Original Article

Breakthroughs and Barriers to Stoma Education: Wisdom Gained from a Pilot Study

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Abstract

Background: The Ostomy and Continence Diversion Patient Bill of Rights asserts ostomates should receive standardized ostomy education. These programs reduce anxiety, improve self-efficacy, and directly address and lower health disparities.
Objective: The aim of this project was to implement a structured perioperative ostomy education program and evaluate the program's effects on readmission rates due to ostomy complications, postoperative length of stay (PLOS), and quality of life after ostomy surgery.
Methods: A perioperative ostomy education program was implemented in an acute care hospital, with program evaluation. Adult patients undergoing fecal diversion surgery from July 1 to December 31, 2023, were recruited via convenience sampling. Participants completed two validated surveys: the Ostomy Self-Care Knowledge Assessment (OSCKA) (n = 7) and the Stoma Quality of Life survey (n = 7). Readmissions and PLOS were examined six months before (n = 13) and six months after implementation (n = 13).
Results: Seven ostomates completed the OSCKA, with mean scores of 20, a high level of understanding. Seven ostomates completed the two-week Stoma-QOL survey, and three of those seven repeated the survey within two months. Ostomates related improved self-confidence, but sleep and ostomy apparatus concerns persisted. No readmissions occurred in either cohort, but the PLOS decreased.
Conclusions: An evidence-based ostomy education protocol was implemented with subsequent evaluation. Participants showed a high level of comprehension at discharge. Quality of life measures show that further social support is needed. The postoperative length of stay was decreased by two days, and no readmissions occurred.

Keywords: structured clinical guidelines, preoperative site marking, structured patient education, peristomal complications, length of stay, readmissions, and quality of life

Background

An ostomate is a person who has undergone fecal diversion surgery.[1] Approximately 750,000 to one million ostomates reside in the United States, with a reported 15.6 million people living with ostomies worldwide.[2] The Ostomy and Continence Diversion Patient Bill of Rights (PBOR) outlines the rights of patients with ostomies

to receive an internationally agreed-upon standard of care.[1] The PBOR promotes the awareness of needs during the perioperative phase of care and specifically declares that patients have a right to ostomy education and supplies. The surgical creation of an ostomy can result in a myriad of issues. The care and treatment of an ostomy requires education, monitoring, and adjustment of care for the life of the ostomy.[1] Failure to treat complications promptly can lead to hospital readmission and prolonged length of stay. Standardized ostomy education programs reduce anxiety and improve self-efficacy, directly addressing and lowering health disparities for ostomy patients.[3,4]

Objective

A structured perioperative ostomy education program was implemented within an acute care hospital, followed by program evaluation. The aim of this project was to implement a structured perioperative ostomy education program to decrease readmissions related to ostomy complications, reduce the postoperative length of stay, and improve the quality of life for patients who underwent ostomy surgery. The program evaluation included a socio-behavioral study to evaluate the effect of perioperative education in addressing quality of life after stoma creation.

Methods

The design of this project was program implementation and evaluation. The study was performed in a 495-bed hospital in Texas. Participants who underwent colostomy formation during their hospitalization between July 1, 2023, through December 31, 2023, were recruited via convenience sampling. Inclusion and exclusion criteria are listed in Table 1.

Table 1. Inclusion and Exclusion Criteria for Study Participation

Inclusion Criteria	Exclusion Criteria
Age 18 and older Fecal diversion surgery Diagnoses: bowel carcinoma, inflammatory bowel disease, diverticulitis, bowel perforation, or bowel ischemia Trauma Ileostomy or colostomy patients	Under age 18 Inability to consent People who require a guardian People with a psychiatric diagnosis limiting capacity Ostomy revision patients Urostomy patients

The postoperative length of stay was studied. Trauma scores from one to four indicate the most severely injured patients require treatment in a trauma center, while scores from five to eight indicate increased survivability.[5] Patients with a trauma score less than four were expected to require a longer length of stay unless they unexpectedly succumbed to their injuries. Readmissions were recorded for patients who were readmitted only for ostomy complications.

Ethical Acknowledgment

The Texas Tech University Health Sciences Center (TTUHSC) Institutional Review Board for the Protection of Human Subjects reviewed and approved the study procedures, approval number L23-173. All patient and facility information were deidentified and patients were given ostomy education even if they did not elect to participate in the study. Participation in the study was discussed without coercion, and informed consent was obtained with signed consent by each participant, preserving autonomy. Participants completed the education evaluation and quality of life surveys by directly entering their answers into Qualtrics, completing the instruments on paper, or by telephone. Confidentiality was maintained by entering the paper or phone

surveys into Qualtrics and ensuring any written material was shredded after entry. Data was reported in aggregate, ensuring confidentiality.

