Original Study

ANNALS OF SURGERY OPEN

OPEN

Defining Opportunities to Improve Perioperative Ostomy Care and Education

Hannah Ficarino Sheffer, MD, MSPH,* Burkely Smith, MD, MSPH,* Jernell Simmons, MD,† Ivan Herbey, MD,* Daniel Chu, MD, MSPH,* Wendy Landier, PhD,‡ Smita Bhatia, MD, MPH,‡§ and Robert Hollis IV, MD, MSPH*‡

Objective: We sought to qualitatively identify opportunities to improve perioperative ostomy care and education.
Background: Patients with a new ostomy utilize ostomy care–related resources to manage their ostomy. Many patients experience ostomy-related issues after surgery.
Methods: In this qualitative study, patients who underwent the construction of a new ostomy, their caregivers, and healthcare professionals were purposively recruited for semistructured phone interviews. Interviews included questions about ostomy-related experiences, education, and resources in the perioperative phases of care. Interviews were transcribed and thematically coded using inductive content analysis with NVivo 12 Software. Focus groups of patients, caregivers, and healthcare professionals were conducted to validate themes.
Results: Overall, 53 interviews including 20 patients, 16 caregivers, and 17 healthcare professionals were conducted. The average age of patients and caregivers was 59 years, 69% were non-Hispanic White, 72% were female, and 39% had limited health literacy. Themes in the preoperative phase included "not knowing what to expect regarding an ostomy," "patient difficulty understanding their health condition," and "overwhelming amount of information regarding an ostomy." Inpatient phase themes included "not knowing the best ostomy supplies to use," "challenges with ostomy appliance application," and "lack of patient acceptance and maladjustment." Postdischarge themes included "difficulty obtaining supplies," "challenges caring for inflamed skin," "variability in the utility of home healthcare," "missing outpatient resources," and "limited information on hydration and diet management." Themes were subsequently validated in focus groups.
Conclusions: Patients, caregivers, and healthcare professionals reported key perioperative barriers to obtaining, understanding, and utilizing ostomy care–related resources and education. These findings inform the development of interventions to improve ostomy care and education.

Keywords: barriers, ostomy, ostomy care, qualitative, stoma care

INTRODUCTION

A new ostomy is a life-altering procedure.[1] With more than 100,000 ostomies created each year, patients with a new ostomy remain a high-risk population for several ostomy-related issues occurring after discharge such as dehydration, skin irritation, and failure to thrive.[2] Nearly one-third of new ostomy patients have an unplanned healthcare visit within 60 days following hospital discharge, and this creates a substantial cost burden for the healthcare system.[3–6] Complications occurring among patients with a new ostomy can have negative impacts on quality of life within multiple domains including psychological impact, physical changes, and interpersonal relationships.[7] Proper perioperative education and resource utilization can positively impact the experience for patients and their caregivers.[8,9]

Prior interviews of ostomy patients have highlighted that their educational needs for essential stoma self-care are often unmet before transitioning home after surgery.[10] Following surgery with the construction of a new ostomy, patients describe the negative effects on quality of life and difficulty in navigating the physical and psychological changes that accompany a new ostomy.[7,11] Significant work has focused on the prevention of unplanned healthcare utilization in the new ostomy patient, especially prevention of dehydration-related readmissions,[12–14] but structural educational interventions aimed to improve postostomy outcomes have produced mixed results.[15–17] Caregiver and healthcare professionals' perspectives on barriers to effective perioperative ostomy care have not been explored. To develop interventions that promote self-efficacy and improve the experience for new ostomates, the key barriers to obtaining, understanding, and utilizing perioperative ostomy care–related resources must be defined.[18]

---

*From the *Department of Surgery, University of Alabama at Birmingham, Birmingham, AL; †Heersink School of Medicine, University of Alabama at Birmingham, Birmingham, AL; ‡Institute for Cancer Outcomes and Survivorship, University of Alabama at Birmingham, Birmingham, AL; and §Division of Pediatric Hematology-Oncology, University of Alabama at Birmingham, Birmingham, AL.*

Disclosure: The authors declare that they have nothing to disclose.

H.F.S. is supported by the American College of Surgeons Resident Research Award and NIH Surgical Oncology T32 Award CA229102. R.H. is supported by NIH K08CA293312.

This study was approved by the University of Alabama at Birmingham Institutional Review Board – IRB 300006582.

