Original article

COVID-19 pandemic: Quality of Life and problems faced by ostomates

ABSTRACT

Aim To assess Quality of Life (QoL) among adult stoma patients and problems faced by them during the COVID-19 pandemic.

Methods In this descriptive cross-sectional study 100 adult stoma patients visiting a stoma clinic and ostomy society office in a tertiary health care centre in India were enrolled through purposive sampling. Demographic data and QoL of stoma patients were collected through interviewing the patients using City of Hope – Quality of Life Ostomy Questionnaire. Problems faced by stoma patients were assessed through a pre-validated and tested self-developed structured tool (reliability coefficient=0.825).

Results The study findings revealed that a majority (27%) of the stoma patients had poor QoL, with mean overall QoL scores of 3.64±0.46. The lowest QoL scores were in the social domain. There were several problems faced by stoma patients during COVID-19, including leakage and peristomal skin problems (98%), problems with accessing professional help (87%), financial burdens (95%) and being unable to meet ostomy society members (100%). Significant associations were present between QoL and problems due to the location of their stoma, changes in clothing and adjusting diets due to ostomy (p value=<0.05). There was moderate negative correlation between QoL and financial and mental problems faced by stoma patients during the COVID-19 pandemic with p value <0.01.

Conclusion The majority of the stoma patients had poor QoL during the COVID-19 pandemic. There were several problems faced by stoma patients, including physical, financial, social and psychological problems.

Keywords Quality of Life (QoL), stoma patients, COVID-19, problems of ostomates.

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INTRODUCTION

As per the United Ostomy Associations of America, there are 725,000 to one million Americans currently living with an ostomy (UOAA).[1] Over 13,500 people in the United Kingdom are estimated to undergo stoma surgery every year. It has been also reported that 176,824 people are living with ostomy across the UK - 1 in 500 has an ostomy.[2] Patients adapting to life after stoma surgery can be affected by a multitude of factors, including socioeconomic and clinical parameters. Mukherjee et al 2019 state that, in India, a huge number of stoma surgeries are performed every day with limited specialised stoma care available.[3]

Patients require construction of a stoma for a variety of reasons. The most common reasons are carcinoma of the bowel (73%),[4] carcinoma of bladder, inflammatory bowel conditions (20%)[5] and intestinal obstruction. Depending on the disease condition, it might be permanent or temporary.[6]

A stoma is created through 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. Colostomy, ileostomy and urostomy are the common categories of stoma. These surgical procedures are done to treat gastrointestinal malignancy or other causes including trauma, intestinal obstruction, ischemia or inflammatory diseases that require faecal or urine diversion[4,5,6].

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Quality of Life (QoL), according to WHO, is an individual's view of their place in life in relation to their objectives, aspirations, standards and concerns in the context of the culture and value system in which they live.[7] Patients with a stoma face a variety of physical and psychological challenges either because of their disease, surgery or/and the presence of the stoma that can compromise QoL. Assessing their QoL pattern and its determinants is an essential step toward a better understanding of these patients and improvement in the healthcare provided.[8]

The coronavirus disease 2019 (COVID-19) pandemic was a global outbreak of coronavirus - an infectious disease caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).

Cases of novel coronavirus (nCoV) were first detected in China in December 2019, with the virus spreading rapidly to other countries across the world. This led WHO to declare a Public Health Emergency of International Concern (PHEIC) on 30 January 2020 and to characterise the outbreak as a pandemic on 11 March 2020.[9] The COVID-19 pandemic posed problems to people across the globe. The pandemic situation caused a burden to the health care facility in the treating the emergency condition.

The COVID-19 pandemic also posed novel problems and challenges for adult ostomates, in that continuation of the support of healthcare facilities was impaired due to the lock down situation.

Despite an extensive healthcare system in India, the COVID-19 pandemic created havoc on the existing Indian healthcare system by disrupting the supply of essential healthcare services to patients. During the pandemic period there was a drastic decline in seeking non-COVID-19 disease related healthcare services.[10]

AIM

To assess QoL among adult stoma patients and problems they faced during the COVID-19 pandemic.

METHODS

Study design

The descriptive cross-sectional study design was used to assess the QoL among adult stoma patients and the problems they faced during the COVID-19 pandemic.

