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Original Research Article

Quality of life assessment in stoma patients in a tertiary care hospital in South India: a cross- sectional study

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ABSTRACT

Background: Quality of life (QOL) of patients is affected due to procedures done to treat the disease. A good QOL is essential to achieve a holistic approach in treating patients.
Methods: We did a cross-sectional study in a tertiary care hospital to describe, identify and compare the factors affecting the QOL of these patients.
Results: 42.5% had a permanent stoma and a majority 32.5% were due to a malignancy. Major concerns were skin rash and irritation, depression, loneliness and suicidal thoughts. 62.5% of the total had not gone to work after creation of a stoma. Malignancy was found to be a significant predictor of having a low QOL score.
Conclusions: Quality of life of stoma patients in present study was not ideal. There is a definite need to have support groups for these patients in all hospitals.

Keywords: Colostomy, Ileostomy Quality of life, Stoma patients

INTRODUCTION

Ostomy is a surgery performed for management of bowel dysfunction due to various causes. Therapeutic procedures treat the disease but affect the Quality of life (QOL) of patients. WHO defines QOL as an individual's perspective of his/her health status with respect to a few aspects- physical, psychological, economic, social and environmental.[1]

This surgery causes change in body image and influences the physical, mental, emotional, and social life of the stoma patients significantly. A good QOL is essential to achieve a holistic approach in treating our patients. Support groups are readily available for helping such patients in the western countries but lacking in India.

A study was done in China using the Stoma-QOL, stoma self-care agency scale and Herth Hope Index. They found that their patients had difficulties in work and social situations. They also had concerns about sexuality, body image and concerns about the stoma itself.[3]

Long term effects on quality of life of members of United Ostomy Association of America after 5 years of ostomy surgery was assessed using a questionnaire. They reported that longer the time after the diagnosis and surgery, were more likely to feel better.[4]

Iranian Ostomy society patients showed that factors such as depression, the type of ostomy, the underlying disease that had led to the stoma, depression, dissatisfaction with sexual activities, problem with location of ostomy and change in clothing style affected the Quality of Life.[5]

Geraldo et al looked at the quality of life and self-esteem in patients with intestinal stomas in the Ostomized People's Pole of Pouso Alegre using 3 scalesquestionnaire on demographics and stoma, Rosenberg Self-Esteem Scale/ UNIFESP-EPM and Flanagan Quality of Life Scale. Results showed that most participants were older than 60 years of male gender and attended support groups. Neoplasia was the most common cause that led patients to receive an ostomy.[6] To the best of our knowledge, there is only one study done in India which looked at QOL in patients with temporary stoma.[7]

The QOL of all stoma patients, both temporary and permanent has not been addressed. And, therefore, this study aims to identify factors influencing QOL and to come up with recommendations to help patients with stoma to improve their QOL. The objective of the study is to describe, identify and compare the various patient factors affecting the QOL among stoma patients at a tertiary care hospital in South India.

METHODS

For this purpose, we conducted a cross-sectional study with consecutive sampling. All patients, both males and females, aged 18 years and above with a stoma were included from the stoma clinic of a tertiary care hospital. Patients with conditions that prevented them from understanding and answering the questionnaire (e.g.- dementia), were excluded. A total of 40 patients with a stoma were recruited into the study, after taking consent, over a period of 1 month.

A stoma specific, validated Beckman Research Institute questionnaire was administered which had 3 parts - Part I dealt with demographic data; Part II dealt with 50 open and close ended questions on factors affecting QOL; and Part III dealt with a 10-point scoring scale in 4 main domains (physical health, psychological health, social and spiritual) for the QOL score.[8]

Descriptive and inferential statistics were analyzed based on the objectives in terms of frequencies, percentage, mean, and Chi-square and t-test. Regression analysis was performed to look at influence of various predictors on QOL. All statistical analyses were performed using SPSS V 20.

RESULTS

Patients age ranged from 18 to 80 years, with the mean age being 43.9±16.23 years. 32 (80%) were males and 8 (20%) were females. 5 (12.5%) had diabetes mellitus, 1 (2.5%) had hypertension, 3 (7.5%) had both hypertension and diabetes and 1 (2.5%) had ischemic heart disease. 26 (65%) were married and 14 (35%) were single. 22 (15%) had a colostomy and 18 (45%) had an ileostomy. 17 (42.5%) had a permanent stoma. 13 (32.5%) were due to a malignancy with colorectal carcinoma accounting for 9 (69.2%) (Figure 1). 17 (42.5%) were daily wage workers with a per capita income of 10,675 rupees. 87.5% of our patients had received formal education and 14(35%) belonged to Class III Socio-economic status of B G Prasad scale (Figure 2).