This work was presented orally at American College of Surgeons, San Francisco, CA, October 2024.

SDC *Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site (www.annalsofsurgery.com).*

Reprints: Robert Hollis IV, MD, MSPH, Department of Surgery, University of Alabama at Birmingham, 1808 7th Ave S, BDB 561, Birmingham, AL 35294-0016. Email: rhhollis@uabmc.edu.

Annals of Surgery Open (2025) 1:e563

Received: 29 January 2025; Accepted 17 February 2025

DOI: 10.1097/AS9.0000000000000563

In this study, we leveraged the experience of patients with a new ostomy, caregivers of patients with a new ostomy, and healthcare professionals for patients with a new ostomy to qualitatively identify barriers to perioperative ostomy self-care. Semistructured interviews asked participants to focus on barriers to obtaining, understanding, and utilizing various ostomy care resources in the preoperative, inpatient, and postdischarge phases of care. Barriers identified in this study will provide the framework for future interventions to improve ostomy-related self-care among new ostomy patients.

METHODS

Population and Recruitment

We performed semistructured individual interviews with patients who underwent ostomy construction within the prior year, caregivers of a patient who underwent ostomy construction within the prior year, and healthcare professionals of patients with a new ostomy at a large tertiary care academic institution. Patients were identified as having a new ostomy in the last year from an electronic health record review. To ensure that barriers represented patients of varying health literacy, we utilized purposive sampling to include patients of both adequate and marginal/limited health literacy. Patient health literacy was determined for recruitment using the self-reported Brief health literacy score that was routinely collected as part of the outpatient clinic intake process and stored within the electronic medical record.[19] Patients with experience from a prior ostomy before the index ostomy construction were excluded to capture the needs of “first-time” ostomy patients naive to ostomy care. Patients were sent an introductory mailing explaining the study after which they received a follow-up phone call to schedule and complete a semistructured interview. Caregivers were identified through snowball sampling as a patient’s caregiver’s name and contact information were collected from the patients. Ostomy health professionals were approached via convenience sampling and included wound, ostomy, and continence nurses (WOCN), acute care surgeons, colorectal surgeons, clinical coordinators, nurse practitioners, and inpatient floor nursing staff. All participants were offered \$10 gift cards as compensation after completing individual interviews. Eligible participants who declined participation by either active or passive refusal were excluded from the study.

Interview Techniques

Informed consent was verbally obtained before interview initiation, and interviews lasted 15 to 25 minutes. Interviews were performed by 3 study members (H.F.S., J.S., B.S.) who were not directly involved with the participant’s clinical care and introduced themselves as a research assistant conducting interviews for the study. Interviews were conducted in a secluded location via voice calls without third-party observers. Interviewer training included review and practice of the semistructured interview guide with team members to ensure the goals of the qualitative interviews were met. Interviews for patients and caregivers included demographic questions and the 4-item Brief health literacy screener tool.[20] Semistructured interview guides included questions regarding ostomy education and resources in the preoperative, inpatient, and outpatient settings (see interview guides in Appendices 1 and 2, see http://links.lww.com/AOSO/A484). The semistructured interview guides were developed based on conceptual models of health literacy with a particular focus on patient and caregivers’ ability to obtain, understand, and utilize ostomy care resources in the perioperative phases of care.[21] Caregivers were additionally asked about prior healthcare-related occupational experiences or prior experiences with ostomy care. Healthcare professionals’ interviews consisted of basic demographic questions, questions about the healthcare profession and years of experience with ostomy patients, and questions regarding ostomy education and resources patients utilize in the preoperative, inpatient, and outpatient settings (see Appendix 3, see http://links.lww.com/AOSO/A484 for healthcare professional interview guide).

Qualitative Analysis

All interviews were audio-recorded and transcribed verbatim. Transcripts for each group (patients, caregivers, and healthcare professionals) were thematically coded by 2 to 3 independent coders (H.F.S., J.S., B.S.) using inductive content analysis. Coders were research assistants at the time of coding and consisted of 1 medical student (J.S.) and 2 surgical residents (H.F.S. and J.S.). Elemental codes were identified and organized using Nvivo 12 in conjunction with an expert in qualitative coding and analysis (I.H.). Interviews were not returned to participants for review or feedback. Concurrent with the interview process, elemental codes were discussed by the team and axial coding was used to connect related categories. Interviews within each group of participants continued until thematic saturation was reached, and no further emergent themes were identified. Final themes were identified through selective coding and represent the barriers to ostomy care and education. Intercoder agreement was 93% to 94%.

