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A cross sectional study of quality of life in patients with enterostomy

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ABSTRACT

Background: Enterostomy is one of the commonest surgeries performed in general surgical practise. It leads to considerable alteration in life style of patients after surgery in the form of physical, mental, social, spiritual, economic, educational, vocational, marital, sexual problems. We designed study to assess the extent of these affections on quality of life (QOL) and suggest measure to improve it.

Methods: We conducted a cross sectional survey using validated City of Hope-quality of life-Ostomy questionnaire questionnaire which was administered to patients following up for routine stoma care in stoma clinic of our hospital. We included patients who have undergone stoma creation between 2 months to 1 year prior to taking the QOL questionnaire. Demographic data and data collected about four main domains of QOL namely, physical, psychological, social and spiritual was statistically analysed for significance, dependence and correlation.

Results: Commonest stoma type in our study was temporary ileostomy done for perforative peritonitis. Presence of ostomy makes significant impact on patients clothing style, occupation and sexual activity and suffered depression. Majority of patients (82.5%) fell in fair to average when their scores of QOL were compared. All four domains of life correlated positively to each other.

Conclusions: As all domains of life are related to each other intervention to improve any one of them will cause resultant improvement of all domains of QOL. We suggest holistic approach by pre and postoperative counselling, training by trained enterostomal therapists, psychiatrist, treating surgeons and economic and sexual rehabilitation.

Keywords: Enterostomy, Quality of life, Domains of life, City of Hope QOL ostomy questionnaire

INTRODUCTION

Enterostomy is one of the commonly performed operation in surgical practice for varied indications like perforative peritonitis, ischaemic or inflammatory bowel disease, trauma and malignancy. It can be both temporary or permanent. Creation of ostomy results in bypassing sphincters and loss of voluntary control of bowel movements which necessitates use of external pouch appliances to collect excreta. 1.2

Patients with ostomies need to spend a considerable amount of time and money for its maintainance and care. Patients with proximal enterostomies have to face significant nutritional consequences. Thus creation of stoma leads to various physical, psychological and social problems having impact on lifestyle of patients. Altered perception of body image, diminished self-esteem, sexual dysfunction, marital problems, vocational and educational instability. Patients are anxious about leakage and odour from ostomy and they need frequent privacy and facility for stoma care outdoors; hence they may

avoid social interactions. Many of these patients may have to change or leave job. Moreover maintenance related cost like buying stoma appliances, gloves and other stoma care products pose further financial burden. Thus these patients have to face profound lifestyle issues.

According to World Health Organisation quality of life is defined as "the individual's perception of their position in life in context of the culture and value system in which they live and in relation to their goals". Thus its patient perceived and reported feeling of general well-being outlining positive and negative features of life related to physical health, family, education, employment, wealth, religious beliefs etc. Overall good quality of life (QOL) is essential component of good health as health is not merely an absence of disease. Health related QOL is an indicator of unmet needs and an measure of health related interventions.4 Questionnaire is an assessment tool of QOL which is classified as psychometric tool and it attempts to quantify a range of symptoms, behaviours and feelings by rating individual items and assigning summation score.⁵ Such tools can compare many different groups of individuals on a functional continuum and detects changes in attitude, feelings and perceptions regarding certain intervention.

Tool we used is a standardised and validated questionnaire- City of Hope Quality of Life Questionnaire. This questionnaire has two components. First component has 47 forced-choice and open ended questions related to socio- demographic parameters like age, sex, religion, marital status, work related, health insurance related, psychological support groups related and about diet and clothing. Second part of questionnaire contains 43 QOL items to be reported using 10 point scale. This QOL questionnaire is divided into four domains of well-being; namely, physical, psychological, social and spiritual.

This study aims at assessment of QOL in patients with enterostomy and factors influencing QOL. Thus we may suggest some measures in management to improve QOL of these patients.

METHODS

This is a cross sectional observational study conducted at surgery department of a tertiary care medical college hospital after institutional ethics committee approval. Study was conducted from June 2017 to September 2017 for a total duration of 4 months at stoma follow up care unit of King Edward Memorial Hospital, Mumbai.

Sampling method used was 'complete enumeration technique'. A total of 80 patients participated in study who were at least 18 years of age. Patients who have undergone stoma creation surgery between 2 months to a year earlier were included in study and those outside this time period of 2 months to one year were excluded. The

reason for selecting this time frame was that prior to 2 months QOL may have influence of patient's primary pathology for which stoma was created, may have influence of surgery or its complications. And after 1 year patients may have naturally improved QOL due to adaptation to stoma. Patients with psychiatric conditions and other debilitating chronic conditions having significant impact over QOL were excluded for obvious reasons.

