



# A self-reported survey on oral health problems in patients with inflammatory bowel disease with a stoma

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**Objectives.** Patients with inflammatory bowel disease have an increased risk of developing oral health problems. The aim of this study was to investigate whether oral diseases in these patients are related to inflammation of the intestine and if there is a correlation between inflammatory bowel disease–specific health-related quality of life (IBD-HR-QOL) and oral health problems.

**Study Design.** The study was a cross-sectional survey and analysis of self-reported oral health of individuals with a stoma for Crohn's disease (CD), ulcerative colitis (UC), and treated colon cancer (CC). Validated international questionnaires were sent to members of the Stoma Federation of The Netherlands. Because there was an unequal distribution of male and female patients with CD and CC, data of 169 age-matched female patients with CD, UC, and CC with a stoma were analyzed.

**Results.** Patients with CD had significantly more oral health problems compared with those with UC or CC. Patients with CD and UC both had significantly more gingival-related problems compared with patients with CC. There was a significant negative correlation between IBD-HR-QOL and oral health problems.

**Conclusions.** In the 3 distinguishable groups of patients with a stoma, patients with CD had an increased risk for oral health problems, independently from surgical removal of (a part of) the inflamed intestine, suggesting a general increased susceptibility of patients with CD for oral health problems. (Oral Surg Oral Med Oral Pathol Oral Radiol 2020;130:e80–e86)

Inflammatory bowel disease (IBD) is a chronic, recurring and often disabling disorder of the gastrointestinal (GI) tract. The 2 main types of IBD are Crohn disease (CD) and ulcerative colitis (UC).<sup>1</sup> CD can affect any part of the GI tract, whereas UC mainly affects the rectum and may extend proximally up to the entire colon.<sup>2,3</sup> Clinical symptoms involve abdominal pain, cramps, diarrhea, melena, vomiting, fatigue, weight loss, and sometimes fistula.<sup>4,5</sup> Both types of IBD usually show episodes of clinical activity, characterized by exacerbations or flares interspersed with asymptomatic intervals or remissions. The overall worldwide incidence of CD and UC, depending on the region, ranges from 0.0 to 29.3 and 0.15 to 57.9 per 100,000 person-years, respectively.<sup>6</sup> IBD is currently not curable, and treatment is aimed at symptomatic relief, reduction of inflammation during exacerbations, maintenance of remission, and increasing quality of life. Surgical treatment is indicated in patients who fail drug treatment or develop

severe complications, and approximately 20% of patients with UC and 80% of patients with CD will eventually require surgery.<sup>7</sup>

Although IBD primarily involves the bowel, patients also have a risk of developing oral health problems. The prevalence of oral health problems is higher in patients with CD than in those with UC.<sup>8</sup> Oral diseases that have been reported in patients with IBD are, among others, mucosal ulceration, mucosal swelling and cobblestoning, orofacial granulomatosis, xerostomia, and an increased risk for dental caries, gingivitis, and periodontitis.<sup>9-12</sup> Patients with active CD suffer more from xerostomia<sup>13</sup> and have higher salivary levels of *Streptococcus mutans*, a microorganism that is highly associated with origin of dental caries.<sup>14</sup> In 2011, in a case report published in the patient magazine of the Stoma Federation of The Netherlands, the patient stated that she had fewer oral health problems after surgical removal of the inflamed part of her intestine.<sup>15</sup>

The aim of this study was to investigate whether resection of (a part of) the inflamed intestine may be related to self-reported oral health problems in patients with IBD and, secondary, if there is an association

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Received for publication Dec 31, 2019; returned for revision Apr 6, 2020; accepted for publication Apr 27, 2020.

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2212-4403/\$-see front matter

<https://doi.org/10.1016/j.oooo.2020.04.816>

## Statement of Clinical Relevance

Patients with inflammatory bowel disease, particularly those with Crohn disease, have an increased risk for oral health problems, which remains after surgical removal of (a part of) the inflamed intestine, necessitating special attention to their oral health from gastroenterologists and dentists.

between IBD-specific health-related quality of life (IBD-HRQOL) and oral health problems.