Focus Groups

Following completion of the qualitative analysis of individual interviews, prior participants were recruited to participate in 1 of 3 focus groups comprised of patients, caregivers, or healthcare professionals with 3 to 4 participants each. Focus group participants were convened using a virtual meeting software (Zoom Video Communications, San Jose, CA) and meetings ranged from 60 to 90 minutes. Participants were presented with themes representing the barriers to ostomy care that were identified in the qualitative analysis of individual participant’s interviews. Participants were primarily asked to validate that these themes represent true barriers to ostomy care (see Appendix 4, see http://links.lww.com/AOSO/A484 for patient and caregiver focus group interview guide and Appendix 5, see http://links.lww.com/AOSO/A484 for healthcare professional focus group interview guide). Participants in the focus groups were compensated with \$25 gift cards for their participation.

Quantitative Analysis

The associated patient electronic medical record for patients was queried for underlying disease processes resulting in ostomy formation, presence of ileostomy or colostomy, number of inpatient WOCN educational sessions, and incidence of unplanned healthcare utilization within 60 days after ostomy formation. Unplanned healthcare utilization was defined as readmission or emergency department visits at our institution or clinical documentation of a readmission or emergency department visit at an outlying institution. Continuous variables were described using means with standard deviations or median with ranges as applicable. Categorical data were described using counts or percentages. All methods and findings in this study were reported in concordance with Consolidated Criteria for Reporting Qualitative Research guidelines unless otherwise stated.[22] This study protocol was approved by the Institutional Review Board at the University of Alabama at Birmingham Hospital (IRB 300006582).

RESULTS

Overall, 53 interviews including 20 patients, 16 caregivers, and 17 healthcare professionals were conducted. The demographics of participants are included in Table 1. Patients were an average of 61.8 years old, and 70% of patient participants were female. Most patient participants were of White race (n = 12, 60%) followed by Black race (n = 8, 40%). Nearly half of the patient participants had marginal or limited Brief health literacy score (n = 9, 45%). Caregiver participants were an average of 56.1 years old, and 75% were female. Most were of White race (n = 13, 81.2%), followed by Black race (n = 3, 18.8%). Of caregiver participants, 33.3% (n = 5) had marginal or limited health literacy. Healthcare professionals were an average of 44 years old, and most were female (n = 14, 82.3%). Participants who were healthcare professionals were predominately White (n = 14, 82.3%). Healthcare professionals had an average of 12.7 years prior experience with ostomy patients. Healthcare professionals who participated consisted of WOCN (n = 6, 35.3%), surgeons (n = 5, 29.4%), and clinical coordinators (n = 3, 17.6%).

Emergent themes representing patient-reported barriers to ostomy care in the preoperative, inpatient, and postdischarge and representative quotes are presented in Table 2. Within the preoperative phase of care, patients identified "not knowing what to expect regarding an ostomy" and "overwhelming amount of new information regarding an ostomy" as barriers to ostomy care. In the inpatient phase of care, "not knowing the best materials to use" regarding finding the best ostomy appliance and "challenges with ostomy appliance application" including related issues of limited hand dexterity, preventing leakage, and time for hands-on learning were reported as barriers to ostomy care. Within the postdischarge phase of care, "difficulty obtaining supplies," "caring for inflamed skin," "variability in utility of home healthcare," "hydration and diet management," and "missing outpatient resources" for effective information on managing new ostomy-related issues that arise after discharge were described as barriers to outpatient care.

TABLE 1.