Setting

The study was conducted in the stoma clinic and stoma society office of a tertiary care centre in India, which is an autonomous institute under the Government of India. The study was conducted between September 2021 and December 2021 and focused on the three nationwide lockdowns in India in 2020.

Sample size and sampling method

The minimum sample size required was calculated based on a study[11] which showed the mean QoL (not using a Likert scale) in the physical domain (70.82+_15.96), psychological domain (66.73+_17.29), social domain(50.82+_18.84) and spiritual domain(34.75+_9.37) respectively, with 10% relative precision and 95% desired confidence interval. The estimated sample size for the following domains came out as physical domain(20), psychological domain(26), social domain(53), and spiritual domain (28) respectively. Hence the required minimum sample size for study was 53. In this study 100 patients were enrolled for better precision using purposive sampling. The physical, psychological, social and spiritual domain were individually considered for sample size estimation to ensure that required sample size for respective domain was known.

Inclusion criteria

All adult patients, including colostomy, ileostomy and urostomy within three years of stoma construction, who could understand Hindi or English languages and were willing to participate in the study.

Exclusion criteria

Adult patients who were not willing to participate.

Tool 1

The City of Hope – Quality of Life Ostomy Questionnaire, developed by Marcia Grant,[12] was used in this study. Permission has been granted for its use for research purposes. It has three sections - demographic information, a lifestyle assessment section with items that related to the patient's work, health insurance, sexual activity, psychological concerns, clothing, diet and daily ostomy care. The third part contains 43 QoL assessment items, categorised into four subscales including physical (items: 1–11), psychological (items: 12–24), social (items: 25–36) and spiritual well-being (items: 37–43).

Methods of scoring

Each question is answered with a Likert scale response in the range of 0–10, in which 0 reflects the worst and 10 is the best outcome. 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[12] established the validity and reliability of the City of Hope – Quality of Life Ostomy Questionnaire tool. All subscales showed high level of internal consistency (Cronbach's α = 0.73–0.89). The test–retest reliability indicated very satisfactory, as r = 0.77–0.90. The demographic part of this questionnaire was modified and validated by two medical experts from the field of surgical gastroenterology and two nursing experts.[12]

Tool 2

Problems faced by stoma patients during the COVID-19 pandemic were assessed with a self-developed questionaire. It was pre-validated by eight experts, four from the nursing faculty and four medical experts from surgical disciplines, and tested (reliability coefficient=0.825).

Ethical considerations

Approval was granted by the Institute Ethics Committee (ref no. IECPG-274). Informed consent was obtained from all the participants in the study. The purpose of the study was explained to the participants and they were invited to ask questions. The participants were informed about the expected duration of participation, maintenance of confidentiality of records and their right to withdraw from the study at any point of time. Confidentiality of the data and anonymity of the participants were maintained.

Data collection procedure:

By using a purposive sampling technique, patients who fulfilled the inclusion criteria were selected. After explaining the purpose of the study and obtaining informed consent from the study subjects, structured interviews and record reviews were carried out. It was one-time data collection requiring 45–50 minutes duration. Information regarding the participants' diagnoses, type of stoma, duration of stoma and treatments were obtained from records.

Data analysis

All data were coded and entered in an Excel spreadsheet. Stata 16.0 Statistical software was used for data analysis. Descriptive statistics used in the study were frequency, percentages, mean and standard deviation. Inferential statistics used in the study were t-test, Pearson's correlation and Analysis of Variance (ANOVA). In this study, $p<0.05$ was considered as statistically significant.

RESULTS

In the present study more than half, 58 of the study population patients (n=100) were male. Their mean age was 43.79±16.39, ranging from 19 to 85 years. The mean weight (in kg) of the stoma patients was 55.72±10.48, ranging from 35kg to 90kg. All the stoma patients were of Asian ethnicity (100). The majority (80) were married, 19 were single and only 1 was divorced. (Table 1).

With regards to the distribution of stomas by the type, the majority (53) had a colostomy, 36 had an ileostomy and 11 had urinary diversions. Most, 59, of patients had a permanent stoma, 54 had lived with their stoma for more than two years, 27 had been ostomates for 1 to 2 years and 19 had had their stoma for less than one year. (Table 2).

