Original Article

Quality of Life Assessment in Patients with Stoma in Muslim Population

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Objective: To assess the effects of stoma on the quality of life of Muslim patients.
Study Design: Questionnaire Survey.
Place and Duration: *Dept. of Generel Surgery, Pakistan Institute of Medical Sciences, Islamabad*
Materials and Methods: We developed questionnaire to address QoL issues to be studied in Muslim patients. This instrument was tested and retested and then 100 patients were studied to assess the influence of stoma on QoL of Muslim Patients with stoma.
Results: A total of 100 patients were studied with mean age 38.56(range 16-78 years) and male to female ratio of 3.54:1 Majority of patients (n=82) had ileostomy while 18 patients had colostomy. Majority (80 %) of stomas were due to infective causes, while 12 were for trauma and 8 due to malignant disease. Permanent stoma was fashioned in only 3 for malignant disease. Mean Prescore of 79.63 fell to a postscore of 55.79 (P value 0.000). Mean score of work and social function was 33.75, sexuality and body image was 39.45, stoma function was 7.56, financial concern was 34.50, skin irritation was 25.10, religious well being was 49.60.
Conclusion: Stoma adversely affects QoL in our population. QoL in religious matters is however relatively preserved, indicating a better counseling and control of religious leaders in Muslim community. This is probably because of poor management and counseling services provided to stoma patients in our community. standards of QoL in our population may be improved by proper education and management by stoma care nurses.
Key Words: Stoma, Quality of Life (QoL), ileostomy, colostomy, Muslim Population

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Introduction

Stoma is a surgical creation of an opening in the abdomen involving parts of either the gastrointestinal or urinary tract. Colostomy involves discharging feces from the large intestine, ileostomy from the small intestine, while urostomy means discharging urine through the surgical opening. Despite recent advances in surgery, in particular the development of restorative surgical techniques, formation of stoma is still sometimes necessary and at other times mandatory. Stoma brings a major change in physical appearance and bodily function and patients with stoma are challenged with a number of quality of life (QOL) issues. Traditionally, technical details were discussed in great detail about stomas but impact of stoma on a person's quality of life was ignored. Recently impact of stoma on quality of life is being increasingly recognized and studied.[1-6] Quality of life is increasingly becoming an important outcome measure in surgery. It is a multidimensional construct, representing an individual's subjective perception of physical, social and psychological well-being, as well as satisfaction with the balance between disease control and adverse effects of treatment [1-6]. A number of generic quality of life scales are available to assess the impact of disease on various aspects of a person's quality of life (QoL). The SF-36 and QLQ systems measure QoL within a range of domains, as well as providing an overall indication of QoL. The SF-36 is a generic measure of health status developed in the USA and can be used to measure health outcomes of clinical interventions.[7-8] The scoring method for SF-36 uses an algorithm to transform dichotomous and continuous variables into a scale from zero to 100, with higher scores indicating best possible health. In most of studies, SF36 short form and QLQ c30/cR38 have been used to determine the impact of stoma on quality of life.[9-12] The results obtained have lead to drawing controversial results.[13-14] It has long been felt that generic QOL instruments are deficient in assessing the impact of quality of life in stoma patients.[13-14] Another domain being ignored is personal hygiene and most religions emphasize on personal hygiene. QoL of a person with religious inclination may be adversely affected when stoma interferes with his personal hygiene and there is soiling of body and clothes. We

chose Muslim population to study the impact of stoma on the religious well being of a patient. We believe that SF 36 is a generic instrument which cannot incorporate unique domains influenced by stoma and QLQ c30/cR38 is for cancer patients. So impact of stoma in a religiously inclined society needs to be studied with its own unique quality of life scale. Islam has five pillars which make the foundation of the religion.[15] 1 Creed or shahada which is verbal commitment to enter the religion. 2. Giving alms or Zakat 3. Fasting especially in the month of Ramadhan 4. offering Pilgrimage to Makah or Hajj 5. offering the Prayers. Prayers have greater reward (27 times) if offered in Mosque along with other Muslims as a gathering or class or called Jamat. The pre-requisite of offering a prayer is to have Ghusal which means that Muslims should take a bath in a specified manner after sexual intercourse or ejaculation, otherwise they are not fit enough to perform religious activities. Even some believe that without proper ghusal they cannot socialize with righteous people[15]. Another pre-requisite before offering prayer or recitation from Quran (an Islamic duty of a Muslim) is wudhoo or ablution which means washing of some parts like hands up to elbows, face and feet and hair before offering a prayer. Passage of flatus needs wudhoo to be repeated. Stoma patients have no control over passing of flatus and there may be some soiling because of stoma which makes it mandatory to wash it, otherwise they are considered unfit to offer a prayer. It is difficult for a stoma patient to offer prayer in mosque in Jamat because the fellow Muslims offering prayer may react negatively on hearing the sound of flatus being passed. It may influence negatively on a person's well being not only in the discharge of his religious duties but also social wellbeing. The Ulema or scholars have passed a decree (Fatawa)[16] that a person with stoma needs not repeat wudhoo between two prayers(five prayers are offered in one day), no matter how many times flatus is passed till next prayer time. But fellow Muslims may not be aware of this fact. It is because of these reasons that we felt a different quality of life stoma scale be devised for Muslim patients which should asses not only the customary quality of life domains but also their religious well being.

