Quality of Life of Patients After Temporary Ileostomy for Ileal Perforation- A Questionnaire Based Study

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Abstract In India and some neighboring countries, ileal perforation is a leading indication for an emergent laparotomy, and making a temporary ileostomy is probably the safest practice for these patients with peritonitis. This apparently disfiguring surgery changes body image, and significantly influences physical, mental, emotional, and social life of the stoma patients. Further stress is added by the stoma related complications. The quality of life (QoL) issues of patients with temporary ileostomy for ileal perforations have not been addressed; hence, there is a gap in our

existing knowledge about the various factors affecting the quality of life of these patients. This study aimed at assessing the QoL in this particular group of patients with the help of an objective standardized proforma-based interview. Despite being limited by its small sample size, the study identifies important associations and provides a platform for further research to improve QoL of these patients.

Keywords Quality of life · Ileal perforation · Temporary ileostomy · Stoma complications

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Introduction

In Northern India, peritonitis due to ileal perforation constitutes one of the most common indications for an emergency laparotomy. Studies from this geographical region have found that a temporary ileostomy is probably the safest practice for patients of ileal perforation with peritonitis [1, 2]. Having recovered, patients are discharged with stoma and readmitted for closure of stoma at a later date. Several perceptions and concerns related to the stoma affect the quality of life (QoL) of the patient during the interval between the primary surgery and the stoma closure. This apparently disfiguring surgery causes change in body image and significantly influences the physical, mental, emotional, and social life of the stoma patients. Further, stress is added by the complications that may develop in relation to stoma. Stoma therapists are readily available for helping such patients in the western countries but not in a country like ours. The QoL issues in the patients who undergo ileostomy for ileal perforation have not been addressed, and there is a clear gap of knowledge about the factors affecting satisfaction of these stoma patients with their lives after temporary ileostomy.

The aim of the study was to assess QoL in patients of temporary ileostomy for ileal perforation with the help of an objective standardized proforma-based interview. The objectives were to study patients' level of satisfaction with their day-to-day life, effect of stoma on social life of patient, restrictions in physical activity, and to identify the common complications associated with temporary ileostomy. The study identified some significant associations and the need for dedicated stoma care personnel for the large number of patients requiring ileostomy at our institute.

Methods and Methodology

This study was a questionnaire-based interview conducted at a tertiary care teaching hospital in New Delhi after getting clearance from the ethical committee. The sampling technique was non-probability convenience sampling. All willing patients aged 16–60 years with temporary ileostomy for ileal perforation were included. Unwilling patients, patients with intestinal fistulae, and with permanent ileostomy were excluded from the study. A written informed consent was obtained from all willing patients after explaining the intention of the study with the help of a patient information sheet. Objective questionnaires were used and data was cross-sectionally collected by a single interviewer from patients following up in the surgery outpatient department. The questionnaire had two parts. Part 1 had questions related to demography, details of surgery, and complications related to ileostomy. Part 2a was a standard, structured, validated, and reliable objective questionnaire having 20 questions related to stoma QoL [3]. Part 2b was a standard, structured, validated, and reliable objective questionnaire having 36 items related to overall quality of life [4]. A stoma QoL score was calculated from part 2a. From part 2b, eight health scales, two health dimensions, and overall general QoL score were separately calculated. Results were drawn and associations were seen in between the demographic measures, scores of scales, health dimensions, and total scores to fulfill objectives of the study.

Observations and Results

A total of 40 eligible patients consented to participate in the research. The age of patients was between 16 and 60 years, with a mean age of 30 years. There were 29 males and 11 females. Around 85 % participants had never been to high school and 85 % belonged to poor- or low-income grade strata. The mean duration between ileostomy operation and time of interview was 19 weeks (range 4–102 weeks). The indications for ileostomy and the various types of ileostomies made in patients in this study are shown in Table 1.

The most common stoma-related complication seen was dermatitis/skin excoriation (90 %). Flatus and odor problem was reported by 57.5 % patients. The other complications seen in the study group are shown in Table 2. The major concerns of the patients related to stoma are shown in Fig. 1. The most common concerns were about staying away from home overnight, anxiety about stoma bag filling, or loosening and disturbed sleep.

