



Research Article

Sexual and Relationship Satisfaction of Ostomy Patients

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Abstract

Sexual satisfaction is a crucial element in overall well-being and life satisfaction, yet individuals with an ostomy face challenges that might significantly impact their self-esteem and sexual experiences, which decreases sexual satisfaction. This study aimed to investigate the sexuality of patients with an ostomy, considering the shortage of literature on this topic. Conducted as an anonymous online questionnaire approved by the ethics commission of Freiburg, Germany, the study gathered responses from 58 participants who met the inclusion criteria. Results revealed that a considerable number of participants (58.3%) underwent emergency surgeries without remembering prior discussions of an ostomy, indicating a lack of preoperative awareness. Only a small percentage (20.7%) reported discussing sexuality ever with healthcare professionals. Relationship satisfaction was explored, with a weak correlation found between relationship satisfaction and the short form of the Gastrointestinal Quality of Life Index (Pearson = 0.17, $p < 0.001$). Moreover, participants reported low sexual satisfaction and frequency. The findings underline the necessity to sensitize medical personnel about the importance of addressing sexuality with ostomy patients. The study highlights the impact of an ostomy on relationship dynamics, emphasizing the potential role of partners in preoperative consultations and the need for specialized counseling and support. Despite challenges, some participants reported positive aspects, suggesting the need to consider individual benefits and preferences when discussing procedures in which an ostomy presents an alternative. This pioneering study sheds light on the often-neglected aspect of sexuality in ostomy patients and calls for increased awareness among healthcare providers. Addressing sexual concerns pre- and postoperatively may enhance overall patient care and satisfaction, underscoring the importance of tailored counseling programs and collaborative efforts to improve the quality of life for individuals with an ostomy.

Keywords: Ostomy; Relationship Satisfaction; Sexual Satisfaction

Abbreviations: IBD: Inflammatory Bowel Disease; STROBE: Strengthening the Reporting of Observational Studies in Epidemiology; sGIQLI: Short form of the Gastrointestinal Quality of Life Index

Introduction

Sexual satisfaction is a key in the overall well-being of people, and it is an important factor of general life satisfaction. [1] Surgical modifications of the body, such as mastectomies, which may negatively impact the perceived body image, result in lower self-esteem and sexual problems in a high proportion of patients. [2] According to a qualitative study of fourteen participants [3], this phenomenon likely similarly exists in patients with an ostomy: Patients who temporarily or permanently need an ostomy face great challenges and changes in their daily life and many patients report trouble to adapt psychologically and physically. A decrease in sexual desire and changes in body image were widely reported by individuals with an ostomy and seem to improve with time after the initial operation. [4] Main causes for the need of an ostomy are Inflammatory Bowel Disease (IBD) and Colorectal Cancer.[5] Individuals suffering from these diseases feel less confident with their body image and have higher rates of sexual problems, which are rooted in gastrointestinal health issues such as abdominal pain, diarrhea or a bloated abdomen.[6] Colorectal surgery is associated with sexual difficulties such as erectile dysfunction and ejaculation problems in men as well as dyspareunia in women, but such symptoms are frequently overlooked. [7] Given the high impact, cancer or an ostomy can have on one's body image and the resulting possibly life-threatening situation for the patient, sexuality might not be an initial priority for these patients. The current literature on sexuality and individuals with an ostomy is sparse and existing studies usually have a qualitative design and normally consist of a small number of participants. Nevertheless, they indicate that sexuality is an important issue for individuals with an ostomy and sexual counselling might represent a way to support patients and enable them to challenge sexual difficulties and increase their self-esteem. [3,4] An ostomy might represent a way to treat symptoms such as bloating or abdominal pain in certain patients but is usually only performed when conservative treatment fails. [8] Postoperatively, symptoms such as abdominal pain or bloating decrease, which might lead to a decline in dyspareunia and increase sexual desire. On the other hand, having an ostomy might lead to insecurities and feelings of shame or disgust. Patients might fear that problems with their ostomy could arise during sexual activities, which could decrease sexual desire significantly. However, to our knowledge there is no current data

