Applying the Chronic Care Model to Support Ostomy Self-Management: Implications for Oncology Nursing Practice

Elizabeth Ercolano, RN, MSN, DNSc, Marcia Grant, RN, PhD, FAAN, Ruth McCorkle, RN, PhD, FAAN, Nancy J. Tallman, BSN, Martha D. Cobb, BSN, MSN, MED, CWOCN®, Christopher Wendel, MS, and Robert Krouse, MD

Background: Living with an ostomy requires daily site and equipment care, lifestyle changes, emotional management, and social role adjustments. The Chronic Care Ostomy Self-Management Training Program (CCOSMTP) offers an ostomy self-management curriculum, emphasizing problem solving, self-efficacy, cognitive reframing, and goal setting.

Objectives: The qualitative method of content analysis was employed to categorize self-reported goals of ostomates identified during a nurse-led feasibility trial testing the CCOSMTP.

Methods: Thirty-eight ostomates identified goals at three CCOSMTP sessions. The goals were classified according to the City of Hope Health-Related Quality of Life Model, a validated multidimensional framework, describing physical, psychological, social, and spiritual ostomy-related effects. Nurse experts coded the goals independently and then collaborated to reach 100% consensus on the goals’ classification.

Findings: A total of 118 goals were identified by 38 participants. Eighty-seven goals were physical, related to the care of the skin, placement of the pouch or bag, and management of leaks; 26 were social goals, which addressed engagement in social or recreational roles and daily activities; and 5 were psychological goals, which were related to confidence and controlling negative thinking. Although the goals of survivors of cancer with an ostomy are variable, physical goals are most common in self-management training.

Ostomies are the surgical attachment of bowel or ureter to the abdominal wall to allow elimination of feces or urine. Ostomies cause major life disruptions to the well-being of the whole individual: physically, psychologically, socially, and spiritually. Impacts include daily care of the stoma and skin, correct fitting of pouches, diet and elimination strategies, adjustments in social routines to integrate daily care requirements, and attending to potentially negative emotional and spiritual changes that may accompany chronic care demands (Crawford et al., 2012; Recalla et al., 2013; Sun et al., 2014). The trend toward shorter hospital stays has resulted in fewer opportunities for specialized trained ostomy nurses to support patients with new ostomies. Therefore, oncology nurses in both the hospital and outpatient settings may need to play a role in assisting ostomates to self-manage disease-related effects (Crawford et al., 2012).
The Chronic Care Ostomy Self-Management Training Program (CCOSMTP) was developed to address the consequences of living with an ostomy and to support patient self-management. The CCOSMTP builds on the principles of the CDSMP and the Chronic Care Model. The CCOSMTP curriculum addresses practical and physical, emotional, social, and spiritual quality-of-life concerns (see Figure 2). The program includes strategies to enhance problem solving, self-efficacy, reframing of cognitive responses, and goal setting (Grant, McCorkle, Hornbrook, Wendel, & Krouse, 2013; Lorig & Holman, 2003; Wagner et al., 2001).

Identification of illness-related goals has been shown to be beneficial in chronic illness self-management (Lorig & Holman, 2003). Goal setting helps individuals to identify and prioritize new behaviors required to master illness-related effects. When the goal is designed to address, mediate, or improve the chronic illness effect, the greater the likelihood of behavioral change (Martin, Turner, Bourne, & Batchup, 2013). Goal setting has been incorporated into chronic disease self-management programs for diabetes and arthritis, and more recently in cancer (DeWalt et al., 2009; Kralik, Koch, Price, & Howard, 2004; Martin et al., 2013; McCorkle et al., 2011; Schulman-Green et al., 2012). The purpose of this study is to report on the goals identified by a group of ostomates who participated in a nurse-led self-management intervention. The study's purpose was accomplished by using the City of Hope Health-Related Quality of Life (COHHRQOL) Model to analyze the goals of ostomates who participated in the CCOSMTP.

**Background**

Chronic illness self-management has been increasingly studied now that more individuals are living beyond acute episodes of most major diseases (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). As a result, healthcare professionals’ concerns have shifted from cure to control of symptoms and disease effects. In chronic illness management, patients become experts about their illnesses and their healthcare providers serve as coaches or consultants. This shared responsibility for illness-related activities by patients and healthcare professionals has earned the label self-management versus self-care because of the complexities of the skills and tasks required (Coster & Norman, 2009). The Chronic Disease Self-Management Program (CDSMP) (Lorig & Holman, 2003) is a formal course that teaches patients about self-management techniques and incorporates content on care strategies along with activities to improve self-efficacy, problem solving, and communication. The CDSMP has been tested and proven beneficial in a variety of chronic illnesses, including arthritis, diabetes, and asthma (Barlow et al., 2002; Cockle-Hearne & Faithfull, 2010; Ory et al., 2014).