**MATERIALS AND METHODS**

The study was a cross-sectional survey of self-reported oral health status in 2 groups of patients with a stoma for chronic intestinal inflammation (CD and UC). Patients with a stoma for a noninflammatory cause (surgically treated colon carcinoma [CC]) served as control group. The first part of the questionnaire was related to the presence of a stoma and contained the 9 items of the shortened IBDQ-9 (Inflammatory Bowel Disease Questionnaire-9).<sup>16,17</sup> Responses to each item of the IBDQ-9 were scored on a 7-point Likert scale, in which a score of 1 indicates the worst and a score of 7 the best possible condition. The scores of the individual items were summed, resulting in a total IBDQ-9 score ranging from 9 to 63, with higher scores reflecting a better health status of patients.

The second part of the questionnaire contained the oral health problems of the Toegepast-Natuurwetenschappelijk Onderzoek (TNO) oral health questionnaire,<sup>18</sup> with 2 additional questions about the oral hygiene practices of the participants. The TNO oral health questionnaire consisted of 21 questions about oral health practices in the last 12 months, with the answer options being “yes” or “no.” A group without a stoma was not included in the study. However, data on oral health was obtained from a study by Kalsbeek et al. That study had investigated the differences in oral health in the general population in The Netherlands (n = 1407) after the change in the insurance system in 1995 (TNO-cohort).<sup>18</sup>

The third part of the questionnaire was the Xerostomia Inventory (XI),<sup>19</sup> an internationally validated questionnaire to quantify the severity of xerostomia. The XI comprises 11 items on a Likert scale of 1 to 5, corresponding to the answers “never,” “hardly ever,” “occasionally,” “fairly often,” and “very often.” The responses to the individual items were summed to a total XI score ranging from 11 (no xerostomia) to 55 (extreme xerostomia).

The final part of the questionnaire related to information about the frequency of visits to the dental office during the past 12 months and contained general questions on age, gender, work experience, and educational level.

The questionnaire was programmed in NewCom Research & Consultancy software version 3.38, and a “closed” web link to the questionnaire was distributed to all 2180 resident members of the Stoma Federation of The Netherlands. Completion of the questionnaire was on a voluntary base and completely anonymous. After a week, the members were sent a reminder via e-mail, and in addition, a public access “open link” was created and made available through social media:

Facebook, Twitter, and a digital newsletter. The questionnaire was closed exactly 3 weeks after the initial access date. Members of the Dutch Stoma Association without online access could request a printed version of the questionnaire. The collected data were downloaded into an Excel spreadsheet.

This study followed the tenets of the Declaration of Helsinki on medical protocol and ethics, and the data were collected in accordance with the guidelines of the Medical Ethical Committee of the VU University Centre. The Ethics Review Committee of the VU University confirmed that the Medical Research Involving Human Patients Act (WMO) did not apply to this study, and therefore, institutional review board approval was not required.

**Statistical analysis**

Data were expressed as mean ± standard deviation (SD) or percentages and were analyzed statistically with SPSS Statistics for Windows version 25.0 (SPSS Inc., Chicago, IL).  $\chi^2$  tests were used to determine whether sample frequencies differed significantly. Differences between median values were established by using the Kruskal-Wallis test, followed by Mann-Whitney tests as a post hoc procedure, where appropriate. Correlations were explored by using Spearman’s rank order correlation tests. Statistical significance was set at  $P < .05$ .

The total number of returned questionnaires was 773. Of these, 125 questionnaires were incomplete, and 7 members reported that they did not have a stoma, resulting in 641 respondents, with equal numbers of male and female respondents. Of the respondents, 171 had other reasons for their stoma (e.g., bladder dysfunction, preventive removal because of a genetic disorder, or removal as a result of an accident). In the CD group, there were far more females than males; in the UC group, males and females were equally distributed; and in the CC group, there were more males than females (Table I). With regard to age and gender differences ( $\chi^2$  test: males vs females:  $P < .001$ ), we decided to analyze age-matched female patients with CD, UC, or CC with a stoma.