Materials and Methods

After a thorough search of the literature.[1-14] We developed a quality of life scale which can be applied to Muslim patients. We call it "Quality of life scale for Muslim stoma patients" (QOLS-MSP). The scale is a questionnaire which contains 27 questions with intent to study 6 domains of quality of life in Muslim stoma patients comprising Work/Social Function, Sexuality/Body Image, Stoma Function, Financial Concerns, Skin Irritation and Religious Well Being. The questionnaire is given as table I. After approval from Hospital ethical committee, all patients enrolled were approached and consent was obtained.

Table I: Questionnaire

1. Stoma allows me to participate in the hobbies that I ----------
2. I can go out with my friends----------
3. My stoma interferes with my ability to work or attend school. ----------
4. Traveling or idea of traveling makes me worry because of my stoma.----------
5. I can enjoy sexual activity/ies. ----------
6. I feel myself attractive. ----------
7. My wife/sexual partner is bothered by my stoma.----------
8. Awareness of others about my stoma makes me worry/bothersome
9. I need privacy to empty my pouch and lack thereof makes me anxious/worrisome ----------
10. My clothing is comfortable despite stoma.----------
11. Although I have to adjust what I can eat but I am satisfied with my food/diet.----------
12. I have financial concerns regarding my ostomy supplies.----------
13. Stoma emits odour and I am concerned about it.----------
14. I am able to share my feelings and concerns about my ostomy with a family member or friend.---------
15. Stoma causes noises or fills rapidly because of gas causing embarrassment.---
16. Fear of leakage worries me----------
17. Skin irritation around and at the site of stoma is bothersome.----------
18. I am anxious in social gatherings.----------
19. I perform the same household and family duties.----------
20. I performed my prayers regularly before creation of stoma and recited Quran----------
21. I still perform prayers and recite Quran regularly----------
22. Fellow Muslims react negatively in Mosque during prayers other religious activities----------
23. I cannot perform prayers in Mosque ----------
24. I cannot hold ghusal or wudhoo----------
25. I can keep fast and would fast if required.----------

They were asked to score their quality of life on a scale from 0 to 100 over a one month period, preceding the formation of stoma, when they were otherwise healthy. The score in response to question 1

was labeled as Pre-score. Then question 2 was asked to rate the quality of life, in patients view, during the last one month after fashioning a stoma on a score of 0 to 100, when they had completely recovered from surgery and had no other disease. It was labeled as Post-score. Question 3 to 25 was scored on Likert-type 5-point frequency scale (Never 1, Seldom 2, Occasionally 3, Frequently 4, and Always 5). The questions asked either inquired a positive or a negative impact of a stoma on QoL. Impact of stoma was scored in a fashion that score of questions measuring negative impact of stoma was subtracted from the score of questions measuring a positive impact and it was divided by the number of total questions, measuring that particular domain and multiplied with 25 to bring the score between 0 and 100. Formulae to calculate score on Work/Social Function Scale, Sexuality/Body Image, Stoma Function, Financial Concerns, Skin Irritation and Religious wellbeing are given appendix 2.Patients will score between zero and hundred on this scale depending upon their level of satisfaction with the quality of life. Patient having maximum satisfaction with their quality of life after stoma will score 100 and zero means worst outcome.