All patients satisfying inclusion criteria were given detailed information about the study and the questionnaire to be answered. Those who were willing to participate freely, informed consent was obtained. Patients undertook questionnaire during their routine follow up visits to the stoma clinic. Literate patients undertook questionnaire themselves either in English, Hindi or Marathi. Assistance if required for interpretation of questions was provided by investigating team members. Adequate time, privacy and comfort were made available to patients undertaking questionnaire. For illiterate patients questionnaire was administered by one of study team members.

Data collected from City of Hope QOL Questionnaire was entered in Microsoft Excel Sheets. Quantitative and qualitative data such collected was analysed statistically for significance and correlation using ANOVA, Pearson correlation and independent sample test.

RESULTS

A total of 80 patients with stoma were studied of which 57 (71.25%) were males and 23 (28.75%) were females. Ileostomy was the most commonly performed stoma in 67 (83.8%) of patients compared to colostomy in 13 (16.3%) patients. Majority of patients in the study had temporary stomas 70 (87.5%) compared to permanent stomas 10 (12.5%)

Most common indication for stoma in our study was perforative peritonitis in 44 (55.8%) of cases followed by ischemic bowel disease 10 (12.5%) and some other less common indications like small intestinal obstruction 7 (8.8%), sigmoid colon perforation 7 (8.8%), carcinoma rectum, necrotising pancreatitis with colonic fistula, small bowel mass.

Most of the patients interviewed between 3 to 4 months after stoma creation 57 (71.3%). Most patients, 64 (80%) were married whereas 15 (18.8%) were unmarried and one patient was widowed. Out of total of 80 patients exactly half, that it, 40 patients were working full time prior to enterostomy and 40 were not working (7 retired and 33 were unemployed). Of the 40 patients who were working full time 22 left the job after surgery due to problems related to stoma.

37 (46.3%) patients were sexually active prior to enterostomy and 41 (51.3%) were not active. 2 patients

did not answer to this question. After surgery only 25 (31.25%) patients resumed sexual activity of which only 8 (32% of those who resumed sexual activity) had satisfactory sexual life and the other 17 (68%) did not have satisfactory sexual life.

47 (58.75%) patients felt depressed after surgery compared to 30 (37.5%) who had no such feelings. And 3 (3.75%) patients preferred not to comment on depression question. One patient (1.25%) even attempted committing suicide.

Majority of patients 74 (92.5%) had changed their style of clothing and only a minority of our study population that is 12 (15%) patients adjusted their diet post stoma creation. More than 90% of patients spend 1hour or less for stoma care.

Mean scores in physical psychological, social and spiritual domain was 43.86, 71.22, 55.51 and 43.41 respectively (Table 1). Findings of application of Pearson Correlation test to these results in order to examine dependence are presented in Table 2.

Table 1: Distribution of scores of each domains of life.

	Physical	Psychological	Social	Spiritual
Mean	43.8625	71.2250	57.5125	43.4125
Median	44.0000	71.0000	59.0000	44.0000
Std. deviation	6.03102	9.49480	8.70907	8.33582
Minimum	30.00	42.00	27.00	24.00
Maximum	57.00	101.00	81.00	64.00

Table 2: Correlation between scores in domains of life Pearson correlation.

		Age	Physical	Psychological	Social	Spiritual
	Pearson correlation	1	-0.090	-0.021	-0.195	-0.195
Age	Sig. (2-tailed)	-	0.426	0.856	0.084	0.084
	N	80	80	80	80	80
	Pearson correlation	-0.090	1	-0.260*	-0.431	-0.431
Physical	Sig. (2-tailed)	0.426	-	0.020	0.000	0.000
	N	80	80	80	80	80
	Pearson correlation	-0.021	-0.260*	1	0.585	0.585
Psychological	Sig. (2-tailed)	0.856	0.020	-	0.000	0.000
	N	80	80	80	80	80
	Pearson correlation	-0.034	0.040	0.471**	0.346	0.346
Social	Sig. (2-tailed)	0.764	0.724	0.000	0.002	0.002
	N	80	80	80	80	80
	Pearson correlation	-0.195	-0.431**	0.585**	1	1
Spritual	Sig. (2-tailed)	0.084	0.000	0.000	-	-
	N	80	80	80	80	80

Table 3: Type of enterostomy and scores in various domains of life.