Instruments

The reliable and valid Ostomy Self-Care Knowledge Assessment (OSCKA), as seen in Table 2, was used to measure patients' understanding of postoperative education before discharge.[6] The instrument includes 26 questions answered by the subjects via a Qualtrics link provided by an ostomy education team member. The OSCKA was scored with 1 point for each correct answer and 0 points for each incorrect or "I don't know" answer. The goal was a score of 18 or higher, indicating good ostomy care knowledge. A score of 10 to 17 indicates average stoma knowledge, while a score of 0 to 9 denotes poor knowledge.[6] Scores below 18 indicated a need for further education before discharge, which was completed with the teach-back method, where patients recount information they have been taught.[7]

Table 2. Ostomy Self-Care Knowledge Assessment: True-False Questions to Assess Knowledge of Ostomy Care[6]

Number	Phrases	True	False	I do not
1	An ostomy is an opening that is surgically created in a patient's abdominal	■		
2	The ostomy is placed only permanently.		■	
3	Drainable pouches can be used for 5-7 days.	■		
4	The best time to change the pouches for most people is in the early	■		
5	Choosing the right pouch plays an important role in preventing ostomy	■		
6	It is better to consume low fluids (1 to 2 glasses) during the day.		■	
7	It is better to eat small meals with more meals (4-5 servings) per day.	■		
8	Wearing a tight belt or tight abdominal band should be avoided.	■		
9	The skin around the stoma should only be cleaned with a damp cloth.		■	
10	Bathing with an ostomy pouch should be avoided.		■	
11	Strenuous exercise with an ostomy pouch should be avoided.	■		
12	The stoma bleeds easily from the impact.	■		
13	It is recommended to use hot water to clean the skin around the stoma.		■	
14	Shaving the hair around the stoma should be avoided.		■	
15	The size of the ostomy does not change in the first weeks after surgery.		■	
16	When 1/3 of the pouch is full, it is better to replace or empty the bag.	■		
17	The natural color of the stoma is dark purple or light red.		■	
18	Bleeding from around the ostomy is normal.		■	
19	Changes in the shape and size of the stoma (protrusion or indentation) are		■	
20	If you have abdominal pain or cramps with no stools coming out of the	■		
21	Persistent diarrhea from the ostomy site is normal.		■	
22	Use spinach and parsley to reduce the smell of feces.	■		
23	Consumption of legumes (lentils, beans, etc.) is recommended in patients		■	
24	Fish causes an unpleasant odor in the stool.	■		
25	Apple compote hardens the stool, so it is recommended.	■		
26	Nuts can clog the stoma if not chewed well.	■		

The Stoma Quality of Life survey (Stoma-QoL), as described in Table 3, was used to evaluate the participants' psychological adjustment and concerns regarding their stoma surgery.[8] The instrument is validated and has been proven to be a reliable instrument.[8] The survey consists of 20 Likert scale questions, with scores of 1 to 4 assigned to each category. Responses to the questions were scored as: Always = 1, Sometimes = 2, Rarely = 3, and Not at All = 4.[8]

Table 3. Stoma Quality of Life Survey Questions[8]

Please check the response that best describes how you are feeling at the moment.

	Always	Sometimes	Rarely	Not-at-all
1. I become anxious when the pouch is full.				
2. I worry that the pouch will loosen.				
3. I feel the need to know where the nearest toilet is.				
4. I worry that the pouch may smell.				
5. I worry about the noises from the stoma.				
6. I need to rest during the day.				
7. My stoma pouch limits the choice of clothes that I can wear.				
8. I feel tired during the day.				
9. My stoma makes me feel sexually unattractive.				
10. I sleep badly during the day.				
11. I worry that the pouch rustles.				
12. I feel embarrassed about my body because of my stoma.				
13. It would be difficult for me to stay away from home overnight.				
14. It is difficult to hide the fact that I wear a pouch.				
15. I worry that my condition is a burden to people close to me.				
16. I avoid close physical contact with my friends.				
17. My stoma makes it difficult for me to be with other people.				
18. I am afraid of meeting new people.				
19. I feel lonely even when I am with other people.				
20. I worry that my family feels awkward around me.				

