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Ostomy and Continent Diversion Patient Bill of Rights

Research Validation of Standards of Care

Joanna Burgess-Stocks ◆ Jeanine Gleba ◆ Kathleen Lawrence ◆ Susan Mueller

ABSTRACT

An estimated 725,000 to 1 million people are living with an ostomy or continent diversion in the United States, and approximately 100,000 ostomy surgeries are performed each year in the United States. As a result of ostomy surgery, bodily waste is rerouted from its usual path because of malfunctioning parts of the urinary or digestive system. An ostomy can be temporary or permanent. The ostomy community is an underserved population of patients. United Ostomy Associations of America, Inc (UOAA), is a nonprofit organization dedicated to promoting quality of life for people with ostomies and continent diversions through information, support, advocacy, and collaboration. Over the years, UOAA has received hundreds of stories from people who have received inadequate care. In the United States, patients receiving medical care have certain health rights. For ostomy and continent diversion patients, these rights are known as the "You Matter! Know What to Expect and Know Your Rights—Ostomy and Continent Diversion Patient Bill of Rights" (PBOR). These rights define and provide a guide to patients and health care professionals as to what the best practices are when receiving and providing high-quality ostomy care during all phases of the surgical experience. This includes preoperative to postoperative care and throughout the life span when living with an ostomy or continent diversion.

In 2020, the National Quality Forum released "The Care We Need: Driving Better Health Outcomes for People and Communities," a National Quality Task Force report that provides a road map where every person in every community can expect to consistently and predictably receive high-quality care by 2030 (thecareweneed.org). One of the core strategic objectives this report stated is to ensure appropriate, safe, and accessible care. Actionable opportunities to drive change include accelerating adoption of leading practices. The adoption of the PBOR best practices will drive the health care quality improvement change needed for the ostomy and continent diversion population. There are concerns in the ostomy and continent diversion communities among patients and health care professionals that the standards of care outlined in the PBOR are not occurring across the United States in all health care settings. There are further concerns stated by health care professionals that the patient-centered recommendations outlined in the PBOR need to be strengthened by being supported with available published health care evidence.

The work of this task force was to bring together members of UOAA's Advocacy Committee, members of the Wound, Ostomy, and Continence Nurses Society (WOCN Society) Public Policy and Advocacy Committee, and representatives from surgical organizations and industry to create a systemic change by validating through evidence the Ostomy and Continent Diversion PBOR. Through the work of the task force, each component of the PBOR has been substantiated as evidence-based. Thus, this article validates the PBOR as a guideline for high-quality standards of ostomy care. We show that when patients receive the standards of care as outlined in the PBOR, there is improved quality of care. We can now recognize that until every ostomy or continent diversion patient receives these health care rights, in all health care settings, will they truly be realized and respected as human rights in the United States and thus people living with an ostomy or continent diversion will receive "the care they need."

KEY WORDS: Acute care, Colostomy, Continent diversions, Ileostomy, Ostomy, Patient rights, Post–acute care, Standards of care, Urostomy.

INTRODUCTION

Approximately 725,000 to 1 million people are living with an ostomy or continent diversion in the United States, and approximately 100,000 ostomy surgeries are performed each year in the United States.[1] As a result of ostomy surgery, bodily waste is rerouted from its usual path because of malfunctioning

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parts of the urinary or digestive system. An ostomy can be temporary or permanent.

The ostomy community is an underserved population of patients. United Ostomy Associations of America, Inc (UOAA), is a nonprofit organization dedicated to promoting quality of life (QOL) for people with ostomies and continent diversions through information, support, advocacy, and collaboration. Over the years, UOAA has received hundreds of stories from people who have received inadequate care. In the United States, patients receiving medical care have certain health rights. For ostomy and continent diversion patients, these rights are known as the "You Matter! Know What to Expect and Know Your Rights—Ostomy and Continent Diversion Patient Bill of Rights" (PBOR) (see Supplemental Digital Content Appendix A, available at: http://links.lww.com/JWOCN/A72). These rights define and provide a guide to patients and health care professionals as to what the best practices are when receiving and providing high-quality ostomy care during all phases of the surgical experience. This includes preoperative to postoperative care and throughout the life span when living with an ostomy or continent diversion.

In 2020, the National Quality Forum released "The Care We Need: Driving Better Health Outcomes for People and Communities," a National Quality Task Force report that provides a road map where every person in every community can expect to consistently and predictably receive high-quality care by 2030 (thecareweneed.org). One of the core strategic objectives this report stated is to ensure appropriate, safe, and accessible care. Actionable opportunities to drive change include accelerating adoption of leading practices. The adoption of the PBOR best practices will drive the health care quality improvement change needed for the ostomy and continent diversion population.

There are concerns in the ostomy and continent diversion communities among patients and health care professionals that the standards of care outlined in the PBOR are not occurring across the United States in all health care settings. There are further concerns stated by health care professionals that the patient-centered recommendations outlined in the PBOR need to be strengthened by being supported with available published health care evidence.

Thus, the goal of this task force was to bring together members of UOAA's Advocacy Committee, members of the Wound, Ostomy, and Continence Nurses Society (WOCN Society) Public Policy and Advocacy Committee, and representatives from surgical organizations and industry to create a systemic change by validating through evidence the Ostomy and Continent Diversion PBOR (Box). Through the work of the task force, each component of the PBOR has been substantiated as evidence-based. This article validates the PBOR as a guideline for high-quality standards of ostomy care. We show that when patients receive the standards of care as outlined in the PBOR, there is improved QOL. We assert that until every ostomy or continent diversion patient receives these health care rights, in all health care settings, will they truly be realized and respected as human rights in the United States and thus people living with an ostomy or continent diversion will receive "the care they need."

BOX.
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Abbreviation: UOAA, United Ostomy Associations of America, Inc.

BACKGROUND

People living with an ostomy have undergone surgery to remove their bladder or part of their bowel, which impairs their ability to store and eliminate bodily waste. Some people have a surgically created opening (stoma) in their abdomen for the discharge of waste and an external "pouching prosthetic system" is continuously worn over the stoma to replace the lost functions of waste storage and elimination. Ostomy prosthetic devices are unique to each individual's body profile and medical needs. Other people have surgically created internal diversion for the containment of stool or urine called a continent diversion.

An ostomy may be necessary due to birth defects, cancer, inflammatory bowel disease (IBD), diverticulitis, incontinence, and multiple other medical conditions. Ostomies are also necessary in cases of severe abdominal or pelvic trauma. Ostomy or continent diversion surgery can occur at any age and does not lower life expectancy. However, it may affect health-related QOL if not managed and cared for properly.

An ostomy can be temporary or permanent. A temporary ostomy gives the surgical site time to heal and ranges on average from 6 weeks to 6 months. A temporary ostomy may also be indicated to divert stool away from difficult-to-heal wounds located in the perirectal area, buttocks, or sacrum. A permanent ostomy is indicated if the small intestine is completely removed or a large part of the colon, rectum, and anus. A permanent ostomy (such as an ileal conduit) is always indicated when the bladder is removed unless a continent diversion or neobladder is the preferred surgical option.