Demographics of Interview Participants

	Patients (n = 20)	Caregivers (n = 16)	Healthcare Professionals (n = 17)
Age, years, mean ± SD*	61.8 ±12.7	56.1 ± 12.8	44 ± 10.8
Sex, female (%)	14 (70%)	12 (75%)	14 (82%)
Race/ethnicity			
White	12 (60%)	13 (81%)	14 (82%)
Black	8 (40%)	3 (19%)	1 (6 %)
Asian	0 (0%)	0 (0%)	1 (6 %)
Hispanic or Latino	0 (0%)	0 (0%)	1 (6 %)
Interview Brief health literacy score*			
Adequate	11 (55%)	10 (67%)	NA
Limited or marginal	9 (45%)	5 (33%)	NA
Ostomy type			
Ileostomy, n (%)	11 (55%)	13 (81%)	NA
Colostomy, n (%)	9 (45%)	3 (19%)	NA
Underlying disease process			
Cancer, n (%)	9 (45%)	7 (44%)	NA
IBD, n (%)	4 (20%)	5 (31%)	NA
Diverticulitis, n (%)	2 (10%)	2 (13%)	NA
Other, n (%)	5 (25%)	2 (13%)	NA
No. WOCN visits inpatient, mean ± SD	3.85 ± 1.9	3.4 ± 1.1	NA
Readmission/ED visit after ostomy, yes (%)	12 (60%)	NA	NA
Years of experience with ostomy patients, mean ± SD	NA	NA	12.7 ± 7.2
Profession, n (%)			
WOCN	NA	NA	6 (35 %)
Surgeon	NA	NA	5 (29 %)
Nurse practitioners	NA	NA	2 (12 %)
Clinical coordinator	NA	NA	3 (18 %)
Inpatient nursing	NA	NA	1 (6 %)

*Value missing for one caregiver participant.

ED, emergency department; IBD, inflammatory bowel disease; NA, not applicable; SD, standard deviation.

Perioperative themes among caregivers with representative quotes are shown in Table 3.

New emergent themes within the caregiver group included "lack of patient acceptance and maladjustment" as an inpatient barrier with some caregiver participants noting the patient's refusal to perform their own ostomy care. Caregivers described similar preoperative and postdischarge barriers to ostomy care as the patient participants. In the postdischarge setting, caregivers described significant variation in home healthcare utility with one caregiver stating, "Home health didn't ever do nothin' but talk to us," and another stating they "would recommend home healthcare" to any new ostomy patient.

Barriers identified by healthcare professionals of ostomy patients with representative quotes are shown in Table 4. Health professionals reported barriers were similar to the themes noted by patients and caregivers in the inpatient and outpatient settings, though "difficulty obtaining ostomy supplies" did not emerge as a theme among healthcare professionals. One preoperative theme that was unique to healthcare professionals was "patient's difficulty in understanding their health condition" with one WOCN stating, "I think it's just the grasping of what an ostomy really is." Composite overall themes among patients, caregivers, and healthcare professionals are shown in Table 5.

Focus groups consisted of 3 to 4 participants per group (patients, caregivers, or healthcare professionals) who previously completed individual interviews. The patient focus group consisted of 3 females and 1 male. The caregiver focus group consisted of 3 females and each identified as the spouse of a patient with an ostomy. The healthcare professionals' focus group consisted of 3 female nurses, of which 1 was an inpatient floor nurse and 2 were wound ostomy continence nurses. Participants from each group validated the themes presented to them and provided additional insight into personal experiences with the themes presented (see Appendix 6, see http://links.lww.com/AOSO/A484 for example quotations).

DISCUSSION

Patients undergoing surgery with the construction of an ostomy face significant postoperative challenges related to ostomy care resulting in high readmission rates of poor quality of life. Through interview of patients, their caregivers, and ostomy healthcare professionals, we identified 11 themes that represent barriers to perioperative ostomy care and education. Preoperative barriers surrounded patient and caregiver knowledge in which there were unclear expectations, difficulty understanding one's health condition, and challenges of wading through overwhelming amounts of information. Inpatient barriers included practical ostomy care issues such as selecting the best materials and technique of application as well as patient acceptance and adjustment to having an ostomy. Postdischarge barriers focused on obtaining supplies, caring for inflamed skin, the utility of home health nursing, managing hydration/diet, and missing outpatient resources. These themes define key targets for interventions seeking to improve perioperative ostomy care and outcomes.

Several themes align with previously known challenges existing among ostomy patients or in postoperative discharge care processes. Dehydration is known to be a major cause of unplanned healthcare utilization in patients with a new ostomy and accounts for up to 40% of readmissions in new ileostomy patients within 60 days of discharge.[6] Bodily self-image and emotional adjustment after a new ostomy are known to significantly affect quality of life.[23] Patient and caregiver preparedness after discharge including practical knowledge on

TABLE 2.