Study Procedures

A structured ostomy education protocol was developed using the Wound, Ostomy, and Continence Nurses Society guidelines for ostomy care.[9] The ostomy program included preoperative, inpatient postoperative, and post-discharge phases. Preoperative skin marking for stoma placement and education were performed in the surgery clinic or hospital by a nurse practitioner, a certified Wound, Ostomy, and Continence Nurse (WOCN), or the surgeon. Postoperatively, daily education was performed from postoperative day one through postoperative day four. Literature was provided to reinforce the education, and families were included when available. For patients too ill to participate in the education process on postoperative day one, education began once the patient's condition allowed.

The project team included the primary researcher, the WOCN, hospital nursing staff, clinic nursing staff, and advanced practice provider staff. Each team member was educated on the study protocol. Patients were enrolled in the program from July 1, 2023, through December 31, 2023, and data were collected until the last patient reached the eight-week postoperative point. Participants completed the Ostomy Self-Care Knowledge Assessment on the day of hospital discharge. Participants were scheduled for follow-up with their surgeon one to two weeks post-discharge and again six to eight weeks after discharge. The Stoma-QoL survey was completed at each of the two visit timeframes. Thirty-day readmission rates for ostomy complications and initial hospitalization length of stay data from January 1, 2023, through June 30, 2023, were used as a pre-program baseline to compare the post-program readmission and length of stay. The post-implementation data was collected from July 1, 2023, through 30 days after discharge for the final program participant.

Outcome Measures

Outcomes were measured using the post-education Ostomy Self-Care Knowledge Assessment (OSCKA) to identify and address education gaps before discharge.[6] Outcomes also included comparing the postoperative length of stay and readmissions for ostomy complications pre- and post-implementation. Data were retrieved from the hospital's electronic medical record system, Cerner, based on specified CPT codes, listed in Table 4, for colostomy formation and complications. Patient quality of life scores via the Stoma-QoL survey were used to inform further development of the ostomy program.[8]

Table 4. CPT Codes Utilized for Data Collection at the Target Facility

CPT	Description
44141	Colectomy, partial; with skin level cecostomy or colostomy
44146	Colectomy, partial; with coloproctostomy, with colostomy
44187	Laparoscopy, Surgical ileostomy or jejunostomy, non-tube
44188	Laparoscopy, Surgical; Colostomy or skin level cecostomy
44206	Laparoscopy, Surgical; Colectomy, partial, with end colostomy and closure of distal segment (Hartmann type procedure)
44208	Laparoscopy, Surgical; colectomy, partial, with anastomosis, with coloproctostomy with colostomy
44320	Colostomy or skin level cecostomy

Data Analysis

The validated OSCKA and Stoma-QoL survey results were evaluated using the Stata/MP version 18.0 for analysis, and listwise deletion was applied to the missing data. Descriptive statistics were calculated for all variables, including frequency with percentages for categorical and mean with standard deviation or median with interquartile range for continuous, depending on the level of measurement. Data obtained from the hospital reflecting pre- and post-implementation measures were compared using the Fisher's exact test for categorical analysis and the Wilcoxon rank-sum test for comparison of repeated measures with an alpha of 0.05 established *a priori* for statistical significance.

Results

Full Sample

A total of 26 patients had colostomies placed during the study window, with 13 in each cohort (e.g., pre- and post-program). The majority were male and white, averaging 63.9 years **(Table 5)**. Only two patients in the pre-program cohort had colostomies placed due to trauma, though more than 90% were placed emergently due primarily to perforation, infection, or a mass with obstruction. Home, home health, or skilled nursing facilities were the primary dispositions of patients discharged after colostomy placement, and the median hospital length of stay was 12.5 days. The median postoperative length of stay was seven days.

Pre- and Post-Program Comparisons

There were no statistically significant differences across patient characteristics or outcomes between the pre- and post-program cohorts. However, there was a clinically significant reduction in the median post-surgery length of stay in the post-program cohort (six days) compared to the pre-program cohort (eight days), as noted in Table 5. Additionally, a more significant proportion of patients were discharged to home health in the post-program cohort (38.4%) compared to the pre-program cohort (0.0%). Lastly, no patients in either cohort were readmitted due to complications or concerns of the colostomy. Thus, we could not evaluate the differences in readmission rates between cohorts.