Quality of Life findings

The mean of the physical well-being scores among the patients was 4.4±0.63, which was the highest among all the subscales. The lowest subscale mean was 2.90 and the highest was 6.82. The mean for the psychological well-being scores was 3.81±0.69 (range 2.3 to 6.38). The mean for the social well-being scores was 2.62±0.73 (range 1.41 to 5.66). The mean for the spiritual well-being scores was 3.88±0.64 (range1.71 to 6). The mean score of overall QoL was 3.64±0.46 (range 2.51 to 5.58). (Table 3 and Figure 1).

Based on the Quartile of the study data findings, the QoL was defined in 4 categories. Among the QoL domains: physical; psychological; and spiritual well-being of the stoma patients was good, social well-being was poor and the Overall QoL was average. Among the total study samples, percentage of stoma patients falling in the categories based on the QoL as poor (27%), fair (24%), average (25%), and good (24%). (Table 4 and Figure 2).

Among 100 study respondents, 13 continued working in the same occupation as before their ostomy surgery and 10 reported that they changed the occupation after the construction of ostomy, and that it was the reason for their change in the occupation. Many of the ostomates reported being unemployed. (Table 5a).

In the health insurance-related items, only five of the 100 ostomates said they had health insurance, while 95 were uninsured. The five with health insurance reported that only parts of the total cost of their stoma care appliances and skin related accessories were covered by their insurance.

The majority, 63 of the 100 ostomates, were sexually active before the stoma construction. Only 32 (51% of

Table1. Distribution of participants by socio-demographic characteristics.

Variables	Categories	n=100
Gender	Male Female	58 42
Age	Mean(years) Range	43.79 19–85
Height	Mean(cm) Range	160.59 154.94-182.88
Weight	Mean(kg) Range	55 35–90
Ethnicity	Asian Others	100 0
Marital status	Single Married Divorced	19 80 1

Table 2. Distribution of subjects as per the Clinical characteristics.

Variables	Categories	n=100
Type of ostomy	Urinary diversion	11
	Ileostomy	36
	Colostomy	53
Nature of stoma	Temporary	41
	Permanent	59
Diagnosis	Cancer	56
	Non-cancer	44
Duration	<1 year	19
	1year-2year	27
	>2yrs	54

these ostomates) resumed their sexual activity after stoma construction. None of the ostomates reported satisfactory sexual activity after the stoma construction. Among the males, 17 (74%) had a problem with erectile dysfunction, while 6 (26%) did not have a problem getting or keeping an erection.

In the psychological support-related items all the ostomates were depressed after having their stoma. Of the 100 ostomates, 19 considered or attempted suicide since having the ostomy, while 81 did not. All of the patients belong to an ostomy support group.

The majority, 77 of the 100 ostomates reported that the location of their ostomy caused problems, while 23 were not having problems related to the location of the ostomy. Most patients 82 changed the style of clothing that they wore because of their ostomy.

In diet-related items, 79 of the 100 stoma patients had adjusted their diet because of their ostomy while 21 did not.

Table 3. QoL of stoma patients, subscales and overall QoL.

Domains of Quality of Life	Mean (SD)	Range	
		Minimum	Maximum
Physical wellbeing	4.40(±0.63)	2.90	6.81
Psychological wellbeing	3.81(±0.69)	2.30	6.38
Social wellbeing	2.62(±0.73)	1.41	5.66
Spiritual wellbeing	3.88(±0.64)	1.71	6.00
Overall QoL	3.64(±0.46)	2.51	5.58

Table 4. Levels of QoL reported by stoma patients.

QoL categories	QoL score	Frequency
Poor	<3.37	27
Fair	3.37–3.53	24
Average	3.54–3.79	25
Good	>3.791	24

Approximately 66 ostomates changed their diet to prevent passing gas in the public. (Table 5b).

IMPLICATIONS FROM COVID-19

During COVID-19 Nationwide lockdowns (phase 1: 25 March 2020–14 April 2020; phase 2: 15 April 2020–3 May 2020; phase 3: 4 May 2020–17 May 2020) many problems were faced by the ostomates who were enrolled in this study. 98 of our 100 stoma patients faced leakage and peristomal skin problems during the COVID-19 lockdown, out of which 87 needed professional help for stoma care. Of this 87, most (79 patients/91%) were not able to contact their stoma care services. Of the eight patients who were able to contact the health care services, three made contact through a physical visit to the stoma clinic, while five used telehealth stoma services.