The reaction to intestinal or urinary diversion surgery is individualized and personal. To some, it will be a problem, to others, a challenge; where one person considers it lifesaving from cancer or life-restoring after being sick for years with IBD, another finds it a devastating experience. Each person will adapt or adjust in their own way and in their own time.

COMMON TYPES OF OSTOMIES

A colostomy is a surgically created opening in the abdomen in which a piece of the colon (large intestine) is brought outside the abdominal wall to create a stoma through which digested food passes into an external pouching prosthetic system. A colostomy is created when a portion of the colon or rectum is removed or needs to be bypassed due to a disease process or damaged area of the colon.

An ileostomy is a surgically created opening in the abdomen in which a piece of the ileum (lowest part of the small intestine) is brought outside the abdominal wall to create a stoma through which digested food passes into an external pouching prosthetic system. An ileostomy is created when the colon needs to be removed or bypassed due to a disease process.

A urostomy is a surgically created opening in the abdominal wall through which urine passes. A urostomy is created when the bladder is either not functioning or must be removed. The bladder is surgically removed or bypassed. A conduit is typically made from a short segment of the ileum. One end of the conduit is sewn closed, and the other end is brought to the outside of the surface of the abdomen to create a stoma. The ureters are connected to the conduit. There are several different types of surgeries, but the most common are ileal conduit and colonic conduit.

Not all ostomy types require an external pouching prosthetic system. For people who meet specific surgical requirements, and desire not to wear an external pouch, a continent fecal or urinary diversion may be a preferred option.

COMMON TYPES OF CONTINENT FECAL DIVERSIONS

A continent ileostomy, also called Kock pouch or Barnett Continent Intestinal Reservoir (BCIR), depending on the surgical approach, is an internal pouch (reservoir) with a nipple type valve that is constructed from a section of the small intestine. The valve is connected to a stoma located on the abdominal wall. The valve helps keep stool and gas from leaking out of the stoma. A catheter is inserted into the stoma to empty the reservoir every 4 to 6 hours throughout the day and for purposes of irrigation and emptying.

An ileoanal reservoir/pelvic pouch is constructed from loops of the small intestine connected to the internal anal sphincter, which provides continence. Depending on the surgical configuration of the internal reservoir, it is sometimes called a J, S, or W pouch. Stool is eliminated through the anus. This procedure most often is performed on patients with ulcerative colitis or familial polyposis who have not previously lost their anal sphincters. It is also called ileoanal anastomosis, endorectal pull-through, and ileal pouch anal anastomosis (IPAA).

COMMON TYPES OF CONTINENT URINARY DIVERSIONS

Continent urinary pouches are called by different names according to how they are surgically constructed and where they are located. Names include Indiana pouch, Kock pouch, Mitrofanoff, Miami, and Mainz. This is a surgical procedure in which the bladder is removed or bypassed. An internal reservoir is created by opening loops of the small or large intestines and then using them to create an internal pouch or pseudobladder. A stoma is created on the abdomen and is connected to the reservoir. Urine is drained using a catheter every 4 to 6 hours throughout the day.

An orthotopic urinary diversion (also referred to as a neobladder) is a reservoir surgically created from the small intestines, much like the continent pouch. It is created to store urine and connected to the urethra to allow urine to be voided per the urethra. It is considered a bladder substitute.

EVOLUTION OF OSTOMY AND CONTINENT DIVERSION PATIENT BILL OF RIGHTS

For decades, there has been a worldwide trend recognizing human rights in health and expanding patient rights across all health care.[2] In 1946, the World Health Organization Constitution foresaw "…the highest attainable standard of health as a fundamental right of every human being."[3] A subset of human rights is patient health rights. In the United States, patients receiving medical care have certain rights. Most are not legally binding declarations; however, some are guaranteed by federal law, such as the right to high-quality care and the right to informed consent. This means that if a person needs a treatment such as ostomy surgery, their health care provider must give them the information they need to make a decision.

The original "Ostomate Bill of Rights" was presented to the United Ostomy Association (UOA—the predecessor organization to United Ostomy Associations of America, Inc [UOAA]) by the International Association of Enterostomal Therapists (now known as the Wound, Ostomy, and Continence Nurses Society [WOCN Society]) at the UOA House of Delegates Meeting during the Annual Conference in 1977, where they were adopted by UOA. The goal then was to inform people living with an ostomy that all elements of quality care should be available to them. According to Merriam Webster dictionary, "ostomate" is a medical term that is defined as someone who has undergone an ostomy.[4] This informal term, also used internationally, to characterize someone with an ostomy will be used throughout this article.

In recent years, UOAA's goal has been to drive change across the country to help improve the quality of health care for people with an ostomy or continent diversion and ensure higher standards of care in all health care settings. As a result, in 2017, UOAA's Advocacy Committee revised these rights through a consensus-building format, now known as the "Ostomy and Continent Diversion Patient Bill of Rights."[5] At the 2017 National Conference board meeting, UOAA's Management Board of Directors formally adopted the revised Ostomy and Continent Diversion PBOR. They were most recently revised in 2021.

In 2019, UOAA presented a poster at the WOCN Society WOCNext Conference, titled "What's in Your Wallet? Utilizing UOAA's Patient Bill of Rights, Nurses Can Act as Influencers for Ostomy Patients" (see Supplemental Digital Content Appendix B, available at: http://links.lww.com/JWOCN/A73). The purpose was to raise awareness and increase utilization of the PBOR among ostomy nurses with the objective to reinforce through education that this is a tool to promote best practice in all health care settings. An accompanying tool, "Inspire Excellence," was created for nurses to help them understand how to utilize the PBOR.

These patient rights have received the endorsement of medical professional societies and organizations such as the American Society of Colon & Rectal Surgeons, the WOCN Society, the Wound, Ostomy and Continence Nursing Certification Board, the Society of Urologic Nurses and Associates,

the International Foundation for Gastrointestinal Disorders, and the National Alliance of Wound Care and Ostomy, as well as industry endorsements from companies such as Coloplast, ConvaTec, and Hollister, Inc. They are also included in the WOCN Society's *Clinical Guidelines for Management of the Adult Patient With Fecal or Urinary Ostomy* and UOAA's New Ostomy Patient Guide.

PURPOSE OF THE OSTOMY AND CONTINENT DIVERSION PATIENT BILL OF RIGHTS

Similar to the American Hospital Association PBOR that were first adopted in 1973, the Ostomy and Continent Diversion PBOR were revised to fill a void in quality ostomy care and meet the needs specific for this patient population with the expectations that:

- Health care facilities would support these rights to deliver high-quality ostomy patient-centered care, as well as improve patient outcomes and patient satisfaction. Delivery of care includes access to outpatient ostomy clinics and certified WOC nurse/ostomy specialists.
- Health care providers would utilize and recognize these rights as guidelines for best in practice standards of quality care.
- Patients would be involved in all phases of the surgical experience except in emergent situations.
- Patients would have a tool that empowers them to advocate for their own care. They would know what is reasonable to ask for to facilitate the best outcome, as well as have clear expectations when they undergo treatment.
- Patients and their health care providers would recognize the importance of a strong collaborative relationship with each other.