The minimum observed score, maximum observed score, and calculated mean score of various scales of health dimensions, stoma QoL, and general QoL questionnaires are shown Fig. 2. Compared to the standardized average of 50, the mean general QoL score was 48 and the mean stoma QoL score was 52. Role physical (mean=19), role emotional (mean=22), and body pain dimensions (mean=40) were most hampered domains of life in our study group. The scores (score=worst <30, poor 31–50, good 51–70, best >70) of patients across various scales of health dimensions, stoma QoL, and general QoL have been shown in Fig. 3. Physical and social function scores were either good or best in 60–65 % of patients, and role physical and role emotional scores in majority were worst, as seen in Fig. 3. Role physical, role emotional, and body pain were the three domains of life in which more than 50 % of the patients had below average scores. Role physical and role emotional scores in 75 % of patients were below average. The mean score of females was less than the mean score of males in all important outcomes. Using the chi-square test, a significant association was found between the following:

- General QoL and stoma-related QoL (P value=0.000)
- Physical health and stoma-related QoL (P value=0.001)
- Mental health and stoma-related QoL (P value=0.000)

Duration of stoma at the time of interview was also significantly associated with the following:

- General QoL (P value=0.005)
- Stoma-related QoL (P value=0.039)
- Physical health (P value=0.010)
- Mental health (P value=0.001)

Discussion

In India and many other countries from Southeast Asia region, ileal perforation as a complication of conditions such as enteric fever, abdominal tuberculosis, and penetrating abdominal trauma constitutes the main indication for an emergent laparotomy that usually culminates into a temporary ileostomy [1, 2, 5]. These indications are unlike the developed world where most ileostomies are carried out to protect the rectal anastomosis after cancer surgery. Poor nutritional status, delayed presentation, presence of purulent

Table 1 Showing indication of ileostomy and type of ileostomy made

S No.	Ileostomy indication	No. of patients (%)	Ileostomy type	No. of patients (%)
1	Enteric fever	20 (50)	Loop	19 (47.5)
2	Tuberculosis	14 (35)	End	14 (35)
3	Bowel ischemia/gangrene	4 (10)	Divided loop/end with mucus fistula	7 (17.5)
4	Penetrating injury	2 (5 %)	-	-

peritonitis, and sepsis are few factors that make primary repair of perforation unsafe in patients of ileal perforation with peritonitis [1, 2, 5]. Typhoid and tuberculosis that remain public health problems in our country emerged as the main cause for ileal perforation in our study (Table 1) similar to that reported in other studies [1, 2, 5]. The conditions leading to ileal perforation were seen more in patients aged between 16 and 45 years (90 %, $n=36$), thus affecting the socially productive age groups. Eighty-five percent ($n=34$) participants had never been to high school, 85 % ($n=34$) belonged to poor or low-income grade, and 65 % ($n=26$) were semi-skilled or less in work experience. One may conclude that less educated people end up acquiring lesser skills, earn less and may be forced to live in conditions with poor sanitation facilities, unsafe water supplies, and low standards of food and personal hygiene that may expose them to diseases such as typhoid and tuberculosis.

The complications of a temporary ileostomy are governed by many factors including age, comorbidities such as obesity and diabetes, surgical technique, and surgeon's experience [1]. The reported incidence of various complications is from 5 to 100 % [1, 2, 6]. Peristomal skin excoriation or dermatitis is a seemingly minor but troublesome

common complication that may set in early and trouble the patient till stoma closure. The most common stoma-related complication in our study was dermatitis/skin excoriation (Table 2). In our experience, this is the most challenging complication to handle, occurs to some extent in almost all patients, and we are yet to find a perfect solution. The various reasons for development of dermatitis are leak of contents, poor fitting bag, aperture larger than stoma, badly chosen stoma site, inadequate stoma pout, and contact dermatitis due to the plastic material of the bag used [6]. Some of these can be minimized by preoperative planning of stoma site and improved surgical technique [6]. We follow a policy of applying disposable stoma bags immediately at the end of surgery. The bags that are changed meticulously by resident doctors in ward are seen to be associated with less excoriation. If the contents of bag seep under the edges of stoma bag excoriation sets in fast and then it becomes difficult to apply the subsequent bags. Switching over to reusable colostomy bags with straps does keep the bag in place, but it cannot prevent leakage. In fact, the straps can absorb the stoma contents by capillary action and then strap site also becomes excoriated. The problem may aggravate in patients after discharge when they are on their own to handle the stoma at home.

The other common reported problem was disturbing flatus and odor (57.5 %). The problem can be dealt with by modifying diet, avoiding green leafy vegetables, avoiding aerated drinks, using bags with odor filters, or using deodorants capsules in the bag [6]. The last two options are not viable in our setup because of nonavailability.

