# The impact of an ostomy on older colorectal cancer patients: a cross-sectional survey

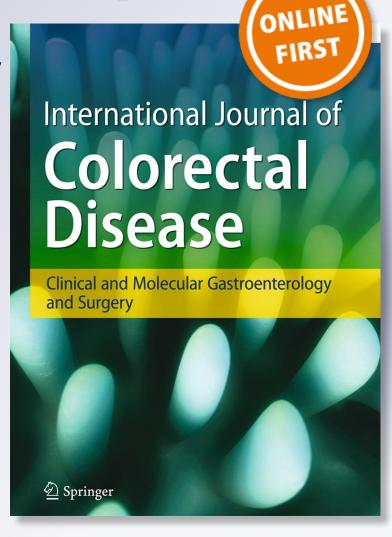
N. M. Verweij, M. E. Hamaker,
D. D. E. Zimmerman, Y. T. van Loon,
F. van den Bos, A. Pronk, I. H. M. Borel
Rinkes & A. H. W. Schiphorst

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#### **ORIGINAL ARTICLE**



## The impact of an ostomy on older colorectal cancer patients: a cross-sectional survey

N. M. Verweij<sup>1</sup> · M. E. Hamaker<sup>2</sup> · D. D. E. Zimmerman<sup>3</sup> · Y. T. van Loon<sup>3</sup> · F. van den Bos<sup>4</sup> · A. Pronk<sup>5</sup> · I. H. M. Borel Rinkes<sup>6</sup> · A. H. W. Schiphorst<sup>5</sup>

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#### Abstract

*Background* Ostomies are being placed in 35 % of patients after colorectal cancer surgery. As decision-making regarding colorectal surgery is challenging in the older patients, it is important to have insight in the potential impact due to ostomies.

*Methods* An internet-based survey was sent to all members with registered email addresses of the Dutch Ostomy Patient Association.

Results The response rate was 49 %; 932 cases were included of whom 526 were aged <70 years old ("younger respondents"), 301 were aged between 70 and 79 years old ("the elderly"), and 105 were aged ≥80 years old ("oldest old"). Ostomy-related limitations were similar in the different age groups, just as uncertainty (8–10 %) and

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N. M. Verweij nverweij@diakhuis.nl

- Department of Geriatric Medicine/Department of Surgery, Diakonessenhuis, Bosboomstraat 1, 3582KE Utrecht, The Netherlands
- Department of Geriatric Medicine, Diakonessenhuis, Utrecht, The Netherlands
- Department of Surgery, Elisabeth-Tweesteden Ziekenhuis, Tilburg, The Netherlands
- Department of Internal Medicine, Haga Hospital, The Hague, The Netherlands

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- Department of Surgery, Diakonessenhuis, Utrecht, The Netherlands
- Department of Surgery, University Medical Center Utrecht, Cancer Center, Utrecht, The Netherlands

dependency (18–22 %) due to the ostomy. A reduced quality of life was experienced least in the oldest old group (24 % vs 37 % of the elderly and 46 % of the younger respondents, p < 0.001). Over time, a decrease of limitations and impact due to the ostomy was observed. *Conclusion* Older ostomates do not experience more limitations or psychosocial impact due to the ostomy compared to their younger counterparts. Over the years, impact becomes less distinct. Treatment decision-making is challenging in the older colorectal cancer patients but ostomy placement should not be withheld based on age alone.

**Keywords** Ostomy · Ileostomy · Care-dependence · Colorectal cancer · Geriatrics

#### **Background**

According to the Dutch ostomy care nurses society, there are about 32,000 permanent ostomy carriers in the Netherlands (0.2 % of the population) and approximately 7000 ostomies (temporary and permanent) are being placed each year (0.04 % of the population) [1]. Due to increasing life expectancy, aging of the population and active screening programs for colorectal malignancies, both the overall number of ostomy carriers as well as the proportion of elderly ostomy carriers, is expected to rise even further in future years [2–7].