Key Takeaway

Patients are guaranteed high-quality care in hospitals. The PBOR specifically defines what high-quality care should be expected and received during the ostomy surgical experience and for continuum of care.

PURPOSE OF WHITE PAPER

Concerns remain in the ostomy and continent diversion communities that the standards of care outlined in the PBOR are not occurring across the United States in all health care settings and patients are not receiving high-quality ostomy care. The first study (Miller[6]) to report a gap in our knowledge of the PBOR standards of care versus the care patients reported receiving following ostomy surgery was published in 2020. Miller's[6] results indicate that some care measures in accordance with the PBOR were not consistently provided to ostomy patients and that ostomy care in the hospital can improve. In Gleba and colleagues,[7] preliminary results corroborates the Miller study. In this study, a majority of both clinicians and patients reported that the recommended standards of care outlined in the PBOR are being utilized but not consistently and not all of the standards of care in the PBOR are being performed by clinicians during the surgical experience.[7]

United Ostomy Associations of America, Inc, has also received feedback from health care professionals that the PBOR should be strengthened and supported with evidence-based research. As a result, a task force was formed by UOAA's Advocacy Committee. The task force created was diverse and represented by patients, health care professionals, and industry. The goal was to build consensus statements validating the Ostomy and Continent Diversion PBOR through a comprehensive literature review. The literature review substantiates the PBOR as an evidence-based document that provides the standards of high-quality care as best in practice for those living with an ostomy or continent diversion.

In 2021, the European Ostomy Association (EOA) declared the motto for World Ostomy Day as "Ostomates' Rights Are Human Rights—anytime and anywhere!" The COVID-19 pandemic brought several unforeseen outcomes that impacted the ostomy community around the world. There were delays in diagnosis and this lifesaving surgery. The ability for patients to meet with visitors stopped. This included ostomy mentor visits, which provided the needed emotional support from someone living with an ostomy. Home care by ostomy nurses was also reduced, and there was limited access to ostomy products due to supply chain issues and decreased affordable appliances in some countries. These concerns rekindled a focus on the International Charter of Ostomates' Rights. The EOA's goal is to "underline that ostomate rights are not negotiable. They must be respected by governments, politicians, health care authorities, companies and suppliers, by doctors and nurses, by every human and by every society—even in uncertain times." This White Paper aspires to achieve this goal in the United States.

RESEARCH VALIDATION OF STANDARDS OF CARE RECOMMENDED IN THE PBOR

To achieve a desirable QOL, a person undergoing ostomy or continent diversion surgery must have access to high-quality care in all health care settings. The components outlined in the PBOR including counseling, care, and educational instruction should be provided by a health care professional who specializes in ostomy care such as a Certified Wound Ostomy Continence Nurse,[8] Certified Ostomy Care Nurse, Ostomy Management Specialist, or Ostomy Care Associate. Coca and colleagues[9] found in their research that patients experienced significant improvements in health-related QOL such as self-management of the ostomy and greater security in their ability to obtain ostomy supplies when they received care from an ostomy nurse specialist in hospitals versus those who did not receive care by specialty nurses.[9] A disclaimer appears on the PBOR indicating that the following rights/standards of care may be limited or compromised due to instances when surgery is emergent. Additionally, the PBOR notes that the patient shall be involved in all phases of the surgical experience.

PREOPERATIVE PHASE

Statement 1: Preoperative stoma site marked by a certified medical professional following the standards of care established by the WOCN Society with the American Society of Colon &Rectal Surgeons and the American Urological Association.

Preoperative ostomy education and stoma site selection are vital to the success of postoperative rehabilitation. These elements should be performed for all ostomy patients whenever medically possible. The global standard requires preoperative education and stoma site selection administered by educated and trained clinicians such as surgeons and ideally certified WOC nurses/enterostomal therapists. Preoperative stoma site marking by qualified clinicians such as a certified WOC nurse serves a highly protective role in preventing peristomal skin complications

(PSCs) and improving QOL.[10,11] Proper siting of the ostomy location decreases complications postoperatively (eg, pouch leakage) and improves wear time, which enhances self-care and patient adaptation to an altered elimination process.[8,12,13]

Proper preoperative marking of the prospective stoma is a multistep process that takes into consideration body contours, patient build, expected location based on proposed surgical procedure, and the individual patient demographic, physical, and comorbid conditions, which all factor into proper stoma marking.[12,13]

In a retrospective analysis of 1076 patients, the most important finding by Arolfo and colleagues[14] was the highly protective role of preoperative stoma site marking in dramatically reducing complications. The QOL of the patients whose stoma sites had been preoperatively marked was significantly better than that of the unmarked patients. Also noted in this study was that enterostomal (WOC) nurses have a key role in preoperative marking and counseling and are in a position to raise awareness among surgeons on the importance of this practice.[14] Hsu and colleagues[15] in a systematic review of the literature noted preoperative stoma site marking for fecal diversions reduced early and late PSCs and hernia incidence compared to patients with unmarked stomas.

Regardless of the type of ostomy, Person and colleagues[16] found in a comparison study that preoperative stoma site marking resulted in significantly better QOL, improved patients' confidence and independence, and lowered rates of postoperative complications versus those patients who did not get stoma site marking. This work also validated the role of the enterostomal therapist (WOC nurse) in the preoperative evaluation and assessment of all future ostomates.[16]

Statement 2: Explanation of the surgical procedure and the rationale for surgery.

Statement 3: Education provided on living with an ostomy/continent diversion and self-care postdischarge.

Preoperative ostomy/continent diversion education prior to surgical intervention is a standard of care that decreases emotional stress, improves postoperative outcomes, and improves the quality of the surgical experience for the patient. Preoperative education starts with the first interaction with the surgical team and continues through the perioperative process. Research is lacking on the exact components of preoperative education for the patient having urinary or bowel diversion. However, the literature does support the integral role of the WOC nurse/enterostomal therapy nurse in the preoperative educational process.[8,13] In the WOCN Society's *Clinical Guideline: Management of the Adult Patient With a Fecal or Urinary Ostomy*, by consensus of an expert panel, the components of education should include discussion of anatomy and physiology of the genitourinary or gastric tract, description of planned surgical procedure, overview of lifestyle modifications, introduction of pouching system, and a focus on psychological preparation.[17] The World Council of Enterostomal Therapists International Ostomy Guideline asserts that preoperative education for both the patient and the family should include the surgical procedure and postoperative management.[18]

In Ontario Province, an Enhanced Recovery After Surgery (ERAS) guideline was developed by a network of enterostomal therapy (WOC) nurses from 15 hospital organizations.[19] The intent of the ERAS guideline was to standardize care and mitigate postoperative complications and enhance timely recovery from surgical interventions. This guideline suggested additional preoperative information that included postoperative expectations of learning self-care and possible postoperative complications. For nonemergent surgery, patients should be encouraged to practice wearing and emptying a pouch and doing a pouch change at home prior to surgery.[19]

Statement 4: Information about the impact of surgery on daily activities including adapting physically and emotionally and lifestyle changes such as clothing choices, exercise, diet, and sexuality.