The main stoma-related concerns of the patients have been shown in Fig. 1. The reasons behind all these concerns were lack of knowledge, lack of self-confidence about handling the stoma, fear of stoma getting injured, and social taboo of having an "unusual thing on the body." Although we counsel the patients at the time of discharge, but the time given for these one-time sessions is probably inadequate. Most of these concerns can be addressed adequately with counseling by trained stoma care nurses or therapists who can help stoma patients by teaching practical skills in caring for their stoma [6, 7].

Quality of life (QoL) has been defined as "contentment with everyday life: the degree of enjoyment and satisfaction

Table 2 Showing stoma related complications seen in the study group

S no.	Stoma related complication	No. of patients(%)
1	Dermatitis	36(90)
2	Flatus and odour	23(57.5)
3	High stoma output	9(22.5)
4	Stomal edema	7(17.5)
5	Peristomal infection	7(17.5)
6	Stoma retraction	5(12.5)
7	Bleeding	4(10)
8	Stoma ischemia/necrosis	3(7.5)
9	Stoma prolapse	2(5)
10	Hypergranulation	2(5)
11	Non functioning stoma	0(0)
12	Stenosis	0(0)
13	Parastomal herniation	0(0)
14	Mucocutaneous separation	0(0)

Fig. 1 Stoma-related concerns of patients in the study group

experienced in everyday life” as opposed to financial or material well-being [8]. The World Health Organization

defines it as individuals’ perceptions of their position in life in the context of the culture and value systems in which they

Fig. 2 Minimum, maximum, and observed mean of various health dimensions and QoL scores

Fig. 3 Distribution and grades of scores of patients across various health dimensions and QoL scores

live, and in relation to their goals, expectations, standards, and concerns. The central theme in both these definitions is satisfaction with everyday life as a whole. Studies addressing the QoL issues in patients undergoing temporary ileostomies for ileal perforation could not be found in PubMed/Medline®. However, other studies available in patients with stomas indicate that stoma affects QoL [6, 7, 9]. The minimum, maximum observed and calculated mean of various health dimensions and QoL score is shown in Fig. 2. General QoL and stoma-related QoL mean scores were 48 and 52 against the standard average of 50. Although the stoma QoL score was above average, but the below-average general QoL score indicates that the patients were less satisfied with their lives as a whole. Patients with a poor general QoL had a statistically significant (P value=0.000) poor stoma QoL. Physical and social function scores (mean score=66 and 53, respectively) that indicate patients' perception about their ability to do physical and social activities were good (good score=51–70) or best (score>70) in 60–65 % patients

(Fig. 3). The below-average role physical and role emotional scores (Fig. 3) however indicate that the patients were actually not performing their activities for various reasons, of which the most important were fear of trauma to stoma and lack of confidence in handling stoma. These two scores (mean score=19 and 22, respectively) were the most hampered scores in our study. Mental health and physical health scores were significantly associated with stoma QoL (P value=0.000 and 0.001, respectively), indicating that physically and mentally tough individuals could cope with stomas in a better way. The mean duration between ileostomy operation and time of interview was 19 weeks (range 4–102 weeks). One female patient stopped following up due to personal reasons and reported back for closure of stoma after 102 weeks when she was interviewed. Duration of stoma at the time of interview was significantly associated with general QoL score (P value=0.005), stoma QoL (P value=0.039), physical health (P value=0.010), and mental health (P value=0.001) suggesting that with time the patients were gradually coping

with the stoma and their scores improved significantly. Counseling the patients preoperatively and at discharge may help them to gain better experience in self stoma care, hence reducing the physical, emotional, and social problems [9]. Stoma therapists can identify complications, offer solutions, influence, and educate patients and their care takers, show empathy, and reinforce coping skills to promote better QoL [6, 7]. Early recognition of complications by stoma personnel ensures early intervention that avoids patient distress thus leading to improved quality of life [6].

Conclusion and Suggestions

To our knowledge, the study is first of its kind at our institute and also the first to address QoL issues in this specific group of patients. These temporary ileostomies sometime linger on for months for various reasons and affect physical, emotional, social, mental, and general health and overall the quality of life of these patients. Although the study is limited by its small sample size, it has some important implications. It opens up new avenues for research about QoL issues in this particular patient group which is not only unique but also in abundance in this geographical region of the world. A larger randomized study needs to be undertaken to get further insight. There is also a felt need for specialized stoma nurses/therapists who can counsel the patient at the time of stoma conception to improve patient outcomes in terms of QoL. It will be good to start a staff development program for nursing personnel in this relatively untouched clinical area for the benefit of patients. We suggest that community nurses and auxiliary nurse midwives (ANMs) should be trained to assume the role of community stoma nurses in the

time of need. The available resources at government institutes should be further organized to reduce waiting period for closure of ileostomy.

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