Decision-making regarding colorectal surgery is challenging in the elderly. As ostomies are being placed in 35 % of the older colorectal surgery patients [8], it is important to have insight in the potential physical and mental impact, as well as care-dependency due to an ostomy in elderly patients. This information can be useful in preoperative patient counseling as well as in shared decision-making. To support future decision-making, more data on elderly ostomates is necessary. Consequently, we



performed a survey on the impact of ostomies in elderly compared to their younger counterparts.

#### Methods

An internet-based anonymous survey was developed using SurveyMethods software (www.surveymethods.com). It consisted of 27 questions (Appendix) on the impact of an ileo- or colostomy. Briefly, the first part focussed on personal characteristics of the respondents, such as age, gender, and living- and social situation. The second part consisted of questions regarding ostomy characteristics, such as the location of the ostomy (colostomy, ileostomy). The final part focussed on the impact and care-dependency due to the ostomy (such as limitations in (instrumental) activities of daily living-(i)ADLand the frequency and amount of help required for emptying or changing the ostomy bag). The survey took about 15 minutes to complete. It was sent to the members of the Dutch Ostomy Patient Association with registered email addresses. This association, which fights for the rights of ostomates in the Netherlands, requested members by email to respond to the survey; no reminder was sent. To assess possible age-related differences, the outcomes of respondents aged <70 years old ("younger respondents") were compared with the respondents aged between 70 and 79 years old ("elderly") and with those aged ≥80 years old ("oldest old").

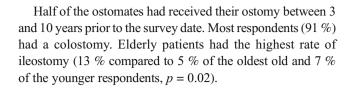
The statistical program IBM SPSS for Windows, version 23 (SPSS, Inc., Chicago, IL, USA) was used for the statistical analyses. For comparisons between groups, the chi-square test was used for nominal and ordinal variables and the ANOVA test for continuous variables. A *p* value of <0.05 was considered statistically significant. All other results are presented as descriptive data.

#### Results

A total of 3190 members received the survery; the overall response rate was 49 %. After the exclusion of 622 responses regarding ostomy placement for reasons other than colorectal cancer and 11 due to insufficient replies, 932 were included. Of those, 526 were completed by younger respondents (56 %), 301 by elderly (32 %) and 105 (11 %) by the oldest old ostomy carriers.

#### Characteristics of respondents

The mean age of the respondents was 68 years (range 33–96 years, Table 1), and 64 % was male. Most respondents (99 %) were living independently. Of the oldest old, 39 % lived alone, compared to 14 % of the elderly and 12 % of the younger respondents (p = 0.007).



#### Impact, care-dependence and quality of life

Most of the respondents (96 %) were taking care of the ostomy themselves. However, 9 % of the oldest old required help or assistance for emptying or replacing the bag (versus 6 % of the elderly and 2 % of the younger respondents, p < 0.001), primarily due to an inability to adequately reach or view the ostomy site. The different age groups experienced similar limitations in (i)ADL, day planning, performing hobbies, participating in social activities, and dealing with other people (Table 2). The oldest respondents had more difficulties in being away from home overnight due to the ostomy (20 % of the oldest old versus 11 % of the elderly and 9 % of the younger respondents, p = 0.02).

In general, uncertainty and dependency due to the ostomy were experienced equally by all respondents (in 8–10 % and 18-22 %, respectively). Oldest old respondents least expressed a reduced quality of life since receiving their ostomy compared to their younger counterparts (24 % versus 37 % of the elderly and 46 % of the younger ostomates, p < 0.001).

#### Limitations over time

Subgroup analyses of the three age groups showed that respondents who received their ostomies during the past 2 years experienced most limitations compared to those who had it for 3–10 years or for ≥11 years (Fig. 1). The oldest old respondents experienced the same impact independently from the time since ostomy placement. The elderly reported significantly less limitations in social activities and less difficulties in being away from home overnight as the time since ostomy placement lengthened. Younger respondents who had their ostomy since many years felt less dependent compared to those who recently received it or had it since a couple of years.

