58 (33%)	42 (30%)	0.40
A little	202 (42%)	77 (46%)	72 (41%)	53 (38%)	
Quite a bit	88 (18%)	23 (14%)	3 (20%)	29 (21%)	
Very much	39 (8%)	13 (8%)	11 (6%)	15 (11%)	
Problems with *caring* for the ostomy					
Not at all	410 (85%)	142 (85%)	159 (89%)	109 (78%)	0.12
A little	48 (10%)	18 (11%)	13 (7%)	17 (12%)	
Quite a bit	17 (4%)	3 (2%)	6 (3%)	8 (6%)	
Very much	10 (2%)	4 (2%)	1 (1%)	5 (4%)	
Irritation of the *skin* around the ostomy					
Not at all	309 (64%)	101 (61%)	117 (66%)	91 (65%)	0.33
A little	133 (27%)	53 (32%)	46 (26%)	34 (24%)	
Quite a bit	28 (6%)	10 (6%)	11 (6%)	7 (5%)	
Very much	15 (3%)	3 (2%)	4 (2%)	8 (6%)	
Embarrassed because of the ostomy					
Not at all	268 (56%)	88 (53%)	105 (60%)	75 (54%)	0.16
A little	128 (27%)	51 (31%)	46 (26%)	31 (22%)	
Quite a bit	52 (11%)	19 (11%)	14 (8%)	19 (14%)	
Very much	34 (7%)	8 (5%)	11 (6%)	15 (11%)	
Feeling *less complete* because of the ostomy					
Not at all	241 (50%)	84 (51%)	89 (50%)	68 (49%)	0.72
A little	131 (27%)	44 (27%)	52 (29%)	35 (25%)	
Quite a bit	70 (15%)	21 (13%)	26 (15%)	23 (17%)	
Very much	39 (8%)	17 (10%)	10 (6%)	12 (9%)	

youngest patients (aged ≤65 years), as the latter also experienced more limitations in physical, role and social functioning and a decrease in global health status compared with the youngest nonostomy CRC patients.

Also, compared with the normative population, the elderly ostomy patients experienced more limitations in both physical and social functioning; these differences were also of small clinical relevance. These functional limitations seem to be more present in the younger ostomy patients, who reported more limitations in physical, role, cognitive and social functioning than the normative population; these differences were of moderate to high clinical relevance. Finally, among the ostomates, no differences in either ostomy-related problems or QoL were observed within the three different age groups.

Our results show that the elderly ostomates experience fewer functional limitations, a similar global health status and similar ostomy-related problems as their younger counterparts. This is in line with our previous study about the impact of ostomies on older CRC patients [16]. In the current study, we also found that the experienced limitations in physical and social functioning were of small clinical relevance compared with the normative population. Among patients aged 66–75 years and ≤65 years, these limitations were of small and medium clinical relevance and of medium and large clinical relevance, respectively. A similar age-related trend was identified in quantifying the impact of cancer treatment on QoL and functioning in other types of cancer [27]. Explanations for the finding that the elderly experience

