

# Ohio Nurse



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Quarterly circulation approximately 222,000 to all RNs, LPNs, and student nurses in Ohio.

## The Never Ending Story of Staffing

by Kathleen Morris

More staff, less overtime. More PCAs, fewer extra duties. More time for charting, less pressure to do more with less. And let's not forget more guaranteed lunch and bathroom breaks.

The results of the Ohio Nurses Association's (ONA) 2012 survey of staff nurses employed in Ohio hospitals tells much the same story as it did last year, and the year before that. Of the 500+ nurses who completed the survey in March of this year, nearly three quarters found that staffing levels were inadequate to provide safe and effective nursing care to their patients. Seventy-three percent stayed beyond normal working hours to complete charting while being pressured to avoid unnecessary overtime. Two-thirds of the respondents were unfamiliar with their facility's staffing plan and/or lacked the opportunity to contribute to the plan.

House Bill 346, passed by the Ohio General Assembly in 2008, required Ohio hospitals to establish a hospital-wide nursing care committee consisting of at least fifty percent registered nurses in direct patient care positions. The task of the committee was to evaluate nurse staffing following certain parameters and to create an evidence-based staffing plan which, at the minimum, met current accreditation and government standards. The bill also required that the staffing plan be prominently posted, made available to all who wish to obtain a copy, and re-evaluated annually.

Since that time, the Ohio Nurses Association has collected copies of these staffing plans, both in 2009-10 and 2011-12. Some plans consist of one page, others are multi-paged treatises of evidence-based practice and principles of nurse staffing. Regardless, the majority of direct care nurses who were meant to participate and benefit from this process remained largely unaware of the staffing law and the process for participating in the development of the staffing plan. Thus, in 2011, ONA offered education sessions to staff nurses. The sessions took place in several locations around the state in an attempt to both better inform nurses about Ohio's staffing law and to encourage participation in the process. Sadly, little seems to

have changed. According to our most recent survey, nurses remain uninformed concerning their facility plan and have little opportunity to participate in the process.

In order to learn more about how we can help nurses to improve their staffing situations, ONA will conduct seven focus groups around the state. Participation will be open to 24-30 persons per site so that all participants have a chance to share their input.

Attendees will be divided into small groups of 6-8 nurses for discussion purposes. The intent of these focus groups is to capture innovative ways to improve nurse staffing in Ohio hospitals and to increase nurse ownership of the staffing process.

Meetings will be held in local venues outside of workplace. Refreshments will be provided. Please think about joining us. Let ONA know how we can improve staffing conditions in your workplace.

To RSVP for a focus group in your area, go to [www.ohnurses.org](http://www.ohnurses.org) and click on the "RSVP for a Nurse Staffing Focus Group" button or by emailing [rwolfe@ohnurses.org](mailto:rwolfe@ohnurses.org).

RSVP for a Nurse Staffing Focus Group



### Focus Groups Dates and Cities:

October 3, 2012	Worthington
October 10, 2012	Perrysburg
October 16, 2012	Akron
October 17, 2012	Independence
October 24, 2012	Boardman
October 25, 2012	Piketon
November 1, 2012	Franklin

Visit [www.ohnurses.org](http://www.ohnurses.org) and click on the "RSVP for a Nurse Staffing Focus Group" button if you're interested in attending!

### A Timeline: Staffing Legislation and Implementation in Ohio

June 12, 2008:	House Bill 346 signed into law
December 9, 2008	Each hospital in Ohio must establish a hospital-wide nursing care committee
March 9, 2009	Each hospital must create a written staffing plan; the staffing plan must be reevaluated annually and posted in a prominent location.
2009-2010	ONA collects Ohio hospital staffing plans.
Spring, 2011	ONA provides educational sessions regarding the staffing bill in Lima, Chillicothe, Akron, Columbus, and Cincinnati.
Summer, 2011	ONA conducts a survey of registered nurses working in Ohio hospitals covered by an ONA collective bargaining agreement concerning comprehensive working conditions issues, including staffing and related matters.
Fall, 2011-2012	Second collection of Ohio hospital staffing plans.
Spring, 2012	ONA conducts a survey of registered nurses employed in Ohio hospitals concerning staffing, nurse participation in the facility staffing plan, and other factors affecting safe staffing.
Fall, 2012	Focus groups regarding staffing to be conducted in Perrysburg, Independence, Akron, Boardman, Franklin, Worthington and Piketon.

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## Free Independent Studies



All independent studies published in the *Ohio Nurse* are FREE to ONA members for three months and can also be completed online at [www.CE4Nurses.org](http://www.CE4Nurses.org).

Non-members can also complete the studies published in this issue online for \$12 per study or by mailing in the tests provided for \$15 per study. See page 3 for more details.

Interested in joining ONA? See page 3 for membership information and five reasons for joining the only professional organization in Ohio for registered nurses.

### LEGAL REGULATIONS & Professional Standards for Ohio Nurses



## Ohio Nurses Association

### Get your copy of Legal Regulations and Professional Standards for Ohio Nurses

The third edition of *Legal Regulations & Professional Standards for Ohio Nurses* is available for purchase from the Ohio Nurses Association. Much has changed in the health care environment since the initial publication of this resource ten years ago and this new, updated edition will enable students and registered nurses alike to become more familiar with the law, rule, and professional standards that define nursing practice.

This resource is available as an Adobe® PDF available via email for \$18.00. To order your copy, please visit [www.ohnurses.org](http://www.ohnurses.org) > Practice > Legal Regulations Guide. Please allow seven to ten business days for email delivery.



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### STD Clinical Update

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- Introduction to the Physical, Psychological, Emotional and Spiritual Care for Ostomy Patients—Improving the Quality of Life
- Using Preferred Practices to Improve Palliative Care at End of Life
- Traumatic Brain Injury: The Sequel

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**ONA MEMBERS:**

Each study in this edition of the Ohio Nurse is free to members of ONA if postmarked by November 30, 2012. Please send post-test and this completed form to: Ohio Nurses Association, 4000 East Main Street, Columbus, OH 43213.

**NON-ONA MEMBERS:**

Each study in this edition of the Ohio Nurse is \$15.00 for non-ONA Members. The studies can also be completed online at CE4Nurses.org for \$12. Please send check payable to the Ohio Nurses Association along with post-test and this completed form to: Ohio Nurses Association, 4000 East Main Street, Columbus, OH 43213. **Credit cards will not be accepted.**

**ADDITIONAL INDEPENDENT STUDIES**

Additional independent studies can be purchased for \$15.00 plus shipping/handling for both ONA members and non-members. (\$12.00 if taken online). A list is available online at [www.CE4Nurses.org](http://www.CE4Nurses.org)

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## Join the Ohio Nurses Association

The Ohio Nurses Association does a lot for the nursing profession as a whole, but what does ONA do for its members?

**FREE AND DISCOUNTED PRODUCTS AND SERVICES** Members take advantage of a wide array of discounts on products and services, including professional liability insurance, continuing education, and special tuition rates to partner RN-to-BSN programs.

**WORKPLACE ADVOCACY** ONA provides members access to a wide range of resources to help them make a real difference in the workplace, regardless of work setting. ONA provides members with resources to create healthy and safe work environments in all health care settings by providing tools to help nurses navigate workplace challenges, optimize patient outcomes and maximize career benefits.

**EDUCATION** Whether you've just begun your nursing career or are seeking to enhance or maintain your current practice, ONA offers numerous resources to guide you. For example, the Ohio Nurses Foundation awards several scholarships annually with preference to ONA members. Members also save up to \$120 on certification through ANCC, and can earn contact hours for free through the independent studies in the *Ohio Nurse* or online at a discounted rate, among many other educational opportunities.

**NURSING PRACTICE** ONA staff includes experts in nursing practice and policy that serve our members by interpreting the complexities of the Nurse Practice Act and addressing practice issues with a focus of ethical, legal and professional standards on a case-by-case basis.

**LEGISLATIVE ADVOCACY** ONA gives members a direct link to the legislators that make decisions that affect nursing practice. Members can become Legislative Liaisons for their district, join the Health Policy Council and participate in the legislative process in many other ways through their ONA membership.

**These are just a few of the benefits nurses receive as ONA members. Dues range from \$33–\$50 a month and we offer reduced dues rates to new graduates, unemployed and retired nurses. Go to [www.ohnurses.org](http://www.ohnurses.org) > Join/Renew to start taking advantage of what ONA has to offer.**

Go to  
[www.ohnurses.org](http://www.ohnurses.org)  
 to join today!

## Independent Study Instructions

To help Ohio's nurses meet their obligation to stay current in their practice, three independent studies are published in this issue of the *Ohio Nurse*.

**Instructions to Complete Online**

1. Go to [www.CE4Nurses.org](http://www.CE4Nurses.org).
2. Click on each study you want to take and add it to your cart. (ONA members will see a price of \$0.00 after they are logged in).
3. Complete the check-out process. **You will receive a confirmation email with instructions on how to take the test.**
4. Go to the CE4Nurses Exam Manager ([www.ohnurses.org/Survey](http://www.ohnurses.org/Survey)) either from your confirmation email or the CE4Nurses site.
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3. Fill out the registration form indicating which studies you have completed, and return originals or copies of the registration form, post test, evaluation and payment (if applicable) to:  
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**References**

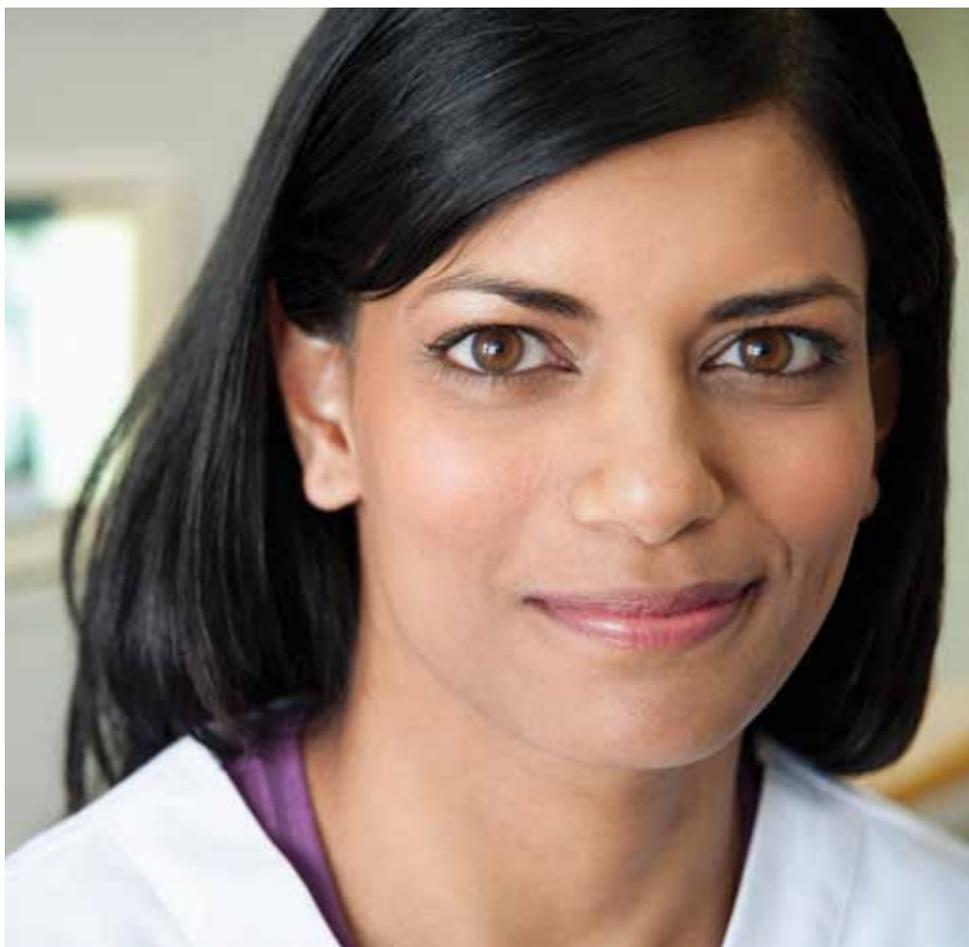
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**Questions**

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# Introduction to the Physical, Psychological, Emotional and Spiritual Care for Ostomy Patients - Improving the Quality of Life

Developed by: James McCombs, RN, and Marilyn McCombs, RN.