Respondents who received their ostomy within the past 2 years needed help with emptying or changing the bags in 8 %, this decreased to 4 % and 1 % of the respondents who had their ostomy for 3–10 years and  $\geq$ 11 years, respectively (p < 0.001). Within the oldest old, 14 % needed help in the first 2 years, which decreased to 10 % and 3 % after 3–10 years and  $\geq$ 11 years, respectively (p = 0.28). This decrease also was observed in the elderly (needed help in 15 %, 5 %, and 0 % within 2 years, 3–10 years, and  $\geq$ 11 years, respectively, p < 0.001) and younger respondents (needed help in 4 % , 2 %, and 0 % within 2 years, 3–10 years, and  $\geq$ 11 years, respectively, although the latter did not reach statistical significance (p = 0.12).



 Table 1
 Baseline characteristics

	Total $(n = 932)$	<70  years  (n = 526)	70–79 years ( $n = 301$ )	$\ge$ 80 years ( <i>n</i> = 105)	p value
Response rate	49 %	48 %	52 %	43 %	0.01
Male	64 %	58 %	72 %	69 %	< 0.001
Median age in years (range)	68 (33–96)	64 (33–69)	73 (70–79)	83 (80–96)	
Living situation					0.007
Independent/on your own	99 %	100 %	99 %	96 %	
Institutionalized	1 %	0 %	1 %	4 %	
Social situation					< 0.001
With family member/partner	84 %	88 %	86 %	61 %	
Living alone	16 %	12 %	14 %	39 %	
Ostomy since					0.09
0–2 years	26 %	27 %	27 %	20 %	
3–10 years	51 %	53 %	50 %	47 %	
≥11 years	23 %	21 %	23 %	33 %	
Ostomy location					0.02
Colon	91 %	93 %	88 %	95 %	
Small intestine	9 %	7 %	13 %	5 %	

Italicized values are significant

#### Discussion

This survey on the impact of ostomies reveals that although older patients more frequently require help in caring for their ostomy, they do not experience higher rates of limitations or psychosocial impact compared to their younger counterparts. In the years after receiving the ostomy, impact becomes less distinct. Decision-making whether or not to choose for ostomy placement in older patients should, therefore, not be different from younger people solely based on a patient's age.

Differences in coping between older and younger patients might be one of the explanations for the finding that this age group does not experience more limitations despite more often requiring help [9, 10]. In general, the aging process leads to increasing limitations in various aspects that comprise quality of life and daily functioning, and as a result, the impact of an ostomy might be less pronounced and older patients with an ostomy experience comparable health-related quality of life compared to those without an ostomy [11]. Additional changes in lifestyle and problems due to an ostomy

Table 2 Ostomy-related limitations and psychosocial impact

	Total $(n = 932)$	<70  years  (n = 526)	70–79 years ( $n = 301$ )	$\geq$ 80 years ( $n = 105$ )	p value
Limited in ADL	6 %	6 %	6 %	7 %	0.86
Limited in iADL	9 %	8 %	9 %	11 %	0.71
Limited in day planning	25 %	25 %	24 %	25 %	0.93
Limited in performing hobby	9 %	10 %	8 %	5 %	0.29
Limited in social activities	9 %	9 %	9 %	8 %	0.90
Difficulty in dealing with other people	3 %	4 %	2 %	2 %	0.30
Difficulty in being away from home overnight <sup>a</sup>	11 %	9 %	11 %	20 %	0.02
Uncertain because of the ostomy	9 %	9 %	8 %	10 %	0.72
Dependent since ostomy	18 %	18 %	18 %	22 %	0.61
Reduced quality of life since ostomy	40 %	46 %	37 %	24 %	< 0.001

Percentage of patients stating always or often feeling limitations due to the ostomy in each category