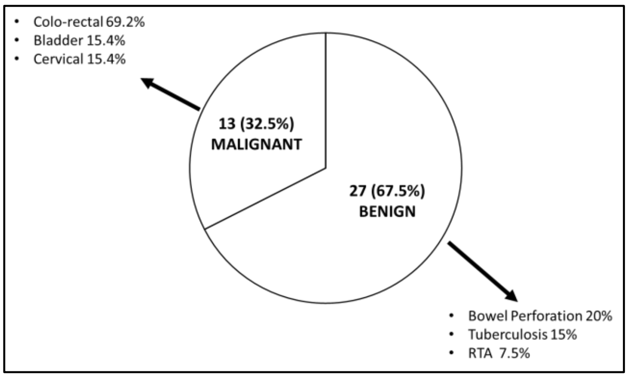

Figure 1: Underlying disease that had led to an ostomy.

25 (62.5%) have had a stoma for <6 months and 15 (37.5%) have had a stoma for ≥6 months. 22 (55%) of the patients had changed style of clothing and 26 (65%) had a disturbed sleep, both due to location of stoma.

19 (47.5%) of the patients found it difficult to do their activities of daily living. A majority, 25 (62.5%) are not working due to the stoma. 26 (65%) of them found it awkward to be with outsiders and all of them felt that they were a burden to their family.

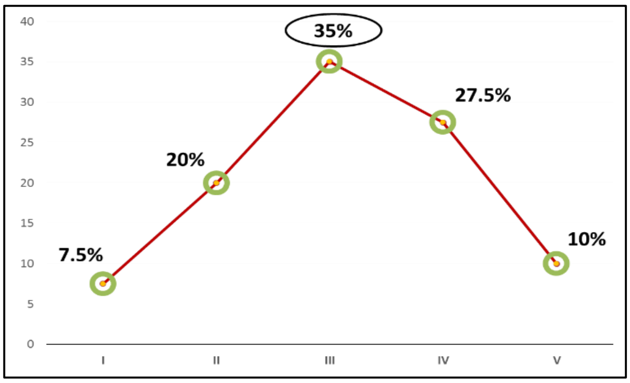

Figure 2: Socio-economic status (BG prasad scale).

They felt lonely and were depressed. 8 (20%) of the also had suicidal thoughts. 25 (65%) patients complained of concerns regarding skin rash & irritation and 24(60%) had issues with stoma leak, smell and noises.

The mean time taken for daily stoma care is 12.65±8.40 mins. Our patients change the pouch once in 6.05±3.10 days and mean cost of the pouch is 316.12±164.38 rupees. The mean distance that a patient has to travel to meet a stoma nurse is 72.88kms.

A chi square test revealed that abdominal pain, clothing and difficulty to hide the pouch was significantly different between males and females ($p<0.05$) (Table 1).

Suicidal thoughts, avoidance of travelling, feeling tired during the day, need for privacy to clean the pouch were significantly different between patients having a stoma for <6months and >6months (p<0.05) (Table 2). 3 (11.1%) and 5 (18.55) of patients having a stoma due to a benign cause went back to working full time and part time, respectively whereas none of the patients who have had a stoma due malignancy went back to work at all (Table 3).

Table 1: Comparison between gender and factors affecting quality of life.

Factors		Male	Female	P value (<0.05)
Abdominal pain	Yes	6 (18.8%)	6 (62.5%)	0.025
	No	26 (81.3%)	3 (37.5%)	
Clothing	No change	17 (53.1%)	1 (12.5%)	0.048
	Limits and changes clothing	15 (46.9%)	7 (87.5%)	
Difficult to hide pouch	Yes	13 (40.6%)	7 (87.5%)	0.044
	No	19 (59.4%)	1 (12.5%)	

Table 2: Comparison between duration of stoma and factors affecting QOL.

Factors		≤6Months	>6 Months	P Value (<0.05)
Suicidal Thoughts	Yes	0 (0%)	8 (29.6%)	0.037
	No	13 (100%)	19 (29.6%)	
Feel tired and need to rest during the day	Yes	6 (25%)	10 (62.5%)	0.025
	No	18 (75%)	6 (37.5%)	
Avoid Travelling	Yes	2 (22.2%)	21 (67.7%)	0.023
	No	7 (77.8%)	10 (32.3%)	
Need to find privacy to clean pouch	Yes	2 (22.2%)	22 (71%)	0.018
	No	7 (77.8%)	9 (29%)	

Table 3: Comparison between diagnosis and working status.

Factors		Benign	Malignant	P value (<0.05)
Work Status	Full Time	3 (11.1%)	0 (0%)	0.004
	Part Time	5 (18.5%)	0 (0%)	
	Not working due to stoma	18 (66.7%)	7 (53.8%)	
	Retired	1 (3.7%)	6 (46.2%)	

The mean QOL scores of the patients in the 4 domains is shown in Table 4. Univariate analysis for predictors of a low physical domain score revealed female gender and malignancy as diagnosis had a p-value<0.2, and were considered for multivariate analysis (Table 5).

Table 4: Mean quality of life scores in 4 domains.