What kind of ostom	y do you have?	Physical	Psychological	Social	Spiritual
	Mean	44.8462	76.6154	61.3077	42.6154
Colostomy	N	13	13	13	13
	Std. deviation	6.42711	13.41975	10.95738	11.13956
	Mean	43.6716	70.1791	56.7761	43.5672
Ileostomy	N	67	67	67	67
	Std. deviation	5.98328	8.26626	8.09755	7.77569
	Mean	43.8625	71.2250	57.5125	43.4125
Total	N	80	80	80	80
	Std. deviation	6.03102	9.49480	8.70907	8.33582

Table 3 shows scores in individual domains of life with respect to type of enterostomy. We found that scores in psychological domain of life were significantly higher in

patients with colostomy than ileostomy (p=0.024) and there was no significant difference in quality of life between patients with ileostomy and colostomy in rest of the domains of life (Table 4).

Table 4: Testing significance in scores in various domains of life in colostomy and ileostomy.

ANOVA table		F	Significance
	Between groups (combined)	0.410	0.524
Physical	Within groups		
	Total		
	Between groups (combined)	5.274	0.024
Psychological	Within groups		
	Total		
	Between groups (combined)	3.023	0.086
Social	Within groups		
	Total		
	Between groups (combined)	0.140	0.709
Spiritual	Within groups		
	Total		

Table 5: Total score-wise stratified grouping of sample population.

Quality of life	Scores	Frequency (%)
Poor	162-189	08 (10)
Fair	190-217	35 (43.75)
Average	219-245	31 (38.75)
Good	246-272	6 (7.5)

Table 6: Comparisons of scores in various domains of life in male and female.

	Gender	N	Mean	Std. deviation	Std. error mean
Dhygiaal	Male	57	45.1228	5.97635	0.79159
Physical	Female	23	40.7391	5.03819	1.05054
Dayahalagiaal	Male	57	69.9474	8.43340	1.11703
Psychological	Female	23	74.3913	11.31266	2.35885
Social	Male	57	56.4211	9.25231	1.22550
Social	Female	23	60.2174	6.61236	1.37877
Cninitual	Male	57	41.8070	7.46764	0.98911
Spiritual	Female	23	47.3913	9.18368	1.91493
Total wellbeing	Male	57	213.2982	18.75877	2.48466
Total wendering	Female	23	222.7391	23.64744	4.93083

Table 7: Testing significance of sex of patients to various domains of life.

Independent samples test		t-test for ed	t-test for equality of means			
		t	df	Sig. (2-tailed)		
Physical	Equal variances assumed	3.098	78	0.003		
Psychological	Equal variances assumed	-1.927	78	0.058		
Social	Equal variances assumed	-1.789	78	0.077		
Spiritual	Equal variances assumed	-2.830	78	0.006		
Total well being	Equal variances assumed	-1.887	78	0.063		

Maximum score possible of the city of hope QOL questionnaire was 430. The scores of patients participated were between 162 and 272 which was 37.67% and 63.25% of the best score possible. The median score was 217 which is only 50.46% of the best score possible (Figure 1). We stratified patients according to their QOL scores evenly into four groups as having good, average, fair and poor QOL (Table 5). About 10% patients had

poor QOL and 7.5% patients had good QOL whereas majority of patients (82.5%) fell into fair to average QOL group.

In comparison of each domain scores between males and females and applying independent sample test, we found that males have significantly higher scores in physical and spiritual domains of life (Table 6 and 7).

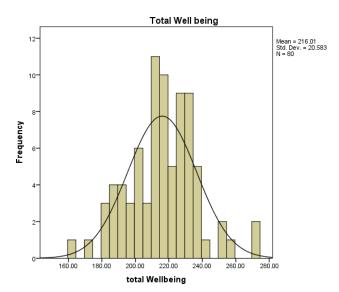


Figure 1: Distribution of total well-being or QOL scores.

DISCUSSION

Mean age of participants in our study was 42.65 years (range 16-75 years) and majority of patients were <40 years of age (56.25%) compared to >40 years of age (43.75%). This was consistent with prospective analysis of 640 emergency ileostomies conducted by Chaudhary et al.⁶ But it was lower than prospective audit by Arumgum et al who found mean age to be 65 years.⁷ A retrospective study by Sashir et al also showed mean age to be 58 years.⁸ A similar study in 2011 by Iranian Ostomy Society, mean age was 53.5 years.⁹

This difference in age distribution can be explained by the attributes of sample, as most of these studies focused mainly on purely permanent stoma or sometimes on purely temporary stomas. But our study included both permanent and temporary stomas.