Statement 5: The opportunity to talk with someone who has been through ostomy or continent diversion surgery.

Statement 6: The opportunity to discuss the emotional impact of surgery.

Ideally, the discussion of patient adaptation and integration of an ostomy or a continent diversion would start in the preoperative phase of preparation. Discussions may include the expected direct postsurgical restrictions on diet and exercise with the projected advancement of diet and activity in acute care. Quality-of-life indicators covering physical and emotional adaptation, activities of daily living, diet, and sexuality are all important elements that may be included preoperatively and also in the postoperative educational process.[8,17-19]

Integration of change in body image and physical and emotional adjustments are facilitated by the opportunity to speak with an individual who has had a bowel or bladder diversion.[19] Those living with an ostomy can share experiences and provide practical and emotional support that contributes to QOL and emotional balance for those with a new ostomy or continent diversion.[20]

Access to UOAA-certified visitors, through their Ostomy Patient Visiting Program, and ostomy support groups has been shown to influence the rate of adaptation.[21] When available, a UOAA mentor/visitor should be called to meet with an ostomy patient either before or after surgery.[22] Grant and colleagues[23] investigated QOL for patients with an ostomy via several surveys and an extensive literature review. Their team developed the Chronic Care Ostomy Management Program based on the Institute of Medicines Chronic Care Model. Identified as integral to the program was peer-to-peer support and education in tandem with ostomy nurse facilitation.[23]

Statement 7: Counseling, care, and educational instruction in a language and at a level of understanding suitable for the patient. Communication will be culturally sensitive and delivered in a dignified manner.

The WOCN Society's *Scope and Standards of Practice*[13] address the important role of patient-focused health teaching and health promotion, as well as the importance of cultural inclusion and diversity. Strategies include the provision of opportunities for the health care consumer to identify needs/topics for education in health promotion, disease prevention, and self- management. This information should be delivered at the correct developmental level, based on learning needs, readiness to learn, and language preference, as well as using tools that are appropriate for culture, literacy, and language. Information should be provided in a variety of modalities including, but not limited to, verbal, written, and digital formats. Multilingual educational resources should be available for non–English-speaking patients and families.[19]

Patients are more than just their medical history. Clinicians should assess any cultural implications related to care to address concerns of these patients and provide appropriate care. Cultural and religious beliefs significantly impact the patient experience. Both cultural competence and cultural humility are concepts that must be utilized by the health care provider when preparing the patient for bowel or bladder surgical

procedures. Understanding the impact of externalization of bowel or bladder contents and various religious tenets is crucial for positive patient outcomes.[24] Modern health disparities are also linked to gender and sexual orientation, which also demand attention of inclusivity by the health care provider when ensuring proper preoperative education and postoperative expectations.

There are many additional individual factors that may contribute to the need to modify counseling and education of ostomy management skills. Language, age, and learning ability must be assessed, and various methods of approaching preoperative education must be utilized for successful comprehension by the patient approaching surgical diversion.[25] Age may influence vision, hearing, and manual dexterity. Learning disabilities and dementia may not only prompt modification of the educational plan to accommodate alternative teaching strategies but also dictate the inclusion of caregivers and family support in the overall process.[26]

OPERATIVE PHASE

Statement 1: A stoma that can be fit with a reliable pouching system.

Almost 50% of ostomies present with postoperative management problems such as pouching difficulties and PSCs, which can result in prolonged medical care and increased costs on the health care system.[8]

It is noted that the construction of the stoma including height and protrusion above the skin is one element under the surgeon's control.[8] A high-quality, multicenter study in which protrusion was measured showed a correlation between stoma protrusion and patient success in self-care.[8] This technical ostomy creation consideration, which addresses minimizing direct contact of effluent on the skin, has been confirmed in other research literature.[22,27,28] Whenever technically feasible, surgeons should avoid ostomies that are flush with the skin to help ensure the stoma can be fit with a reliable pouching system.

Statement 2: A stoma that is well positioned for the patient's unique body shape and medical condition.

The development of many common postoperative stoma-related complications is caused by stomas that have been placed in suboptimal locations.[28] Suboptimal stoma siting can result in poor visualization of the stoma, ill-fitting pouching systems, leakage of effluent, and skin irritation. These difficulties may have a negative psychological impact, create difficulty with self-care, influence poor adjustment to the ostomy, increase emergency department visits and hospital readmissions, and increase use of ostomy supplies to achieve proper prosthetic function.[10,14,27-29]

Issues surrounding stoma placement and management can be avoided through consideration of the needs of each individual patient (eg, age, vision, dexterity, disabilities, and physical factors such as body shape and obesity). It is critical that surgeons pay meticulous attention to the technical aspects of creating a stoma.[28] Numerous studies have found that appropriate stoma siting by the surgeon reduces the likelihood of problems with leakage and other complications.[14,29-31] To reduce PSCs, the most important thing that a surgeon can do is to create stomas that protrude well above the skin. Appropriately constructed stomas can minimize effluent directly touching the skin.[10,28,29] Every patient should have a best attempt made at proper construction and positioning of a stoma that fits their unique needs.

POSTOPERATIVE NURSING CARE SPECIFIC TO OSTOMY/CONTINENCE DIVERSION TYPE

Statement 1: Postoperative nursing care specific to ostomy/continent diversion type for patient and their designated advocate will include:

- *Individual instruction in ostomy care including patient returndemonstration of emptying and changing pouch.*
- *Ways to troubleshoot difficulties with basic skin and stoma issues including skin irritation, stoma blockage, hernia, and prolapse.*
- *Dietary guidelines and strategies to prevent dehydration given both verbally and in a written format.*
- *Providing the most current educational materials based on ostomy type.*

Current Centers for Medicare & Medicaid Services (CMS) regulations §482.43(c)(7) require hospitals implement an effective discharge planning process that focuses on patient-oriented goals and includes the patient and caregivers as active partners in the discharge planning process. This process and the discharge plan must be consistent with the patient's goals for care and treatment plan of care. The process must ensure effective transition of care from acute care to post–acute care at discharge with a focus on preventing hospital readmissions postdischarge.[32]

Patients who have undergone ostomy surgery respond to their stoma, in part, due to the circumstances that necessitate stoma creation (removal of diseased bowel vs advanced cancer vs trauma). Regardless of the reasons for the surgery, new ostomates experience an altered self-concept and body image. They must learn new ways of body self-care and lifestyle changes.

Successful adaptation to ostomy self-care requires a foundation of ostomy education and psychosocial support.[13] Postoperative ostomy-related problems requiring medical assistance are common, and inadequate education of ostomy patients may result in impaired self-care, social isolation, depression, and increased health care costs.[8]

The American Society of Colon & Rectal Surgeons has stated that optimal care for ostomy surgery patients requires preoperative, perioperative, and postoperative care by an ostomy nurse specialist,[33] that is, a nurse who has received additional preparation in ostomy care.

