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Impact of stoma on lifestyle and health-related quality of life in patients living with stoma: A cross-sectional study

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Abstract:

INTRODUCTION: A person with colostomy or ileostomy undergoes a comprehensive treatment with a wide range of adjustments which affect the individual's social and psychological functioning. Quality of life (QOL) is a subjective feeling which includes physical, social, psychological, and spiritual domains of an individual that can be affected by a stoma.

AIM: This study is aimed at identifying the QOL and impact of stoma on their lifestyle pattern among ostomates attending stoma outpatient department of gastroenterology department of a government tertiary care center in South India during 2018.

METHODS: A descriptive study using a cross-sectional survey design was conducted among 55 ostomates, following consecutive sampling technique. The data were collected using a City of Hope QOL Questionnaire for Ostomy patients which had QOL Assessment Questions from four subdomains including physical, psychological, social, and spiritual aspects. This tool also had open-ended questions on lifestyle assessment components.

RESULTS: 63.6% of the participants had colostomy; 72.7% of the stomas were due to cancer. The mean QOL score of the participants was 4.13 ± 1.07 . The ostomates scored relatively well in both physical (5.68 ± 1.76) and spiritual (4.32 ± 1.36) domains, but the sociological (2.85 ± 1.3) domain score was very low. Permanent ostomates scored significantly higher than the temporary ostomates ($P = 0.04$).

CONCLUSION: The QOL score of ostomates was less than the scores reported in the Western population and living with stoma significantly alters their lifestyle. Therefore, follow-up services and counseling services to the ostomates by the health-care professionals are needed.

Keywords:

Cancer, lifestyle, ostomates, ostomy, quality of life, stoma

Introduction

Stoma is a surgically made opening in the skin of the abdomen that allows intestinal contents to pass from the bowel rather than being eliminated through the anus. It may be placed on a permanent or temporary basis. Colostomy, ileostomy, and urostomy are the common categories of stoma.^[1] These surgical procedures are

done to treat gastrointestinal malignancy or other causes including trauma, intestinal obstruction, ischemia, or inflammatory diseases that require feces or urine diversion.^[2]

In addition to the risk of undergoing surgical procedure, the existence and functioning of the stoma leads to an intense change in one's body image that can adversely impact their self-respect.^[3] The loss of control over the elimination of feces

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and urine, the possible leaks from the pouch, the loud flatulence, and bad odors are also distressing factors that can deeply compromise social relations and the individual's well-being.^[4]

In general, living with a temporary or permanent stoma leads to variety of physical and psychological challenges associated with stoma's functioning and poses a unique challenge to the patients which affects their quality of life (QOL).^[5]

At present, the existing health-care mainly concentrates on medical aspects of ostomates, but the psychological impact of stoma remains unfocused. Assessing their QOL pattern and its elements is a vital step for a better understanding of these patients and improvement in the health care provided. Hence, there exists urgency in identifying the magnitude of the problem. Therefore, this study is performed to determine the QOL of ostomates in South Indian population.^[2,6,7]

Methods

Study design

The cross-sectional survey design was used to assess the QOL of ostomates and impact of stoma on their lifestyle pattern among ostomates.

Setting

The study was conducted in the surgical gastroenterology outpatient department and stoma clinic of a tertiary care center in South India, which is an autonomous institute under government of India. This study was conducted during 2017–2018.

Sample size and sampling method

The minimum sample size required was estimated based on a study finding, which showed that almost their entire participants had impaired QOL after stoma creation in Indian setting.^[8] Hence, it is calculated as expected percentage of patients with impaired QOL as 90% with 8% relative precision and 5% level of significance. The estimated minimum sample size required for estimating the quality life of ostomates was 55. The sample size was

calculated by Open-Epi software, version 3 as mentioned in [Table 1].

Participant characteristics

Inclusion criteria of the study included patients over the age of 18 years, having ostomy in place for at least 2 months. Critically ill patients, patients having known mental disorders, patients with urostomy, and patients with input stoma, e.g., gastrostomy and jejunostomy, were excluded.