The majority, 95 of the 100 patients, had to buy stoma pouches and stoma care appliances from the market during the pandemic. All of these the patients bore financial burdens related to their stoma care. Of them, 67 found it difficult to purchase their ostomy equipment on the open market. Almost all, 99 ostomates, faced financial burdens of taking care of their stomas.

The majority, 83 of the 100, found having a stoma affected their social life to a great extent while 17 had their social life affected to some extent. Half (50) said they were withdrawn to a great extent, a further 46 were withdrawn to some extent, three to a small extent, and only one was not withdrawn.

Table 5a. Impact of ostomy on particpants' lifestyles (Work-related items).

Work-related reasons for impact	Frequency N=100	Percentage
Working full time	12	12%
Working part time	12	12%
Retired	11	11%
Continuing in the same occupation as before ostomy	13	13%
Ostomy as the reason to change the occupation	10	10%

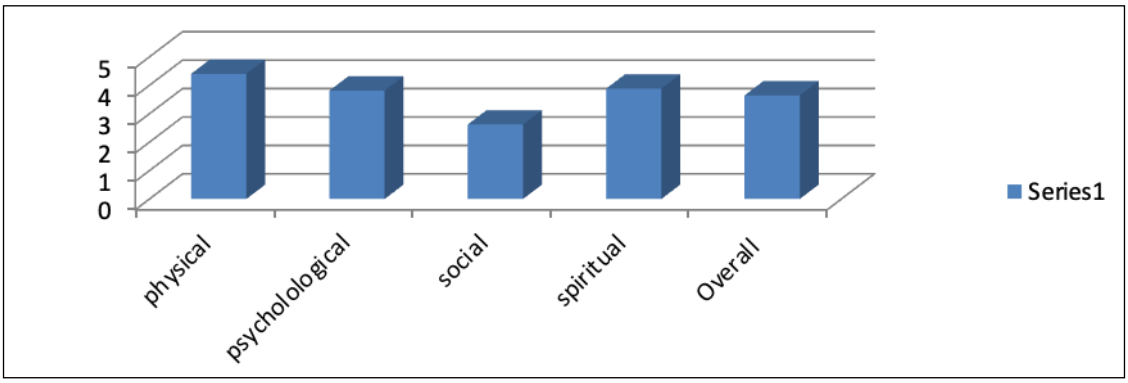

Figure 1. Mean QoL scores of stoma patients by sub-domains.

Table 5b. Distribution of subjects as per impact of ostomy on their lifestyle (N=100).

	No	Yes
Health insurance		
Have health insurance	95(95%)	5(5%)
Difficulty getting health insurance	5(100%)	0
Insurance pays all cost for your ostomy supplies	5(100%)	0
Insurance pay part of the costs	0	5(100%)
Sexual activity		
Sexually active before ostomy	37(37%)	63(63%)
Resumed sexual activity since having ostomy	31(49%)	32(51%)
Sexual activity is satisfying	32(100%)	0
Problem getting an erection or keeping an erection (male)	6(26%)	17(74%)
Psychological support		
Depressed after having ostomy	0	100(100%)
Considered or attempted suicide	81(81%)	19(19%)
Belong to an ostomy support group	0	100(100%)
Belong to another kind of support group	99(99%)	1(1%)
Had the chance to talk to someone who was planned to have or had a new ostomy	85(85%)	15(15%)
Clothing		
Location of ostomy cause problems	23(23%)	77(77%)
Changed style of clothing	18(18%)	82(82%)
Diet		
Adjusted diet	21(21%)	79(79%)
Change diet to prevent passing gas in public	34(34%)	66(66%)

During the COVID-19 pandemic 98 of the 100 ostomates also faced mental/psychological problems. Of these, 97 reported anxiety due to leakage problems. Out of these 97, 73(75%) reported a severe level of stress, and 24(25%) had moderate stress.

Of the 98 patients with stress due to peristomal skin problems, 75(77%) had severe stress, 22(23%) had moderate stress, and 1(1%) had mild stress. Anxiety due to financial burdens was reported by 98 respondents. 97 had a severe level of stress and only one had a moderate level of stress.

The level of stress caused difficulties with concentration among 40 of the 100 patients, leading to irritability for 83, mood changes for 84 and 46 had their daily activities affected due to their levels of stress.