Ostomy education involves more than how to empty a pouch; it begins with this basic skill and the expectation of patient/caregiver participation and return demonstration.[34] Recommended components of basic ostomy education include physiology (gastrointestinal and urinary systems), ostomy management (ostomy appliances), diet and fluid guidelines, psychological issues (body image, personal relationships, depression, anxiety), common complications, sexual and intimacy issues, and how to order supplies.[13,34]

Steinhagen and colleagues[35] suggest using trusted resources for patient education. These include videos, webinars, podcasts, and printed materials to increase patient comprehension and skill acquisition. Reliable sources for education materials include medical organization Web sites such as the American College of Surgeons and the WOCN Society and patient-based organization Web sites and publications such as UOAA. Other trusted sources to inform the patient include product manufacturers' online educational materials.

In the acute care setting, patient readiness to assimilate the new skills and retain information is impacted by the effects of surgery, anesthesia, and patient level of function. Over the decades, hospital stays have become shorter and the progression of ostomy education continues into the community—to home health care, acute rehabilitation hospitals, long-term acute care hospitals, and skilled nursing facilities. The majority of education of long-term ostomy management must be provided after hospital discharge.[36] Assistance with transitions of care requires communication with all caregivers and settings about patient care needs, required supplies, and level of independence in ostomy management.[34]

Patients who receive proper education have fewer complications, fewer hospital readmissions, and higher QOL scores.[37,38] As ostomy patients learn to live with their new circumstance and begin to adapt, they need to advance their skills and learn to troubleshoot problems such as dehydration, blockages,[39-42] and PSCs.[43] Follow-up visits in the community promote patient independence in self-care and promote successful adaptation.[19]

Statement 2: Postoperative nursing care specific to ostomy/continent diversion type for patients and their designated advocate will include:

- *Information on the variety of product choices available from manufacturers.*
- *Information about the supply ordering process.*
- *Resources for obtaining supplies specific to patient circumstances (eg, uninsured/underinsured).*
- *Information about manufacturers' postdischarge support programs.*

Once in the community, the provision of supplies is of prime importance to the person new to living with an ostomy. People living with an ostomy need to understand and be able to communicate what supplies they need, what is authorized by their payer source, and where and how to order.[34,36] Although this process is similar to other health care product supply systems, it is less familiar and because ostomy products replace bodily functions, shortages can result in inappropriate hospital emergency department visits.

Once the ostomate has returned home, resumption of normal diet, life activities, and changes in stoma size and protrusion may test the pouching systems implemented during health care facility admission and adjustments may be necessary. A well-prepared ostomate will realize that there are options and resources to ensure a well-functioning pouching system.[34,44]

Findings in several studies suggest that Web-based patient support resources[45] and enrolling patients in the postdischarge ostomy support programs provide other cost-saving and effective approaches to reducing preventable health care utilization.[46] Another study that surveyed patients found that 99.7% were satisfied with the support received from clinical ostomy nurses from product call centers. This type of support included education and recommendations, which positively impacted their pouch wear time, thereby improving the customer's QOL.[47]

Availability of ostomy aftercare varies significantly in communities so that some communities have no local choices. In this case, the ability to access contact with certified WOC/ostomy specialists and supply experts through manufacturers' support services is important.[34,46,48]

Statement 3: Postoperative nursing care specific to ostomy/continent diversion type for patients and their designated advocate will include providing information about organizations that support and advocate for patients living with an ostomy or continent diversion such as UOAA and their affiliated support groups.

Managing waste elimination with medical prosthetic supplies is a significant challenge. How a patient processes the way they feel about oneself, and the way a person living with an ostomy or continent diversion relates to their close social circle and to the community, is a different challenge. Cultural beliefs regarding body waste present another barrier to acceptance of the new way of function.[21,49] The road to acceptance and integration is mined with emotional challenges. Persons with an ostomy report that these challenges are easier to speak about with another ostomate. They favor group learning with peers.[50,51] Studies have concluded that "layperson led self-management education may improve self-efficacy, self-rated health, and cognitive symptom management."[51(p410)]

WOC nurse clinical experiences were published by Cross and Hottenstein,[50] who were able to demonstrate that when patients have the opportunity to attend a hospital-based ostomy support group they move quicker toward acceptance of their ostomy when they interact with others who have shared similar experiences. Many UOAA-affiliated support groups are led by certified WOC nurses.

It is easy to feel alone when a person is new to an ostomy. However, organizations that support and advocate for people living with an ostomy provide solidarity. That sense of feeling alone begins to dissipate when an ostomate joins a support group, receives a magazine about living with an ostomy, runs a race and cheers for runners participating in ostomy awareness events, or writes a letter to legislator about bills to assist ostomates.[21,50]

ONGOING OSTOMY CARE

Statement 1: During the life span of the ostomy or continence diversion, access to ongoing ostomy care and support includes health care professionals with knowledge specific to the care of an ostomy/continent diversion in all health care settings including telemedicine.

Patients who have had surgery for an ostomy will face risks of developing a stoma complication or a PSC at some point during their life whether the ostomy is temporary or permanent. It is vital that patients learn self-assessment skills of their ostomy site and have access to a clinician who is an expert in ostomy care. More than 80% of the patients within 2 years of surgery will develop PSCs, such as irritant contract dermatitis, which is one of the many postoperative skin and stoma complications.[52] During the first 5 years after stoma creation, the incidence of a complication is highest.[28] Postoperative evaluation is recommended 1 to 6 weeks after discharge, with a follow-up visit 3 months after surgery. Evaluation is meant to address any persisting complications both physically and psychologically, to provide care, and to refer to any additional services that may be needed. Evaluation annually is recommended for ongoing preventive care and includes making any necessary changes to the ostomy pouching system that may be indicated and providing continued emotional support.[53,54]

Results of an international consensus and several studies support the vital role that certified ostomy nurse specialists play in providing care to ostomy patients postoperatively. Results validate that there are reduced complications by the provision of follow-up stoma care, support, information, and resources. This role also aids in the adaptation process to an ostomy and thus improves long-term outcomes and overall QOL.[17,28,55,56]

To further validate the importance of postoperative follow-up care, the American Society of Colon & Rectal Surgeons Clinical Practice Guidelines state, "…the optimal care for patients undergoing ostomy surgery includes preoperative, perioperative, and postoperative care by an ostomy nurse specialist, such as a nurse certified by the Wound, Ostomy, and Continence Nurses Society (WOCN) Certification Board."[8(p381),17] For surgeons who do not have access to a certified WOC/ostomy specialist, it is an opportunity to advocate for these positions and offer opportunities for nursing staff to get certified at their facility/institution by providing the rationale for their services to leadership in administrative roles. Surgeons should also refer their patients to support groups and manufacturer post-discharge support programs that have certified WOC/ostomy specialists on staff.

The role of the certified WOC/ostomy specialist in the outpatient setting is recommended for ongoing follow-up care for the recent postoperative patient and for the patient with a long-term ostomy. The role is supported by a multidisciplinary medical community and by the patient who faces ongoing challenges related to stoma complications and PSCs. Without expert follow-up care, patients often turn to lay people with ostomies through support channels where information may be misrepresented and misinterpreted and may not be medically accurate for their individualized needs. Certified WOC/ostomy specialists in the outpatient setting serve roles of care provider, educator, and counselor and thus increase the potential of a patient to adapt to their ostomy and eventually thrive leading to a restored QOL.