Tools: City of Hope QOL questionnaire developed by Marcia Grant was used in this study. This was an open questionnaire that can be used by the health professionals. It has two sections including lifestyle assessment part which contains open-ended items that related to the patient's work, health insurance, and sexual activity, psychological concerns, clothing, diet, and daily ostomy care. Another part contains 43 QOL assessment items, which are categorized into four subscales including physical (Item: 1–11), psychological (Item: 12–24), social (Item: 25–36), and spiritual well-being (Item: 37–43). Methods of scoring: Each question is answered with a Likert-graded response in the range of 0–10, in which 0 reflects the worst outcome and 10 is the best. Subscale scores are calculated by adding all the scores of each subscale and dividing their sum by the number of items in that subscale. A total QOL score is calculated by adding the scores on all 10-point items and dividing by the total number of items. Validity and reliability: Grant *et al.* established the validity and reliability of the tool. All subscales showed high level of internal consistency (Cronbach's $\alpha = 0.73$ – 0.89). The test–retest reliability indicated a very satisfactory as $r = 0.77$ – 0.90 . The demographic part of this questionnaire was modified and was validated by two medical experts from the field of surgical gastroenterology and two nursing experts.^[9]

Ethical consideration

Following an approval from the Institute Research Committee, approval from the Institute Ethical Committee was obtained (No.JIP/IEC/SC/4/565). Informed consent was obtained from all participants under the study. The participants were explained about the expected duration of participation, maintenance of confidentiality of records, the right to withdraw from the study at any point of time, and voluntary participation. Confidentiality of the data and anonymity of the subjects were maintained throughout the study.

Data collection procedure

By convenience sampling technique, patients who fulfilled the inclusion criteria were selected. After explaining the purpose of the study and getting informed consent from the participants, structured interview and record review were carried out. It was a one-time data

Table 1: Sample Size Calculation

Frequency	Population
Population size (for finite population correction factor or fpc) (n)	1,000,000
Hypothesized % frequency of outcome factor in the population (P)	90±8
Confidence limits as % of 100 (absolute± %)(d):	8
Design effect (DEFF)	1
Sample size $n = (DEFF \times Np [1-p]) / ((d^2 / Z_{1-\alpha/2}^2 \times (N-1) + p \times (1-p)))$	

collection requiring 30–40 min duration. Information regarding type of stoma, diagnosis, duration of stoma, and previous and current treatment was obtained from the records. Participants were asked to mark their response on the rating scale.

Data analysis

All data were analyzed using IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp. The data on categorical variables such as gender, marital status, religion, income, and education level were expressed as frequency and percentages. The continuous variables such as age were expressed as mean with standard deviation. The total QOL score and domain scores were represented as mean with standard deviation. The comparison of QOL scores in relation to different sociodemographic and clinical variables were carried out by independent *t*-test and one-way ANOVA. All the tests were carried out at 5% level of significance.

Results

Out of 55 ostomates, majority of the study participants (65.5%) were male, the mean age of the ostomates was 48.95 years, 92.7% of them were married, and majority of them belonged to Hindu religion (94.6%). 45.5% of the study participants had secondary education and 21.8% had formal education only. Most of them (83.6%) belonged to the below poverty line income group [Table 2].

Majority of them (63.5%) had colostomy and the remaining members had ileostomy. Most of them (80%) were temporary ostomates and 72.7% had cancer as a reason for ostomy. 10.9% of the participants received either chemotherapy or radiotherapy as part of their cancer therapy. 78.2% of them had stoma for ≤6 months. Only 25.5% of them received preoperative and postoperative counseling for creation of stoma. The minimum score obtained was 1.16 and maximum score is 7.28. The mean score obtained by the participants is 4.13 with a standard deviation 1.07 [Table 3].

The mean score obtained by the participants is maximum in the physical domain and minimum in the sociological domain [Figure 1].

After stoma creation, ostomates day-to-day activities have impaired as shown in lifestyle components. Regarding work-related items, of those working, only 10.9% were working in the same occupation after stoma, and majority of them (81.8%) changed their job after ostomy. Among the persons who changed their job after ostomy, 66.66% expressed that the change was purely due to an ostomy. Majority of the participants (60%) of the study had health insurance

and reported no difficulty in getting health insurance. None of the participants got full insurance coverage for

Table 2: Sociodemographic characteristics (n=55)

Variables	Categories	Frequency, n (%)
Age (years), mean (minimum-maximum)		48.95±14.609 (21-75)
Sex	Male	36 (65.5)
	Female	19 (34.5)
Marital status	Unmarried	3 (5.5)
	Married	51 (92.7)
	Single	1 (1.8)
Educational status	No formal education	12 (21.8)
	Primary	9 (16.4)
	Secondary	25 (45.5)
	Senior secondary and others	9 (16.3)
Religion	Hindu	52 (94.6)
	Christian	2 (3.6)
	Muslim	1 (1.8)
Income	Below poverty line	46 (83.6)
	Above poverty line	9 (16.4)

Table 3: Clinical characteristics of participants (n=55)