Key Patient Themes With Example Quotations

Phase of Care	Patient-Reported Barrier	Example Quotation
Preoperative	Not knowing what to expect regarding an ostomy	“I really didn’t look up any ’cause I really didn’t know—it really didn’t talk about a whole lotta about the bag itself or anything until I was in the hospital and had the surgery...”
	Overwhelming amount of new information regarding an ostomy	“Yeah, there’s a lot of information out there, but you’re wading through too much junk.”
Inpatient	Not knowing the best materials to use	“…because it’s just knowin’ how to put it on and what worked best for you. What may work best for the person teaching you may not totally work for you at all.”
	Challenges with ostomy appliance application	“Yeah, trying to keep your bags on. It was hard. It was frustrating. I stayed depressed.”
Outpatient	Difficulty obtaining supplies	“I would just say maybe a little bit more prepared as far as just like the logistics of stuff afterwards, and maybe… well, your home health company will have all these samples for you and these catalogs. You can order whatever. They had none of that.”
	Caring for inflamed skin	“I took my first bag off after leaving the hospital and the skin come off with it. Then, they got inflamed and irritated. Then, that’s still what I’m dealin’ with today….”
	Variability in utility of home healthcare	“Well, we did, but it was the biggest waste of time I ever heard. We let “em go “cause, as far as them helpin’ us with everything havin’ to do with bags, they never did that “
	Hydration/diet management	“Trying to figure out what you can eat, what you can’t eat, what’ll cause a blockage, what won’t cause the blockage”
	Missing outpatient resources	“I did go online and read some stuff. I feel like there wasn’t as much information as I would’ve liked”

TABLE 3.

Key Caregiver Themes With Example Quotations

Phase of Care	Caregiver-Reported Barrier	Example Caregiver Quotation
Preoperative	Not knowing what to expect regarding an ostomy	“I guess I had no idea about what to expect.”
Inpatient	Not knowing the best materials to use	“Just there’s so many different options about the paste and the paste rings, and this kinda bag and that kinda bag. It was overwhelming. I know we both felt overwhelmed with all the options.”
	Challenges with ostomy appliance application	“I guess the most difficult, I would say, would probably be makin’ sure to cut around the—to cut the circle to make sure it would fit on.”
	Lack of patient acceptance/maladjustment	“That my husband did not participate with that...just him not really participating”
Outpatient	Difficulty obtaining supplies	“I had a difficult time finding my husband[“s] ostomy bags”
	Caring for inflamed skin	“’Cause he would be raw and really red around it... we learned just what we could use to kinda treat it and get it where it wasn’t so red.”
	Variability in utility of home healthcare	Well, the little girl from home health didn’t ever do nothin’ but talk to us. She never changed it. Just looked at it, but never took one off or none of that”
	Hydration/diet management	“The only problem that my wife’s havin’ right now is she’s havin’ a lotta ballooning from passing gas... She’s trying to learn what to not to eat to pass the gas, or to have the gas”
	Missing outpatient resources	“We just tried to figure it out as best we could on our own”

TABLE 4.

Key Healthcare Professional Themes With Example Quotations

Phase of Care	Healthcare Professional-Reported Barrier	Example Healthcare Professional Quotation
Preoperative	Patients not knowing what to expect regarding an ostomy	“They don’t always make the connection that [it] is a fecal diversion... but it doesn’t always click that it’s a fecal diversion until it’s actually there”
	Overwhelming amount of new information regarding an ostomy	“If any patient already is healthcare illiterate or has a new diagnosis on top of having a new surgery, it could be overwhelming...”
	Patient difficulty in understanding health condition	“I think there’s just the grasping of what an ostomy really is”
Inpatient	Not knowing the best materials to use	“I think, though, sometimes the issue we come onto is just trying to find the right bag to fit. There’s some people need a belt and other ones don’t.”
	Challenges with ostomy appliance application	“Their dexterity is a little bit more limited, right after that they have surgery. I think with the medications and pain, it is a bit harder for them to figure out how to cut the circle and put on the bag appropriately.”
	Lack of patient acceptance/maladjustment	“There was one lady... who would just not look at the ostomy. She... came back with ostomy related complications.. she was not doing the ostomy care as predicted”
Outpatient	Caring for inflamed skin	“…It becomes unpouchable because the skin just gets so excoriated and the stoma can be retracted.”
	Variability in utility of home healthcare	In my experience home health has been very individualized based on the home health nurse that comes out to help them. I hear from patients all the time that home health doesn’t—came out, and they don’t even know how to deal with an ostomy. Sometimes they’ve had great experience that’s very, very much dependent on who comes to talk to them.”
	Hydration/diet management	“I think they learn pretty quickly that this thing is functioning all the time. They need to drink to keep up with it”
	Missing outpatient resources	“The older patients it seems to me most times don’t have any resources… They’re just out there flailing in the wind if they’re having trouble”

TABLE 5.