to answer this question. To initiate programs and counselling there is a need for more studies regarding sexuality of individuals with an ostomy and it is necessary that physicians know more about sexual issues among individuals with ostomies. However, there seems to be little awareness among physicians regarding this topic, as sexuality is still widely ignored in colorectal surgery which is also reflected by a small number of studies regarding sexuality in colorectal and stoma surgery. [8,10] In a study regarding sexual and relationship satisfaction of partners of patients suffering from endometriosis, an early preoperative discussion about sexual issues and including of the partner in preoperative and postoperative appointments were recommended to educate patients as well as their partners about sexual issues, which could arise after such an operation [11] Given the similarity of the impact an ostomy might have on one's body image and a sexual relationship this might also be an option for sexually active patients who need an ostomy. However, there is only very limited data available regarding this issue. It was therefore the aim of this pilot study to investigate sexuality among patients with an ostomy and to illustrate the current weight sexuality has in the treatment of such individuals as well as to work out suggestions for an adequate counselling and treatment of such patients. Future studies will be needed to confirm our results and to further analyze treatment options for ostomy patients.

Material and Methods

Overview

This study was conducted as an anonymous online questionnaire and was approved by the ethics commission of the state of Freiburg, Germany. It was registered on ClinicalTrials.gov (NCT05344781). The manuscript was drafted according to the STROBE (Strengthening the reporting of observational studies in epidemiology) criteria [12].

Recruitment

Various self-help groups as well as stoma therapists in Germany, Austria and Switzerland were contacted and asked to distribute an information leaflet about the study among ostomy patients. Various official ostomy self-help groups in Switzerland, Germany and Austria were contacted repeatedly from March – September 2022. The questionnaire could be reached online and included information about the aim of the study.

The Questionnaire

The comprehensive questionnaire utilized in this study is structured into distinct sections, designed to assess sexual and relationship satisfaction of individuals with an ostomy. The initial segment, focusing on ostomy and ostomy care, was designed by healthcare professionals renowned for their expertise in daily

interactions with ostomy patients. Following this, the relationship dynamics and satisfaction section was collaboratively developed by the lead researcher and fellow experts in sexual satisfaction and relationship research and was specifically developed for individuals with an ostomy. For the third section the Sexual Satisfaction Questionnaire [13] was used, which is recognized and employed in various research studies with a Cronbach alpha of 0.92 to ensure robust reliability in measuring participants' sexual satisfaction. Concluding the questionnaire was the short form of the Gastrointestinal Quality of Life Index (sGIQLI) with a Cronbach alpha ranging between 0.72 and 0.96. [14] This section contributes to the comprehensive evaluation of participants' overall quality of life in the context of their underlying diseases which led to the ostomy. The whole questionnaire consisted of a total of 67 questions.

Number of Participants

A total of 58 participants filled out the online questionnaire from March to September 2022. For the general part of the questionnaire, all participants who matched the inclusion criteria (aged 18 and above with a confirmed ostomy status) were included in the statistical analysis. For the analysis regarding sexuality, only participants who had sexual intercourse at least once in the 30 days prior to filling out the questionnaire were included, resulting in 34 participants. For the part regarding relationship satisfaction only participants with a partner were included, which resulted in 45 participants.

Statistics

To compare means between continuous and ordinal data Student's t-test and Mann-Whitney U-test were used. We calculated a Pearson correlation coefficient regarding sexual satisfaction, desire, and frequency of sexual intercourse with the time passed after the stoma operation. An index of (-)0.1 to (-)0.3 was considered as a weak, an index of (-)0.3 to (-)0.5 as a moderate, of (-)0.5 to (-)0.8 as a strong and of (-)0.8 to (-)1 as a very strong correlation. A P value of less than < 0.05 was considered as statistically significant.