In 1996, the Chronic Care Model was proposed as an alternative healthcare delivery system to improve illness-related outcomes (Gugiu, Westine, Coryn, & Hobson, 2013; Wagner et al., 2001). Figure 1 illustrates the model’s components, including self-management support (between patients and healthcare providers) and health system reorganization (clinical guidelines, integrated clinical information systems, and enhanced coordination of services) to enable care of chronic illness effects and health promotion efforts. The model transforms how chronic illness should be viewed and proposes, instead, that facilitation of patient self-management results in informed, self-directed patients, more engaged and appropriate provider responses, and improved health-related outcomes (Gugiu et al., 2012).

### FIGURE 1. Chronic Care Model


### FIGURE 2. Chronic Care Ostomy Self-Management Training Program Topics and Curricula

Note. Based on information from Wagner, 1998.

---

**Practical concerns of living with an ostomy**
- Self-management of equipment
- Complications
- Establishing a regular pattern of elimination

**Physical effects and general well-being**
- Skin care
- Managing leakages, odors, gas, pain, and fatigue
- Clothing changes
- Sleep disturbances
- Nutrition
- Exercise
- Other lifestyle changes

**Psychological effects and general well-being**
- Managing depression, anxiety, uncertainty, and privacy
- Fear of recurrence
- Negative thinking

**Social effects and general well-being**
- Preparation for emergencies
- Travel, work, social, and public obligations
- Intimacy and sexuality
- Caregiver and partner relationships
- Financial management

**Spiritual effects**
- Acknowledging and applying meaning
- Faith
The COHHRQOL model is composed of four dimensions: physical well-being and functional status, psychological well-being, social well-being, and spiritual well-being. The model guided the study design and analytical procedures. This framework was developed from the findings of qualitative and quantitative studies on ostomy-related changes in quality of life. The model depicts the interrelationships of the four quality-of-life dimensions and their general and disease-specific effects. This holistic model illustrates that comprehensive management of all domain-related effects is needed to support improvement in overall quality of life (Grant et al., 2013) (see Figure 3).

Design and Setting

Directed content analysis was employed to describe and categorize self-reported goals of ostomates who participated in a nurse-led feasibility trial on ostomy self-management (Grant et al., 2013; Hsieh & Shannon, 2005). Thirty-eight ostomates enrolled and participated in nurse-led sessions about wound, ostomy, and continence (WOC), based on a well-defined ostomy self-management curriculum, as part of a feasibility trial testing the effects of this ostomy self-management curriculum. The feasibility trial was approved by the University of Arizona Institutional Review Board. The curriculum addressed physical effects associated with ostomies and their related management, including care of the appliance, stoma, nutrition, and lifestyle changes. Other areas of the curriculum included management of psychological effects, such as depression, uncertainty, and adjusting to social changes at work and in other social or public obligations. Nurses asked ostomates to list three goals, either broad or specific, prior to the first session and again at two later sessions. They were instructed to describe the goal-directed behaviors that they desired to achieve to alter or manage their treatment-related effects.

Analysis Processes and Procedures

As defined by Hsieh and Shannon (2005), directed content analysis is used by researchers to confirm a theoretical framework. In this case, the approach was employed to validate the COHHRQOL model and its relationship to the CCOSMTP. Two oncology and two WOC nurses created and agreed on a coding system derived from the components of the COHHRQOL model. The coding system outlined the four broad domains of the model. Next, the nurse experts created a coding system for the treatment effects specific to each domain. They assumed that the goals identified by the participants at the three sessions would match the domain and treatment-related effects outlined in the model. For example, a physical treatment-related effect that would lend itself to a goal would be managing leaks or dealing with odor or gas.

Once the coding template was created and agreed on, each nurse expert independently applied the codes in the first round to the participant-identified goals and organized the codes by domains and treatment effects and by session. In the second round, the nurse experts collaborated to discuss any coding discrepancies by domain or treatment effect. Overall, few discrepancies were noted, with the most frequent related to distinguishing among problems or goals about leaking and skin care. Each coding discrepancy was discussed to reach 100% agreement on the goals’ classification.