The questionnaire was tested and retested and then applied on the patient population being studied. The study was carried out on a random sample of 100 patients who could be contacted from hospital records. To be eligible, patients had to meet the following inclusion criteria (1) no additional complicating or disabling disease that necessitated nursing help (e.g., mental illness), (2) at least 1 month follow-up from the time of surgery to entrance into the study, (3) no chemo-radiotherapy within the previous month, (4) no admittance to a hospital during the study period for any other reasons, (5) patient free of clinical evidence of disease

The questionnaire was worded in the language of the respondent according to his/her educational level. Patient's age, sex, type of stoma (ileostomy vs colostomy), etiology of the stoma (infective, trauma or malignancy), and marital status were recorded. Afterwards responses to questions 1 through 27 were recorded. Quality of life score was calculated with the help of Microsoft Excel. Then all these variables including age, sex, type of stoma(ileostomy vs colostomy), etiology of the stoma (infective, trauma or malignancy), marital status and scores of Sexuality/Body Image, Stoma Function, Financial Concerns, Skin Irritation and religious wellbeing were entered into SPSS 18 programme and various statistical tests were performed. P value of < 0.05 was considered significant.

Results

A total of 100 patients were studied. Age range was 16-78 years with mean age 38.56(Std D 13.89). There were 78 males and 22 females. Majority of patients (n=82) had ileostomy while 18 patients had colostomy. All ileostomies were temporary loop ileostomies. Majority of colostomies were also loop colostomies except three cases of end colostomy for malignant disease. Majority (80 %) of stomas were due to infective causes, while 12 were for trauma and 8 due to malignant disease. Out of 8 stomas made for malignant disease, 3 were permanent stomas. Majority of older patients had permanent stoma as given in table II. Majority of patients were married (n-94, while only six were unmarried. Some of the basic statistics of the various domains studied to gauge quality of life of stoma patients are given in table III.

Table II: Stoma type in relation to age and whether stoma is permanent or temporary

Stoma type			Whether stoma was permanent or temporary		Total
			Temporary	Permanent	
Ileostomy	Age	15-35	41		41
		36-55	37		37
		>55	4		4
	Total		82		82
colostomy	Age	15-35	3	0	3
		36-55	6	1	7
		>55	6	2	8
	Total		15	3	18

Discussion

Many patients require the formation of a surgical stoma each year, and some are permanent. Nonetheless, relatively little is known about the QOL of these patients from religious perspective or about modifiable factors that influence their QOL. Even less is known about the quality of life of Muslim stoma population. Certainly the general consensus has been that a stoma has a negative influence upon a person's quality of life.[1-6] Measurement of quality of life is necessary in order to determine the impact of a disease and its treatment on an individual's well-being.[17] In the western hemisphere most of stoma formations are secondary to either malignant disease or inflammatory bowel disease, so patients tend to score higher and report a better quality of life after surgery.[6, 11, 12-13 18-19] Despite an overall good QoL, colorectal cancer survivors have specific physical and psychological problems. [20] However in our country most of stomas are for benign disease fashioned as emergency, and majority are loop ileostomies. Typhoid is the commonest cause for ileal perforation which is seen in 63.8% patients, followed by intestinal tuberculosis 21.3% patients.[20-21] Construction of a temporary ileostomy to provide defunctioning for repair of ileal perforations reduces the incidence of fatal complications like faecal fistula. Ileostomy, however, is associated with a number

Table III Basic statistics of QoL domains studied

		Work and social function	Sexuality and body image	Stoma function	Financial concerns	Skin irritation	Religious well-being	Prescore	Postsscore
N	Valid	100	100	100	100	100	100	100	100
	Missing	0	0	0	0	0	0	0	0
Mean		33.75	39.45	27.56	34.50	25.10	49.60	79.6300	55.4900
Median		33.00	35.00	25.00	25.00	25.00	50.00	80.0000	50.0000
Mode		54	25[a]	33	0[a]	25	0	100.00	50.00
Std. Deviation		16.543	21.188	14.375	37.231	23.953	29.680	17.90697	23.26896
Variance		273.662	448.937	206.648	1386.111	573.727	880.884	320.660	541.444
Range		67	80	67	100	100	100	70.00	100.00
Minimum		0	0	0	0	0	0	30.00	.00
Maximum		67	80	67	100	100	100	100.00	100.00

Table IV: Paired Samples Test

		Paired Differences							
					95% Confidence Interval of the Difference				
		Mean	Std. Deviation	Std. Error Mean	Lower	Upper	T	df	Sig. (2-tailed)
Pair 1	Work and social function - Religious	-15.858	30.649	3.065	-21.939	-9.777	-5.174	99	.000
Pair 2	Sexuality & Body Image – Religious	-10.154	30.757	3.076	-16.257	-4.051	-3.301	99	.001
Pair 3	Stoma Function – Religious	-22.044	32.886	3.289	-28.569	-15.519	-6.703	99	.000
Pair 4	Financial Concerns – Religious	-15.104	46.134	4.613	-24.258	-5.950	-3.274	99	.001
Pair 5	Skin Irritation – Religious	-24.504	38.857	3.886	-32.214	-16.794	-6.306	99	.000
Pair 6	Prescore – Religious	30.02600	32.29350	3.22935	23.61827	36.43373	9.298	99	.000
Pair 7	Postsscore – Religious	5.88600	32.08097	3.20810	-.47956	12.25156	1.835	99	.070
Pair 8	Postsscore - Prescore	-24.14000	20.03634	2.00363	-28.11564	-20.16436	-12.048	99	.000