Results

General Part

Of all the ostomies 46 (79.3 %) were done in an elective setting whilst 12 (20.7 %) were emergency operations. In seven out of 12 (58.3 %) emergency operations the ostomy was not discussed as an option preoperatively with the patient. Only in four (6.9 %) cases sexuality was discussed preoperatively and 46 (79.3 %) patients reported that sexuality has never been addressed

by a professional ostomy therapist or a doctor. All the patients reported to take care of the ostomy by themselves and only two (3.4 %) patients reported difficulties regarding the ostomy care. The ostomy bag had to be changed more than daily by 27 (62.1 %) patients, daily by 18 (31.0%) and less than daily by 13 (22.4 %) patients. Various secondary diagnoses are summarized in Table 1. Of all the patients 13 (22.4 %) reported not to be able to perform sexual activities due to underlying conditions. The results of the sGIQLI can be seen in Figure 1.

Gender	Male n = 13 (22.4 %) Female n = 45 (77.6 %)
Nationality	German n = 40 (70.0 %) Swiss n = 9 (13.8 %) Austrian n = 8 (15.5 %) Other n = 1 (1.7 %)
Ostomy type	Colostomy n = 20 (34.5 %) Ileostomy n = 38 (65.5 %)
Indication for ostomy	IBD n = 36 (62.1 %) Tumor n = 11 (19.0 %) Other n = 11 (19.0 %)
Secondary diagnosis	Psychiatric disease n = 5 (8.6 %) Cardiovascular disease n = 2 (3.4 %) Pulmonary disease n = 3 (5.2 %) Neurological disorder n = 7 (12.1 %)
Type of operation	Elective surgery n = 46 (79.3 %) Emergency surgery n = 12 (20.7 %)
Social data	In a relationship n = 45 (77.6 %) - heterosexual n = 43 (95.6 %) - homosexual n = 2 (4.4 %) Sexually active* n = 34 (58.6 %) Currently working n = 38 (65.5 %) Heterosexual
Personal data	Mean (with SD) BMI = 23.01 kg/m ² ± 4.5 Mean (with SD) age = 42.2 years ± 14.95 Time with ostomy (mean with SD) = 8.5 years ± 11.7
* Had sexual intercourse at least once in 30 days prior to the questionnaire	

Table 1: Epidemiologic data.

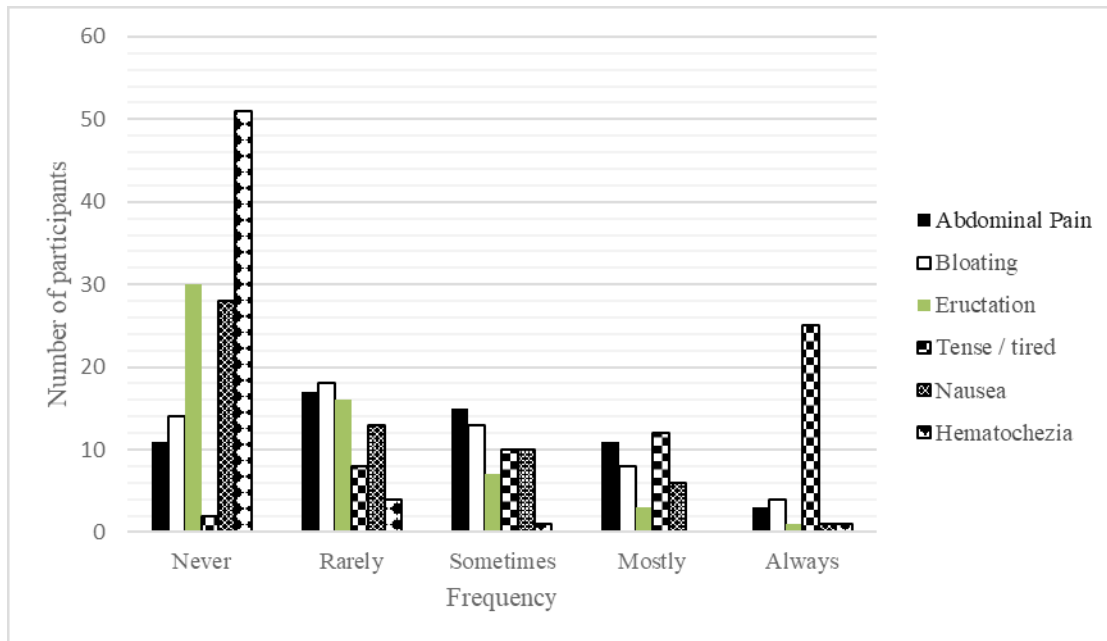


Figure 1: Gastrointestinal Quality of Life Index (short form).