The credibility of the content of the ostomy self-management curriculum is based on extensive qualitative and quantitative research by the team (Grant et al., 2004), literature review (Krouse et al., 2006; McMullen et al., 2008), and use of the Quality of Life-Ostomy model as the foundation for the content (Grant et al., 2013). The model was derived from an extensive literature

### FIGURE 3. City of Hope Health-Related Quality of Life Model

Note. Based on information from Grant et al., 2013.
Findings

All 38 individuals living with an ostomy completed one or more of the goal-setting sessions. Thirty-eight (100%) participants completed the first session, 30 (79%) completed the second session, and 27 (71%) attended the third session. Session participation varied because of illness or inability to travel to the session. Ostomates were recruited from multiple sources, including brochures describing the study, direct ostomy nurse or surgeon referral, and from the Tucson Ostomy Support Group peer meetings. The first session was conducted approximately three weeks after enrollment and then monthly. Most of the participants had an ostomy because of colorectal cancer or bladder cancer. The majority were Caucasian and male. The mean number of days living with an ostomy was 201 (SD = 305 days) (see Table 1).

The participants identified 118 goals during the three sessions. Eighty-seven goals (74%) were related to ostomy-specific physical effects and general physical well-being, followed by 26 goals (22%) that addressed social concerns. Few psychological goals were reported, and no spiritual goals were noted. Table 2 summarizes the goals by the HRQOL domain; these domains are contained within the COHHRQOL model.

The next level of the content analysis resulted in detail about the specific treatment effects. The major categories in physical goals associated with treatment effects were placement and care of the pouch or bag, nutrition, skin problems, and leaks. Categories of social goals were related to recreation and social engagement, followed by achieving activities of daily living. The categories of goals described for psychological treatment effects, although not as predominant as the physical goals, were building confidence, controlling obsessive thinking about the ostomy, achieving awareness, and maintaining a positive attitude. For all treatment effects, the number of goals decreased over time.

Discussion

This study described goal setting as a component of an ostomy self-management program based on a validated holistic model of ostomy care and evidence-based ostomy self-management curriculum. The findings demonstrated how, in the context of education, cognitive reframing, and self-enhancing approaches, ostomates reported individualized goals that targeted a range of problems. Because goal setting is an accepted component of self-management interventions, self-management curriculum and cognitive and affective approaches offer the potential for participants to identify accurate, realistic behaviors they have confidence to achieve (DeWalt et al., 2009; Schulman-Green et al., 2012).

The goals described by the study participants were predominately physical ones. These goals addressed managing ostomy-related effects or complications, including care of the appliance, skin issues, and problems with leakage. Goals based on social treatment effects, including socialization, recreation, or capacity to achieve activities of daily living, were consistent with social adjustments reported previously by ostomates (Mullen et al., 2008; Recalla et al., 2013). Although participants identified fewer social and psychological goals than physical goals, the researchers hypothesized that ostomy-related physical

<table>
<thead>
<tr>
<th>TABLE 1. Sample Characteristics (N = 38)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristic</td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
<tr>
<td>Time since ostomy (days)</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Race</td>
</tr>
<tr>
<td>Caucasian</td>
</tr>
<tr>
<td>African American</td>
</tr>
<tr>
<td>Missing data</td>
</tr>
<tr>
<td>Cancer type</td>
</tr>
<tr>
<td>Colorectal</td>
</tr>
<tr>
<td>Bladder</td>
</tr>
<tr>
<td>Colorectal, bladder, and prostate</td>
</tr>
<tr>
<td>Ovarian</td>
</tr>
<tr>
<td>Prostate</td>
</tr>
<tr>
<td>Missing data</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TABLE 2. Goal Categories Identified by Ostomates in Order of Cancer-Related Treatment Effects (N = 118)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal</td>
</tr>
<tr>
<td>Physical effects</td>
</tr>
<tr>
<td>Odor, gas, or noise</td>
</tr>
<tr>
<td>Skin problems</td>
</tr>
<tr>
<td>Leaks</td>
</tr>
<tr>
<td>Elimination</td>
</tr>
<tr>
<td>Care of appliance</td>
</tr>
<tr>
<td>Placement of pouch or bag</td>
</tr>
<tr>
<td>Nutrition</td>
</tr>
<tr>
<td>Aches or pain</td>
</tr>
<tr>
<td>Sleep disturbance</td>
</tr>
<tr>
<td>Social effects</td>
</tr>
<tr>
<td>Perform activities of daily living</td>
</tr>
<tr>
<td>Recreational or social activities</td>
</tr>
<tr>
<td>Travel challenges</td>
</tr>
<tr>
<td>Daily adjustments</td>
</tr>
<tr>
<td>Psychological effects</td>
</tr>
<tr>
<td>Confidence</td>
</tr>
<tr>
<td>Controlling obsessive thoughts</td>
</tr>
<tr>
<td>Awareness of feelings</td>
</tr>
<tr>
<td>Maintaining positive attitude</td>
</tr>
</tbody>
</table>