This independent study has been developed for nurses to enhance nurses' knowledge of special needs of ostomy patients. The authors and planning committee members have declared no conflict of interest. There is no commercial support for this independent study. Disclaimer: Information in this study is intended for educational purposes only. It is not intended to provide legal and/or medical advice.

**1.0 contact hour will be awarded** for successful completion of this independent study.

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## OBJECTIVE:

1. Describe the needs of ostomy patients.

## STUDY

The purpose of this continuing education (CE) study is to assist nurses to develop a comfortable nurse patient relationship with ostomy patients utilizing education, evidence-based practice, and listening to the needs and desires of the ostomy patient. The United Ostomy Association estimates that slightly more than 750,000 Americans now have some type of stoma. Each year approximately 120,000 people will undergo ostomy surgery. The stoma in the abdominal wall permits the passage of effluent, flatulence, and water and requires continuous maintenance. Ostomy surgeries are required for different reasons including bladder cancer, colorectal cancer, irritable bowel syndrome (IBS), ulcerative colitis, and Crohn's disease. Emergency cases of diverticulitis, trauma or radiation complications also require ostomy surgery to be performed (Dorman, 2009).

The most common reasons for the formation of a stoma are due to colorectal cancer, ulcerative colitis, and Crohn's disease. Stoma formations impact the lives of patients causing many psychological problems ranging from fear and anxiety of social activities, negative body image, sexuality issues, and spiritual well-being. It has been shown that patients who received counseling before and after surgery are most likely to have more positive feelings that promote perceived perception in order to control physical recovery (Brown & Randle, 2005).

The perception of negative body image is considered one of the largest effects of having stoma surgery. The initial feelings associated with having ostomies are shock, hate, disgust, embarrassment, and devastation (Brown & Randle, 2005). One's body image is not only the central aspect of one's identity, but also in how activities are performed and goals are set for his or her future (Clark & Griffin, 2008). Those living with a stoma perceive themselves to have undergone body image changes as a direct result of their surgery. Women more often than men considered body-image the most negative aspect of surgery (Brown & Randle, 2003). The nurse's personal feelings toward ostomies play a significant role in patient outcomes (Dorman, 2009).

According to Simmons, Smith, Bobb, & Liles (2007), an estimated one million cases of colostomy surgeries occur annually. Patients may be required to have a colostomy, ileostomy, or urostomy. For particular ostomates with a debilitating disease, the stoma surgery provides a better quality of life. However, many face significant physical, psychosocial, and emotional challenges that require lifestyle modifications.

The American Cancer Society (ACS) has reported colon cancer as the third most common cancer in both men and women in the United States and the 2010 statistics reported 102,900 new cases of colon cancer in addition to 39,670 new cases of rectal cancer. The advancements in quality of care have healthcare professionals focused on education for their ostomy patients to promote independence and ensure holistic quality of care. Support groups and individual spiritual well-being provide security for the patient. Positive teaching approaches encourage learning and confidence in self-care. Teaching the patient about nutrition, skin care, and how to maintain their ostomy promotes a higher quality of life. Developing a mutual trusting bond is of the utmost importance when caring for an ostomy patient (Dorman, 2009).

## The Basics

New ostomy patients are affected in different ways after their surgery. Nurses can also be affected depending upon their comfort level when teaching a patient how to perform ostomy self-care (Dorman, 2009). Knowledgeable certified nurses are experts in ostomy care and focus on promoting better patient outcomes.

Dorman (2009) indicates the physical and emotional disabilities of the surgery may have an impact on the ability to perform ostomy care. These disabilities, such as inadequate coordination and function as seen in

Parkinson's disease and post-stroke weakness, are barriers to self-care (Dorman, 2009). Self-care can be awkward and frustrating in the beginning, but confidence is gained with experience as patients develop new skills to perform the task of cleaning and changing appliances. Coping with emotional distress can be challenging and may cause a delay in the learning process.

According to Gwen Turnbull, BS, RN, CETN, education is critical for an ostomy patient to perform successful self-care. Ostomy rehabilitation is dependent on the mastery of self-care. As a result, the mastery of self-care is dependent on the quality, quantity, and consistency of patient teaching. While preparing to write this continuing education study, a telephone interview was conducted with Denise Taylor, MSN, APRN-BC, CWOCN, where she expressed her concern regarding *inadequate ostomy knowledge* in nursing. She continued to say, "If the nurse doesn't know ostomy care, then they will not be able to teach ostomy care to their patients." Taylor believes there is a lack of ostomy education and experience with ostomy patients in the nursing community.

Unfortunately, in nursing school, ostomy care is not a major topic of discussion and is not practiced as a nursing skill. Therefore, many nurses have inadequate training to know how to discuss ostomy preoperative and postoperative treatments with the patient. These discussions with the ostomy patient should happen as early as possible to address any fears expressed by the patient. The major goal for ostomy patients after surgery is to regain independence and maintain a sense of well-being as a part of the community.

Turnbull (2008) indicates the process of teaching ostomy education has changed dramatically for the patient, the caregiver, and the healthcare professional with decreased hospital stays, early discharge for continued recovery, and insurer's coverage and payment constraints contributing to the stress and intensity of ostomy surgery. When a patient has been diagnosed and told about the need for surgery, there is increased psychological stress from all of the unknown expectations which hampers the initial learning process.

Holistic nurses find it essential to care for both the patient and the family because of an increased shift to care by family members at home. Today, healthcare professionals are more likely to bring awareness to lifestyle adaptations through communication and education. There are gender related differences in the physical and emotional recovery of patients after ostomy surgery.

## Preoperative Teaching

The certified Wound Ostomy Continence Nurse (WOCN) or surgeon locates the optimal site for the stoma. They mark the patient having ostomy surgery after the patient's abdomen is observed sitting, bending, and lying down paying special attention when assessing for skin folds, dips, scars, or any potentially problematic skin issues. The best possible position will be marked with an indelible marker prior to surgery (Dorman, 2009). During the preoperative teaching session, patients view the pouching system and supplies that will be used at home. This is an opportunity for patients to practice using the pouching system, to express any concerns, and ask questions for their own knowledge and confidence.

Many nurses suggest that preoperative teaching cannot prepare ostomates for those early reactions toward their stomas or for the physical attractiveness that is significantly decreased. After the initial shock of seeing the stoma for the first time, adjustment becomes more comfortable, but nevertheless, many patients reported an initial theme that the body had been significantly altered (Persson & Helstrom, 2002). Stoma patients reported that touching the stoma for the very first time was an unpleasant experience and described it as an emotional shock (Persson & Helstrom, 2002). To ease this initial shock, nurses hold the key to a successful transition and adjustment with planned teaching-learning sessions that include nutrition, wound and skin care to relieve the fear and anxiety patients experience during those first few days. Patients need to be aware that a skin barrier helps protect the skin from getting sore and irritated. It also helps to heal skin that is already sore and irritated and provides a protective layer between the skin and urine, stool, or drainage (Mt. Carmel, 2009).

Fluid intake must be given special attention during preoperative teaching, especially with ileostomy patients because they will not have a colon for the second reabsorption of fluid as a preventative mechanism for dehydration. They should drink 10 to 12 cups of caffeine-free fluid daily unless otherwise instructed from the physician. Good sources of fluid include water, 100% fruit juices, milk, soups, sports drinks, and liquid nutritional supplements. Vitamins, minerals, and nutritional supplements may help with wound healing if the patient has a poor appetite (United Ostomy Associations of America, 2008).

According to the United Ostomy Associations of America, controlling odor and leakage are two major concerns of the ostomy patient that need to be addressed during the preoperative education. As documented in the

Pensacola Florida Stoma Gram and published by Columbus Discovery for the Central Ohio United Ostomy Association, an important part of a new ostomate's rehabilitation is learning to control odor. It is important to feel good about oneself and be secure in relationships with others. The ostomate can be extremely sensitive to odors and the reactions of those around them especially family and friends (United Ostomy Associations of America, 2008).

There are significant differences between a colostomy and an ileostomy. A colostomy tends to emit more odor than an ileostomy because of the bacterial abundance in the colon. Ileostomates experience almost continual peristaltic waves, which sweep the ileum and prevent stagnation of the intestinal contents, thereby eliminating the major cause of odor due to bacterial growth (United Ostomy Associations of America, 2008). There are products that prevent odor by neutralizing the effluent and odor proof filtered pouches that can also eliminate buildup of embarrassing odors in the pouch. The neutralizing gel can be added from the bottom opening of the pouching system after emptying and cleaning. Caution should be taken when using the neutralizing gel, as some products can burn and irritate skin. Nurses should be aware that extreme and persistent odor from an ileostomy could be an indication of a secondary problem such as a stricture or blockage (United Ostomy Associations of America, 2008).

In regard to urinary ostomates, urine has a characteristic odor, but a foul odor could be a sign of infection due to overgrowth of bacteria. Certain foods will affect the odor of both feces and urine. Avoiding such odor-producing foods such as fish, onions, asparagus, and eggs will help. Eating foods that contain parsley or yogurt help to reduce odor of effluent and drinking cranberry juice will reduce bacterial growth and reduce the risk of infections. Urinary ostomates should clean their pouches periodically with such agents as Uri Kleen. Vinegar solutions are no longer recommended because they tend to damage certain manufactured pouches. With proper care of the appliance, personal hygiene and dietary precautions, odor should not be a problem (United Ostomy Associations of America, 2008).

Preoperative teaching research found that there are still several areas not well addressed in terms of support and adjustment to life changes. Some research suggests there is a need for ostomy patients to talk with someone other than a health care professional, such as a spouse or family member, because some professionals are not able to provide all the emotional support required when seeing the stoma for the first time (Persson & Helstrom, 2002). Keeping the patient informed provides control over certain situations and promotes a positive psychological and emotional well-being.

Traveling tips are important to mention during the preoperative teaching to ensure the patient will be able to continue enjoying life with only minor changes required. These tips include ostomy supplies, accessories, and extra clothing needed during the trip to prevent embarrassment.

The American Medical Association defines informed consent as more than just getting the patient to sign a written document. It is a process of communication between the patient and physician agreeing to undergo a specific medical intervention (Turnbull, 2010). Best results are achieved when the patient is well informed of the basic maintenance requirements such as emptying, cleaning, changing, and odor and leakage control. The ostomy patient may be overwhelmed with so many life-altering changes taking place, that it is difficult to process all the new information.

## Postoperative Teaching

Assess the stoma often to ensure it appears beefy red in color and warm and moist to the touch. This indicates adequate blood flow to the ostomy. The pouching system may leak if there is not a tight seal. Leakage is a major concern for an ostomy patient. It is not only emotionally stressful, but it also causes serious peristomal skin breakdown, infections and skin complications. Teach the patient that, if the pouching system does spring a leak, that this should not be cause for panic.

Being prepared can help maintain a sense of calmness and confidence. Wearing an appliance cover provides extra protection from moisture reaching the outer layer of clothing. The pouching cover has the ability to absorb moisture from the skin as perspiration can quickly undermine the best adhesives. The pouching system should be changed every 4 days to help prevent leakage. When changing the pouching system, placing paper tape around the four outer edges of the wafer works well to secure a tighter seal.

Ostomates should empty their pouch when it becomes one-third to one-half full. The pouch should be emptied approximately 6 to 8 times daily for an ileostomy or urostomy and less for a colostomy. Full pouches are very heavy and risk the possibility of leaking. Steps to emptying a pouch are as follows: Sit far back on the toilet and place the end of the pouch between both legs, or stand and lean over the toilet when emptying the pouch. Place tissue into

**Ostomy Patients continued from page 4**

the toilet while emptying or flushing to prevent splashing. Hold the end of the pouch up and remove the clamp or Velcro® when opening and let the contents drain into the toilet. If stool is thick, add tap water into the pouch to help loosen the stool (Coloplast, 2009).

**Sexuality Concerns**

The influence on ostomate's sexual life suggests that their attractiveness had decreased since surgery. Because of the change in physical appearance, many stoma patients worry about sexual issues and claim their sexual attractiveness has decreased since having their ostomies.