Relationship Satisfaction

Of the 45 participants who are currently in a relationship, 34 (75.6 %) have been in a relationship for more than 5 years, 7 participants (15.6 %) between 1 and 5 years and 4 participants (8.9 %) for less than one year. A majority (n = 38, 84.4%) of participants are either satisfied or very satisfied with their relationship. Only 4 participants (8.9 %) were unsatisfied and 3 (6.7 %) were neither satisfied nor unsatisfied. For 13 participants (28.9 %) the ostomy led to a change in relationship satisfaction. Of these participants 11 (84.6 %) reported to have become more unsatisfied. Preoperatively, 16 (43.2%) of partners were present during the pre-treatment consultation and 21 (56.8 %) were not, 21 participants did not have a partner at the time of the operation. Regarding the satisfaction of the partner, 34 participants (77.3 %) reported that their partner was either satisfied or very satisfied. Only 4 participants (9.1 %) reported that their partner was unsatisfied, and 6 participants (13.6 %) reported that their partner was neither satisfied nor unsatisfied. No participant reported that their partner has become more unsatisfied because of the ostomy and 3 participants (9.4 %) reported that their partner has become more satisfied with the relationship since the ostomy. There was a weak correlation between relationship satisfaction and the sum of the sGIQLI (p<0.001, Pearson correlation coefficient = 0.13)

Sexuality

Of all the participants, 34 (58.6 %) reported to have had

sexual intercourse in the month prior to the questionnaire. Of these participants, 18 (53.4 %) reported not to be satisfied with their sex life. Of all the 58 participants, there were 33 participants (56.9 %) who were not satisfied with their sex life (p = 0.116). The Pearson correlation coefficient regarding sexual satisfaction and frequency of sexual intercourse was 0.22 (p = 0.031). Table 2 gives an overview about answers regarding sexuality for the whole group. Of the whole group 26 (44.8 %) participants reported to be as sexually active as wished, 31 (53.4 %) were less and 1 (1.7 %) participant was more sexually active than wished. A total of 41.4 % (n=24) reported not to have had sexual intercourse in the month prior to the questionnaire, 17.2 % (n=10) have had sexual intercourse once, 8.6% (n=5) more than once, 17.2% (n=10) weekly and 15.5% (n=9) more than weekly. No participants reported to have had sexual intercourse daily. The mean of sexual desire from 1 – 10 by all patients was 5.53 +- 2.77 and 6.44 +- 2.3 for patients with sexual intercourse in the prior 30 days to the questionnaire (p = 0.114). The time since the operation that led to a stoma was not or only weakly correlated with sexual satisfaction (Pearson correlation coefficient = 0.03, p = 0.153), sexual desire (person correlation coefficient = 0.18, p = 0.424) or sexual frequency (Pearson correlation coefficient = -0.24, p = 0.021). Figure 2 shows frequency of sexual intercourse and sexual desire of participants regarding to the time since the operation. There was a weak correlation between sexual satisfaction and the sum of the sGIQLI (p<0.001, Pearson correlation coefficient = 0.17).