Table 5. Patient Characteristics and Outcomes: Pre- and Post-program Implementation Cohorts

Characteristic	**Full Sample (n = 26)**	**Pre-Program (n = 13)**	**Post-Program (n = 13)**
Age [Mean (SD)]	63.9 (14.4)	59.1 (13.7)	68.8 (13.9)
Gender [n (%)]			
Female	10 (38.5)	5 (38.5)	5 (38.5)
Male	16 (61.5)	8 (61.5)	8 (61.5)
Surgery status [n (%)]			
Emergent	24 (92.3)	11 (84.6)	13 (100.0)
Scheduled	2 (7.7)	2 (15.4)	0 (0.0)
Trauma [n (%)]	2 (7.7)[a]	2 (15.4)	0 (0.0)
Procedure – colostomy [n (%)]	26 (100.0)	13.0 (100.0)	13.0 (100.0)
Total length of stay [Median (IQR)]	12.5 (8.0, 19.0)	10.0 (8.0, 20.0)	13.0 (8.0, 17.0)
Post-surgery length of stay [Median (IQR)]	7.0 (4.0, 15.0)	8.0 (6.0, 13.0)	6.0 (3.0, 15.0)

Characteristic	Full Sample (n = 26)	Pre-Program (n = 13)	Post-Program (n = 13)
Discharge disposition [n (%)]			
Home	8 (30.8)	5 (38.4)	3 (23.1)
Home health	5 (19.2)	0 (0.0)	5 (38.4)
Acute rehabilitation	3 (11.5)	2 (15.4)	1 (7.7)
Skilled nursing facility	5 (19.2)	2 (15.4)	3 (23.1)
Long-term acute care	3 (11.5)	2 (15.4)	1 (7.7)
Outpatient therapy	2 (7.8)	2 (15.4)	0 (0.0)
Reason for surgery [n (%)]			
Diversion	6 (23.1)	4 (30.7)	2 (15.4)
Mass/obstruction	8 (30.8)	3 (23.1)	5 (38.5)
Perforation/infection	11 (42.3)	5 (38.5)	6 (46.1)
Trauma	1 (3.8)	1 (7.7)	0 (0.0)
Notes: SD = standard deviation, n = frequency, % = percentage, IQR = interquartile range [a]Trauma scores were 3 and 8			

Colostomy Knowledge Assessment

Of the 13 ostomy patients in the post-implementation cohort, only seven agreed to complete the OSCKA, as described in Table 6. There was a similar distribution of male and female patients, and patients were primarily discharged to home (n = 3) or with home health (n = 5). All surveyed patients underwent colostomy for medical diagnoses. The median hospital length of stay was 9.9 days, while the median post-surgery length of stay was three days. The mean score on the OSCKA was 20 points, with an expected score of 18 or greater, indicating a good level of post-education knowledge.

Patients demonstrated knowledge of ostomy placement, the temporality of the ostomy, and essential aspects of changing the pouch. They also demonstrated competency related to oral consumption of food and drinks and appropriate clothing. However, patients struggled to understand the normal and abnormal characteristics of the stoma. For example, only 57% of the patients correctly identified that bleeding or changes in the size and shape of the stoma are abnormal. A total of 72% of the patients

demonstrated uncertainty regarding shaving around the stoma and managing odor with food products.

Table 6. Characteristics of Participants Who Completed the OSCKA and Stoma-Qol Surveys

Characteristic	Study Participants (n = 7)
Age [Mean (SD)]	72.5 (12.1)
Gender [n (%)]	
Female	3 (42.9)
Male	4 (57.1)
Post-surgery length of stay [Median (IQR)]	
Discharge disposition [n (%)]	
Home	2 (28.7)
Home health	2 (28.7)
Acute rehabilitation	1 (14.2)
Skilled nursing facility	1 (14.2)
Long-term acute care	1 (14.2)
Notes: SD = standard deviation, n = frequency, % = percentage	

Stoma Quality of Life Survey

The seven consented patients completed the initial Stoma-QOL survey at the two-week follow-up, and three completed the survey during the six-to-eight-week follow-up. Scores from both intervals were compared. Improvement was noted in questions about comfort with interpersonal activities and the ability to return to normal daily activities. Difficulty sleeping and concern for potential loosening of the ostomy apparatus were persistent.

Discussion

The project met with breakthroughs and barriers, informing program modifications. The ostomy education program's success depended upon coordinating multiple services to address patient-specific issues. The following discussion describes the evolution of the program.

Colostomy Supplies

Planning for the ostomy education program required ensuring supplies were available and utilized appropriately. Pouching systems include an adhesive flange with a skin barrier and a pouch that typically snaps onto the affixed portion. Varied types of pouching systems are available. For this program, the ostomy supply representative for the facility was consulted. The representative ensured that the pouching systems were available in the central and operating supply rooms. Education was provided to staff members working in the departments caring for ostomates. The hospital WOCN provided each patient with a month of ostomy supplies and patient education folders on discharge.