In fact, preoperatively, many patients reported swimming on a regular basis followed by a sauna. Now, being naked in the shower with the stoma and the pouch hanging down, is impossible. Stoma patients reported a loss of functional abilities that instigated or exacerbated their multiple chronic illnesses (Persson & Helstrom, 2002).

Regardless of a person's age, diagnosis, or sexual preference, ostomy surgery infringes on the high values that society places on beauty, body, sexuality, cleanliness, and self-control. These changes to the ostomate's body are not only visible to the ostomate themselves, but also visible to their sexual partner, altering any sexual desires as well as any sexual activity. Depression after ostomy surgery is usually normal, creating a loss of libido. Therefore, couples need time to adjust and recuperate psychologically as well as physically (Turnbull, 2010).

It is normal to feel sensitive about any changes which occur to the body; therefore, it is essential that ostomy patients express their feelings about how they feel to their spouses or loved ones. It is important to know that sexual relations cannot harm the stoma. For those who feel a little intimidated, there are specially made pouches designed just for intimate moments; furthermore, pouches may also be covered with specially designed underwear, such as lingerie, or pouch covers (ConvaTec, 2006).

**Discharge Teaching**

Post-discharge follow-up is frequently provided by a non-specialized home care nurse who focuses his or her attention mainly on stoma management than on what is happening to the patient's psychological state of mind. One researcher suggested that most psychological problems for patients are related in some way to the individual's inability to perform self-care and that an improvement in this area could have a positive impact on the psychological well-being of the patient (Turnbull, 2010).

Good nutrition and hydration play a key role in helping wounds and incisions heal. Nutrients and oxygen must reach the tissues of the wound in order for the healing process to occur. Key nutrients for wound healing include protein, carbohydrates, fats, vitamin C, vitamin A, iron, zinc, and fluids (Mt. Carmel, 2009). Ostomy patients must be careful to chew foods thoroughly and consume small portions during meals to avoid the dumping syndrome.

Certain dietary restrictions such as high-fiber cereals, popcorn, raw vegetables, and nuts must be avoided initially after surgery because these foods cause obstruction during digestion (Dorman, 2009). Patients with an ileostomy usually have a very high output and thus there is a risk of dehydration (Wright, 2009). Ostomy patients should eliminate carbonated drinks completely, as these drinks are gas producing and may cause the pouching system to swell, which could potentially loosen the skin barrier seal and cause leakage.

Patient education begins before surgery and should continue after hospital discharge until the individual can perform self-care successfully. The patient teaching goal is for the patient to transfer information presented and the skill practiced to everyday life. Patient education is the single most important action toward independence, confidence, and rehabilitation (Turnbull, 2010).

**Physical Issues and Quality of Life**

Comorbidities are a significant predictor indicating how Health-Related Quality of Life (HR-QOL) affects stoma patients in the domains of physical functioning, general health and social functioning. Among some of these comorbidities, studies have found prevalence in patients that experienced a significantly higher occurrence of depression, loneliness, suicidal thoughts, feelings of stigma, and low self-esteem. Current studies are trying to evaluate whether this low quality of life is due to the presence of the ostomy itself or because of the comorbid disease that often accompanies stoma (Jain et al., 2007).

Colorectal cancer is not the only reason for placement of an ostomy. In some cases, non-cancerous diseases can also be the cause of the acquiring of an ostomy. Colostomies in non-cancerous patients are the result of complications stemming from inflammatory bowel disease and diverticulitis. No differences were found related to sexual function between the two groups, indicating that both cancerous and non-cancerous groups were less sexually active post-colostomy. In general, colostomy patients with cancer reported having a better quality of life compared to patients with benign diagnoses (Krouse, et al., 2009).

Often people with disabilities use disengagement as a way of coping. For example, they may avoid certain situations that may arouse fear and distress because of concerns of not being accepted socially. Studies have suggested people who receive emotional support perceive less discrimination and have a higher self-esteem, whereas people with a colostomy who find it difficult to engage with family and friends are more likely to be poorly adjusted (Simmons, Smith, Bobb, & Liles, 2007).

In most cases, patients undergo stoma surgery due to the fact that they have cancer; therefore, these patients cope with a physical life-threatening condition in addition to accepting an emotionally dramatic change in body image. Younger patients, on the other hand, usually have diseases that are not life-threatening such as ulcerative colitis or Crohn's disease (Marquis, Marrel, & Jambon, 2010).

Patients undergoing surgery for an ileostomy have the entire colon removed with the anus sewn closed creating liquid output from the stoma. This has the potential for additional difficulties associated with the stoma. Patients that have surgery for a urostomy may experience difficulties in coping with their stoma as a result of urine leakage that causes skin irritation and breakdown (Marquis et al., 2010).

Summer produces a great deal of anxiety for someone living with an ostomy, because body image often produces the fear of public embarrassment. Today, there is a broader selection of outfits made for summer than there has been in the past. Flowered or textured patterns that provide camouflage are now manufactured making everyday clothing attractive. Also, there are one piece and two piece swimming suits that are made appealing, while at the same time covering up any appearance of the pouch (Turnbull, 2010).

New advancements in pouching systems allows ostomy patients to choose from a closed-end pouching system that can be worn under a bathing suit that will prevent leaking onto the suit or switch to a drainable pouch for easier disposal while traveling on the road (Turnbull, 2010). Ostomy pouches today are designed to lie flat against the abdominal wall making them almost unnoticeable beneath clothing so there is no need for a special wardrobe; however, here are some key points to consider before dressing. If the stoma is in a waistline, avoid pressure from tight belts or pants. If the patient is wearing a girdle, make sure it is soft and stretchy, and the supporter should be worn one size larger (ConvaTec).

**Ostomy Patients continued on page 6**


**DEDICATED  
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**Ostomy Patients continued from page 5**

Research concerns by Simmons (2007) suggest that perceived personal control and stoma care self-efficacy are influencing factors to ensure a quality of life. Education is another major concept influencing life satisfaction. To gain knowledge about new ostomy appliances and accessories including application methods can provide a sense of confidence in the daily self-efficacy of care. New appliances and accessories are manufactured every year to improve care and ease of application for ostomates.

According to Smith, Loewenstein, Jankovic, & Ubel, (2009) regarding recent research on a permanent versus temporary ostomy, the prediction is that overall life satisfaction and quality of life increased with time for patients with a permanent ostomy rather than a temporary ostomy. The idea that hoping one's circumstances will improve can impede adaptation. The test results by Smith et al., (2009) indicated that the patients with a permanent ostomy had a higher level of life satisfaction and quality of life than those with a temporary ostomy. The humanistic concept of hoping for something better interfered with the ability to adapt and reduced the quality of life (Smith et al., 2009).

New ostomy patients often become dietary cripples based upon incorrect information received pertaining to their newly "restricted diet." Therefore, ostomates are often afraid to venture out into restaurants or accept an invitation to dinner from friends. The idea of ostomy care is to optimize the quality of life for ostomy patients; we must investigate and identify the patient's problems and use the science and technology available to us to help solve them (Turnbull, 2010).

Consequently, the entire range of stoma operations precipitates a wide variety of problems deteriorating a person's quality of life. The quality of life has been defined as "contentment with everyday life: the degree of enjoyment and satisfaction experienced in everyday life as opposed to financial or material well-being" (Marquis et al., 2010).

**Psychological and Spiritual Support**

Regardless of the disease process, a colostomy, ileostomy, and urostomy are known to severely impact a patient's life. Patients must be encouraged to express fears, concerns, worries, disgust, and embarrassment regarding their ostomies (Dorman, 2009). It is crucial that the appropriate referrals are made to various departments, such as social work, psychiatry, occupational therapy, physical therapy, and the Wound Ostomy Continence Nurse (WOCN).

According to Weinert, Cudney, and Spring (2008), the computer-based intervention is maturing and has provided an important link to bring ostomy patients together via the internet. Their study shows that ease of use and convenience allows accessibility to supportive information for ostomy patients living in isolated rural areas. This communication technique has provided a sense of support, especially for the elderly living with a chronic-illness. The elderly patients can obtain answers to their questions and share their personal stories with others who also experience similar lifestyle changes.

According to Carlsson et al., (2001) the most significant observation was the limited ability to act spontaneously because all daily activities involved considerable planning. Numerous ostomy problems exist with ileostomy leakage and peristomal skin breakdown being the most common. The negative aspects of living with a stoma were insecurity, fear of leakage, noise, odor, and having to locate nearby toilets when in unfamiliar surroundings. The most limiting aspect to daily life was the inability to act spontaneously. For those living with an ostomy, staying connected with friends and working outside the home was considered to be psychologically and emotionally therapeutic. For these people, working part-time was the utmost importance to experience the highest quality of life (Carlsson et al., 2001).

It appears that, in short, patients experience negative feelings after stoma formation. If nurses provide opportunities for open and general communication for patients with stomas then it is more likely that positive feelings will be enhanced. Qualified nurses should encourage patients to express their feelings and seek counseling as needed, which may be provided by a specialist stoma nurse (Brown & Randle, 2005).

Spirituality is an integral, but yet overlooked component of care in the medical setting. Studies suggest that ostomy patients who include religion and spiritual belief in life could positively influence emotional acceptance of the stoma. Also, using the City of Hope Quality-of-Life Questionnaire, U.S. veterans were surveyed about their influence regarding spirituality after placement of an ostomy and found that a provision of holistic care in this population may be beneficial. The therapeutic use of incorporating spirituality has shown benefits in terms of new personal insights and brought comfort to a number of patients (Baldwin et al., 2008). Having a spiritual connection increases a person's emotional and psychological well-being, especially when faced with an illness.

**Gender Differences**

Research suggests females, more than males, are receptive to the health promotion of communication to manage their illness. According to the experts, women have a tendency to communicate more than men and they use communication as a means to emotional healing. Communicating with others is therapeutically beneficial

for the emotional and psychosocial recovery after ostomy surgery. According to Weinert et al., (2008) women-to-women conceptual model for adaptation is continually evolving and has anticipated that the current research will further strengthen the notion that interventions of this nature that foster positive psychosocial responses to chronic illness will enhance self-management skills and improve quality of life.

Many women attribute weight gain to the use of medications that treat their chronic conditions or the inability to be physically active. In addition, some patients reported that their illness exacerbated these individuals' feelings of oldness, and expressed they no longer felt attractive. Women continue to be concerned about their appearance, especially their weight, even following the onset of numerous and debilitating health issues (Clark & Griffin, 2008).

Research suggests that attention to appearance frequently declines when serious health issues arise. For many women, the appearance of their bodies are said to influence their felt age. None of these women talked about other visible markers such as wrinkles, sagging skin, or gray hair. Women's focus on illness-related body changes may be interpreted in terms of a shifting emphasis from the body as an object to the body as a tool for action (Clark & Griffin, 2008).

The altered body image and the loss of power to control defecation can have a major influence on an ostomate's personal life. People often become unsure about their images and sexual ability and often require counseling. This study has found that one year after stoma surgery, women eventually viewed themselves as sexually attractive, but the men had difficulties with masculinity (Persson & Helstrom, 2002).

Most men denied experiencing any negative body image dissatisfaction. Those who did expressed discontent with their bodies and largely focused on their changing physical abilities. Men reported the importance of strength, autonomy, and the need for gratitude for what they were still able to do. The differences between men and women reflect norms of masculinity. Men deliberately minimized their feeling of inadequacy to retain a more positive self and body evaluation (Clark & Griffin, 2008).

Both men and women described their feelings of uncertainty, such as fear of the stoma being visible to others or that gas and odors might occur. Flatulence often causes the pouch to fill with gas giving the impression that it could be seen through clothes. Most women prefer wearing loose dresses to prevent placing pressure on the stoma, whereas, men preferred wearing trousers with suspenders for comfort and security (Persson & Helstrom, 2002).

The qualitative research of Weinert et al., (2008) indicated through online exchanges women were able to gain insights into their own experiences by forming a partnership and utilizing information. Learning from others via the internet promotes successful adaptation, empowerment, and confidence to better control and improve their quality of life. Patients who were forced to interact with healthcare professionals because of chemotherapy and radiation treatments were more likely to benefit from the regular contact (Simmons et al., 2007). Those ostomates who have weekly scheduled clinical visits with their doctors and nurses have a better success rate of adaptation than those who do not have a close relationship with their healthcare professionals (Simmons et al., 2007).