“I am not satisfied with my sex life”	Totally true 31.0% (n=18) Slightly true 25.9% (n=15) Slightly untrue 27.6% (n=16) Totally untrue 27.6% (n=9)
“Sex is fun for me”	Totally true 51.7% (n=30) Slightly true 22.4% (n=13) Slightly untrue 17.2% (n=10) Totally untrue 8.6% (n=5)
“Feelings about sex generate negative emotions in me”	Totally true 12.1% (n=7) Slightly true 24.1% (n=14) Slightly untrue 25.9% (n=15) Totally untrue 37.9% (n=22)
“I am a bad sex partner”	Totally true 17.2% (n=10) Slightly true 29.3% (n=17) Slightly untrue 24.1% (n=14) Totally untrue 29.3% (n=17)
“I feel sexually attractive”	Totally true 13.8% (n=8) Slightly true 37.9% (n=22) Slightly untrue 31.0% (n=18) Totally untrue 17.2% (n=10)
“I have no problems with my sex life”	Totally true 29.3% (n=17) Slightly true 31.0% (n=18) Slightly untrue 20.7% (n=12) Totally untrue 19.0% (n=11)
“I like to think about sex”	Totally true 22.4% (n=13) Slightly true 44.8% (n=26) Slightly untrue 22.4% (n=13) Totally untrue 10.3% (n=6)
“My sex life frustrates me”	Totally true 22.4% (n=13) Slightly true 29.3% (n=17) Slightly untrue 20.7% (n=12) Totally untrue 27.6% (n=16)
“I am afraid not to please my sex partner”	Totally true 15.5% (n=9) Slightly true 24.5% (n=20) Slightly untrue 24.1% (n=14) Totally untrue 25.6% (n=15)
“For me my sex life is fulfilling”	Totally true 29.3% (n=17) Slightly true 24.1% (n=14) Slightly untrue 24.1% (n=14) Totally untrue 22.4% (n=13)

Table 2

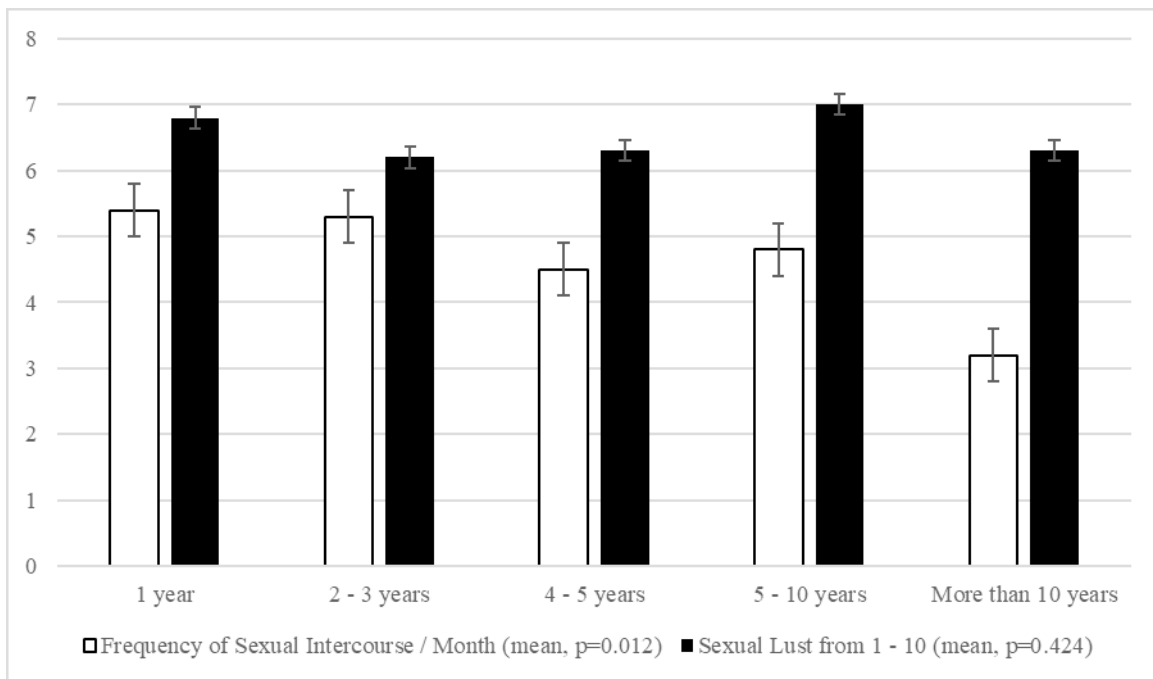


Figure 2: Sexual Frequency and Desire within Years after an Ostomy Operation.