ADL activities of daily living, iADL instrumental activities of daily living

Italicized values are significant

<sup>a</sup> If applicable



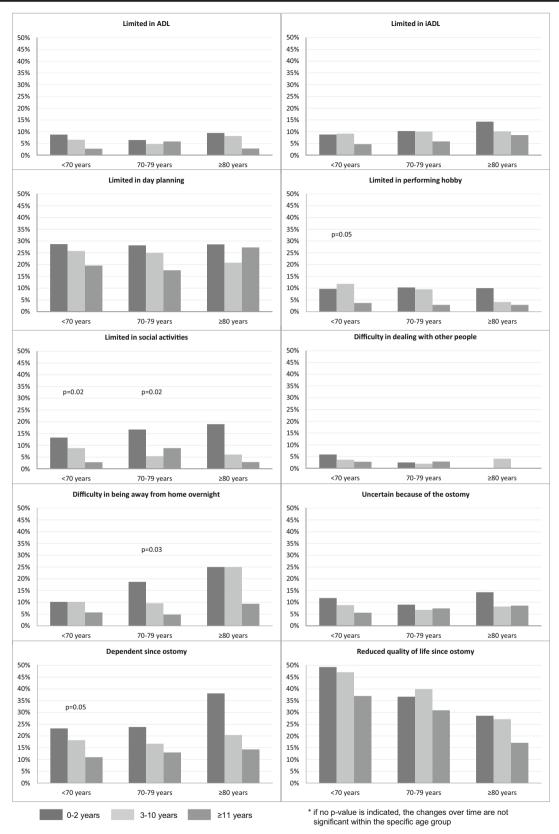


Fig. 1 Limitations and impact due to the ostomy over time. \* If no p value is indicated, the changes over time are not significant within the specific age group

might be experienced in a different way compared to younger people [12].

A baseline measurement in a Dutch teaching hospital showed that 98 % of the new ostomy patients were dependent



on home care at discharge due to their ostomy [13]. Introduction of a 4-day in-hospital educational ostomy pathway resulted in a reduction of home care at discharge by 25 %. This pathway, based on preoperative education, daily inhospital guidance, and patient training, shows that patients of all ages are able to learn to take care of their ostomy in a short amount of time. Incorporating such educational pathways preoperatively could increase independency of new elective ostomy patients.

Our results show that it would be incorrect to withhold ostomy placement in older patients based on age alone. When surgery has been chosen as a treatment, it is important to weigh the benefit of not placing the ostomy against the risks of anastomotic leakage which occurs in 5–6 % of cases and which is associated with higher short-term mortality and longer hospital stay [14, 15]. However, irrespective of placing an ostomy or not, elderly patients experience higher rates of postoperative complications and postoperative mortality than younger patients [8]. In addition, older patients suffer more frequently from fecal incontinence. Furthermore, they experience high rates of functional decline after treatment, with reported rates of over 60 % in those aged 80 years or older [16]. This decline may result in increased dependency [17].

This study is limited by a selection bias of respondents. We assume that the elderly and oldest old respondents are a selection from the general population because they mostly lived on their own, were often taking care of their ostomy themselves, had a valid email address, and responded adequately to the questionnaire. In addition, not all ostomy carriers in the Netherlands are member of the Dutch Ostomy Association. Another limitation might be that we decided to include only colorectal cancer as reason for the ostomy placement, aiming to reduce the heterogeneity of the respondent population. The impact of ostomies placed for other reasons could be different from our current findings. However, despite the limitations, this is one of the first studies focussing on ostomy impact in various age groups. In future, comparing the impact and quality of life of the older ostomy carriers with a normative cohort (reference population) and including participants in a longitudinal study could be helpful in making the right treatment decisions in this frail population.

#### Conclusion

Older ostomates do not experience more limitations or psychosocial impact due to their ostomy compared to their younger counterparts. During the years, impact becomes less distinct. Treatment decision-making is challenging in the older patients, but ostomy placement should not be withheld based on age alone.

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**Authors contribution** N. M. Verweij study design, interpretation of data, and wrote the paper.

M.E. Hamaker study design, interpretation of data, revising and approved the final version.

D. D. E. Zimmerman revising and approved the final version.

Y.T. van Loon revising and approved the final version.

F. van den Bos revising and approved the final version.

A. Pronk revising and approved the final version.

I. H. M. Borel Rinkes revising and approved the final version.

A. H. W. Schiphorst study design, interpretation of data, revising and approved the final version.

#### Compliance with ethical standards

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Conflict of interest The authors declare that they have no competing interests

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