According to Simmons et al., (2007), talking with patients helps these individuals make sense of their experience to achieve emotional resolution related to psychological well-being. Nurse practitioners believe that patients with ostomies who are assisted to help themselves can lead to a more functional family life (Wong & White, 2002). Independence remains an important attribute in the quality of life. People who successfully adapt to their condition will have more control over their health care and will live a healthier life (Weinert et al., 2008). Gaining independence and control provides a road to an emotional recovery and social stimulation necessary for the normal rhythm of life. Isolation is punishment and an ostomy patient should not regard themselves as a prisoner in their own home because of their ostomy. Patients experiencing social isolation have a potentially high risk of experiencing depression. Being fatigued can also lead to depression, and depression can result in fatigue in many cases.

**Nutrition and Dietary Teaching**

Nutrition deficit and dehydration are constant concerns for the ostomy patient. Patients with short bowel syndrome experience nutritional complications affecting the individual's quality of life and independence along with his or her emotional health. A stoma operation causes profound changes in a patient's life because of resulting physical damage, disfigurement, loss of body functions, and changes in personal hygiene (Persson, Gustavsson, Hellstrom, Lappas, & Hulten, 2005).

According to Ostomy Basics written by Christine Dorman, RN, ANPC, CWOCN, the surgeon usually advises a low-fiber diet following surgery. The patient with an ileostomy is at risk for a mechanical obstruction if high-fiber foods are eaten without careful chewing or if a large quantity is taken at one time. High-fiber foods such as beans, corn, nuts, and raw fruits and vegetables have been known to trigger problems. In ileostomy patients, these types of food will be seen undigested in the pouch. That is why it is very important to chew these foods thoroughly. (Dorman, 2009).

Foods that help thicken the effluent and reduce the risk of dehydration include; applesauce, pretzels, bananas, yogurt, creamy peanut butter, white rice, and white bread. Certain foods produce more odor causing gas than others for ostomy patients. These odor and gas producing foods consist of eggs, fish, onions, broccoli, Brussels sprouts, cabbage, broccoli and cauliflower. To help decrease the odor, patients may consume yogurt, parsley, buttermilk, and cranberry juice. Depending upon the individual, most ostomy patients will learn by personal experience what foods are best for them (Dorman, 2009).

**Family Care**

Research suggests the family provides the greatest support for the ostomy patient and the nurse provides the most accurate information, which in turn has an effect on family life and coping (Wong & White, 2002). The focus on healthcare provisions for seniors seems to be shifting away from an institutional professional care facility toward family care in the home (Stoltz, Willman, & Uden, 2006). In Sweden, because of this shift in healthcare, there are indications that legislation will facilitate letting seniors remain in their home which means a better quality of life for the seniors. In the qualitative research by Stoltz et al., (2006) care giving illuminated on the meaning of support as narrated by family caregivers.

As more families are caring for their loved ones at home, there is a developing concern for the caregivers. The lived experience and sense of togetherness translates into support for the caregiver. The network of home health nurses provide a great asset to the caregiver's reassurance of honoring the promise that many had made to care for their relative at home until the end (Stoltz et al., 2006).

Self-efficacy refers to the conviction by patients that they can successfully manage their own stoma, which can minimize adverse outcomes. Adjustment seems to be better if patients accepted their stoma and were able to manage it effectively. Therefore, ensuring that people have the skills to manage their colostomy is very important (Simmons et al., 2007).

Living with uncertainty has influenced ostomy patient's social lives. Recurring issues are how to tell people they had a stoma, how to choose whom to tell, and concerns about how people will react. Some patients have limited their social contact and isolated themselves all together, while others reported that they have resumed their social life and have told friends, workmates, neighbors, and others (Persson & Helstrom, 2002).

According to a review of studies published in 1969 and 1992 the major impact involving a stoma placement is on the patient's social and leisure activities. None of the patients reported being treated differently by people who knew they had an ostomy, but said they themselves watch people and wonder if any one of them has an ostomy. Problems described by people are most often about their frequent and urgent bowel movements. Being close to facilities provides an enormous relief during these emergency situations (Persson & Helstrom, 2002). Recreation activities, including playing sports and traveling, are among the most problematic issues for all ostomy patients (Krouse et al., 2007).

**Summary**

There have been significant advances in stoma appliances and accessories and an increase in nurses specializing in stoma care. How people adjust has become the focus of much research. Taking personal control with stoma care self-efficacy are influencing factors. The placement of an ostomy requires that the ostomates adjust to a number of challenges, such as peristomal skin irritation, accidental leakage, and embarrassment related to sound and smells (Baldwin et al., 2008).

Ostomies are created to cure disease and to relieve suffering, but they can also lead to suffering. Providing the best care possible is not always enough. Understanding the ramifications and knowing how to respond to them with compassion, care, and understanding may contribute to holistic care more than to simply remove the disease.

By utilizing the Quality of Life Questionnaire as a tool, patients respond to questions in their own words about their greatest challenges and acceptance (Krouse et al., 2009). Coping strategies described positive attitudes, humor, and focus on enhancing the meaning of life. Adjusting to the body changes varied from individual to individual. It appears that coping and acceptance are made more frequently if ostomates have the support of a spouse or a partner (Krouse et al., 2009).

Comorbidities affect the physical function of patients to a large extent, but the fact of just simply having an ostomy plays a major role in mental functioning. Comorbidities have not been well described in many studies; however, it is quite obvious that they have generated a low health-related quality of life (Jain et al., 2007). Healthcare professionals can provide ostomates with self-management strategies in coping and accepting the ostomy. With positive thinking and humor, some ostomates have found that changes can result over time and bring some normalization to life (Krouse et al., 2009). People with a high level of spirituality were more likely married and had a higher quality of life. Studies have suggested patients with a religious or spiritual understanding might improve their overall well-being.

According to Weinert et al., (2008), the ultimate goal is to achieve a fully conceptual model that will serve

**Ostomy Patients continued from page 6**

to further inform nursing research, define research questions, and identify targets of interventions affecting nursing practice today. Research suggests the family with its strong supportive relationships and meaningful ties can help an individual member cope with the stress of life (Wong & White, 2002).

From current research, the ostomy patient's perspective on quality of care is considered inadequate because the healthcare system gives little time or opportunity for consultations and there are also serious defects in continuity of care from both nurses and doctors. The information provided by the physician and the nurse was unsatisfactory as it did not address psychosocial and emotional issues related to colostomy and ileostomy concerns (Persson & Helstrom, 2005). Today, there is a shift to address psychological education curricula into the academics to better prepare nurses to gain appropriate skills for helping stoma patients (Simmons et al., 2007).

Nursing has traditionally used a holistic approach to health care, blending curative and restorative treatment with disease prevention and health promotion (Nichols et al., 2005). Research has made it possible to produce beneficial findings and implement quality of care improvements that will better serve our nurses and patients in the future.

**Support Groups**

Nurses may refer ostomy patients to support groups within local hospitals and to the online United Ostomy Associations of America at <http://www.uoaa.org/>; the site has active discussion boards for various types of incontinent and continent diversions, along with youth, adult, and parent networks (Dorman, 2009).

Where to find more help and information:

<a href="http://www.uoaa.org">www.uoaa.org</a>	The United Ostomy Associations of America Inc. (UOAA).
<a href="http://www.uoa.org">www.uoa.org</a>	United Ostomy Association, Inc.
<a href="http://www.wocn.org">www.wocn.org</a>	Wound, Ostomy and Continence Nurses Society (WOCN)
<a href="http://www.rally4youth.org">www.rally4youth.org</a>	Youth Rally
<a href="http://www.cdfa.org">www.cdfa.org</a>	Crohn's and Colitis Info
<a href="http://www.NAFC.org">www.NAFC.org</a>	National Association for Continence
<a href="http://www.options-ostomy.com">www.options-ostomy.com</a>	Options™ Ostomy Support Barrier (Security Undergarments)
<a href="http://www.qia-ostomy.org">www.qia-ostomy.org</a>	Quality Life Association
<a href="http://www.ostomyworld.com">www.ostomyworld.com</a>	Hollister brand ostomy equipment
<a href="http://www.convatec.com">www.convatec.com</a>	ConvaTec brand ostomy equipment
<a href="http://www.edgepark.com">www.edgepark.com</a>	Ostomy and surgical supply company
<a href="http://www.us.coloplast.com">www.us.coloplast.com</a>	Coloplast brand ostomy equipment
<a href="http://www.ostomyfreebies.com">www.ostomyfreebies.com</a>	Ostomy Freebies (all brands)

**On a Personal Note:**

My father was diagnosed with colon cancer at 82 years of age, requiring three major surgeries over the next five years that eventually required an ileostomy. These surgeries were devastating and life-altering, leaving independence and self-care unobtainable for him. My mother dedicated her life caring for dad. After she passed away, my husband and I decided to care for my father in our home. As registered nurses, this experience was the greatest gift and the most rewarding experience for both of us. My father thanked us daily for the care we provided and his appreciation was more than we expected. The best gift in life comes from caring.

There were many complications that we worked through one-at-a-time, day-by-day. My father had the finest specialist in Central Ohio that contributed to the quality of his life. Eventually, we learned that the best time to change the ostomy appliance was in the early morning hours while the peristalsis activity was minimal. This timing consideration increased the efficiency of the procedure.

To reduce the risk of dehydration that ileostomy patients often experience, the nephrologist suggested drinking Gatorade and eating salty foods, like pretzels and cheese to maintain the sodium levels. Applesauce is another helpful food to thicken the consistency of output and reduces the risk of dehydration. The primary care physician provided thoughtful solutions by prescribing sodium bicarbonate that would provide an added benefit in sodium level maintenance.

Ileostomy patients experience symptoms similar to those with short bowel syndrome. In order to slow the peristalsis, his physician also prescribed Diphen/atrop (Lomotil) and Imodium giving the small intestines a longer period of time to absorb nutrients. Lying down after eating also reduced the peristalsis waves. We discovered that applesauce created a firm consistency reversing the liquid consistency. We took it upon ourselves to eliminate all artificial sweeteners and any foods containing artificial sweeteners from his diet because he experienced negative results with excessive effluent causing dehydration. This change significantly reduced the output volume and allowed him to retain fluids and maintain electrolyte balance more efficiently.

When informing this dietary change to the primary care physician, he responded with a question to us: "what is more important... dehydration or slightly increased glucose levels?" Of course, the answer to that question is dehydration, which is much more severe for someone with an ileostomy. Along with the physical care of the ostomy patient, it is critical to address the psychological and emotional care.

Our goal was to provide my father with the best quality of life possible. He felt confident to travel with the pouching system and by adding osto-gel to the pouch to eliminate odors which reduced anxiety and embarrassment. He was able to enjoy the Ohio State Fair and the Columbus Museum of Art for the first time in years. It was important to keep him connected with others by scheduling social outings. He loved to be in nature at the city parks and visit his favorite Italian restaurants. These social connections allowed my father to have a meaningful life with a sense of normalcy rather than being isolated. He enjoyed the last two years of his life with us because we encouraged confidence living with an ileostomy. He certainly enjoyed talking with everyone and he was especially proud to have represented the United States Army in World War II.

Learning the intricacies of my father's ostomy care was enlightening and will make us feel more comfortable caring for ostomy patients in the future.

**Ostomy Patients Post Test and Evaluation continued on page 8**

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# Introduction to the Physical, Psychological, Emotional and Spiritual Care for Ostomy Patients—Improving the Quality of Life

## Post Test and Evaluation

**DIRECTIONS:** Please complete the post-test and evaluation form. There is only one answer per question. The evaluation questions must be completed and returned with the post-test to receive a certificate.

Name: \_\_\_\_\_

Date: \_\_\_\_\_ Final Score: \_\_\_\_\_

Please circle one answer.