Statement 2: During the life span of the ostomy or continence diversion, access to ongoing ostomy care and support includes reevaluation of ostomy management and supplies following changes in medical condition, aging, and social/economic status.

Ostomy surgery does not discriminate. It is performed at any age from the neonate to the senior citizen and on all races. Many persons with stomas can expect to have problems with stoma complications and issues with physical, social, and psychological adaptation, including depression.[57,58] In the WOCN Society's *Clinical Guidelines: Management of the Adult Patient With a Fecal or Urinary Ostomy*, the lifelong needs of the person living with an ostomy are discussed. These needs include follow-up care, assessing physical characteristics of the stoma and peristomal skin, and postoperative management of at-risk patients such as those with high ileostomy output.[17] In one qualitative study cited, the investigators concluded that periodic checkups and follow-up care with a WOC nurse can address the needs for long-term, supportive care for both patients and their families.[49]

In 2019, Colwell and colleagues[56] released an international consensus study regarding the need for ongoing assessment and consultation with an ostomy care nurse. Of importance, it was noted the need to select and change products as necessary for the patient due to stoma or skin complications. It also showed that 63% in this study reported having at least one ostomy self-care problem such as leakage.[56] Furthermore, it has been shown that annual visits with a clinician are important for preventive ostomy care.[53] These visits also provide the opportunity to address issues and concerns such as a new medical condition affecting self-care such as a change in mental status or mobility/dexterity issues. It is also an opportunity to address individual cultural concerns and psychological needs.[53]

Aging can bring a new set of needs and challenges in learning or maintaining independence with ostomy self-care.[26,44] Cognitive changes and hearing and vision loss may impact whether instructions are being understood and whether instructional modifications are necessary.[44] Changes in fine motor skills and dexterity can affect the ability to cleanse the skin, open supply packaging, empty a pouch, and apply ostomy products with the proper technique.[44,59] Howson[59] reported involvement by a stomal therapy nurse to identify the barriers to self-care, provide education, and adapt product selection to achieve desired function can help the elderly ostomy patient.

Ostomy care needs change across the life span with each new development stage. As body contour and shape change, there is often a need to alter, update, or change the ostomy pouching system. New medical conditions or a change in lifestyle or socioeconomic status also creates the need for reevaluation of ostomy status by a certified WOC/ostomy specialist. This guidance helps the patient avoid multiple attempts of trial and error and helps prevent ostomy complications.

Statement 3: During the life span of the ostomy or continence diversion, access to ongoing ostomy care and support includes ongoing emotional/social support.

Few hospitals in the United States have structured postoperative follow-up programs or outpatient ostomy clinics for patients with a new ostomy or ongoing care needs. The presence of a stoma in individuals causes physical, psychological, and social problems. For this reason, individuals with an ostomy need effective psychosocial interventions throughout their lives to adapt to the stoma and maintain a positive QOL. One of the most effective psychosocial interventions is support groups to meet social support needs. Many studies show support group interventions have positive effects and individuals improve their QOL.[20] Pittman and colleagues[45] evaluated free Web-based patient support resources designed for those who have recently undergone ostomy surgery. The study found that Web-based resources that contained ostomy patient education content such as self-management training and support materials that met best practice standards are a practical alternative to supplement patient education after surgery.[45] The UOAA Web site scored highest for evidence-based content and usability.[45]

For those living with an ostomy, especially in rural areas without access to a certified WOC/ostomy specialist who provide quality ostomy care and needed support, their medical team should recommend ostomy support groups (online or in-person) and Web-based resources such as UOAA or ostomy supply manufacturer Web sites as choices for ongoing emotional/social support.

Statement 4: During the life span of the ostomy or continence diversion, access to ongoing ostomy care and support includes specific and individualized ostomy supplies chosen in consultation with a health care provider to achieve and maintain a reliable fitting pouching system.

Every individual has unique ostomy pouching needs due to body contours, skin type, type of stoma effluent, the level of protrusion (which determines how well the waste will drain into the pouch), and even environmental concerns. Colwell and colleagues[56] indicate that pouch seal security and peristomal skin integrity are the most important factors in decision making when determining product choices. These authors further state that assessment of the patient's body and stoma profiles is needed to provide patients with confidence and security with pouch placement.[56]

It is crucial that ostomates have access to compatible and securely fitting ostomy products to improve patient outcomes and avoid medical consequences such as PSCs and hospital

readmissions.[60,61] Additionally, when a patient with an ostomy develops a PSC, access to and utilization of a variety of products, such as rings/seals, and stoma skin powder is necessary for intervention and treatment of PSCs.[54]

To attain a properly fitted well-sealed pouching system and achieve prosthetic function for collecting bodily waste, ostomy product selection requires a health care professional's (such as a certified WOC/ostomy specialist) ongoing services for assessment, selection, fitting, training, and adjustments that may be necessary during the continuum of care for the ostomy.[53,56]

GOING FORWARD

The ostomy community is an underserved population of patients. United Ostomy Associations of America, Inc, has received hundreds of stories over the years from people who have not received quality care after ostomy surgery, who were unable to find care, or who were completely uninformed about the care they should have received. The work of this task force was to bring together members of UOAA's Advocacy Committee, members of the WOCN Society Public Policy and Advocacy Committee, and representatives from surgical organizations and industry to create a systemic change by validating through research the Ostomy and Continent Diversion PBOR.

By recognizing the PBOR as best in practice standards of high-quality care for people undergoing surgery or living with an ostomy or continent diversion, substantiated as evidence-based, it is hopeful that this is the start of a system-wide change across all health care settings. By using these standards of care, we want to make our voices known that there is a need for more certified ostomy care nurses, more outpatient ostomy care services, and more access to ostomy and continent diversion education and peer support for all people who face and will face ostomy or continent diversion surgery. It is important to note that the amount of evidence-based research that exists in supporting these standards of care far exceeds what is included in this policy paper.

The task force recognizes that there is substantial evidence found in research to show that if patients receive the standards of care outlined in the PBOR, improved quality of care would be seen, decreased costs would be incurred, and people facing ostomy surgery would be better informed and aware of the importance of this surgery, thus ending the fears and stigma associated with an ostomy and ultimately saving more lives. Only when every ostomy or continent diversion patient receives these health rights in all health care settings will they truly be recognized and respected as human rights in the United States.