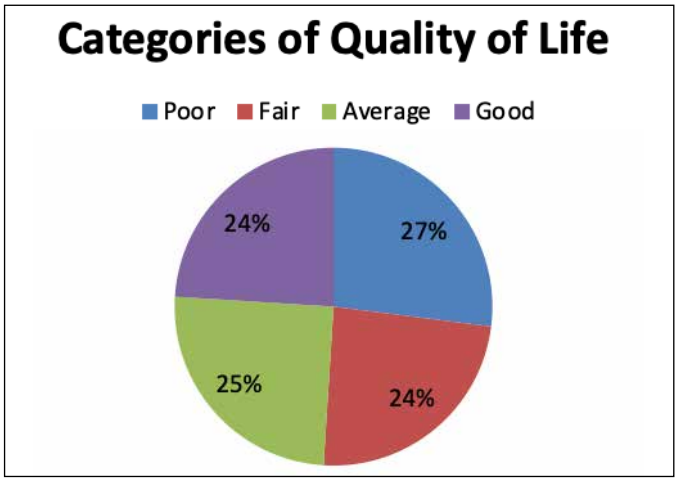

Figure 2. Distrubtion of levels of stoma patients' QoL scores.

The majority, 97 of the 100 ostomates, expressed fear about future care of their stomas, related to ontaining stoma appliances from the hospital and being able to seek advice from stoma clinic nurses. Of the 100, 99 felt anxious because of being withdrawn: six reported mild levels of anxiety, 28 had mild to moderate levels of anxiety, and 12 reported moderate to high levels of anxiety, moderate level of anxiety was reported by 53 patients. Of the 100, 97 had fear of being infected with COVID-19 when planning to seek professional help. Out of this 97, 78(81%) sometimes avoided seeking professional help; 11(11%) always avoided seeking professional help; and only 8(8%) never avoided seeking professional help (Table 6).

Looking at associations between QoL and demographic variables, there was no significant association found between age, weight, and QoL among study subjects as the p-value for all relationships was >0.05. There was no significant association found among the variables by type of stoma, diagnosis that led to stoma surgery, gender, marital status, and QoL. There was a statistically significant association between the kind of ostomy (urinary diversion, colostomy, ileostomy) and QoL, but no statistically significant association between duration of ostomy and QoL (Tables 7a, 7b and 7c).

There was significant association between QoL and other variables, including problems with location of stoma (p=0.018), change in clothing style due to stoma (p=0.001), adjusted diets (p=0.011), and changes in diet to prevent passing gas in public (p =0.035) (Table 7d).

There was a weak negative correlation between QoL and physical problems faced by stoma patients. There was moderate negative correlation between QoL and financial problems (p=0.0013) and mental problems (p=0.0001). There was a moderate positive correlation between QoL and social problems (p=0.0011) (Table 8).

Table 6. Problems faced by stoma patients duringthe COVID-19 pandemic in different sections (N=100).

Variables	Categories	Frequency (n%)
Physical problems		
Leakage from the stoma site	Yes No	98(98%) 2(2%)
Peristomal skin problems	Yes No	98(98%) 2(2%)
Requirement for professional help related to stoma care	Yes No	87(87%) 13(13%)
Able to contact your doctor or stoma nurse	Yes No	8(9%) 79(91%)
Mode of contact with doctor/stoma nurse	Physical visit Tele-consultation	3(37.5%) 5(62.5%)
Financial problems		
Bought stoma pouches and stoma care appliances from the market during pandemic	Yes No	95(95%) 5(5%)
Got materials easily from market	Yes No	28(29%) 67(71%)
Financial burden due to buying the materials from market	Yes No	95(100%) 0
Care of stoma a financial burden during COVID-19	Yes No	99(99%) 1(1%)
Social problems		
Social life affected during COVID-19	Great extent Some extent Little extent Not at all	83(83%) 17(17%) 0 0
Feel withdrawn because of stoma during COVID-19	Great extent Some extent Little extent Not at all	50(50%) 46(46%) 3(3%) 1(1%)
Meeting with ostomy society members during COVID-19 situation	Yes No	0 100(100%)
Mode of meeting	Physical Virtual	0 0
Mental/psychological problems		
Stress-related to the leakage from the stoma site	Yes No	97(99%) 1(1%)
Degree of stress	Mild Moderate Severe	0 24(25%) 73(75%)
Stress-related to peristomal skin problems	Yes No	98(100%) 0
Degree of stress	Mild Moderate Severe	01(1%) 22(22%) 75(77%)
Stress due to the financial burden	Yes No	98(98%) 2(2%)
Degree of stress due to financial burden	Mild Moderate Severe	0 1(1%) 97(99%)
Level of stress caused: A) inability to concentrate	Yes No	40(40%) 60(60%)
B) irritability	Yes No	83(83%) 17(17%)
C) mood changes	Yes No	84(84%) 16(16%)
D) affected daily activities	Yes No	46(46%) 54(54%)
Fear about future care of the stoma	Yes No	97(97%) 3(3%)
Fear related to	Getting the stoma appliances and receiving clinical advice	
Feeling anxious because of being withdrawn	Yes No	99(99%) 1(1%)
Level of anxiety	Mild Mild-moderate Moderate Moderate to high	06(6%) 28(28%) 53(54%) 12(12%)
Fear of being infected by COVID19 when seeking in person the professional help	Yes No	97(97%) 03(3%)
Ignore seeking professional help	Always Sometimes Never	11(11%) 78(81%) 08(8%)