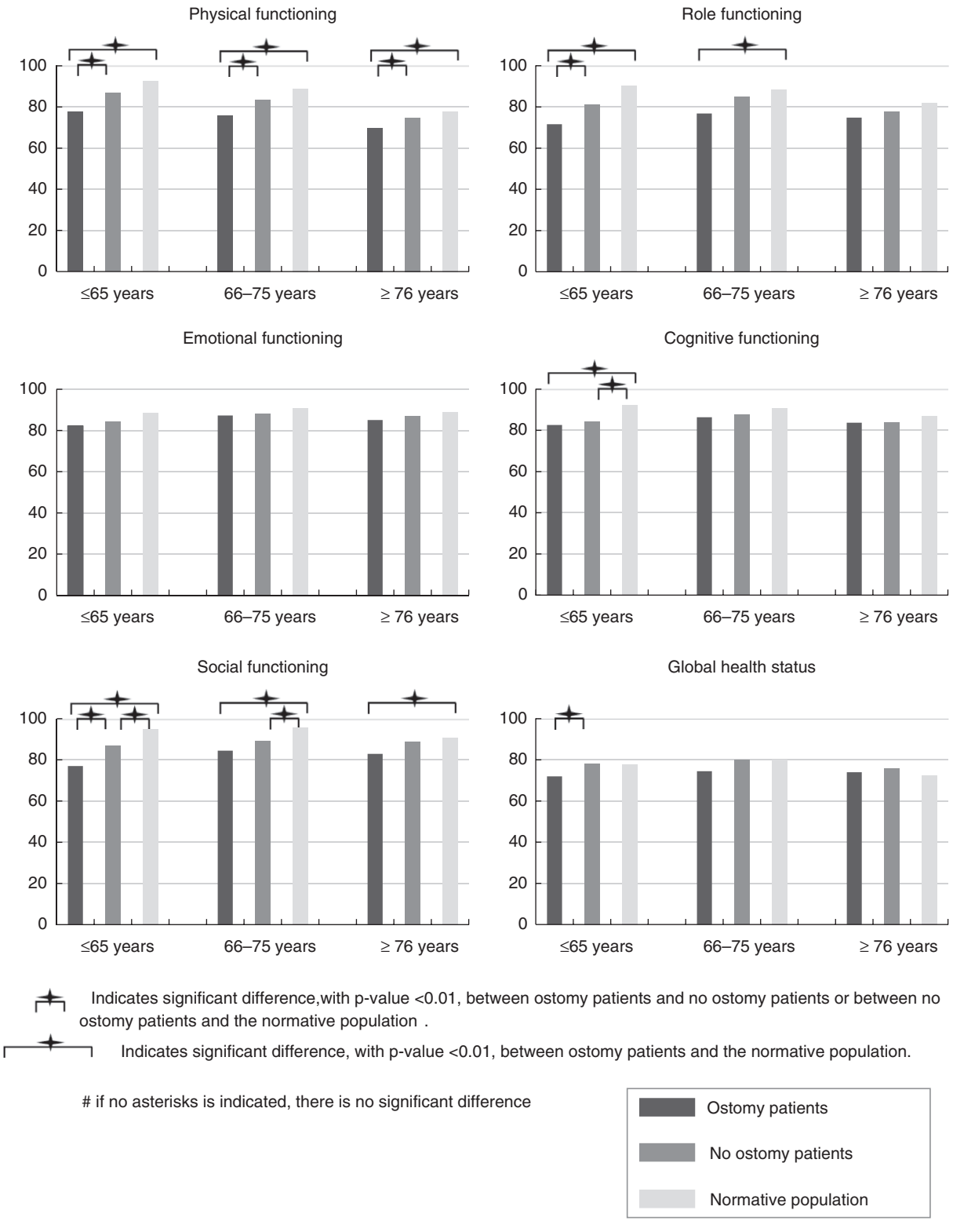

Figure 1 Comparison of quality of life between the different age groups. The comparisons are between patients with ostomies, patients without ostomies and the normative population.

fewer limitations, as well as limitations of a small(er) clinical relevance, could be due to a difference in coping and body image between elderly and younger patients [28]. In addition, aging itself brings increasing limitations in various aspects that in themselves comprise QoL and daily functioning irrespective of the ostomy [29,30]. Moreover, this group of patients might be less demanding, a phenomenon which is referred to as 'response shift' [31,32]. This is an internal psychological process of change in standards, values or conceptualization of quality of life over time. As a result, required changes in lifestyle and problems due to the ostomy might be limited or experienced in a different way. Specific preoperative ostomy education aimed at the issues faced by elderly ostomy patients might facilitate acceptation of the ostomy and could limit the occurrence of ostomy-related problems and functional limitations even further [33].

This research confirms that it would be incorrect to withhold ostomy placement in elderly patients based on age alone [16]. Often there is no pre- and/or peroperative doubt about whether or not ostomy placement is required, but sometimes the decision is less clear cut. If the surgeon decides to place an ostomy this may result in limitation of the physical functioning of the patient. On the other hand, creating a primary anastomosis without an ostomy could result in anastomotic leakage which occurs in up to 7% of elderly patients in whom no ostomy is placed [15,34,35]. (Elderly) patients with calcification of the vessels and those with reduced blood flow are particularly at risk for this surgical complication [36–38]. Anastomotic leakage is associated with increased mortality (30% mortality in patients aged >80 years compared with 5% mortality in those aged <65 years) and longer hospital stay. Thus, the limitations caused by having an ostomy need to be weighed against the risk of complications that is inherent in creating an anastomosis. However, irrespective of placing an ostomy or not, the elderly patients experience higher morbidity rates after treatment, more functional decline and more (excess) mortality compared with their young(er) counterparts [10–12]. Colon cancer surgery (with or without adjuvant chemotherapy) in the elderly is itself not a predictor for worse health-related QoL in the long term [39].

This study has some limitations. First of all, the database included no respondents older than 86 years. Although it is likely that the elderly patient group which consists of patients aged between 76 and 86 years is a reasonable reflection of elderly CRC patients, some caution is needed with extrapolating the results of this study to the 'oldest old' CRC patients (>86 years). Second, there is a risk of selection bias of both patients and normative respondents. Patients who responded to the questionnaire were fit enough and willing to participate in research. The normative group is a slightly different group with minor baseline differences, especially in educational level, although we corrected for this potential confounder in the analyses. Moreover, it is likely that the type of ostomy affects the QoL, but the type of ostomy was registered in only 29% of the ostomates. Future research could focus on these data and correct for this (potential) confounder. Another limitation is that (post-treatment) we had no information on (surgical) complications. Older patients are generally more prone to developing complications after treatment and this might influence their functionality and QoL. As this was not registered, we could not correct for this potential confounder. Finally, as the normative population included few respondents over 80 years ($n = 21$), no subgroup analyses for this age cohort could be performed.

Despite these limitations, this is one of the first studies to focus on the impact of ostomies on elderly CRC patients with a normative cohort as a reference population. These data could be helpful in multidisciplinary treatment decision-making for older CRC patients as it is incorrect to withhold (surgical resection with) ostomy placement based on age alone. In the future, studies could assess the impact of ostomies in the 'oldest old' (>86 years) patients, and aim to develop an older normative population cohort for comparisons. The inclusion of more treatment details, such as morbidity, in longitudinal studies could provide a further depth of data that can aid decision-making. As the aging of Western society is expected to result in a significant increase in the number of elderly CRC patients, data particular to this age group will become increasingly relevant.

Conclusion

Elderly (≥76 years old) CRC patients with an ostomy report more limitations in physical functioning compared with their counterparts without an ostomy, and more physical and social limitations compared with the normative population; these differences appear to be of small clinical relevance. However, the impact of an ostomy seems to be more prominent in younger (all patients aged ≤75 years) ostomates as they experience more functional limitations and a decrease in global health status compared with younger nonostomy patients and the normative population. Furthermore, these differences were of moderate to high clinical relevance. Thus, age itself is not a reason for withholding an ostomy.

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Conflict of interest

None.

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