Domain	Total score	Mean score
Physical	110	70.82±15.96
Psychological	130	66.73±17.29
Social	110	50.82±18.84
Spiritual	60	34.75±9.37

Only malignancy was a significant predictor of a low physical domain score (Adjusted odds ratio=0.168, p=0.025). On analyzing the predictors of the low psychological, social and spiritual domain scores, multivariate analysis could not be performed as the p values in univariate analysis was not <0.2 (Table 6).

Table 5: Predictors of low physical domain score.

Factors	Odds ratio (p-value)	Adjusted odds ratio (95% CI)	P-value
Female	0.25 (0.130)	0.239 (0.037-1.52)	0.129
Malignancy	0.17 (0.024)	0.168 (0.035-0.796)	0.025
Lesser duration	1.23 (0.744)	-	-

DISCUSSION

Constructing a stoma is a surgical procedure that is undertaken for a number of conditions, such as bowel perforations, intestinal obstruction, mesenteric ischemia, neoplasia, inflammatory bowel diseases. Patients with a stoma have to learn to adjust to the stoma bag, into which faeces collects, which has to be emptied manually every day. A majority of our patients were married, implying that they had a support system. Most of our patients were daily wage workers and found it difficult to work after the ostomy surgery. Malignancy (32.5%) was the most common cause of doing an ostomy, which was consistent with the other studies.[1]

Table 6: Predictors of low psychological, social and spiritual domain score.

Factors	Psychological domain score	Social domain score	Spiritual domain score
	Odds ratio (p-value)		
Female	1.88 (0.43)	0.88 (0.87)	0.88 (0.87)
Malignancy	0.79 (0.73)	0.68 (0.57)	2.81 (0.14)
Lesser Duration	0.80 (0.74)	1.45 (0.56)	0.94 (0.93)

Many of our patients reported a limitation in physical activity after their ostomy. They also have not resumed going to work after disease onset and their ostomy, and this had affected their income. Moreover, stoma care costs, like buying bags and gloves, had caused further financial problems.

We found, in present study, certain factors were significantly different between patients having a stoma for <6months and >6months. El-Tawil et al found that participants in the group with a longer elapsed time after diagnosis were more likely to feel better (p=0.042).[4] The mean time taken by our patients to adjust (diet, stoma care, clothing) to the stoma and stoma care is 4.08±2.23 weeks while previous studies have shown that the time to adapt to the stoma is 24 weeks.

Major concerns of our stoma patients were stoma related problems such as skin rash and irritation and leakage, difficulties in social and family interactions. Our results are in contrast to previous studies, which reported that issues regarding sexual activity was the most commonly cited problem.[9] This may be due to the cultural differences between study populations which may result in differential reporting of stoma-related concerns.

Some participants expressed a preference to avoid any family gatherings because of fear of offensive gas emission, fullness and smell. Collet et al suggested that poor psychological adjustment to stoma surgery has been shown to correlate to depression and predict death later on.[10] Location of the stoma also forced our patients to change the style of clothing, which itself reduced their quality of life. Iranian Ostomy Society patients reported that change in clothing style had significant effects on overall QOL and its subscales ($P < 0.05$).[7] Abdominal pain, clothing and difficulty to hide the pouch were some of the factors which were significantly different between males and females ($p<0.05$). This is because women are more conscious and were worried about their body appearance. We also found that lesser the duration of the stoma, lesser will be the scores in the 4 domains.

Aditi et al, assessed the quality of life of ostomates in a selected hospital of Delhi with a view to develop Guidelines for the health professionals and found that there was a significant association between QoL score of Ostomates with age, sex, duration of surgery, education, income, and occupation.[11]

The Montreux Study revealed that patients who had a good relationship with the stoma care nurse and felt confident about changing the appliance had significantly higher Stoma Care Quality of Life Index scores than those who did not have a good relationship or feel confident.[12]

Chunli Lioa et al found that improvements in health care professional team relationship with the patient and inspiring hope in patients played an important role in bettering their stoma-QOL.[3] 95% of our patients were not aware of any support groups whereas other studies showed that more than 50% of their patients were members of an ostomy-specific support group.[13]

Our hospital has a trained stoma nurse, who teaches the patients on stoma care once after the ostomy surgery. There is no sustained counselling done for the patients. Ostomates of India, is a support group for ostomised patients in India. But as most of our patients belong to a lower socio-economic status, they do not seek professional help in psychological counselling. And therefore, it becomes necessary to sensitize clinicians and stoma nurses to provide some form of in-house support in counselling.

CONCLUSION

Authors found that the Quality of Life of stoma patients in our study was not ideal. Counselling and rehabilitation of patients requiring a stoma, irrespective of it being temporary or permanent must be given importance in our clinical practice. Authors recommend that support groups have to be formed in all individual hospitals treating stoma patients. Authors intend to form a support group in our hospital to offer pre-and post-counselling and financial support to ostomised patients and their families.

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