Overall Themes for Barriers in Perioperative Ostomy Care

Preoperative	Patients not knowing what to expect regarding an ostomy
	Overwhelming amount of new information regarding an ostomy
	Patient difficulty understanding health condition
Inpatient	Not Knowing the best materials to use
	Challenges with ostomy appliance application
	Lack of patient acceptance/maladjustment
Outpatient	Difficulty obtaining supplies
	Caring for Inflamed skin
	Variability in utility of home healthcare
	Hydration/diet management
	Missing outpatient resources

ostomy materials, application, and troubleshooting has been shown to have a significant negative impact on stoma quality of life.[8,24] Limitations in obtaining, understanding, and utilizing health-related resources are known to be negatively associated with health-related quality of life and other outcomes after surgery.[8,25–28] Our study additionally highlighted important barriers related to the variability of the utility of postdischarge home health nursing and the lack of outpatient resources for new ostomy patients.

A strength of our findings is the inclusion of barriers as identified by patients, caregivers, and healthcare professionals. Prior studies have emphasized changes in quality of life and educational needs for the new stoma patient from the patient's perspective.[1,10,29] It is known that caregivers contribute significantly to ostomy self-care activities and that caregiver support can persist for several years for patients with a permanent ostomy.[16,17,30] The presence of similar perceived barriers to care among patients and caregivers in our study highlights common needs that may be exacerbated if a caregiver is ill-equipped to manage ostomy-related issues.[16] In a qualitative analysis by Altschuler et al,[16] high caregiving needs in elderly patients were associated with poor quality of life due to the inability to address ostomy-related issues. Caregivers in our study highlighted patient adjustment issues to having an ostomy, particularly the acceptance of this change to their basic activities of daily living. Ongoing challenges with ostomy care may increase social isolation and negatively impact self-confidence in the new stoma patient.[31,32] Thus, future interventions may leverage caregiver support to help provide high-quality ostomy care during emotionally laden times for the patient.

Prior interventions for ostomy patients have mostly focused on individual barriers to ostomy care and management. Inpatient checklists, oral rehydration solutions, and comprehensive post-discharge monitoring programs have all targeted and improved rates of dehydration after ileostomy creation.[12,14,33] Receipt of preoperative and postoperative stoma education has been associated with significantly lower postoperative anxiety when compared to patients who received postoperative ostomy education alone.[34] A structured ostomy care program that included informational and practical training sessions with a certified WOCN has resulted in reduced anxiety and improved quality of life for new stoma patients.[35] Implementation of universal precautions for health literacy can positively impact barriers identified such as “overwhelming amount of information” and “patient’s difficulty in understanding their health condition.”[36] Previously described ostomy care–related interventions are heterogeneous and target various outcomes, such as quality of life, readmissions, or length of stay.[15] Future interventions should focus on more comprehensive barriers to ostomy care as outlined by the barriers identified in this study with the goal of improving patient-reported outcomes in addition to clinical outcomes.

Our findings inform the development of future multicomponent interventions from a multi-viewpoint stakeholder perspective. Standardized educational interventions or toolkits could impact several perioperative ostomy care barriers identified in our study, particularly “not knowing what to expect,” “not knowing the best materials to use,” “issues with ostomy appliance application,” “caring for inflamed skin,” “hydration and diet management,” and “missing outpatient resources.” While existing comprehensive toolkits, such as the American College of Surgeons Ostomy Home Skills kit,[37] address some of these key identified barriers to ostomy care, several barriers such as patient difficulty understanding their health condition, lack of patient acceptance/maladjustment, difficulty obtaining supplies, and variability in utility of home healthcare will require policy, institutional, and healthcare professional-level intervention components beyond a patient-level educational toolkit.