**Table I.** Reason for stoma, stratified according to gender

	All (n = 470)	Males (n = 259)	Females (n = 211)
Crohn disease	78	16	62
Ulcerative colitis	120	64	56
Colon cancer	272	179	93

$\chi^2$  test: males versus females:  $P < .001$ .

**RESULTS**

Female patients with CD had a significantly higher total XI score compared with patients with UC or CC. Statistical differences between the groups were found for the following individual items of the XI: “The skin of my face feels dry” and “My lips feel dry.” Female patients with CD reported more that their skin and lips felt dry compared with patients with CC, but not those with UC. Female patients with UC also reported dry skin of the face more than did CC patients. Female patients with CD had a significantly lower IBDQ-9 score compared with those with UC or CC, reflecting the poorer health status of patients with CD (Table II).

Table III shows the results of self-reported oral health problems in age-matched female patients with CD, UC, or CC with a stoma and in the general population. Female patients with CD reported a significantly higher mean number of oral health problems compared with the other 2 groups, in which the patients experienced discolorations of the oral mucosa, irritated oral mucosa, and pain significantly more frequently than patients with UC and CC. Bad taste was more frequently reported by patients with CD than by those with UC but did not differ significantly from patients

with CC. Female patients with CD suffered from angular cheilitis and oral blisters or aphthae significantly more frequently than did patients with CC, but not significantly more than patients with UC.

Table IV shows the results of self-reported dental problems of dentate female patients with CD, UC, or CC with a stoma and of the general population. Dentate female patients with CD or UC with a stoma experienced gingival problems both significantly and more frequently than did patients with CC. No differences in frequency of gingival problems were observed between patients with CD and those with UC. There were significant differences among the 3 groups with regard to other tooth-related problems.

Table V shows the results of self-reported swelling of the orofacial areas of female patients with CD, UC, or CC with a stoma. Female patients with UC less frequently reported swelling of the lips and a significantly lower number of orofacial swelling problems compared with patients with CD or CC.

Tables VI and VII show that there were no statistical differences in the frequency of tooth brushing and use of interdental cleaning devices among the 2 groups for females.

Table VIII shows the relationship among the IBDQ-9 score and the total number of oral health problems, total number of orofacial swelling problems, and XI scores in female patients with a stoma.

There was a significant negative correlation between the IBDQ-9 score and the total number of oral health problems in female patients with CD or UC, reflecting more oral health problems in patients with lower well-being scores. There was a significant correlation between the IBDQ-9 score and the number of orofacial swelling problems in female patients with CD,

**Table II.** Age-matched groups of female patients with CD, UC, or CC and XI and IBDQ-9 scores

	CD (n = 60)	UC (n = 54)	CC (n = 55)	P value
Age	53.8 ± 11.9	53.2 ± 11.8	57.6 ± 6.5	.080
XI score	30.9 ± 7.4	28.1 ± 6.3*	26.7 ± 6.5*	.004
IBDQ-9	44.1 ± 12.0	48.8 ± 10.0*	50.3 ± 7.9*	.003

\*Chi-square test: *P* < .05 versus CD.CC, colon cancer; CD, Crohn disease; IBDQ-9, Inflammatory Bowel Disease Questionnaire-9; UC, ulcerative colitis; XI, Xerostomia Inventory.