of ileostomy-specific complications. It is observed in our set up that defunctioning ileostomy has better outcome compared to all other surgical options in cases of ileal perforations.[20-21] However patients in our study have reacted adversely to stoma formation. In this study, as is quite evident from table II that mean pre-score of 79.63(sd 17.90) fell to a mean post score 55.49(sd 23.26) which was quite significant. (P value 000). A cursory view of the mean scores of three domains determining quality of life (Work and social function, Sexuality and body image and Financial concerns) suggests that subjective well being fell to one third of its level before surgery, while in two(stoma function and skin irritation) it dropped to one fourth of pre operative levels. Patients have scored best on the score of religious well being where scores dropped only to half of their prescore (49.60 sd 28.68).This is far below the average or mean score of the stoma patients in western population as Overall SQOLS score were 55 (SD 21.4) and 61(SD) 17.4) respectively. The sharp contrast was the difference in the score of financial concerns. In mayo clinic study[14] the score was 66(SD36.8) and 63(34.3), while in our study the overall score for both varieties of stoma was 34.50 (SD37.24). This all may be because of the reasons that probably the cost of colostomy bag and wafer is too high considering our socioeconomic status of the nation. One further reason may be the weather and type of job in our population. Most of our patients are engaged in heavy physical activity in hot climate leading to excessive sweating and extreme body flexion. It leads to frequent replacement of the costly bag. There is hardly any stoma nurse in any community in Pakistan available. The only available source of counseling and information is doctors. The time spent with the doctor is never appropriate to train a patient effectively about the use and care of stoma. Most of surgeries performed for the creation of stoma are performed in emergencies by junior surgeons and incidence of complications is quite significant.[20-21]

There is no time for the patients to make up their mind

and discuss it with psychologist, if available. The score of religious well being is relatively high near the score of overall QOL score in western population. In our study mean score of religious well being is 49.60 (SD29.680). This was contrary to our belief because we hypothesized that because Muslim patients will lose their feeling of effective hygiene necessary to perform religious rituals (ghusal/bath and wudhoo/ablution), they may feel themselves frustrated. To the contrary, religious well being was preserved with a statistically significant difference to other health related QoL domains (table III). This may be partly because of effective psychological counseling by the religious leaders. It further emphasizes that probably Muslim religious leaders better counsel their followers about religious matters and they have greater influence and control over the followers than doctors, nurses and psychologists. The same patients score worse with other domains of QOL standards like work and social function, sexuality and body image, financial concerns. The worst scores around 25 on skin irritation and stoma function emphasizes poor counseling and care provided to them by our health care system as shown in table III. A similar conclusion has been drawn by Nundy et al who suggest that patients in developing countries score badly in QOL issues probably because poor care and counseling available.[23] Another observation had been that in other studies there was a mix of patients. Some reported deterioration while others reported that their QOL improved with stoma especially those with ulcerative colitis and cancer. In our population no patient reported improvement in QOL. It may be partly because of the reason that in western countries most of stomas are fashioned for cancer and inflammatory bowel disease while in our population stomas are fashioned in emergency as unexpected outcome.[6, 11, 16 20-21] A very poor score in terms of skin irritation points towards an observation made by Agarwal S and Ehrlich A, that stoma related dermatitis is quite common but it is being ignored.[24] If same patients can score better on their religious score, they can score fare on other domains of QOL if properly counseled and managed by stoma care nurses.

Conclusion

Stoma adversely affects QoL in our population. QoL in religious matters is relatively preserved, indicating a better counseling and control of religious leaders in Muslim community. Poor QoL is probably because of inadequate management and counseling services provided to stoma patients in our community. By proper education and management by stoma care nurses, standards of QoL in our population may be improved.