DISCUSSION

The mean age of the adult stoma patients in our study was 43.79±16.39 (range 19 to 85 years). Similar findings were reported in other studies conducted in India by Roshini et al[11] in 2017 and by Davis et al[4] in 2020. They reported mean age of the stoma patients as 43.9±16.23 (18 to 80 years) and 48.95±14.60, (21 to 75 years), respectively. In the study conducted in Sri Lanka by Jayarajah et al[13] in 2017 a similar age range of 18 to 83 years was reported.

The mean age of stoma patients reported in an Iranian study by Rafiei et al[14] in 2020 was 63±14.1, and in a Chinese study by Zhang et al[15] in 2019 it was 62.14±4.78 years. The mean age of the stoma patients in these studies,[14,15] is higher than the ages reported in the Indian studies.[4,11]

In the present study, most (58%) of the stoma patients were male. Similarly, 61% of study participants were male in a study by Zewude et al[16] in 2021, and males accounted for the majority of stoma patients in Zhang et al[15] and Davis et al,[4] studies, at 56% and 66% respectively. While in a study by Rafiei et al[14] 51% of the participants were female.

Most of the stoma patients in the current study (80%) were married. Similarly Zhang et al[15] reported 86% of their participants were married. However, Davis et al[4] reported that 93% of their study population were married, a higher percentage. Whereas Jayarajah et al[13] reported that only 67% of their study participants were married, a lower percentage.

More than half (53%) of the stoma patients in the present study had a colostomy. While Davis et al,[4] Jayarajah et al[13] Zhang et al[15] all reported higher rates of colostomy stomas at 64%, 74% and 73% respectively. Colostomy formation was reported as the most common type of stoma surgery (94%) by Zewude et al,[16] higher than the present study.

Most (59%) of the stoma patients in the present study had permanent stomas. Zewude et al[16] reported 59% of their study participants had a colostomy. In Jayarajah et al[13], Davis et al[4] and Rafiei et al[14] the stoma patients with colostomy were 74%, 64% and 67% respectively. These rates were a little higher than those found in the present study.

Malignancy as indication of stoma construction in the present study was 56%. In Roshini et al[11] and Davis et al[4] malignancy was reported as the most common indication for stomas, at 69% and 73% respectively. These percentages of patients with malignancy as indications for stoma construction were higher than the present study.

The overall QoL score among the stoma patients in this study was 3.64±0.46. In Davis et al[4] in Puducherry India, the overall QoL score was 4.13±1.07. Raffiei et al[14] and Jayarajah et al[13] reported mean overall QoL as 4.4±0.7 and age as 53.07±12.68 (range 18-82) respectively.

The mean overall QoL score in the study conducted by Zewude et al[16] in Ethiopia was 7.42±0.53, higher than the present study. The QoL scores in the study conducted in Ethiopia may be due to better health facilities for the stoma patients. The low QoL scores among the stoma patients in the present study can be partly attributed to the lockdown due to COVID-19,

Table 7a. Association between QoL and key demographic variables (N=100).

Variables	Mean	r value	P value
Age	43.79±16.39	-0.06	0.50
Weight	55±10.48	-0.03	0.75

Table 7b. Association between QoL and other demographic variables (N=100).