Variables	Categories	Frequency, n (%)
Total QOL score, mean (minimum-maximum)		4.13±1.07 (1.16-7.28)
Type of ostomy	Ileostomy	20 (36.5)
	Colostomy	35 (63.5)
Nature of stoma	Temporary	44 (80)
	Permanent	11 (20)
Diagnosis	Cancer	40 (72.7)
	Noncancer	15 (27.3)
Duration	≤6 months	43 (78.2)
	>6 months	12 (21.8)
Counseling before surgery	No	41 (74.5)
	Yes	14 (25.5)
Counseling after surgery	No	41 (74.5)
	Yes	14 (25.5)
Present treatment	With radiotherapy/ chemotherapy	6 (10.9)
	Without radiotherapy/ chemo therapy	49 (89.1)

QOL=Quality of life

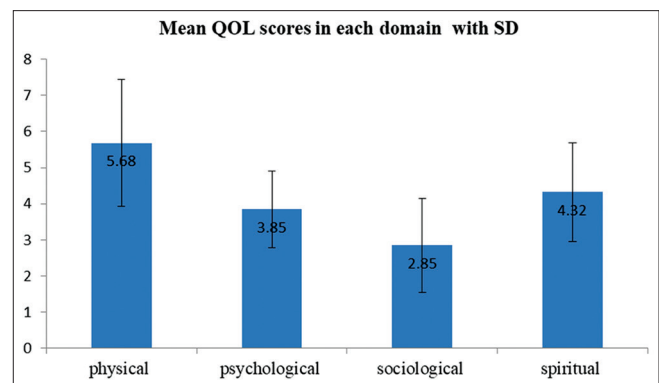


Figure 1: Quality of life scores in different domains

ostomy appliances. Among the participants, 61.8% were sexually active before ostomy. Among them, only four members resumed sexual activity after ostomy. When the participants were asked about the problems related to clothing, 43 (78.2%) reported that the location of the ostomy created problems for them. More than half of the members (54.5%) changed their style of clothing after ostomy. Most of the participants (89.1%) reported that they changed their diet because of ostomy and 85.5% members changed their diet to prevent passing gas in public [Table 4].

The permanent ostomates were found to have significantly high QOL scores when compared with

the temporary ostomates. The QOL score differences obtained between other groups are not statistically significant [Tables 5 and 6].

Discussion

Participant characteristics were comparable to a previous study, in which majority of the ostomates belonged to the age group of 41–59 years, 70% had colostomy, and 70% were male.^[9]

The QOL score obtained by the participants in this study was 4.13 ± 1.07 . These results suggest that compared to Western settings,^[9,10] patients in Indian population have

Table 4: Description of the lifestyle impact section of the study participants (n=55)

Questions	No, n (%)	Yes, n (%)	NA, n (%)
Work related items			
Are you working full time?	50 (90.9)	5 (9.1)	-
Are you working part-time?	42 (76.4)	13 (23.6)	-
Are you retired?	51 (92.7)	4 (7.3)	-
Are you working in the same occupation that you had before your ostomy?	45 (81.8)	6 (10.9)	4 (7.3)
If you are not working in the same occupation as before your ostomy, was the change related to having an ostomy?	25 (45.5)	30 (54.5)	-
Health insurance			
Do you currently have health insurance?	22 (40)	33 (60)	-
Have you had difficulty getting health insurance?	48 (87.3)	7 (12.7)	-
Does your insurance pay all costs for your ostomy supplies?	55 (100)	0 (0)	-
Does your insurance pay parts of the costs for your ostomy supplies?	49 (89.9)	6 (10.9)	-
Sexual activity			
Were you sexually active before getting your ostomy?	21 (38.2)	34 (61.8)	-
Have you resumed sexual activity since having your ostomy?	45 (81.8)	4 (7.3)	6 (10.9)
Psychological support/concerns			
Were you depressed after having your ostomy?	29 (52.7)	26 (47.3)	-
Since having your ostomy, have you ever considered or attempted suicide?	51 (92.7)	4 (7.3)	-
Do you belong to an ostomy support group?	55 (100)	0 (0)	-
Do you belong to another kind of support group?	55 (100)	0 (0)	-
Have you had the opportunity to talk with someone else who was going to have or had a new ostomy?	21 (38.2)	34 (61.8)	-
Clothing			
Does the location of your ostomy cause you problems?	12 (21.8)	43 (78.2)	-
Have you changed the style of clothing you wear because of your ostomy?	25 (45.5)	30 (54.5)	-
Diet			
Do you adjust your diet because of your ostomy?	6 (10.9)	49 (89.1)	-
Do you change your diet to prevent passing gas in public?	8 (14.5)	47 (85.5)	-

Table 5: Comparison of domain scores of ostomates in relation to type and nature of ostomy (n=55)