References

1. Follick MJ, Smith TW, Turk DC. Psychosocial adjustment following ostomy. Health Psychol 1984;3:505–17.
2. Brennan JC, Steele RJC. Objective assessment of quality of life following panproctocolectomy and Ileostomy for ulcerative colitis. Ann R Coll Surg Engl 2001; 83: 321-324
3. Prieto L, Thorsen H and Juul K. Development and validation of a quality of life questionnaire for patients with colostomy or Ileostomy. Health and Quality of Life Outcomes 2005, 3:62
4. Walsh BA, Grunert BK, Telford GL, Otterson MF. Multidisciplinary management of altered body image in the patient with an ostomy. J Wound Ostomy Continence Nurs 1995;22:227–36.
5. Nugent KP, Daniels P, Stewart B, Patankar R, Johnson CD. Quality of life in stoma patients. Dis Colon Rectum 1999;42:1569–74
6. Pachler J, Wille-Jorgensen P. Quality of life after rectal resection for cancer, with or without permanent colostomy. Cochrane Database Syst Rev 2004:CD004323
7. Bowling A, Bond M, Jenkinson C, Lamping DL. Short Form 36 (SF-36) Health Survey questionnaire: which normative data should be used? Comparisons between the norms provided by the Omnibus Survey in Britain, the Health Survey for England and the Oxford Healthy Life Survey. J Public Health Med 1999; 21:255–270.
8. Gandek B. Translating functional health and well being: International Quality of Life Assessment (IQOLA) project studies of the SF-36 Health Survey. J Clin Epidemiol 1998;51:891–1214
9. Julie A. Cornish, Henry S. Tilney, Alexander G. Heriot, Ian C. Lavery, MD,3 Victor W. Fazio, Paris P. Tekkis. A Meta-Analysis of Quality of Life for Abdominoperineal Excision of Rectum versus Anterior Resection for Rectal Cancer. Annals of Surgical Oncology 14(7):2056–2068
10. Brennan J, Steele RJ. Prospective analysis of quality of life after reversal of a defunctioning loop ileostomy. Colorectal Dis 2002;4:167–71.
11. O'Leary DP, Fide CJ, Foy C, Lucarotti ME. Quality of life after low anterior resection with total mesorectal excision and temporary loop ileostomy for rectal carcinoma. Br J Surg 2001;88:1216–20
12. Kuz TO, Ucar K, et al. Effect of sphinctersacrificing surgery for rectal carcinoma on quality of life in Muslim patients. Dis Colon Rectum 2002;45:1359–66.
13. Lone Ross, Annemette G. Abild-Nielsen, Birthe L. Thomsen, Randi V. Karlsen, Ellen H. Boesen, Christoffer Johansen. Quality of life of Danish colorectal cancer patients with and without a stoma. Support Care Cancer (2007) 15: 505–513
14. Nancy N. Baxter, Paul J. Novotny, Therese Jacobson, R.N., Laurie J. Maidl, Jeff Sloan, Tonia M, Young-Fadok. A Stoma Quality of Life Scale. Dis Colon Rectum 2006; 49: 205–212
15. Penny S. Five pillars of Islam. In Discovering Religions Islam. London UK; Heinemann Education Publishers. 1999 14-15.
16. Abd Allah Abd-Alkalik Al Mishad, Chairman of Fatwa Commission of AL-AZHAR signed and issued on 8 Jumada 1, 1407, 8 January 1987and can be viewed on http://www.ostomyinternational.org/Fatwa.html
17. O'Boyle CA. Assessment of quality of life in surgery. Br J Surg 1992; 79: 395-8.
18. Brennan JC, Robert JC Steele. Objective assessment of quality of life following panproctocolectomy and Ileostomy for ulcerative colitis. Ann R Coll Surg Engl 2001; 83: 321-324

19. McLeod RS, Churchill DN, Lock AM. Quality of life of patients with ulcerative colitis preoperatively and postoperatively. Gastroenterology 1991; 101: 1307-1
20. Jansen L, Koch L, Brenner H, Arndt V Quality of life among long-term (5years) colorectal cancer survivors - Systematic review Eur J Cancer. 2010 Jul 3.
21. Siddiqui FG, Shaikh JM, Soomro AG, Bux K, Memon AS, Ali SA. Outcome of Ileostomy in the management of ileal perforation J Liaquat Uni Med Health Sci Oct - Dec 2008;7(3):168-72.
22. Safirullah, Mumtaz N, Jan MA, Ahmad S. Complications of intestinal stomas J Postgrad Med Inst Oct - Dec 2005;19(4):407-11.
23. Somashekar U, Gupta S, Soin A, Nundy S. Functional outcome and quality of life following restorative proctocolectomy for ulcerative colitis in Indians. Int J Colorectal Dis. 2010 Aug;25(8):967-73
24. Agarwal S, Ehrlich A. Stoma dermatitis: prevalent but often overlooked. Dermatitis. 2010 Jun; 21(3):138-47.