**Table III.** Self-reported oral health problems in age-matched female patients with CD, UC, or CC with a stoma

	CD (n = 60)	UC (n = 54)	CC (n = 55)	P value	General population (n = 1407)
Problems with eating/drinking	10 (17%)	8 (15%)	5 (9%)	.473	17%
Temporomandibular joint complaints	11 (18%)	8 (15%)	7 (13%)	.700	7%
Oral blisters or aphthae	27 (45%)	18 (33%)	10 (18%)*	.009	9%
Discolorations of the oral mucosa	16 (27%)	2 (4%)*	2 (4%)*	.000	—
Angular cheilitis	20 (33%)	10 (19%)	7 (13%)*	.022	—
Irritated oral mucosa	18 (30%)	4 (7%)*	7 (13%)*	.003	—
Bad taste	18 (30%)	6 (11%)*	10 (18%)	.039	5%
Decreased taste	15 (25%)	9 (17%)	9 (16%)	.412	—
Halitosis	10 (17%)	11 (20%)	9 (16%)	.829	10%
Bad odor	12 (20%)	10 (19%)	9 (16%)	.880	—
Problems with speaking	6 (10%)	2 (4%)	2 (4%)	.248	—
Oral fungus	7 (12%)	2 (4%)	2 (4%)	.131	—
Pain	17 (28%)	7 (13%)*	3 (6%)*	.003	13%
Burning tongue	9 (15%)	4 (7%)	7 (13%)	.442	—
Other mouth problems	14 (23%)	12 (22%)	7 (13%)	.298	—
Mean of number of oral health problems (+ SD)	3.5 ± 3.3	2.1 ± 1.8†	1.7 ± 2.6†	.001	

\*χ<sup>2</sup> test: *P* < .05 versus CD.

†Kruskal-Wallis test: *P* < .05 versus CD.CC, colon cancer; CD, Crohn disease; SD, standard deviation; UC, ulcerative colitis.

**Table IV.** Self-reported dental problems of dentate female patients with CD, UC, or CC with a stoma

	CD (n = 55)	UC (n = 51)	CC (n = 50)	P value	General population (n = 1407)
Cavities	16 (29%)	20 (39%)	17 (34%)	.546	25%
Gingival problems	34 (62%)	25 (49%)	13 (26%)* †	.001	24%
Missing/loose teeth	6 (11%)	7 (14%)	6 (12%)	.906	22%
Malposition of teeth	3 (6%)	7 (14%)	4 (8%)	.316	14%
Sharp teeth	10 (18%)	7 (14%)	5 (10%)	.483	13%
Sensitive exposed root surfaces	32 (58%)	25 (49%)	21 (42%)	.250	–
Other problems	5 (9%)	14 (28%)	6 (12%)	.023	–
Mean of total number of tooth problems (+ SD)	1.9 ± 1.4	2.0 ± 1.7	1.4 ± 1.4	.102	

\* $\chi^2$  test:  $P < .05$  versus CD.

† $\chi^2$  test:  $P < .05$  versus UC.CC, colon cancer; CD, Crohn disease; SD, standard deviation; UC, ulcerative colitis.

**Table V.** Self-reported swelling of the orofacial area of female patients with CD, UC, or CC with a stoma

	CD (n = 60)	UC (n = 54)	CC (n = 55)	P value
Swelling of lips	8 (13%)	0 (0%)*	2 (4%)	.007
Swelling of buccal oral mucosa	6 (10%)	3 (6%)	3 (6%)	.553
Swelling of the face	5 (8%)	1 (2%)	2 (4%)	.239
Mean number of orofacial swelling problems (+ SD)	0.3 ± 0.7	0.0 ± 0.3†	0.1 ± 0.5	.040

\* $\chi^2$ :  $P < .05$  versus CD.

†Mann-Whitney U test:  $P < .05$  versus CD.CC, colon cancer; CD, Crohn disease; SD, standard deviation; UC, ulcerative colitis.

reflecting more orofacial swelling problems in those with lower well-being scores. For patients with UC or CC, no significant correlation between the number of orofacial swelling problems and the IBDQ-9 score was observed. There was a negative correlation between the IBDQ-9 score and the total XI score in female patients with CD, UC, or CC, reflecting more severe xerostomia in patients with lower well-being scores.

There was a significant negative correlation between the IBDQ-9 score and the total number of dental problems, reflecting more dental problems in female patients with lower well-being scores, especially in patients with CD or CC with a stoma.