Variables	QoL	P value
Type of stoma		
Temporary	3.65±0.49	0.610
Permanent	3.59±0.48	
Diagnosis lead to stoma		
CA	3.71±0.55	0.077
Non-CA	3.54±0.42	
Gender		
Male	3.57± 0.44	0.237
Female	3.68± 0.54	
Marital status		
Single	3.68±0.61	0.493
Married	3.60±0.45	

Table 7c. Association between QOL and stoma variables (N=100).

Variables	F-value	P-value
Kind of ostomy Urinary diversion Colostomy Ileostomy	3.78	*0.026
Duration with ostomy <1year 1-2Year >2year	0.42	0.658

Table 7d. Association between QoL with other stoma variables (N=100).

Variables	QoL	P-value
Problems with the location of stoma		
No	3.83±0.67	
Yes	3.55±0.40	*0.018
Changed clothing style due to stoma		
No	3.94±0.71	
Yes	3.54±0.39	*0.001
Adjusting of diet due to ostomy		
No	3.86±0.77	*0.011
Yes	3.55±0.366	
Change in diet to prevent passing gas in public		
No	3.76±0.71	*0.035
Yes	3.55±0.40	

Table 8. Correlation between QoL and problems faced by stoma patients during the COVID-19 pandemic (N=100).

Domains of problems faced by stoma patients during COVID-19	r-value	P-value
Physical	-0.0018	0.9855
Financial	-0.3177	*0.0013
Mental	-0.5936	*0.0001
Social	0.3221	*0.0011

which reduced accessibility of health care services for stoma patients, including consultations with healthcare providers, unavailability of stoma care supplies and loss of contact with the ostomy society members.

The mean of QoL scores in various domains in the present studies were: physical (4.40±0.63), psychological (3.81±0.69), social (2.62±0.73) and spiritual (3.88±0.64). Davis et al's[4] study in India reported mean QoL scores as: physical (5.68), psychological (3.85), social (2.85) and spiritual(4.32), Rafiei et al's[14] Iran study reported mean QoL scores as: physical (5.7±0.8), psychological (4.2±0.7), social (3.2±0.7), and spiritual (4.7±1.1). Similar patterns of highest scores in the physical domain, and lowest scores in the social domain were found in the present study. While Roshini et al's[11] Indian study, reported the QoL mean scores (not using a Likert scale) as physical (70.82±15.96), psychological (66.73±17.92), social (50.82±18.84) and spiritual (34.75±9.37) where highest score was in physical domain, followed by psychological, social, and least in the spiritual domain.

Zewude et al[16] in Ethiopia reported mean QoL mean scores as: physical (7.34±0.58), psychological (7.47±0.60), social (7.10±0.51), and spiritual (7.77±0.51). The QOL scores in this study are higher as compared to the present study. In the present study the lowest score was in the social domain. The lowest score in the social domain in our study may be attributed to lockdown, social distancing due to pandemic situation, and not able to meet the ostomy support group members.

The change in occupation due to ostomy was reported among 10% of stoma patients in our study, whereas by Davis et al[4] in Puducherry reported 67% of their study participants had change in occupation due to ostomy. In our study about 74% stoma patients were not working, therefore did not require change in occupation. Similarly, Irshad et al[17] also reported only 34.8% of stoma patients were working, others were on bed rest after construction of the stoma.

Most, 63%, of the stoma patients in the present study reported that they were sexually active before the stoma construction, 50.8% had since resumed sexual activity. Similarly Zewude et al[16] reported a majority, 78%, being sexually active before construction of and only 34% resumed the sexual activity after stoma construction. These results are not consistent with Davis et al,[4] where it was reported that 62% stoma patients were sexually active before stoma construction, and only four members resumed sexual activity after ostomy. Jayarajah et al[13] in Srilanka reported that only nine patients resumed sexual activity after the construction of the stoma. In the present study none of the patients reported satisfaction with the sexual activity and similar findings are reported in the study, conducted by Zewude et al,[16] where only two patients reported being satisfied with sexual activity after stoma construction. This finding may be attributed to the lack of counselling for the stoma patients in sexual-related aspects, as well as lack of appropriate counselling and training on sexual concerns of the stoma patients.