REFERENCES

1. United Ostomy Associations of America, Inc. What is an ostomy? https://www.ostomy.org/what-is-an-ostomy. Accessed July 16, 2021.
2. Olejarczyk JP, Young M. *Patient Rights and Ethics*. Treasure Island, FL: StatPearls Publishing; 2021. https://www.ncbi.nlm.nih.gov/books/NBK538279. Accessed May 28, 2021.
3. World Health Organization. Human rights and health fact sheet. https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health. Published December 29, 2017. Accessed July 16, 2021.
4. Medical Dictionary, Merriam-Webster. Ostomate. https://www.merriam-webster.com/medical/ostomate. Accessed August 30, 2021.
5. United Ostomy Associations of America, Inc. Ostomy and Continent Diversion Patient Bill of Rights. https://www.ostomy.org/wp-content/uploads/2019/03/BillofRights_Wall_Hanging_format_20180402.pdf. Accessed July 16, 2021.
6. Miller LR. Ostomy care during hospital stay for ostomy surgery and the United Ostomy Associations of America Patient Bill of Rights: a cross-sectional study. *J Wound Ostomy Continence Nurs*. 2020;47(6):589-593. doi:10.1097/WON.0000000000000709.
7. Gleba J, Riggle Miller L, Beck BM, Burgess-Stocks J. United Ostomy Associations of America's Ostomy and Continent Diversion Patient Bill of Rights: an examination as best-in practice care for ostomy patients. *J Wound Ostomy Continence Nurs*. 2022. Pending publication July/August 2022.
8. Hendren S, Hammond K, Glasgow SC, et al. Clinical practice guidelines for ostomy surgery. *Dis Colon Rectum*. 2015;58(4):375-387. doi:10.1097/DCR.0000000000000347.
9. Coca C, Fernández de Larrinoa I, Serrano R, García-Llana H. The impact of specialty practice nursing care on health-related quality of life in persons with ostomies. *J Wound Ostomy Continence Nurs*. 2015;42(3):257-263. doi:10.1097/WON.0000000000000126.
10. Kwiatt M, Kawata M. Avoidance and management of stomal complications. *Clin Colon Rectal Surg*. 2013;26(2):112-121. doi:10.1055/s-0033-1348050.
11. Maydick D. A descriptive study assessing quality of life for adults with a permanent ostomy and the influence of preoperative stoma site marking. *Ostomy Wound Manag J*. 2016;62(5):14-24.
12. WOCN Society, AUA, and ASCRS position statement on preoperative stoma site marking for patients undergoing ostomy surgery. *J Wound Ostomy Continence Nurs*. 2021;48(6):533-536. doi:10.1097/WON.0000000000000820.
13. Wound Ostomy Continence Nurses Society. *Wound, Ostomy, and Continence Nursing: Scope and Standards of Practice*. 2nd ed. Mount Laurel, NJ: WOCN Society; 2018.
14. Arolfo S, Borgiotto C, Bosio G, Mistrangelo M, Allaix ME, Morino M. Preoperative stoma site marking: a simple practice to reduce stoma-related complications. *Tech Coloproctol*. 2018;22(9):683-687. doi:10.1007/s10151-018-1857-3.
15. Hsu MY, Lin JP, Hsu HH, Lai HL, Wu YL. Preoperative stoma site marking decreases stoma and peristomal complications: a meta-analysis. *J Wound Ostomy Continence Nurs*. 2020;47(3):249-256. doi:10.1097/WON.0000000000000634.
16. Person B, Ifargan R, Lachter J, Duek SD, Kluger Y, Assalia A. The impact of preoperative stoma site marking on the incidence of complications, quality of life, and patient's independence. *Dis Colon Rectum*. 2012;55(7):783-787. doi:10.1097/DCR.0b013e31825763f0.
17. Wound, Ostomy, and Continence Nurses Society. *Clinical Guideline: Management of the Adult Patient With a Fecal or Urinary Ostomy*. Mount Laurel, NJ: WOCN Society; 2017.
18. Stelton S, Zulkowski K, Ayello E. Practice implications for peristomal skin assessment and care from the 2014 World Council of Enterostomal Therapists International Ostomy Guideline. *Adv Skin Wound Care*. 2015;28(6):275-284; quiz 285-286.
19. Miller D, Johnston D, Frecea M, McKenzie M, Pearsall E. Perioperative care of patients with an ostomy: a clinical practice guideline developed by the University of Toronto's Best in Practice in Surgery. http://bestpracticeinsurgery.ca/wp-content/uploads/2018/11/ERAS_STOMA_BPS_FINAL_2018.pdf. Published April 2016. Accessed July 23, 2021.
20. Sayar S, Vural F. Should support group intervention be implemented for individuals with stoma? *Turk J Colorectal Dis*. 2019;29(1):1-5. doi:10.4274/tjcd.galenos.2019.59244.
21. Byfield D. The lived experiences of persons with ostomies attending a support group: a qualitative study. *J Wound Ostomy Continence Nurs*. 2020;47(5):489-495. doi:10.1097/WON.0000000000000696.
22. Orkin B, Cataldo P. Intestinal stomas. In: Wolff BG; American Society of Colon & Rectal Surgeons, eds. *The ASCRS Textbook of Colon and Rectal Surgery*. Cham, Switzerland: Springer; 2007:622, 624-626.
23. Grant M, McCorkle R, Hornbrook MC, Wendel CS, Krouse R. Development of a chronic care ostomy self-management program. *J Cancer Educ*. 2013;28(1):70-78. doi:10.1007/s13187-012-0433-1.
24. Black P. Cultural and religious beliefs in stoma care nursing. *Br J Nurs*. 2009;18(13):790-793.
25. Cooper-Gamson L. Are we bridging the gap? A review of cultural diversity within stoma care. *Br J Nurs*. 2017;26(17):S24-S28. doi:10.12968/bjon.2017.26.17.S24.
26. Bird A, Bertinara A, Wilson K, Amos L. Educating patients in stoma care. *Br J Nurs*. 2019;28(5):S4-S5.
27. Pinto I, Queirós S, Queirós C, Silva C, Santos C, Brito M. Risk factors associated with the development of elimination stoma and peristomal skin complications. *Rev Enferm Referência*. 2017;IV Série (N°15):155-166. doi:10.12707/RIV17071.
28. Murken D, Bleier J. Ostomy-related complications. *Clin Colon Rectal Surg*. 2019;32(3):176-182. doi:10.1055/s-0038-1676995.