**DISCUSSION**

As far as we know, this is the first study that compared the oral health of patients with IBD with a stoma. In this study, we found that female patients with CD with

a stoma report more oral health problems compared with patients with UC or CC with a stoma. Further clinical studies are warranted to confirm whether the self-reported oral problems are, indeed, associated with an increased incidence of oral abnormalities. Previous studies have shown a higher prevalence of oral health problems in patients with IBD compared with the normal population.<sup>9,10,13,14,20</sup> The present study also showed that patients with CD have an increased risk for oral health problems, independent of surgical removal of (a part of) the inflamed intestine, suggesting a generally increased susceptibility of patients with CD for oral health problems.

Another finding of the present study is that female patients with IBD experience more gingival problems compared with those with CC. Previous studies have also reported an increased risk of gingival and periodontal problems in patients with IBD and that compared with controls, patients with CD experience more mouth-related problems, including significantly more gingival bleeding,<sup>21</sup> significantly more periodontitis in patients with IBD,<sup>22</sup> and a significantly higher severity of periodontitis among IBD patients.<sup>23</sup> The increased risk of periodontitis in patients with IBD might be related to larger numbers of pathogens, such as *Campylobacter rectus*, *Porphyromonas gingivalis*, and *Tannerella forsythia* found in those with CD.<sup>24</sup> Immunologic mechanisms might also play a role because the co-occurrence of IBD and periodontitis in animals with specific immune disorders suggests that both conditions are at least partly caused by common

**Table VI.** Frequency of tooth brushing of female patients with CD, UC, or CC with a stoma

	CD (n = 55)	UC (n = 51)	CC (n = 50)
Times a day:			
1	9 (16%)	9 (18%)	9 (18%)
2	38 (69%)	31 (61%)	35 (70%)
3	7 (13%)	9 (18%)	4 (8%)
Ø3	1 (2%)	2 (4%)	2 (4%)

$\chi^2$  test:  $P = .084$ .

CC, colon cancer; CD, Crohn disease; UC, ulcerative colitis.

**Table VII.** Use of interdental cleaning devices by female patients with CD, UC, or CC

	CD (n = 55)	UC (n = 51)	CC (n = 50)	P value
Tooth pricks	24 (44%)	23 (45%)	30 (60%)	.187
Floss	22 (40%)	21 (41%)	20 (40%)	.990
Interdental brushes	31 (56%)	25 (49%)	26 (52%)	.748
Other devices	1 (2%)	3 (6%)	5 (10%)	.199
No devices	6 (11%)	7 (14%)	4 (8%)	0.653

CC, colon cancer; CD, Crohn disease; UC, ulcerative colitis.

immunologic mechanisms.<sup>25,26</sup> The increased risk of gingivitis and periodontitis in patients with IBD could potentially lead to premature tooth loss. However, this suggestion was not supported by the present study, as the percentages of (partly) edentulous patients among the 3 groups did not differ significantly.

Xerostomia is a subjective feeling of a dry mouth and is not necessarily associated with a reduced saliva secretion rate.<sup>13,14</sup> In this study, patients with CD had a significantly higher total XI score compared with those with UC or CC. This is in line with studies on xerostomia in patients with IBD, in which an increased prevalence of dry mouth was found in patients with IBD<sup>27</sup> and in those with active CD.<sup>28</sup>

The compromised oral health that was found in patients with CD cannot be explained by reduced oral hygiene because there were no statistical differences in frequency of tooth brushing and use of interdental cleaning among the 3 groups. It has been reported that there were no differences in oral hygiene habits between patients with CD and controls with regard to frequency of tooth brushing and the use of approximal cleaning aids,<sup>29</sup> and the frequency of tooth brushing and the use of dental floss and breath freshener was even higher in patients with IBD at disease onset compared with control groups.<sup>27</sup>

An analysis of the results from male patients with a stoma showed a pattern similar to that of the results of female patients, but because of the small number of male patients in the CD group (16 individuals), the differences frequently failed to reach statistical significance.