- All the following are common reasons for ostomy surgery EXCEPT:
  - Colorectal cancer
  - Crohn's disease
  - Bladder cancer
  - Polyps
- What is the most profound common negative aspect of having a stoma?
  - Odor
  - Body Image
  - Leakage
  - Noise
- The American Cancer Society has reported colon cancer as the third most common cancer in both men and women in the United States.
  - True
  - False
- The most beneficial time for ostomy education should begin:
  - Before surgery
  - After discharge
  - Before surgery and after discharge until the patient can perform ostomy skills successfully
  - With the home healthcare nurse
- The post-discharge follow-up is frequently provided by:
  - Non-specialized home care nurse
  - Physician
  - Psychologist
  - Wound Ostomy Nurse
- What foods are best to help prevent ostomy incurred odor?
  - Parsley and Yogurt
  - Onions and Broccoli
  - Cauliflower and Carrots
  - Asparagus and Nuts
- Which of the following dietary foods is NOT a restriction due to intestinal obstruction?
  - Popcorn
  - Nuts
  - Corn
  - Creamy peanut butter
- How much caffeine-free fluid intake is recommended daily for an ileostomate?
  - 4 to 5 cups
  - 6 to 8 cups
  - 10 to 12 cups
  - 13 to 15 cups
- According to the United Ostomy Associations of America, what are two major concerns of the ostomy patient?
  - Traveling and working
  - Living alone and cooking
  - Controlling odor and leakage
  - Swimming and bathing
- Who provides the greatest support for ostomates?
  - Physician
  - Nurse
  - Family
  - Ostomy Specialist
- Research suggests males more than females are receptive to the health promotion of communication to manage their ostomy.
  - True
  - False
- Approximately how often should an ileostomy pouch be emptied?
  - 1 to 2 times daily
  - 3 to 4 times daily
  - 4 to 5 times daily
  - 6 to 8 times daily
- How often should an appliance be changed to prevent skin irritation and breakdown?
  - Every 2 days
  - Every 4 days
  - Every 5 days
  - Every 6 days
- What function does a skin barrier treatment serve?
  - Protect skin from getting sore and irritated
  - Helps to heal skin that is already damaged
  - Provides a protective layer between the skin and urine, stool, or drainage
  - All the above
- All the following can reduce stress for the ostomate EXCEPT:
  - Packing extra ostomy supplies
  - Wearing a support barrier when traveling
  - Avoiding odor-producing foods and carbonated drinks
  - Restricting fluids
- From the list of websites, which listing has information for security undergarments?
  - [www.uoa.org](http://www.uoa.org)
  - [www.options-ostomy.com](http://www.options-ostomy.com)
  - [www.rally4youth.org](http://www.rally4youth.org)
  - [www.ostomyworld.com](http://www.ostomyworld.com)
- For ostomates, the prediction is that overall life satisfaction and quality of life increases for those with a:
  - Permanent ostomy
  - Temporary ostomy
  - Part-time job
  - Full-time job
- All the following are odor producing foods EXCEPT:
  - Eggs
  - Fish
  - Cabbage
  - Applesauce
- Which of the following can help reduce bacterial growth with urostomates?
  - Yogurt
  - Cranberry juice
  - Parsley
  - Asparagus
- What measurement warrants the need for emptying an ostomy pouch to reduce the risk of loosening the adhesive seal?
  - One-third to one-half full
  - Three-fourths full
  - Half-full
  - Full

### Evaluation

- Were you able to achieve the following objective?  Yes  No
  - Describe the needs of ostomy patients.  Yes  No
- Was this independent study an effective method of learning?  Yes  No
 

If no, please comment: \_\_\_\_\_
- How long did it take you to complete the study, the post-test, and the evaluation form? \_\_\_\_\_
- What other topics would you like to see addressed in an independent study? \_\_\_\_\_



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# Using Preferred Practices to Improve Palliative Care at End of Life

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This independent study has been developed to enhance nurses' knowledge of best practices in palliative care at end of life.

The authors and planning committee members have declared no conflict of interest. There is no commercial support for this independent study. Disclaimer: Information in this study is intended for educational purposes only. It is not intended to provide legal and/or medical advice. *The authors would like to thank the Palliative Care Committee of the Midwest Care Alliance, Drs. Robert Taylor and James Murphy for their editorial assistance.*

**0.8 contact hour will be awarded** for successful completion of this independent study.

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## OBJECTIVE

Discuss preferred palliative care practices and adjuncts to care for the chronically-ill patient and his/her family during their illness and end-of-life.

## STUDY

### Case Study

This day is much like the other nine days that preceded it. Mary lay in bed with the ventilator quietly and rhythmically breathing with her at least twelve times per minute. Her respiratory rate is 14-18 per minute. Her blood pressure is trending downward ranging from 96-110/66-70; pulse 76-86/minute in a normal sinus rhythm. Her temperature is also back down to normal the last two days, after sputum cultures had come back positive for pseudomonas and antibiotics were started.

Although sleeping a lot, Mary arouses when stimulated. An endotracheal tube is in place, making communication difficult. When awake she communicates with hand gestures and mouthing words.

Mary is 69 years old, married with three grown children. She was diagnosed with chronic obstructive pulmonary disorder (COPD) about seven years ago. Her husband believes she has been sicker than this before. Six weeks ago she was on the ventilator, and they were told, in his words, "This is it," but she pulled through. Mary is a fighter and she always pulls through."

Two daughters live in the same city and visit frequently at the hospital. They have taken over more responsibility for their parents' activities such as making sure the bills are paid, arranging and attending doctor appointments and getting a cleaning service occasionally to help. Their younger brother lives in Florida and stays in touch with phone calls, visiting infrequently. He was last home eighteen months ago for Thanksgiving. It is clear to the sisters that he does not understand how their mom's condition has changed.

Today a family meeting is scheduled for 9:30 AM. Mary, her husband, daughters, bedside nurse, pulmonologist, and palliative care nurse coordinator are gathered to discuss options for medical treatment and palliative care. At the last minute, the son from Florida was unable to call in because of urgent business matters.

There are no written advance directives and only the vaguest of conversations regarding health care wishes. During this hospitalization Mary has communicated to the nurses and her daughters that she is tired and that she just wants to go home. Her husband is very tearful and has asked her repeatedly to just "try a little longer."

In clear laymen's terms treatment options are explained and include either a tracheostomy or PEG tube or a terminal ventilator wean and extubation with aggressive palliative symptom management. Now the team's question to Mary and her family is, "How can we help you? How can we best respect your wishes?"

With support, Mary is able to make her wishes known. She wants to be comfortable without any machines and to go home if possible. Plans are made for withdrawal of life-sustaining treatment and extubation. When the brother is notified by telephone he is very angry, upset and certain that his mother's wishes were misunderstood. "How can you even think about stopping the ventilator? Do you WANT her to die?" he shouts over the phone.

### Overview

This article will provide you with a framework to consider when providing this special care. The National Consensus Project, which convened experts from each of the national organizations representing hospice and palliative care, delivered the first palliative care standards to be used in the United States, and proposed eight Domains of Clinical Practice with thirty-eight preferred practices. Domain seven is entitled "Care of the Imminently Dying Patient," and the preferred practices under this domain are as follows:

**Preferred Practice 26:** Recognize and document the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.

**Preferred Practice 27:** Educate the family on a timely basis regarding signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.

**Preferred Practice 28:** As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for site of death and fulfill patient and family preferences when possible.

**Preferred Practice 29:** Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns and fears about using narcotics and of analgesics hastening death.

**Preferred Practice 30:** Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.

**Preferred Practice 31:** Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death, when the family remains in the focus of care.

Mary's family is an example of a patient and family whose loved one is dying. A patient with the diagnosis of COPD was deliberately selected for this article to shed light on an atypical example of the terminally ill patient. Typically, when talking about patients approaching death, we think of patients with diagnoses such as cancers or AIDS, but often overlook the unpredictable but no less fatal organ system diseases such as congestive heart failure or COPD. COPD is a lung disease characterized by chronic obstruction of lung airflow that interferes with normal breathing and is not fully reversible. The more familiar terms 'chronic bronchitis' and 'emphysema' are less often used, but are now included within the COPD diagnosis. COPD is not simply a "smoker's cough" but an under-diagnosed, life-threatening lung disease. At end of life, there are also unique challenges presented by COPD, including how to manage shortness of breath as well as anxiety and the patient's feelings of loss of control.

### According to the guidelines developed by the American Thoracic Society and the European Respiratory Society:

- Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality worldwide, and results in an economic and social burden that is both substantial and increasing.
- Prevalence and morbidity data greatly underestimate the total burden of COPD because the disease is usually not diagnosed until it is clinically apparent and moderately advanced.
- COPD is the fourth leading cause of death in the USA and Europe, and COPD mortality in females has more than doubled over the last 20 years.
- COPD is a more costly disease than asthma and, depending on country, 50-75% of the costs are for services associated with exacerbations.
- Tobacco smoke is by far the most important risk factor for COPD worldwide.
- Other important risk factors are occupational exposures, socioeconomic status and genetic predisposition.

• American Thoracic Society and the European Respiratory Society, <http://www.thoracic.org/clinical/copd-guidelines/>, retrieved 12/21/11

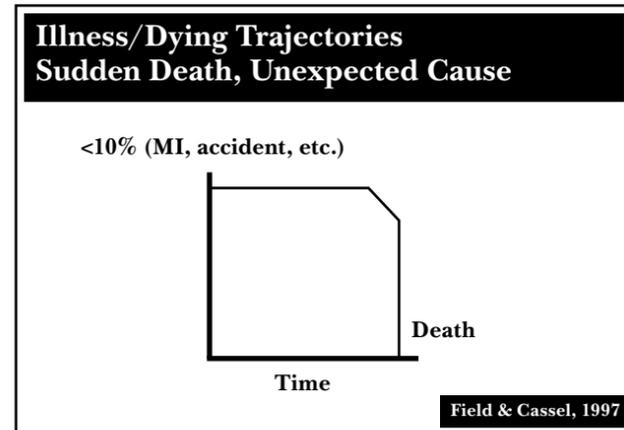
### Physical/Medical aspects of care

As Mary begins to exhibit symptoms that are common at the end of life such as increased secretions, restlessness or shortness of breath, the team needs to take the time to educate her family on the symptoms that they are observing. In this example, Mary's team includes her nurse, pulmonologist, and palliative care nurse coordinator, but could also include a social worker, chaplain, respiratory therapist, and any other discipline whose knowledge and skills could help this family define and meet their goals of care.

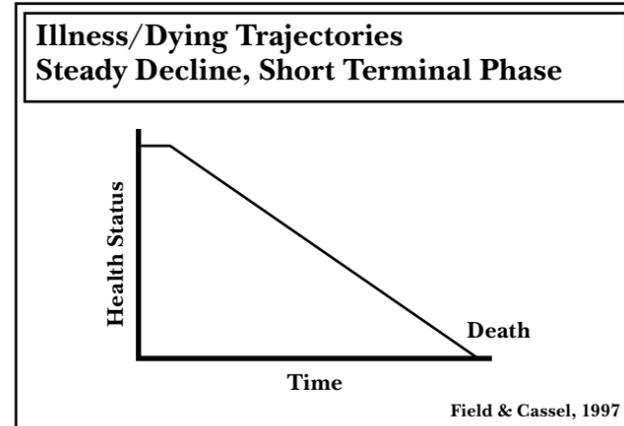
Timely assessment and medication is important for Mary's comfort as well as her family's emotional comfort. Observing a loved one with shortness of breath can be extremely distressing to the family as well as the patient. This is explained in the preferred practice #27, which encourages age-appropriate, developmentally appropriate and culturally appropriate education regarding signs of imminent death. This education needs to include teaching about the recommended medications for the symptoms Mary is exhibiting as well as non-pharmacological therapies as well.