29. Koc U, Karaman K, Gomceli I, et al. A retrospective analysis of factors affecting early stoma complications. *Ostomy Wound Manag*. 2017;63(1):28-32.
30. Burch J. Research and expert opinion on siting a stoma: a review of the literature. *Br J Nurs*. 2018;27(16):S4-S12. doi:10.12968/bjon.2018.27.16.S4.
31. Strong S. The difficult stoma: challenges and strategies. *Clin Colon Rectal Surg*. 2016;29(2):152-159. doi:10.1055/s-0036-1580628.
32. Centers for Medicare & Medicaid Services. Medicare and Medicaid programs; revisions to requirements for discharge planning for hospitals, critical access hospitals, and home health agencies, and hospital and critical access hospital changes to promote innovation, flexibility, and improvement in patient care 42 CFR Parts 482, 484, and 485 [CMS-3317-F and CMS-3295-F] RIN 0938-AS59. https://www.govinfo.gov/content/pkg/FR-2019-09-30/pdf/2019-20732.pdf. Published September 30, 2019. Accessed August 30, 2021.
33. American Society of Colon & Rectal Surgeons Committee Members; Wound, Ostomy, and Continence Nurses Society Committee Members. ASCRS and WOCN joint position statement on the value of preoperative stoma marking for patients undergoing fecal ostomy surgery. *J Wound Ostomy Continence Nurs*. 2007;34(6):627-628. doi:10.1097/01.WON.0000299812.08533.a6.
34. Prinz A, Colwell JC, Cross HH, Mantel J, Perkins J, Walker CA. Discharge planning for a patient with a new ostomy: best practice for clinicians. *J Wound Ostomy Continence Nurs*. 2015;42(1):79-82. doi:10.1097/WON.0000000000000094.
35. Steinhagen E, Colwell J, Cannon L. Intestinal stomas—postoperative stoma care and peristomal skin complications. *Clin Colon Rectal Surg*. 2017;30(3):184-192. doi:10.1055/s-0037-1598159.
36. Colwell JC, Kupsick PT, McNichol LL. Outcome criteria for discharging the patient with a new ostomy from home health care: a WOCN Society Consensus Conference. *J Wound Ostomy Continence Nurs*. 2016;43(3):269-273. doi:10.1097/WON.0000000000000230.
37. Nagle D, Pare T, Keenan E, Marcet K, Tizio S, Poylin V. Ileostomy pathway virtually eliminates readmissions for dehydration in new ostomates. *Dis Colon Rectum*. 2012;55(12):1266-1272. doi:10.1097/DCR.0b013e31827080c1.
38. Gocmen Baykara Z, Demir S, Karadag A. Family functioning, perceived social support, and adaptation to a stoma: a descriptive, cross-sectional survey. *Wound Manag Prev*. 2020;66(1):30-38. doi:10.25270/wmp.2020.1.3038.
39. Willcutts K, Scarano K, Eddins CW. Ostomies and fistulas: a collaborative approach. *Pract Gastroenterol*. 2005;29(11):63-79.
40. Van der Aa F, De Ridder D, Van Poppel H. When the bowel becomes the bladder: changes in metabolism after urinary diversion. *Pract Gastroenterol*. 2012;(Ser 107):15-28.
41. Bridges M, Nasser R, Parrish CR. High output ileostomies: the stakes are higher than the output. *Pract Gastroenterol*. 2019;(Ser 190):20-33.
42. Berti-Hearn L, Elliott B. Ileostomy care: a guide for home care clinicians. *Home Healthc Now*. 2019;37(3):136-144. doi:10.1097/NHH.0000000000000776.
43. Salvadalena GD. The incidence of stoma and peristomal complications during the first 3 months after ostomy creation. *J Wound Ostomy Continence Nurs*. 2013;40(4):400-406. doi:10.1097/WON.0b013e318295a12b.
44. O'Shea HS. Teaching the adult ostomy patient. *J Wound Ostomy Continence Nurs*. 2001;28(1):47-54.
45. Pittman J, Nichols T, Rawl SM. Evaluation of Web-based ostomy patient support resources. *J Wound Ostomy Continence Nurs*. 2017;44(6):550-556. doi:10.1097/WON.0000000000000371.
46. Rojanasarot S. The impact of early involvement in a postdischarge support program for ostomy surgery patients on preventable healthcare utilization. *J Wound Ostomy Continence Nurs*. 2018;45(1):43-49. doi:10.1097/WON.0000000000000395.
47. Mossi L, Kuhlman A, Toennies R. WOC nurses positive impact on wear time with telephone consultation with consumers. Practice Innovation Poster. https://wocn.confex.com/wocn/2018am/webprogram/Paper11245.html. Published 2018. Accessed June 15, 2021.
48. Miller D, Pearsall E, Johnston D, Frecea M, McKenzie M. Executive Summary: enhanced recovery after surgery best practice guideline for care of patients with a fecal diversion. *J Wound Ostomy Continence Nurs*. 2017;44(1):74-77. doi:10.1097/WON.0000000000000297.
49. Sun V, Grant M, McMullen CK, et al. Surviving colorectal cancer: long-term, persistent ostomy-specific concerns and adaptations. *J Wound Ostomy Continence Nurs*. 2013;40(1):61-72. doi:10.1097/WON.0b013e3182750143.
50. Cross HH, Hottenstein P. Starting and maintaining a hospital-based ostomy support group. *J Wound Ostomy Continence Nurs*. 2010;37(4):393-396. doi:10.1097/WON.0b013e3181e45794.
51. Danielsen AK, Soerensen EE, Burcharth K, Rosenberg J. Learning to live with a permanent intestinal ostomy: impact on everyday life and educational needs. *J Wound Ostomy Continence Nurs*. 2013;40(4):407-412. doi:10.1097/WON.0b013e3182987e0e.
52. LeBlanc K, Whiteley I, McNichol L, Salvadalena G, Gray M. Peristomal medical adhesive-related skin injury: results of an international consensus meeting. *J Wound Ostomy Continence Nurs*. 2019;46(2):125-136. doi:10.1097/WON.0000000000000513.
53. Erwin-Toth P. Ostomy Pearls: a concise guide to stoma siting, pouching systems, patient education, and more. *Adv Skin Wound Care*. 2003;16(3):146-152. doi:10.1097/00129334-200305000-00014.
54. Salvadalena G, Colwell JC, Skountrianos G, Pittman J. Lessons learned about peristomal skin complications: secondary analysis of the ADVOCATE Trial. *J Wound Ostomy Continence Nurs*. 2020;47(4):357-363. doi:10.1097/WON.0000000000000666.
55. Zhou H, Ye Y, Qu H, Zhou H, Gu S, Wang T. Effect of ostomy care team intervention on patients with ileal conduit. *J Wound Ostomy Continence Nurs*. 2019;46(5):413-417. doi:10.1097/WON.0000000000000574.
56. Colwell JC, Bain KA, Hansen AS, Droste W, Vendelbo G, James-Reid S. International consensus results: development of practice guidelines for assessment of peristomal body and stoma profiles, patient engagement, and patient follow-up. *J Wound Ostomy Continence Nurs*. 2019;46(6):497-504. doi:10.1097/WON.0000000000000599.
57. Richbourg L, Thorpe JM, Rapp CG. Difficulties experienced by the ostomate after hospital discharge. *J Wound Ostomy Continence Nurs*. 2007;34(1):70-79. doi:10.1097/00152192-200701000-00011.
58. Colwell JC, McNichol L, Boarini J. North America Wound, Ostomy, and Continence and Enterostomal Therapy Nurses current ostomy care practice related to peristomal skin issues. *J Wound Ostomy Continence Nurs*. 2017;44(3):257-261. doi:10.1097/WON.0000000000000324.
59. Howson R. Stoma education for the older person is about keeping it as simple as 1, 2, 3. *J Stomal Ther Aust*. 2019;39(3):20-22. doi:10.33235/jsta.39.3.20-22.
60. Taneja C, Netsch D, Rolstad BS, Inglese G, Lamerato L, Oster G. Clinical and economic burden of peristomal skin complications in patients with recent ostomies. *J Wound Ostomy Continence Nurs*. 2017;44(4):350-357. doi:10.1097/WON.0000000000000339.
61. Taneja C, Netsch D, Rolstad BS, Inglese G, Eaves D, Oster G. Risk and economic burden of peristomal skin complications following ostomy surgery. *J Wound Ostomy Continence Nurs*. 2019;46(2):143-149. doi:10.1097/WON.0000000000000509.