The present study has several limitations. There was a relatively low response rate of 26% from the

members of the stoma panel. In a study on the quality of life in a large group of Finnish patients with IBD, there was a response rate of 63%,<sup>30</sup> and in a survey on the prevalence of halitosis among members of another panel, the response rate was 62%.<sup>31</sup> A probable cause of the low response rate in the present study may be the lack of interest in the topic of the study among patients with a stoma. As a result of the low response rate, a bias may have been introduced because patients suffering from oral health problems might have been more likely to participate. It can also be questioned whether members of the Stoma Federation of The Netherlands are representative of all patients with a stoma because members of this patient federation may have a more-than-average interest in their general and oral health.

The study was limited to patients with a stoma, but one should realize that approximately 20% of patients with UC patients but greater than 80% of patients with CD require surgical treatment.<sup>32,33</sup> Although surgical treatment in patients with CD does not always involve intestinal resection, this may also have introduced a bias of the results because the patients in the UC group may have represented those who had relatively severe UC.

In this study, no differentiation was made between the different types of stoma. Patients with UC usually have an ileostoma and those with CC usually have a colostoma, whereas we did not know whether there was a colostomy or ileostomy in our CD population, and we also did not know if an inflamed intestinal trajectory was removed or if an ostomy was placed above the inflamed intestine to induce remission of disease. We assume that the (diverted) active disease becomes quiescent after creation of the ostomy. The colon is

**Table VIII.** Spearman's rank order correlations between IBDQ-9 score and total number of oral health problems (TNOHP), total number of orofacial swelling problems (TNSP) and XI score in female stoma patients

	Crohn's disease (n = 60)	Ulcerative colitis (n = 54)	Colon cancer (n = 55)
IBDQ-9 score and TNOHP	$r = -0.638 P < .001$	$r = -0.358 P < .001$	$r = -0.380 P = .004$
IBDQ-9 score and TNSP	$r = -0.301 P = .019$	$r = 0.066 P = .638$	$r = 0.144 P = .300$
IBDQ-9 score and XI-score	$r = -0.657 P < .001$	$r = -0.327 P < .001$	$r = -0.312 P = .020$

IBDQ-9, Inflammatory Bowel Disease Questionnaire-9; XI, Xerostomia Inventory.

very important for uptake of water, so the type of stoma might play a significant role in oral health. It should also be considered that patients with UC are in remission after colectomy, whereas those with CD may experience exacerbations in other parts of the GI tract after removal of a part of the intestine. Because the disease activity and the use of medication were not determined when the patients filled out the questionnaires, it may be possible that some patients with CD had active disease at that time. Future studies should take this into consideration.

Another limitation of this study is that the obtained information on oral health was limited to self-reported data. Although several studies have concluded that self-reported oral health may provide reasonable estimates of clinical measures<sup>34-37</sup> and (inter)nationally validated questionnaires, such as the TNO-oral problems questionnaire, the shortened IBDQ-9 questionnaire, and the XI questionnaire, were used in this study, the accuracy of information provided by patients through a questionnaire may be questioned. Accuracy may vary for different items of oral health questionnaires. For example, a study on self-reported data with regard to periodontitis found that self-perceived periodontal disease had sensitivity of 49% and specificity of 67%, whereas self-reported information on bone loss, tooth loss caused by periodontal disease, and mobility of teeth had specificity of greater than 90%.<sup>38</sup> Future studies on the oral health of patients with IBD should not be limited to self-reported data but should also include an oral examination by an expert.

## CONCLUSIONS

The findings of the present study show that the increased risk of oral health problems in patients with IBD, particularly those with CD, remains after surgical removal of (a part of) the inflamed intestine, necessitating special attention to their oral health from gastroenterologists and dentists.

## ACKNOWLEDGMENTS

We would like to thank the Stoma Federation of The Netherlands and their members for their assistance in this study.

## PRESENTATION

Part of the manuscript was presented at the 23rd International Conference on Oral and Maxillofacial Surgery 2017, in Hong Kong.

## DISCLOSURES

N.K.H. de Boer served as a speaker for AbbVie and MSD and as a consultant and/or principal investigator for TEVA Pharma VB and Takeda.

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