Utilizing a fan and turning the temperature down in the room can help provide Mary with a decrease in the feelings of air hunger. This also provides her family with

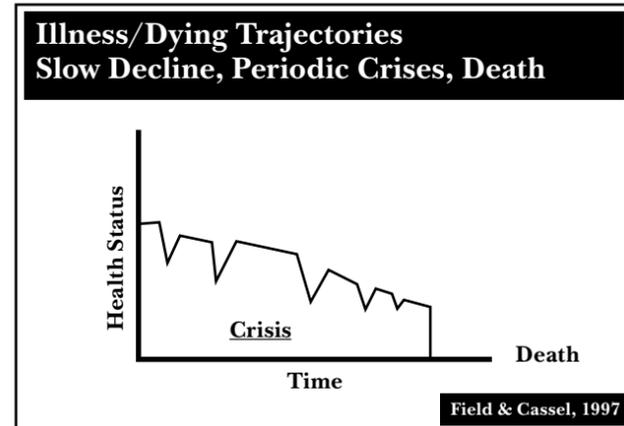
an opportunity to participate in caring for Mary and empowers them to feel involved in Mary's care. At the same time, utilizing medications such as an opioid, most commonly morphine sulfate, for her shortness of breath can provide added comfort. Preferred practice #29 reminds us that adequate doses of appropriate medications should be utilized to assist in achieving comfort for the patient. Because adequate dosage can vary from patient to patient, utilizing the palliative care team for medication titration orders will assist in achieving comfort for Mary during the active dying phase. When withdrawal of life-sustaining treatment is planned, team members should review and adhere to organizational guidelines and if available, order sets. Whenever a ventilator is weaned and discontinued from a conscious patient who is ventilator-dependent, opioid medication will be required for comfort. Concise and easy-to-understand education for Mary's family will assist in addressing their concerns and fears about using narcotics and of the misperception that the use of opioids hastens death. In fact, in this setting, opioids, properly titrated, do not shorten survival, but rather improve comfort and may actually prolong survival by reducing stress and discomfort.



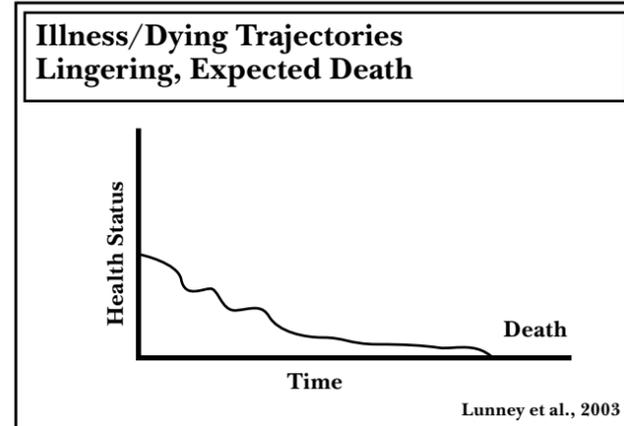
Examples: Myocardial Infarction, accident, etc.



Example: End-stage cancers, etc.



Example: COPD, congestive heart failure, etc.



Examples: Dementia, etc.

Much education about the rationale for using opioids needs to occur for Mary's family. There is often fear associated with the use of opioids. Mary's son stated "are you trying to kill her?" It is the team's responsibility to

*Palliative Care continued from page 9*

reduce her family's distress and provide reassurance that utilization of opioids will assist in optimizing comfort and quality of life for Mary.

It is also important to emphasize that, when a life-prolonging treatment is discontinued in a terminally ill patient, the ultimate cause of death is the underlying disease, not the discontinuation of the life-prolonging treatment.

It is also imperative that a conversation regarding the location of death occurs with Mary if she is able to participate in the conversation and with her family as well. This is a conversation that ideally should occur early on in the disease trajectory. Most patients want to die in their home environment and we are reminded in preferred practice #28 that all attempts should be made to fulfill the patient and family's desires. All patients who are discharged to home or an extended care facility who are expected to die within six months or less should be offered a hospice referral. If the patient wants to die at home but is unlikely to survive long without life-sustaining treatment (for example, ventilator support), some hospices will care for these patients, so they can be transferred home before death. As the physician and nurses begin to see changes in

Mary's physical condition such as mottling, periods of increased sleep, decreased oral intake and urine output, they need to educate the family that death is approaching. The goal should be to honor the wishes of Mary and her family to the extent possible. If it is unrealistic to move Mary because of imminent death, a simple and honest explanation should be provided.

Comfort is often the most common request that family members make as death is approaching. It is necessary to define what comfort means to each individual. For some it may mean relief of symptoms with medication, while to others it may mean something quite different. It is important to ask for clarification of goals and evaluate and support Mary and her family's desires for comfort. It is the nurse's responsibility to assist in providing all options for comfort as well as educating families about the benefits and burdens of each option. Preferred practice #29 encourages this assessment, followed by providing the comfort measures as well as continued education to the family. It is also important to provide emotional support

and address any patient-family or intra-family conflicts regarding any interventions. It is evident that all of Mary's family did not agree on the path of comfort she was choosing. The involvement of the social worker, palliative care team, or other counselor to assist in conflict resolution may help ameliorate stress.

Once death has occurred, it is the responsibility of the care giving team to prepare Mary's body and provide post mortem care. Preferred practice #30 reminds us that we need to care for the body with respect, as well as honor any cultural or religious traditions that are important to Mary and her family. It is respectful and courteous to ask Mary's family if they would like to partake in the bathing and preparation of Mary's body. There are many culturally diverse traditions that should be honored if at all possible and if you are unsure of these practices, do not hesitate to ask the family or other team members for guidance. Chaplains, social workers and family clergy are frequently the most helpful resources for such questions, due to their training and connections to community resources. At the same time it is necessary to treat the body in accordance with the law.

**Psychosocial aspects of care**

Psychosocial aspects of caring for a person with end-stage COPD may take various forms. It is imperative that each member of the interdisciplinary team assess, communicate, and document the needs of Mary as well as her family members. COPD can and does manifest a high level of anxiety. Anyone who has ever experienced breathlessness or has been around those who have difficulty breathing can sense the panic, helplessness, and fear they experience. This sets up a vicious cycle of shortness of breath, leading to an increase in anxiety, leading to increased shortness of breath, which can lead both Mary and family members to panic. It is vital to educate all involved about the disease process, symptom management, and to facilitate discussion about goals of care. Ideally this should be done early in the disease process in order to lay a good framework for a supportive plan of care. This conversation needs to be addressed with each subsequent visit, as goals may change.

In addition to anxiety, shortness of breath may also greatly affect quality of life for not only Mary, but also those around her. Individuals with COPD may have controlling personalities, and understandably so, as they may be desperate to have some control and say in all aspects of their lives, often making it difficult to be around them. This may alienate loved ones and cause the patient to feel isolated. Healthcare providers may avoid going into a patient's room or may begin to question the validity of the shortness of breath because the oxygen saturation levels are stable. Providers need to remind themselves that shortness of breath is a subjective symptom, and that air hunger is a sensation felt only by the patient. Sometimes having a fan circulating in the room or even an open window can do wonders to alleviate this feeling of suffocation.

Another effect of shortness of breath can be decreased independence, because the patient lacks the energy or stamina to complete even routine tasks. This will not only affect Mary's self-esteem and feelings of worth, but also may add additional tasks on to the burdens that her loved ones already have. Learning to pace activities and learning relaxation techniques can help build stamina, thus salvaging some independence and easing caregiver-burden. With advanced illness at end of life, families may be exhausted and may have fatigued coping mechanisms.

Providers need to exercise patience, and respite care may be necessary to address caregiver burden.

In the case of worsening shortness of breath and increased anxiety, Mary and her family are faced with difficult decisions in regards to healthcare options and treatments. Ideally, there would already be advance directives in place, such as a living will and/or a health care power of attorney. A living will is a written document that specifies a patient's individual preferences for medical treatment based on one's own values and goals that takes effect when the patient is terminally ill and unable to make decisions or is permanently unconscious. A health care power of attorney allows a patient to choose a surrogate decision maker to ensure that these preferences are carried out should Mary be unable to speak for herself. The optimal time to begin to identify and discuss these wishes for advance care planning is on the first visit. They should be revisited, as panic and anxiety can sometimes dissolve previous decisions that were made. At moments of crisis, the patient and the caregiver may have differing goals. While it is important for the provider to help the family reconcile differences, ultimately the patient's wishes regarding their care are paramount. A good rule of thumb would be to clarify current goals at each visit or episode, intervene when necessary, and follow up as appropriate. A calm but informed healthcare provider can do much to alleviate the panic and anxiety that Mary and her family may be feeling.

There are often financial burdens which families may be reluctant to discuss. The costs of multiple trips to the hospital and/or emergency room, aggressive treatments, pharmacological interventions, and cost of caregiving may exacerbate Mary's anxiety, especially because Mary has loved ones who will cope with the financial fallout of her illness. Guilt, depression or depression-like symptoms may develop as a consequence of this dynamic. Clinicians should routinely screen for these symptoms and treat when appropriate.

**Spiritual aspects of care**

Addressing spiritual or religious beliefs with the patient and family is essential. Times when Mary is awake and conversant will vary and continue to decrease. Caregivers can encourage the family to use lucid moments to the fullest. Hospice physician Ira Byock identifies four tasks that Mary's family and other families may consider to reconcile and heal hurts: ask for forgiveness, offer forgiveness, offer love, offer heartfelt thanks, and say goodbye.

Ideally, Mary's spiritual beliefs should have been elicited at the time of admission or earlier. Chaplains are an important resource in exploring and addressing patients' religious and spiritual beliefs and concerns. Particular attention should be given to any beliefs that would have an impact on her healthcare choices, as well as those beliefs that may either support or hinder her ability to cope at this point in her illness. It is important to honor her beliefs throughout the course of her stay as her condition worsens.

Discussions of spirituality should not be confined to a particular religion or church. For many individuals, a discussion of life purpose and meaning may have profound spiritual value. Studies have shown that some clinicians are hesitant to broach the subject of religion or spirituality for fear of offending the patient, or simply due to discomfort or unfamiliarity. Ideally, clinicians would be well-prepared to have these conversations in order to further enhance

*Palliative Care continued on page 11*

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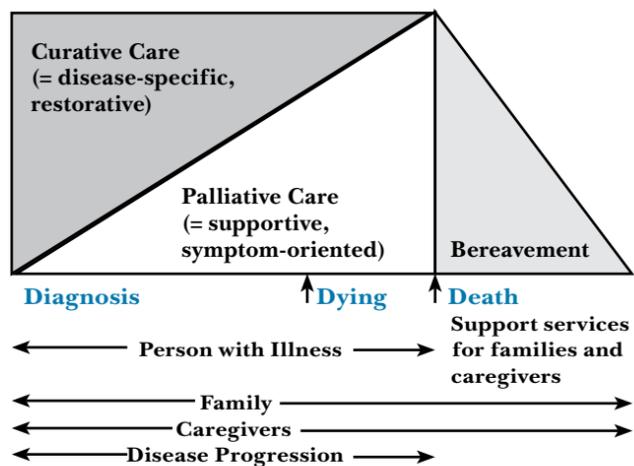
*Palliative Care continued from page 10*

end-of-life-care discussions. However, many are not comfortable or skilled in this area, in which case involving a chaplain is often most helpful. It is important to keep in mind that some patients and families believe rituals at the time of death are just as important as beliefs concerning an afterlife, and these beliefs are particularly important to elicit for the patient who is quickly approaching death. Often simply encouraging a life review or asking the patient or family what stands out in their lives as being most significant can begin the conversation and help ease tensions.

In summation, in order to ensure the best quality of life for Mary and her loved ones, they need to have physical, interpersonal, psychological, and spiritual concerns addressed. It is critical to note that the nurse alone is not responsible for providing for all of Mary's needs. End of life care demands an interdisciplinary approach, which can include a formal Palliative Care Consult Team or an informal group of clinicians coming together to meet Mary's goals for the final phase of her life. With this team approach, the goals of care are defined by the patient and family, and there is a fluid exchange of team members' professional strengths, knowledge and competencies that come together to best achieve those goals.

**Grief & Bereavement**

Preferred practice #31 indicates that post death bereavement requires a plan to support the survivors through the phase of grieving. The location of death and the type of care provided may influence the bereavement plan that is initiated. A palliative care program in the hospital may not have the structure to provide bereavement care outside of the hospital setting. This may be true for deaths that occur in any acute care or long term care setting. If this is the case, then a suggestion would be that the palliative care team or healthcare provider should provide information to the survivors on available hospice or community bereavement resources in the area. Patients who die while under the care of hospice will receive bereavement follow-up for thirteen months after the death, and many hospices provide bereavement services to families of persons who did not die in the hospice.