Note: Session 1 represents practical concerns of living with an ostomy and physical effects and general well-being; session 2 concerns psychological and social effects and general well-being, and session 3 pertains to all curricula topics.
effects often overshadow all other concerns for ostomates. This relates to Maslow’s hierarchy of needs in which physical need provides the foundation for other identified needs (Maslow & Lowery, 1998). However, the types of psychological goals identified by participants (e.g., building confidence, controlling negative thinking) were representative of the self-management affective and cognitive strategies promoted and monitored by the ostomy nurses in the CCOSMTP. Although no spiritual goals were identified by the ostomates, that was not unexpected. In 2007, the National Consensus Project and the National Quality Forum published an article identifying the preferred practices in palliative care. Content was shaped by the four dimensions of the Quality of Life Model (Ferrell et al., 2007). A more recent article indicating progress in this area promotes the need to integrate spirituality education and research, and indicates a lack of professional application of spirituality to the support, education, and clinical care of patients (Ferrell & Borneman, 2015). As this training and evidence from research is incorporated in professional education, the researchers anticipate that spirituality will be included in patient education and goals of care.

Limitations

The focus of this analysis was to understand the primary goals of ostomates. Although participants were helped to articulate achievable goals (by the nurses guiding ostomates on realistic goal identification and behaviors to achieve intended goals), the researchers did not have the resources to follow up on goal attainment and relate quality-of-life changes to goal attainment (Bogardus et al., 2004; DeWalt et al., 2009). This would be important to address in future research (Hurn, Kneebone, & Cropley, 2006). Despite that, the researchers were able to assist the ostomates to consider and prioritize quality-of-life impacts associated with their ostomies. In addition, they helped the ostomates describe quality-of-life consequences as behaviors they desired to change (Grant et al., 2004; Krouse et al., 2007).

Implications for Oncology Nursing

A major clinical implication of this study is that management of ostomies and ostomy-related effects by ostomates is multidimensional and changing. Oncology nurses must also recognize that patients’ concerns can be prioritized and redirected to identify goals that lend themselves to self-management behaviors. The findings reveal that patient concerns such as equipment and daily bowel or bladder routines predominate initially. Therefore, oncology nurses and ostomy-trained nurses should direct and coach ostomates to identify goals that address behavioral changes to meet these concerns. Next, as daily care becomes familiar, attention on the part of nurses should be directed toward management of physical complications (e.g., leakage, skin excoriation, fatigue). Over time, as complications lessen and daily routines are established, oncology nurses and ostomates should collaborate on identifying goals and related behavioral changes that address adjustments in social roles, including work and recreation. Use of therapeutic communication strategies will enable nurses to identify emotional reactions to ostomy-related physical changes and the cancer diagnosis. Nurses may engage ostomates in identifying goals that represent psychological effects of an ostomy. Ongoing education and strategies on the part of nurses to enhance self-efficacy and coping responses of ostomates (psychological or spiritual-based) will promote adjustment and the identification of focused goals (Martin et al., 2013). Educational resources about ostomy management and effects of living with an ostomy may be used by oncology nurses in their goal-planning process.

Conclusion

Cancers of the gastrointestinal and genitourinary systems often require surgical interventions necessitating an ostomy, which results in major life changes affecting patients’ physical, emotional, social, and spiritual well-being. Physical-related effects typically predominate in the early stages of ostomy adjustment. Over time, however, psychosocial-related effects are important areas for goal planning. Self-management training, including goal setting, may be used by oncology nurses to enable ostomates to prioritize ostomy-related effects and their associated care strategies.

Implications for Practice

- Assist ostomates to prioritize ostomy-related effects that require self-management.
- Engage ostomates in goal setting to describe behaviors and address ostomy-related effects.
- Employ other self-management support strategies, including communication, education, and cognitive reframing.

References