Domains	Type of ostomy	Mean±SD	P	Nature of ostomy	Mean±SD	P
Physical	Ileostomy	5.90±1.5	0.507	Temporary	5.61±1.8	0.552
	Colostomy	5.56±1.9		Permanent	5.97±1.62	
Psychological	Ileostomy	3.99±0.79	0.454	Temporary	3.69±1.00	0.023*
	Colostomy	3.77±1.19		Permanent	4.50±1.06	
Social	Ileostomy	3.17±1.19	0.175	Temporary	2.68±1.19	0.052
	Colostomy	2.67±1.35		Permanent	3.53±1.56	
Spiritual	Ileostomy	4.49±1.31	0.487	Temporary	4.21±1.30	0.302
	Colostomy	4.22±1.4		Permanent	4.75±1.56	

Independent t-test *P<0.05. SD=Standard deviation

Table 6: Comparison of quality of life scores of ostomates in relation to clinical and socio demographic variables (n=55)

Variables	Categories	n	Mean±SD	Statistical significance*
Sex	Male	36	4.30±1.14	0.103
	Female	19	3.81±0.86	
Income	Below poverty line	46	4.01±0.95	0.602
	Above poverty line	9	4.74±1.46	
Education	No formal education	12	3.9±1.01	0.185 [#]
	Primary education (Class 1-5 th)	9	4.09±1.67	
	High school (6 th -10 th)	25	3.99±0.88	
Type	Ileostomy	20	4.33±0.80	0.314
	Colostomy	35	4.02±1.20	
Nature	Temporary	44	3.99±1.00	0.049**
	Permanent	11	4.70±1.17	
Duration (months)	≤6	43	4.04±0.98	0.249
	>6	12	4.45±1.33	
Counseling before surgery	No	41	4.13±1.11	0.984
	Yes	14	4.14±0.99	
Counseling after surgery	No	41	4.07±1.20	0.432
	Yes	14	4.33±0.53	
Current treatment	Radio therapy/chemo therapy	6	4.08±1.06	0.295
	No radiotherapy/chemotherapy	49	4.57±1.12	

*Independent t-test, [#]One-way ANOVA, **Significance at P<0.05

a lower QOL. The low QOL can be attributed to poor socioeconomic status, low education level, and lack of adequate social support and acceptance of the ostomates in our society.

In the present study, the participants scored relatively well in both physical and spiritual domains. The mean scores in these domains were 5.68 ± 1.76 and 4.32 ± 1.36 , respectively. Similar results were also reported, in which they reported relatively good performance in physical and spiritual domains.^[10,11] There was a lower score of the ostomates in the sociological domain (2.85 ± 1.3), which could be due to lack of acceptance from the society, lack of counseling services and problem with body image which was consistent with other settings may be due to lack of acceptance from the society, lack of proper counseling services, and problems with body image. Body image plays a significant role in social connectivity. The issues associated with stoma can interfere with a person's social relation.^[12-14]

81.8% of the participants have changed their occupation after ostomy, among them 66.66% expressed that the change of occupation was purely due to an ostomy; this could be due to difficulty in change of ostomy appliances at work place and the nature of job. Further, only 7.3% of them resumed sexual life after stoma creation, which was significantly less than the number reported in the other studies.^[15-19] This may be due to absence of appropriate training on sexuality concerns to stoma patients. Therefore, it may be useful to refer stoma patients for counseling and training about sexual health.

Further, as unlike other countries, none of them belongs to any kind of ostomy support group, which is essential to share their feelings and ask questions and to live with ostomy. Hence, referral and initiation of ostomy support group service is essential in these settings.^[14-17]

The permanent ostomates scored significantly higher than temporary ostomates. Over the course of time, the permanent ostomates get adapted to their stoma. This can be the reason for high QOL scores among permanent ostomates in the present study. As reported earlier, the comparison of QOL scores in relation to different clinical factors such as type of stoma, diagnosis, duration of stoma, pre- and postoperative counseling, and treatment did not present a significant difference. The comparison of subdomain scores based on diagnosis revealed that the patients without cancer scored higher when compared to those with cancer. However, the difference obtained was not statistically significant.

Conclusion

The mean QOL score of considerably low and living with stoma influences the overall aspect of QOL and it affects their lifestyle pattern in our study. As self-efficacy is an essential component to live with stoma, appropriate preoperative counseling and postoperative follow-up services to patients and their families are essential to address multidimensional problems including psychosocial and sexual aspects. Further, integrating with all related specialties including psychosocial well-being and sexual health and formulation of

ostomates support group would be helpful to exchange their experiences.

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Conflicts of interest

There are no conflicts of interest.

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