**Palliative care should be involved in care from the moment of diagnosis. As the disease progresses and fewer curative options are available to a patient, there may be a higher degree of palliative**

**care involvement. Bereavement care should be provided to the family following the patient's death, slowly tapering as the family adjusts to life without the patient.**

Regardless of the structure of the bereavement support, it is important for health care providers to keep in mind that the nature of the death, even the type of disease the person dies from will often affect the grief process for the survivors. For example, for Mary's survivors the significance that the disease was gradual, lasted for nearly a decade and had periods of exacerbation and dyspnea may have a significant impact in her family's grief process. Her survivors may experience questions of doubt as to whether they should have fought harder and kept Mary on the ventilator longer. There may be regrets or anger as to Mary's life style choices that ultimately contributed to her death with COPD. While these factors may have an impact on the grieving process, it is also important not to make assumptions about how certain aspects of a person's illness or death will affect bereavement; instead one should explore the relatives' concerns and assure access to appropriate resources for all family members.

Healthcare providers should also consider how individual family values, religious rituals, and/or cultural customs contribute to the grieving process. Survivors should be encouraged to seek out assistance to understand all of these implications. Grief can be like the illness itself, so that it is important for healthcare professionals to help the survivors navigate the experience.

**Closing**

The care of the imminently dying patient can be among the most challenging and rewarding care that a nurse can provide. The National Priorities Partnership equips providers with a clear framework to help guide professionals who encounter dying patients, but the preferred practices are only a starting place. There are many other resources available to nurses, one of the best of which is the End of Life/Palliative Education Resource Center (EPERC) Fast Facts. EPERC's Fast Facts are a series of over 200 short information sheets that detail different scenarios that professionals may encounter in providing palliative care, from how to recognize grief and depression to dealing with a hospice patient admitted through the emergency room. Each Fast Fact provides a brief summary of key points to keep in mind, and they are all available free online: <http://www.eperc.mcw.edu/EPERC/FastFactsandConcepts>.

Furthermore, it is important that any professional working with patients nearing death closely examine his/her own preconceptions, beliefs and cultural values regarding suffering and death. It is best to undertake this work prior to being confronted with a clinical situation that evokes an emotional reaction and may impede the nurse's ability to provide the best quality of care. Resources to assist with this exploration include one's own religious community, colleagues who work in hospice or palliative care, or formal courses and seminars addressing such topics.

Dying is an intensely personal experience, for both the families involved and the professional caregivers who have the opportunity to shepherd these families during this difficult time. While a professional caregiver may encounter many dying patients over the course of a career, each patient only dies once. Many families remember the final moments of loved ones in vivid detail, and what

the nurse does, whether good or bad, may have a lasting effect. It behooves all nurses to prepare as best they can by familiarizing themselves with the preferred practices framework, identifying tools available to them and equipping themselves emotionally.

**Examples of EPERC Fast Facts that may have been helpful with Mary and her family include...**

- #006 & 001 Delivering Bad News-Part 1 & 2, 2nd ed
- #016 Moderating an End-of-Life Family Conference, 2nd ed
- #027 Dyspnea at End of Life, 2nd ed
- #033 Ventilator Withdrawal Protocol, 2nd ed
- #052 Quality of Life
- #054 Opioid Infusions in the Imminently Dying Patient, 2nd ed
- #059 Dealing with Anger, 2nd ed
- #139 Hospice Referral: Moving from Hospital to Home
- #141 Prognosis in End-Stage COPD
- #203 Managing One's Emotions as a Clinician
- #211 Guided Imagery for Anxiety
- #216 Asking about Cultural Beliefs in Palliative Care

<http://www.eperc.mcw.edu/EPERC/FastFactsandConcepts>

**Palliative Care Post Test and Evaluation continued on page 12**

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# Using Preferred Practices to Improve Palliative Care at End of Life

## Post Test and Evaluation

**DIRECTIONS:** Please complete the post-test and evaluation form. There is only one answer per question. The evaluation questions must be completed and returned with the post-test to receive a certificate.

Name: \_\_\_\_\_

Date: \_\_\_\_\_ Final Score: \_\_\_\_\_

Please circle one answer.

1. Domain 7 refers to:
  - A. The preferred practices for the care of patients with COPD
  - B. The End of Life/Palliative Education Resource Center's work on improving care of the dying
  - C. The portion of the National Consensus Project which addresses care of the imminently dying patient
  - D. None of the above.
2. An example of a disease trajectory which patients experience steady decline and a short terminal stage is:
  - A. End-stage cancers
  - B. Dementia
  - C. COPD
  - D. Congestive heart failure
3. The disease trajectory for COPD is characterized by:
  - A. Steady decline over time & short terminal phase
  - B. Slow decline & periodic crises
  - C. Sudden death
  - D. Lingering & expected death
4. Ideally, a conversation about end of life care preferences should first occur:
  - A. At diagnosis
  - B. On admission
  - C. When a patient's status declines
  - D. When the patient is referred to hospice
5. What is families' most common request when death is approaching?
  - A. Emotional support
  - B. Respite
  - C. Assistance with financial planning
  - D. Comfort
6. The most common psychosocial symptom for patients with COPD:
  - A. Hysteria
  - B. Depression
  - C. Guilt
  - D. Anxiety
7. A \_\_\_\_ is a written document that specifies a patient's individual preferences for medical treatment based on one's own values and goals that takes effect when the patient is terminally ill and unable to make decisions or is permanently unconscious. A \_\_\_\_ allows a patient to choose a surrogate decision maker to ensure that these preferences are carried out should Mary be unable to speak for herself.
  - A. Living Will, Healthcare Power of Attorney
  - B. DNR, Healthcare Power of Attorney
  - C. Healthcare Power of Attorney, Living Will
  - D. DNR, Durable Power of Attorney

8. Preferred Practice 29 recommends that caregivers provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and \_\_\_\_\_.
  - A. Monitor the patient for adverse drug reactions.
  - B. Address concerns and fears about using narcotics and of analgesics hastening death.
  - C. Titrate the dosage according to the patient's desired level of comfort.
  - D. Prepare the family by discussing signs of approaching death.
9. The term Fast Facts refers to:
  - A. The preferred practices outlined in the National Consensus Project.
  - B. The COPD guidelines published by the American Thoracic Society.
  - C. Statistics regarding death and dying in America.
  - D. A series worksheets covering various topics relative to palliative care.
10. Ideally, palliative care should be involved from:
  - A. Diagnosis.
  - B. Admission.
  - C. Significant decline.
  - D. When death is imminent.
11. One non-pharmacological intervention that can help relieve patients' feelings of shortness of breath is:
  - A. A fan in the room.
  - B. Yoga.
  - C. Talk therapy.
  - D. Distraction.
12. If caregiver burden is great, providers may first consider \_\_\_\_\_.
  - A. Nursing facility placement
  - B. Psychiatric referral
  - C. Respite care
  - D. Contacting Adult Protective Services
13. A survivor's bereavement process may be affected by:
  - A. The nature and trajectory of the disease
  - B. Family values
  - C. Religious rituals and cultural customs
  - D. All of the above
14. Prior to providing care for a dying patient, a nurse should examine:
  - A. His/her own preconceptions, beliefs and cultural values regarding suffering and death.
  - B. All of the available Fast Facts applicable to a patient's case.
  - C. The practice guidelines published by professional societies and associations.
  - D. All of the above.
15. Discussions of spirituality
  - A. Are often difficult for providers to initiate.
  - B. Should not be confined to a specific religion or church.
  - C. May include a discussion of life purpose or meaning.
  - D. All of the above.

16. Many hospices provide bereavement services to families whose loved ones did not die in hospice care.
  - A. True
  - B. False
17. End of life care demands a \_\_\_\_ approach to service delivery.
  - A. Medical
  - B. Interdisciplinary
  - C. Holistic
  - D. Psychosocial
18. One way to initiate a spiritual discussion is to:
  - A. Ask the patient what their religion is.
  - B. Encourage life review.
  - C. Ask the family at what church they plan to hold the patient's funeral.
  - D. Ask the patient if s/he'd like a chaplain to visit.
19. It is courteous to ask a patient's family if they would like to partake in the bathing and preparation of a patient's body.
  - A. True
  - B. False
20. The interdisciplinary team may include:
  - A. A specialty physician
  - B. The hospital chaplain
  - C. The social worker
  - D. All of the above

### Evaluation

1. Were you able to achieve the following objective? \_\_ Yes \_\_ No
  - a. Discuss preferred palliative care practices and adjuncts to care for the chronically-ill patient and his/her family during their illness and end-of-life.
2. Was this independent study an effective method of learning? \_\_ Yes \_\_ No  
 If no, please comment: \_\_\_\_\_
3. How long did it take you to complete the study, the post-test, and the evaluation form?  
 \_\_\_\_\_
4. What other topics would you like to see addressed in an independent study?

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# Health Information Technology: A Blend of Clinical and IT in the New Job Market

**Cathy Costello, JD, Project Manager REC Services, Ohio Health Information Partnership**

OK, I admit it. I love to talk. Ask anyone. The best thing, though, is that I get to talk as I travel around Ohio for my job. I talk to all kinds of people, and it gives me a lot of perspective on the crazy patchwork quilt that is this new area of healthcare information technology (HIT). As I meet with folks from medical practices, hospital systems, rural hospitals, health departments, health centers, free clinics and just about any place where care is delivered, it makes me realize how different we all are in our backgrounds. But we are all working for the same thing—to use this new tool of technology to improve the health care in this country.

Most importantly, nurses play a key role in this momentous shift in the healthcare workplace. Nurses are participating more and more in this move to go electronic in healthcare. As of July 2012, more than 525 Ohio nurse practitioners and certified nurse midwives drew down more than \$10 million in EHR incentive payments from Ohio Medicaid, either for themselves or for their employers. Nurses are critical links in Medicaid's effort to bring its providers into the electronic era.

As part of the move to go electronic, there is a fundamental shift in jobs in the healthcare arena. I work in an HIT job that did not exist three years ago. Through the creation of The Ohio Health Information Partnership (The Partnership), I have been able to focus my work on the adoption and implementation of electronic health records (EHR) throughout Ohio. Five years ago, no one would have imagined this role. In this position, I have been able to witness a tremendous effort throughout the healthcare industry to move forward with this new wave of technologies.

Several statewide organizations as well as the State of Ohio formed The Partnership in 2009, drawing down federal funding for the development of HIT in Ohio. As a Regional Extension Center (REC) and the state-designated Health Information Exchange (HIE), we have a two-pronged mission. The first is to assist hospitals and healthcare providers to adopt EHR systems, and the second is to build a statewide structure for health information exchange. A coordinated, federal effort funded states across the nation to bring healthcare technology into the 21st century, while still supporting the community-based, independent practice of medicine.

My role as the REC project manager is to work with healthcare individuals and organizations regionally to provide a clear explanation of the new federal standards for HIT and to demonstrate what it means to them. I meet many nurses who are in charge of teams that oversee the adoption of EHRs in hospitals or other healthcare settings. Because of my work, I have met two expert nurses who have taken their clinical skills and used them to create new jobs in the HIT sector. Each arrived in the HIT area through a different pathway.

### Pathways to EHR through Nursing

Mary Zile, a nurse in Cincinnati, has transitioned from clinical nursing to become the Director of Clinical Consulting for the Tri-State Regional Extension Center. Tri-State is a REC that covers 67 counties in Ohio, Kentucky and Indiana and is affiliated with the HIE HealthBridge. Mary's nursing career began at Wright State University when she earned her bachelor's degree in nursing, then later went back to receive her master's degree in health services administration. Mary first worked in the cardiac and surgical ICU areas but moved into the ambulatory area as she managed a four-provider primary care office. During this time, Mary learned about electronic health records. In 2001, she helped the practice purchase a new EHR system at a time when little guidance was available on this topic.

Mary then combined what she had learned from the selection process with her interest in improving patient health for her master's degree program. She worked on structuring an EHR study to show how the use of an EHR can help a practice manage their chronically ill patients. As part of Mary's work, she constructed a project with diabetics measuring patients' HgA1C before and after EHR implementation. Because of Mary's efforts, her practice became a leader in the Robert Wood Johnson Foundation and Cincinnati Health Collaborative Primary Care Innovation Group. They went on to achieve a Level 3 NCQA Patient Centered Medical Home (PCMH) status. Like many people I meet in the HIT workplace, Mary had no formal training in HIT because none was available. Through her hard work and self-training, Mary developed the skills to work with EHR vendors and the practices that were trying to adopt their products.