Our study is limited by its single institution experience. Recall bias may impact responses by patient and caregiver participants as participants with traumatic or poor experiences after an ostomy may be more likely to remember perioperative ostomy barriers up to 1 year after surgery when interviewed. All patients, caregivers, and healthcare professionals in this study were identified by receiving care at a single tertiary care institution and some viewpoints may be more reflective of the local microenvironment than a more nationally representative perspective. However, many of the themes identified align with previously described barriers by patients in other hospital settings. All participants were contacted by phone or mail, which may unintentionally exclude vulnerable patients with unstable housing or means to communicate by phone who may be the most at risk for issues related to their ostomy.[38] Reasons for refusal to participate in the study were not collected during recruitment and may subject the findings to selection bias. However, a strength of the study was that participants represented broad age groups, racial demographics, healthy literacy, disease processes, and professional backgrounds. While the demographics of the interviewers were not explicitly disclosed to patient or caregiver participants, the assumed demographic of interviewers by interviewees may influence participant responses to interview questions. Finally, data regarding some postoperative outcomes, such as unplanned healthcare utilization, are limited by the availability of clinical documentation of events occurring at outlying institutions.

CONCLUSIONS

A new ostomy is a life-altering procedure, and patients with a new ostomy experience many barriers to effective ostomy self-care. In this qualitative study of patients with a new ostomy, their caregivers, and healthcare professionals caring for patients with an ostomy, we defined 11 barriers to perioperative ostomy care. These barriers provide targets that should be used to inform future interventions aimed at improving the care of patients with a new ostomy.

REFERENCES

1. Keng CJ, Lee J, Valencia M, et al. Transition home following new fecal ostomy creation: a qualitative study. *J Wound Ostomy Continence Nurs*. 2021;48:537–543.
2. Burgess-Stocks J, Gleba J, Lawrence K, et al. Ostomy and continent diversion patient bill of rights: research validation of standards of care. *J Wound Ostomy Continence Nurs*. 2022;49:251–260.
3. Taneja C, Netsch D, Rolstad BS, et al. Risk and economic burden of peristomal skin complications following ostomy surgery. *J Wound Ostomy Continence Nurs*. 2019;46:143–149.
4. Taneja C, Netsch D, Rolstad BS, et al. Clinical and economic burden of peristomal skin complications in patients with recent ostomies. *J Wound Ostomy Continence Nurs*. 2017;44:350–357.
5. Vogel I, Shinkwin M, van der Storm SL, et al. Overall readmissions and readmissions related to dehydration after creation of an ileostomy: a systematic review and meta-analysis. *Tech Coloproctol*. 2022;26:333–349.