Interdisciplinary Team Involvement

Nutrition services departments are responsible for providing nutrition education for patients. Adequate nutrition is required for proper healing. Dietitians were consulted for patient education when patients held a new diagnosis of diabetes or those with a diagnosis of malnutrition. A dietitian evaluated every person with a length of stay greater than five days.

Discharge Planning

Leaving the security of inpatient care can be daunting. Patients should feel their discharge planning is patient-centered and comprehensive; therefore, case management assisted with discharge planning.[10] Physicians agreed to standard orders for home health or outpatient wound care clinic follow-up for patients discharged to home. Charity follow-up wound care was arranged for uninsured patients when available. Ostomates qualifying for inpatient rehabilitation, skilled nursing care, or long-term acute care hospitalization were discharged to the facility of their choice for continued care.

Exceptions occurred. Over half of the counties in Texas are frontier counties, where the population averages less than twenty people per square mile.[11] Many frontier counties lack healthcare access. Uninsured patients who did not qualify for inpatient rehabilitation or skilled nursing care were discharged home. Those who lacked access to outpatient wound care services or home health due to the unavailability of medical services required more frequent outpatient follow-ups, including in-person surgical provider and telehealth appointments.

Readmissions

Previously published studies noted that 17 to 20.6% of ostomy patients are readmitted within 30 days of discharge, while there were no documented readmissions for ostomy complications for this study's pre and post-education study cohorts.[12,13] The limited number of ostomy surgeries at the target facility allowed individualized education. This could be a contributing factor to the lower-than-average readmission rate.

Postoperative Length of Stay

In a retrospective cohort study, the median length of stay (LOS) for patients with ostomy surgery was nine days, with a seven-day LOS postoperatively.[14] Although the ultimate goal of a four-day LOS was not reached during the study period, each inpatient hospital day averages $2,296 across the United States; therefore, the savings can be significant with the reduction of postoperative length of stay to six days.[15] Continued education program use is expected to reduce post-operative LOS further.

Follow-up Care: Unexpected Inconsistency

Program protocols were consistently followed while patients were hospitalized. Regardless of study participation, all ostomy patients received the expected ostomy education. The lack of insurance or access to outpatient care services created variability in discharge disposition planning.

Physician follow-up appointments were not adhered to as expected. Lack of follow-up was due to multiple factors, including incarceration, planned follow-up in another state, or patients who failed to follow-up. The second planned visit was even more inconsistent. Scheduling issues and physician clinic schedules permitted only three patients to complete the second Stoma-QOL survey in the specified time.

Limitations

This pilot program implementation and evaluation project had limitations. The average number of ostomy surgeries per year in the target facility was evaluated at the onset of program implementation. The team expected approximately 24 to 26 ostomy surgeries for the year, limiting the potential study population.

Readmissions after ostomy surgery were evaluated for the six months antecedent to the standardized program and the six months following implementation in the target hospital. A second acute care facility is in the same city, and patients periodically present at one or the other hospital. Ostomates included in the study could have been admitted to the second facility or another facility elsewhere.

Future Considerations

Further study regarding quality of life after ostomy surgery is recommended. Serial evaluations of the quality of life at six months or a year after ostomy surgery are warranted to identify ostomates who may be struggling. Physician support, counseling, and peer support may be needed.

Peer support groups can help reduce feelings of loss or disconnect.[4] Support groups should be offered to patients and their families to improve acceptance and quality of life and to manage expectations.[16] Future community peer support group meetings for ostomates should be included as an extension of the program.

Barriers to post-discharge follow-up appointment attendance were found. While

ensuring patients were provided the Stoma-QOL survey during their postoperative appointments, inconsistencies in scheduling were noted. If no follow-up visit had been scheduled, the patient was contacted via telephone and made an appointment. Limited physician clinic time was determined to be another barrier, and more consistent clinic routines are recommended. A quality improvement opportunity exists to address these concerns.

Conclusions

The Ostomy and Continence Diversion Patient Bill of Rights states that ostomy patients have a right to standardized ostomy education. The education protocol extended services with an interdisciplinary approach, including more comprehensive discharge planning. The effectiveness of the perioperative education was demonstrated by the high scores noted on the participants' Ostomy Self-Care Knowledge Assessment. While few, the Stoma Quality of Life scores indicated increased comfort with interpersonal relationships and a return to normal activities of daily living; however, continued concern regarding ostomy apparatus wear and disrupted sleep were noted. Further work is needed to assess patients' quality of life after stoma creation and to support them through healthcare services and peer support groups. Although challenges were encountered throughout this pilot perioperative ostomy education program, they only serve to illuminate opportunities for further program development important for those facing diversion surgery.

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