"The reason I wanted to implement an EHR so early is that while studying the healthcare system, I realized that there were imminent problems in healthcare," Mary said. "I wanted to be an example of how to 'fix' the primary care system so providers could produce great outcomes if they could reduce the barriers within the system."

Kelly Cornett took a different path to develop her skills as a Clinical EHR Specialist for Knox Community Hospital in Mt. Vernon. Kelly graduated in 2001 with an undergraduate degree in biology and later went back to school to become a registered nurse in 2010. Kelly worked for many years from home managing not-for-

profit organizations and helping with their online services and support areas. Already comfortable with computers, she understood how they could be used to support other aspects of health care. When she heard about the Workforce Development Program that combined clinical training with IT training to support EHR implementation, she felt that this would be a good fit, given her background.

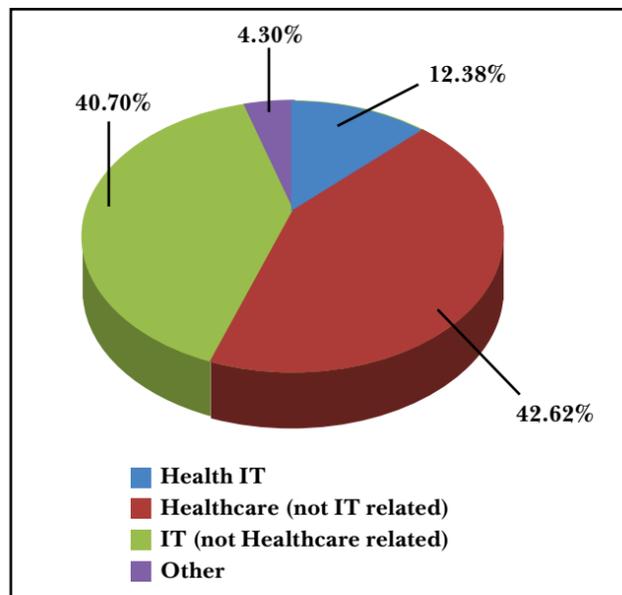
Kelly enrolled in the Columbus State Community College (CSCC) site for its six-month program in healthcare information technology. She is now working at Knox Community Hospital on the EHR implementation team, customizing and transitioning primary care and specialty practices onto electronic health records and coordinating Meaningful Use adoption.

"I started out as a float RN in physicians' practices," Kelly said. "Being interested in computers, I also applied and was accepted into the Health IT grant program at CSCC. To enhance my training, I offered to float to the EHR team whenever needed. It did not take long for the position to become permanent. Although I do not get to serve patients, I enjoy supporting the providers, nurses and clerical staff throughout their EHR experience."

### Workforce Development Program for Healthcare IT

CSCC's program is part of the broader Midwest Community College HIT Consortium. Included in this program are community colleges that have developed programs to train individuals about the workflow changes that must accompany the adoption of an EHR system. In Ohio, this program is funded at four different sites: Cuyahoga Community College in Cleveland; Columbus State Community College in Columbus; Sinclair Community College in Dayton; and Cincinnati State Technical and Community College in Cincinnati. The programs these schools offer combine training from the clinical perspective with IT so that graduates are able to better fill roles that bridge both areas. It is a requirement of the HIT Workforce Program that participants have a healthcare background, an IT background, or both. In Ohio, 43 percent of the program's participants are from the healthcare sector, 41 percent are from IT (non-healthcare related) and only 12 percent have both. There are 730 successful graduates and 437 actively enrolled in this six-month program to teach the basics of the adoption of HIT in the workplace.

**Figure 1: Midwest Community College Health Information Technology Consortium Figures for Ohio Schools, June, 2012**



Although the programs were established to support the adoption of EHR systems in the ambulatory workplace, the program's director, Norma Morganti, is looking at the possible expansion of the program into other HIT areas. This is in recognition that the HIT job market is growing and changing to keep pace with various federal initiatives. The Department of Labor estimates the need for 50,000 workers in HIT to meet the demands for meaningful use, ICD-10 and more between now and 2014. Additionally, hospitals are paying top-notch salaries for those with clinical backgrounds with IT knowledge and skills for clinical application support and clinical informatics.

For more information on Workforce Development Programs in Ohio, go to [http://www.ohhealthjobs.com/health\\_it/education/](http://www.ohhealthjobs.com/health_it/education/), the site developed in conjunction with the Ohio Hospital Association. This site not only provides information on the Workforce Development Programs in Ohio, it also is the posting site for HIT jobs and internships.

### New Healthcare Technology Jobs

At this time, if a hospital or practice is installing software for EHRs, it must meet federal standards called Stage 1 Meaningful Use (MU). These technology standards established by the Centers for Medicaid and Medicare Services (CMS) require that a healthcare organization's computer system has the capability to capture clinical information, produce electronic prescriptions and meet a number of reporting requirements. The software must also have built in security measures. In 2014, CMS will

require new standards for interoperability of medical records called Stage 2 MU regulations. Under the new Stage 2 rules, there will be a greater emphasis on the ability to exchange medical records with other healthcare providers and healthcare locations. There will also be numerous new initiatives involving education and outreach

to the patient population, including requirements for use of patient portals. In 2016 or 2017, the final phase of MU will occur with the adoption of the last set of MU standards—Stage 3. Not yet written, these Stage 3 standards will involve improvement of population health, including many areas of data analytics.

These new areas of HIT development will include corresponding job growth. Clinical individuals will be needed to oversee patient education programs and extensive health and wellness initiatives, to work with IT individuals to assure that privacy and security concerns are addressed, to oversee necessary changes to workflow that will allow the capturing of data electronically, and to develop and monitor the data that arises from clinical quality reporting initiatives. Definitely, there will be ever-increasing opportunities for nurses to use their clinical skills but combine them in a broader role in the HIT marketplace.



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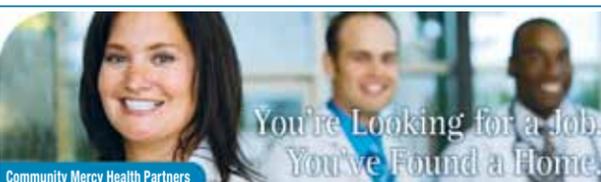
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# Traumatic Brain Injury: The Sequel

Developed by: Barbara Walton, MS, RN

This independent study has been developed to provide nurses with an overview and introduction to traumatic brain injuries and the sequelae. The author and planning committee members have declared no conflict of interest. There is no commercial support for this independent study.

Disclaimer: Information in this study is intended for educational purposes only. It is not intended to provide legal and/or medical advice.

2.5 contact hours will be awarded for successful completion of this independent study.

The Ohio Nurses Association (OBN-001-91) is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

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## OBJECTIVE

1. Differentiate mild, moderate and severe traumatic brain injury.
2. Identify how traumatic brain injury affects children and the elderly.
3. List at least three sequelae to traumatic brain injury.
4. Identify nursing interventions and resources utilized to manage sequelae.

## Traumatic Brain Injury: Types, Causes, Damages and Incidences

A Traumatic Brain Injury (TBI) can change someone's life in an instant. In the snap of a finger, a person can go from being perfectly normal to becoming someone who is now incapable of caring for him or herself. In this educational activity we will explore the types of TBI's and differentiate TBI versus post traumatic stress disorder. The ravages of TBI especially affect children and the elderly. We will highlight those effects. There has been a long-standing myth that children are more resilient to the effects of TBI. We will be busting that myth. The terms "post concussion" and "concussion" have not been used in this module, as these terms are not well defined and are controversial. "Concussion" often refers to a loss of consciousness; however an individual may experience a TBI without loss of consciousness. The bulk of this educational activity will focus on the life altering sequelae that result from a TBI. We will discuss the ramifications and management of these sequelae. Notice the use of the word "management" in that last sentence. In so many instances the sequelae become permanent, and are therefore not "cured", but can be managed through a variety of methods. This module will not focus on the acute phase of caring for someone with a TBI. That discussion generally pertains to the critical care

arena and deserves separate treatment. Last but not least, this educational activity will address the issues of community and technological assistance for the survivor of TBI and resources for the caregiver.

**Incidence of TBI in the United States:** In 2000, the Centers for Disease Control (CDC) were charged with the responsibility to determine the incidence and prevalence of TBI in all age groups. This was part of the Children's Health Act of 2000 (Public Law 106-310) in an effort to address the long-term outcomes of TBI. Currently data is available for 1995 through 2004. Each year at least 1.4 million people sustain a TBI. Of these, approximately 50,000 die of the initial injury sustained; 235,000 are hospitalized; and 1.1 million are treated and released from an Emergency Department. Of the 1.4 million TBI's, 475,000 happen to children between the ages of 0 to 14 years of age. Ninety percent of the Emergency Department visits made by children are due to TBI's. The table below illustrates the incidence of TBI by age, Emergency Department Visits, Hospitalizations and Deaths. Imagine the costs of all these Emergency Department visits and hospitalizations, let alone the emotional and monetary costs of any death as a result of TBI.

Age Years	Emergency Dept Visits		Hospitalizations		Deaths **	
	#	%	#	%	#	%
0-4	200,000	92.4	15,000	7.1	1,099	0.5
5-9	122,000	91.5	11,000	8.0	628	0.5
10-14	113,000	90.2	11,000	9.0	957	0.8
15-19	129,000	81.2	25,000	15.9	4,756	3.0
20-24	79,000	77.3	18,000	17.8	5,092	5.0
25-34	146,000	79.4	30,000	16.4	7,720	4.2
35-44	129,000	77.7	29,000	17.7	7,619	4.6
45-54	75,000	74.1	20,000	20.2	5,776	5.7
55-64	35,000	65.7	14,000	26.9	3,927	7.4
65-74	29,000	59.1	16,000	32.5	4,188	8.4
75 +	54,000	51.0	44,000	41.3	8,095	7.7
Total	1,111,000	79.6	235,000	16.8	49,900	3.6

Of the 49,900 total annual deaths due to TBI, one can see more males die of these injuries than females. This is because more males sustain TBI than females. There tends to be a propensity for boys and men to engage in riskier activities, thus the greater incidence of TBI.

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For the remainder of this independent study, please refer to [CE4Nurses.org](http://CE4Nurses.org) and click on Ohio Nurse Independent Studies.

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# Patient Protection and Affordable Care Act—What Every Nurse Needs to Know About Health Care Reform

## Addendum to the Continuing Education Independent Study on the Affordable Care Act (ACA)

On June 28, 2012, the U.S. Supreme Court declared in a 5-4 vote that the ACA is Constitutional. The most controversial provision—the individual mandate—was upheld when the majority of justices recognized the provision was permissible under the taxation powers of Congress. While many ACA supporters argued the Constitutionality on the basis of the Commerce Clause, that argument did not garner a majority of the justices' support.

In his majority opinion, Chief Justice John Roberts wrote, "Congress' use of the Taxation clause to encourage buying something is.... not new. Tax incentives already promote for example, purchasing homes and professional educations."

The Court's ruling addressed more than the mandate, however. The ACA extended Medicaid eligibility to an additional 16 million Americans through 2019. The states that opposed the ACA contended that their Medicaid programs had no choice but to participate in the expansion or forfeit their federal Medicaid funding.

"At issue were the partnership roles of federal and state governments. Medicaid exemplifies that partnership because it is administered by states but funded with both state and federal dollars. States argued the potential loss of funds was coercion to expand Medicaid, which they stated they would be hard-pressed to fund." (Lowe 2012).

All of the justices except Sonya Sotomayor and Ruth Ginsburg agreed with the state officials that the threatened loss of existing federal Medicaid funds constituted unconstitutional coercion. However, Chief Justice Roberts joined Justices Sotomayor, Ginsburg, Elena Kagan, and John Breyer in ruling the flaw could be corrected by forbidding the federal government from withdrawing its federal contribution if a state opts out of the Medicaid expansion.

(Citation-Lowe, R. Supreme Court Upholds Affordable Care Act; Medscape Medical News. 2012 WebMD, LLC retrieved June 28 from [www.medscape.com](http://www.medscape.com)).

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