6. Fish DR, Mancuso CA, Garcia-Aguilar JE, et al. Readmission after ileostomy creation: retrospective review of a common and significant event. *Ann Surg*. 2017;265:379–387.
7. Vonk-Klaassen SM, de Vocht HM, den Ouden ME, et al. Ostomy-related problems and their impact on quality of life of colorectal cancer ostomates: a systematic review. *Qual Life Res*. 2016;25:125–133.
8. Lin H, Lin R, Yan M, et al. Associations between preparedness, perceived stress, depression, and quality of life in family caregivers of patients with a temporary enterostomy. *Eur J Oncol Nurs*. 2024;70:102557.
9. Yang F, Cui S, Cai M, et al. The experiences of family resilience in patients with permanent colostomy and their spouses: a dyadic qualitative study. *Eur J Oncol Nurs*. 2024;70:102590.
10. Werth SL, Schutte DL, Stommel M. Bridging the gap: perceived educational needs in the inpatient to home care setting for the person with a new ostomy. *J Wound Ostomy Continence Nurs*. 2014;41:566–572.
11. Alenezi A, McGrath I, Kimpton A, et al. Quality of life among ostomy patients: a narrative literature review. *J Clin Nurs*. 2021;30:3111–3123.
12. Hardiman KM, Reames CD, McLeod MC, et al. Patient autonomy-centered self-care checklist reduces hospital readmissions after ileostomy creation. *Surgery*. 2016;160:1302–1308.
13. Stokes AL, Tice S, Follett S, et al. Institution of a preoperative stoma education group class decreases rate of peristomal complications in new stoma patients. *J Wound Ostomy Continence Nurs*. 2017;44:363–367.
14. Nagle D, Pare T, Keenan E, et al. Ileostomy pathway virtually eliminates readmissions for dehydration in new ostomates. *Dis Colon Rectum*. 2012;55:1266–1272.
15. Phatak UR, Li LT, Karanjawala B, et al. Systematic review of educational interventions for ostomates. *Dis Colon Rectum*. 2014;57:529–537.
16. Altschuler A, Liljestrand P, Grant M, et al. Caregiving and mutuality among long-term colorectal cancer survivors with ostomies: qualitative study. *Support Care Cancer*. 2018;26:529–537.
17. McMullen CK, Schneider J, Altschuler A, et al. Caregivers as healthcare managers: health management activities, needs, and caregiving relationships for colorectal cancer survivors with ostomies. *Support Care Cancer*. 2014;22:2401–2408.
18. Bekkers MJ, van Knippenberg FC, van den Borne HW, et al. Prospective evaluation of psychosocial adaptation to stoma surgery: the role of self-efficacy. *Psychosom Med*. 1996;58:183–191.
19. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med*. 2004;36:588–594.
20. Haun J, Luther S, Dodd V, et al. Measurement variation across health literacy assessments: implications for assessment selection in research and practice. *J Health Commun*. 2012;17(Suppl 3):141–159.
21. Sorensen K, Van den Broucke S, Fullam J, et al; (HLS-EU) Consortium Health Literacy Project European. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health*. 2012;12:80.
22. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349–357.
23. Duluklu B, Celik SS. Lived experiences of patients after colorectal cancer and permanent colostomy: a parallel-design mixed-methods study. *Adv Skin Wound Care*. 2024;37:312–318.
24. Henriksson A, Arestedt K. Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: a correlational, cross-sectional study. *Palliat Med*. 2013;27:639–646.
25. Koole D, Lans A, Lang JH, et al. Limited health literacy results in lower health-related quality of life in spine patients. *Spine J*. 2024;24:263–272.
26. Baker S, Malone E, Graham L, et al. Patient-reported health literacy scores are associated with readmissions following surgery. *Am J Surg*. 2020;220:1138–1144.
27. Wright JP, Edwards GC, Goggins K, et al. Association of health literacy with postoperative outcomes in patients undergoing major abdominal surgery. *JAMA Surg*. 2018;153:137–142.
28. Chang ME, Baker SJ, Dos Santos Marques IC, et al. Health literacy in surgery. *Health Lit Res Pract*. 2020;4:e46–e65.
29. Ketterer SN, Leach MJ, Fraser C. Factors associated with quality of life among people living with a stoma in nonmetropolitan areas. *Nurs Res*. 2021;70:281–288.
30. Giordano V, Iovino P, Corvese F, et al. Caregiver contribution to self-care and its associated variables among caregivers of ostomy patients: results of a cross-sectional study. *J Clin Nurs*. 2022;31:99–110.
31. Sun V, Bojorquez O, Grant M, et al. Cancer survivors' challenges with ostomy appliances and self-management: a qualitative analysis. *Support Care Cancer*. 2020;28:1551–1554.
32. Nasiriziba F, Saati M, Haghani H. Correlation between self-efficacy and self-esteem in patients with an intestinal stoma. *Br J Nurs*. 2020;29:S22–S29.
33. Migdanis A, Koukoulis G, Mamaloudis I, et al. Administration of an oral hydration solution prevents electrolyte and fluid disturbances and reduces readmissions in patients with a diverting ileostomy after colorectal surgery: a prospective, randomized, controlled trial. *Dis Colon Rectum*. 2018;61:840–846.
34. Harris MS, Kelly K, Parise C. Does preoperative ostomy education decrease anxiety in the new ostomy patient? A quantitative comparison cohort study. *J Wound Ostomy Continence Nurs*. 2020;47:137–139.
35. Khalilzadeh Ganjalikhani M, Tirgari B, Roudi Rashtabadi O, et al. Studying the effect of structured ostomy care training on quality of life and anxiety of patients with permanent ostomy. *Int Wound J*. 2019;16:1383–1390.
36. Reading Turchioe M, Mangal S. Health literacy, numeracy, graph literacy, and digital literacy: an overview of definitions, evaluation methods, and best practices. *Eur J Cardiovasc Nurs*. 2024;23:423–428.
37. The American College of Surgeons. Adult Colostomy/Ileostomy Home Skills Course for Patient. 2024. Available at: https://store.facs.org/adult-colostomyileostomy-home-skills-course-for-patient. Accessed June 29, 2024.
38. Decker HC, Kanzaria HK, Evans J, et al. Association of housing status with types of operations and postoperative health care utilization. *Ann Surg*. 2023;278:883–889.