Sex distribution in our study was similar to most of the studies including study by Iranian Ostomy Society.⁹

Most common indication for stoma creation in our study was perforative peritonitis as we had chosen 'complete enumeration' as sampling technique and our study site is a busy tertiary care medical college catering to a large population and provides emergency surgical services. It is interesting to note that it correlates well with other studies from Indian subcontinent where commonest indication is typhoid ileal perforation. In our study too, ileostomy was the most common subtype.

Majority of patients (22 out of 40 previously occupied means 55%) reported that they had to leave or change their occupation post stoma creation and this along with increased cost of stoma care products caused significant economic crisis and burden to patients which had direct negative influence on QOL of these patients. This is

consistent with study from Iran and China where 83.33% patients reported changing or leaving their jobs after enterostomies.^{8,9}

Effect of stoma creation on marital status was negligible. There were no incidences of divorce or separation post stoma creation. This may be attributed to Indian marital system and sociocultural values which Indian people adhere to.

As reflected from results about post-surgery sexual activity resumption and satisfaction from sexual life it is evident that ostomy is associated with lower rates of sexual activity, satisfaction and higher erectile dysfunction. Thus this sexual dysfunction causes negative impact on QOL. It may thus be prudent to refer these patients to professional counselling and training services about sexual health before and after stoma surgery. ^{10,11}

Though incidence of suicidal tendencies amongst these patients is low; incidence of depression is considerably high up to 58.75% in our study. It is similar to findings in study by Anaraki et al. Depression causes direct negative impact on psychological domain of QOL in these patients. And because as shown in this study as physical, psychological, social and spiritual domains are related and dependent on each other depression indirectly cause significant lowering of QOL of all other domains as well. Formal preoperative stoma education, counselling, creation and active involvement of these patients in stoma support groups, early reversal of temporary stoma, financial and vocational rehabilitation, early recognition and timely appropriate treatment are some of the measure we suggest to control this problem and effectively increase QOL in stoma patients.

In our study, about 60% of patients had problems with location of stoma. Post enterostomy 74% patients admitted to have changed their style of clothing for various reasons like location of ostomy, weight change, change in body appearance etc. But changing their usual clothing style reduced their QOL. This finding was similar to an Iranian study where about 40% of patients had problems with stoma location which could be due to poor placement, improper technique, development of hernia or leakage from stoma. To modify this problem and to improve QOL related to it we suggest thorough preoperative evaluation of patients body habitus, their routine clothing style and life style, judging their expectations and proper informed preoperative selection and marking of stoma site, as well as stoma training postsurgery for use of stoma care appliances.

Time spent daily on stoma care in our study (<1 hour) faired favourably to Iranian study (39 mins).⁸ But still it can be reduced further with resultant increase in QOL by stoma training.

Mean scores in physical psychological, social and spiritual domain was 43.86, 71.22, 55.51 and 43.41 respectively (Table 1). By applying Pearson Correlation

test to examine dependence of these domains we observed that (Table 2).

- Higher age did not correlate with higher scores in physical, psychological, social and spiritual domain of life.
- Higher scores in physical domain of life correlated with higher scores in psychological, social, spiritual domains of life which means patients with good physical health also did well in psychological, social and spiritual domains of life and vice versa.
- Higher scores in psychological domain of life correlated with higher scores in social and spiritual domains of life; means patients with good psychological domain score also did well in social and spiritual domain and vice versa.
- Higher scores in spiritual domain of life correlated with higher score in social domain and vice versa.
- Thus physical, psychological, social and spiritual domains of life are positively correlated to each other.

In our study, spiritual domain did not positively correlate in our study. This is in contrast to study carried out to determine influence of intestinal stoma on spiritual QOL of U.S. veterans wherein higher spiritual QOL was more likely in elderly.¹²

Thus improvement in any one of these domains would lead to improvement in all other domains. Thus we conclude that overall improvement in QOL can be achieved with holistic approach aiming at better scores in each one of these domains of life.

In our study we found psychological domain scores were significantly higher in colostomy patients compared to ileostomy. This is possibly because of solid colostomy contents, lesser chance of leakage, better adaptation to colostomy maintenance practise by patients, where as other domains were unaffected by type of stoma.

CONCLUSION

Thus a large proportion (82.5%) of our sample population fell in the fair to average QOL group strata (Table 5). This is our target population for interventions so that they can be upgraded to higher strata of QOL by improving their QOL further. And the interventions we suggest are holistic multimodal approach towards improving each of these four domains of life by proper pre and post-operative counselling, training and support by trained enterostomal therapists, treating surgeons, psychiatrists, psychosocial therapist, social worker as well as economic and vocational rehabilitation.

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Institutional Ethics Committee

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