After the construction of the stoma all the patients in the present study reported being depressed. Most participants were reported to be depressed in Irshad et al[17] and Zewude et al[16] at 72% and 58% respectively. Mungai et al[18] also found the majority of stoma patients reported being depressed. The prevalence of depression after the construction of the stoma may be due to body image disturbance, fear of not being accepted by family and society, loss of control over the body functions.

In the present study all participants belonged to the Indian Ostomy Society. This finding was inconsistent with other studies[4,16] where it was reported that none of the stoma patients in their study belonged to an ostomy society or support group. Self-help and ostomy society groups can help stoma patients improve their overall QoL, and specially in the social domain. In our study the social domain score was low, this is possibly attributable to not being able to meet with ostomy society members, and not being able to visit the stoma clinic regularly due to the COVID-19 constraints, and also the high prevalence of fear among stoma patients of being infected while seeking professional help.

In the present study 79% stoma patients adjusted their diet and 66% changed their diet to prevent passing gas in public. It was also found that 82% of the stoma patients had changed their style of clothing after construction of their stoma. These finding are consistent with the findings of other research studies.[4,16] The change in diet to prevent passing gas in public may be attributed to fear of bad odour, embarassment and not being accepted by people. The change in the dressing style may be to cover the stoma pouch, which is the factor for disturbed body image and acceptability in the society.

Living with an ostomy is very challenging. There are various problems faced by the stoma patients. In all the domains (physical, psychological, social and spiritual) stoma patients encounter various difficulties like adapting to oneself with a stoma, body image disturbances, social stigma, feeling depressed feelings, sexual problems, fear of the recurrence of the disease condition and problems with travelling. Sylvia vonk-Klaassen et al[19] conducted a systematic review and reported that living with ostomy had an impact on overall QoL. Sexual issues, gas, constipation, unhappiness with looks, travel difficulties, feeling depressed, fatigue and fear were among ostomy-related issues identified by stoma patients.

During the COVID-19 most (98%) of participants in our study faced physical problems like leakage and peristomal skin problems. 87(87%) required professional help for the stoma care. Of these 87, only 8(9%) were able to contact their health care provider. This was due to the fear among the stoma patients of being infected by COVID-19 when seeking the professional help. As evidenced by the findings of the study 78 of the 97 (81%) avoided seeking professional help sometimes, 11 (11%) always avoided and 8 (8%) did avoid seeking professional help. Multiple reasons for not meeting with health care providers included the lockdown situation in the country,

sealing of the geographical borders, the need for compulsory COVID screening before visiting health care facilities, as well as the focus of health care providers on emergency services. A study conducted by Spencer et al[20] reported that 57% of ostomy end-users in the United States and the United Kingdom had experienced peristomal skin concerns and 84% of ostomy end-users reported not notifying a health care provider about their concern. In addition, 52% were unaware of the virtual mode (telehealth), as alternative for their care.

Most stoma patients in out study (95%) had to buy stoma care products from market which added to the financial burden of stoma care. The financial burden was due to the unavailability of the stoma care appliances at subsidised rates. The social lives of 83% of the stoma patients were affected to great extent, for 17% to some extent during COVID-19. None of the ostomy patients were able to meet the ostomy society members as Ostomy Society meetings were not held due to the pandemic.

Burch's review of stoma care services[21] during COVID-19 in the United Kingdom (UK) identified many stoma patients raised concerns regarding availability of stoma products. While identified as a potential problem very few patients in the UK encountered delays in obtaining stoma products. Reassurance, however, for ostomates was reported to be more necessary and important post COVID-19 pandemic.

Nozawa et al[22] reported that the percentage of people who visited a stoma clinic within a year of their stoma construction increased from 50% in 2019 to 54% in 2020. But it was also reported that visits by other stoma patients reduced during this time.[22]

Sufficient studies were not found related to the problems faced by stoma patients during the COVID-19 pandemic, therefore no other comparative discussion is possible at this stage.

CONCLUSION

The overall QoL of the stoma patients in this study was 3.64±0.46. This study showed that having a stoma affected patients' physical, social, psychological and spiritual life. The problems faced by stoma patients during COVID-19 included delayed contact with health care providers and ostomy society members, withdrawal from society and increased financial burdens due to directly purchasing stoma care supplies.

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CONFLICT OF INTEREST

The authors declare no conflict of interest for this study.

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