Discussion

To the best of our knowledge this is the first study to analyze data regarding stoma patients, sexual satisfaction, and relationship satisfaction. The results show that there is a huge necessity to further sensitize medical personnel regarding the importance of sexuality for stoma patients. It is surprising that 58.3 % participants who underwent emergency surgeries reported that an ostomy was not discussed preoperatively. However, we do not know the exact circumstances regarding the operations. Patients might not have been accessible for a pre-treatment consultation and patients tend to not correctly recall information especially in anxious situations. [15] Only 6.9% of all participants in our study reported that sexuality has been discussed preoperatively with a treating doctor or therapist. This indicates that many patients have not felt adequately informed about an ostomy. Furthermore, 79.3 % of participants reported that sexuality has never been discussed by any therapist or doctor even though an ostomy leads to changes in the sex life of ostomy patients: 67.2 % reported to have less sexual intercourse because of the ostomy and most participants are frustrated with their sex life. Only a very small minority in our study feels sexually attractive. The frequency of sexual intercourse of our participants is low compared to literature [16] and decreases slightly with time after the ostomy operation, whereas sexual desire is relatively high and stays stable over time. Current literature and many guidelines about rectal cancer or ostomy operations do not address sexuality

at all [7]. This work indicates that sexuality still plays a big role in the life of many patients with an ostomy. Research on other diseases with a similar impact on sexuality such as endometriosis show that sexual dissatisfaction is very common among people suffering from such diseases but there is a potential in helping people by addressing sexuality pre- and postoperatively: Including a partner from early on and talking about sexual difficulties and worries might lead to a higher relationship satisfaction. [11,17] Giving patients and their partners space to address sexual issues and discussing alternatives to sexual intercourse could lead to an increase of the frequency of sexual activity which has a positive impact on sexual and relationship satisfaction of both partners. [10,11] Supporting patients psychologically could enhance the body image of individuals with an ostomy and help them to feel more attractive and secure. [18].

Positive Aspects of an Ostomy?

There is little research about long term benefits of ostomies compared to procedures such as primary anastomosis in rectal cancer with a high risk of anastomotic leakage. Usually, an ostomy is regarded as a last resort or a temporary state and patients who hear about it for the first time often react with despair. However, a permanent ostomy, despite its inconveniences, might rarely even be a better solution for a certain group of patients, especially regarding the benefit of not having side effects like fecal incontinence or recurrent anal or abdominal pain after high risk

operations such as deep rectal cancer or operations of IBD patients [19]. Sexuality and long-term satisfaction could be a new factor when discussing treatment options in such cases. The results of the sGIQLI show that about a third of our participants never or only rarely suffer from symptoms such as abdominal pain, bloating or eructation. These symptoms are known to decrease general life and sexual satisfaction. [20] Accordingly, there was a weak negative correlation between the sum of the sGIQLI and sexual satisfaction as well as relationship satisfaction in our study (the higher the sum of sGIQLI, the more symptoms participants have). Half of the participants are at least slightly satisfied with their sex life and a small minority even reported to have become more satisfied with their relationship after the ostomy. Chronic abdominal and pelvic pain usually lead to sexual problems. [10] Therefore, it is reasonable, that after an ostomy and the accompanying relief of certain symptoms such as pain might also increase sexual desire and performance, which is supported by the results of our study and to our knowledge has not been discussed in literature so far. Further research is needed to support this hypothesis. An ostomy could help a certain group of patients regarding sexual issues and dyspareunia. It might be reasonable to give life and sexual satisfaction a higher importance in guidelines.

Strengths and Limitations

This study is one of the first to address sexuality of ostomy patients and therefore seen as a pilot study to assess the need for this topic and future engagement in this field. Our results cannot be used to evaluate causal relationships and we could not compare data to the preoperative state. However, the clarity of our results indicates clearly that there is a huge awareness gap between professionals and patients regarding this topic and that there is a clear need to address sexuality pre- and postoperatively more often when working with patients who need or have an ostomy.

Conclusion

This study shows that sexuality is an important and not adequately addressed part regarding the care of ostomy patients. Neither pre- nor postoperatively sexuality is usually addressed by doctors or ostomy experts. Whereas it seems that many ostomy patients face sexual challenges and insecurities, there might be a minority of patients who could improve their sexual and life satisfaction with an ostomy. There is a need to improve awareness among treating physicians and therapists regarding sexuality and relationship issues of ostomy patients. As research in similar situations shows, it might be useful to include partners in preoperative appointments when dealing with patients needing an ostomy.

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