


PAPER

Costs of an ostomy self-management training program for cancer survivors

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Abstract

Objective: To measure incremental expenses to an oncologic surgical practice for delivering a community-based, ostomy nurse-led, small-group, behavior skills-training intervention to help bladder and colorectal cancer survivors understand and adjust to their ostomies and improve their health-related quality of life, as well as assist family caregivers to understand survivors' needs and provide appropriate supportive care.

Methods: The intervention was a 5-session group behavior skills training in ostomy self-management following the principles of the Chronic Care Model. Faculty included Wound, Ostomy, and Continence Nurses (WOCNs) using an ostomy care curriculum. A gender-matched peer-in-time buddy was assigned to each ostomy survivor. The 4-session survivor curriculum included the following: self-management practice and solving immediate ostomy concerns; social well-being; healthy lifestyle; and a booster session. The single family caregiver session was coled by a WOCN and an ostomy peer staff member and covered relevant caregiver and ostomate support issues. Each cohort required 8 weeks to complete the intervention. Nonlabor inputs included ostomy supplies, teaching materials, automobile mileage for WOCNs, mailing, and meeting space rental. Intervention personnel were employed by the University of Arizona. Labor expenses included salaries and fringe benefits.

Results: The total incremental expense per intervention cohort of 4 survivors was \$7246 or \$1812 per patient.

Conclusions: A WOCN-led group self-help ostomy survivorship intervention provided affordable, effective, care to cancer survivors with ostomies.

KEYWORDS

bladder cancer, cancer survivorship, Chronic Care Model, colorectal cancer, costs, oncology, ostomy, self-care, social support, wound and ostomy care nursing

1 | BACKGROUND

Emulating the development of consensus care for colorectal and urostomy surgery,¹ the WOCN Society Consensus Conference on discharge criteria from home care for persons with new fecal or urinary diversions recommended that "... every person with an ostomy should have access to an ostomy nurse specialist in the ambulatory care setting who can provide ongoing education, counseling, and assistance with physical problems associated with the individual's ostomy."² The Wound, Ostomy, and Continence Nurse (WOCN) research literature emphasizes the importance of postdischarge care for stoma patients for physical, psychological, and social problems.^{3,4} From 20% to 71% of persons with ostomies experience complications such as pouch leakage and peristomal skin problems.⁴ Peristomal skin problems affect one-third of colostomy patients and two-thirds of urostomy and ileostomy patients.⁴ Postdischarge support and education are needed to prevent, diagnose, and treat peristomal skin problems.⁵

As one step towards this goal, the authors pilot-tested the Ostomy Self-Management Training (OSMT) program to improve patients' health-related quality of life (HRQOL) through a systematic program driven by ostomates' needs.⁶ Formal teaching by hospital-based WOCNs may begin preoperatively and continue postoperatively but usually does not continue after discharge.⁷ Wound, Ostomy, and Continence Nurses are typically hospital or skilled nursing facility employees, and most hospitals and skilled nursing facilities have not developed outpatient clinics staffed by WOCNs. As hospital stays have shortened, so has the time available for ostomy teaching and practice in inpatient settings. Current perioperative and long-term ostomy care is also constrained by lack of formal postdischarge follow-up with WOCNs. Time constraints faced by WOCNs, absence of reimbursement for such activities, and lack of research are factors contributing to this care gap. Ostomates and their families are often left to trial-and-error methods to improve self-management.⁶ Only when severe complications arise do surgeons and/or WOCNs become involved in a patient's recovery after discharge. In hospital settings, other forms of patient information, such as booklets and websites, may be biased from ostomy product companies, anecdotal without rigorous analysis from patient advocacy groups, or variable in content.⁸

Ostomy Self-Management Training is a novel outpatient self-management educational and coaching program to assist ostomates who have completed their cancer treatments to understand and adjust to their ostomies.⁶ The goals of OSMT are to reduce the postdischarge care deficit and assist with adaptation and long-term needs for cancer survivors with an ostomy.⁶ Based on the Chronic Care Model using planned, proven strategies, management, and patient activation,^{9,10} self-management skills and strategies are essential components of OSMT, as are partnerships formed between patients and providers to empower patients so they can increasingly manage their own care. We drew upon extensive research on survivors with ostomies^{6,8,11-22} and the skills of our WOCNs^{7,17,18} to design the OSMT program to be participative with peer support from other ostomy survivors as well as spouses, partners, and family caregivers. Previous articles have described OSMT and demonstrated impacts on patient activation and self-efficacy to manage their ostomies, as well as improved HRQOL for ostomates.^{6,18}

2 | SPECIFIC AIM

The specific aim of this analysis was to conduct an economic analysis of a community-based, ostomy nurse-led, peer-ostomate assisted, small-group, behavior skills-training intervention designed to help ostomates (eg, urostomies, ileostomies, and colostomies) to understand and adjust to their ostomies and to improve their HRQOL, as well as to assist their designated informal caregivers, where a "peer-ostomate" is an ostomy survivor of the same gender and similar age as the study subject with considerable experience in self-care.

3 | METHODS

3.1 | Human subjects

All study procedures were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000, and were approved by the University of Arizona Human Subjects Protection Program (FWA00004218). The University of Arizona IRB approval number for this project is 0800000679R002. Written informed consent was obtained from each participant.

3.2 | Setting

Our demonstration was based in an academic medical center—The University of Arizona College of Medicine. We assumed that the OSMT program is sponsored by a surgical practice that performs ostomy surgeries on cancer patients and that the surgeons provide continuing ostomy care to patients after they are discharged from their surgical inpatient stays.

3.3 | Program scale

Our implementation of OSMT was 4 cancer patients per intervention cohort, one cohort at a time. Our program formally covered both ostomy and cancer care. Wound, Ostomy, and Continence Nurses' (WOCNs) scopes of practice include care of many other types of surgical procedures, traumatic injuries, pressure sores, and causes of bladder and bowel incontinence. Our WOCN interventionists addressed all concerns raised by ostomy patients and their family caregivers during and between group sessions. They provided referral information for questions outside their knowledge scope.

3.4 | Participants

Cancer survivors with ostomies were recruited from multiple sources and methods in the Tucson, AZ metropolitan area, including distribution of brochures, direct surgeon or ostomy nurse referral, e-mail solicitations, and, most commonly, from the Tucson Ostomy Support Group peer group sessions. Our pilot demonstration included ostomates (urostomies and colostomies) and their spouses/significant others/family caregivers. Ostomy Self-Management Training enrolled 35 patients. Time between ostomy surgery and baseline survey averaged 201 days, with a range of 22 to 1626 days. Nine participants dropped

out of the intervention before completing the full curriculum: 1 before session 1, 3 before session 2, and 5 before session 4. Reasons for drop-out included death (2), illness (2), early ostomy reversal (1), travel distance (1), and no longer wishing²² to participate (3).

3.5 | Program faculty and curriculum

Program faculty were two experienced ostomy nurses (M.D.C. and N.J. T.) who were trained in the program curriculum by a board-certified cancer surgeon (R.S.K.). Following the principles of the Chronic Care Model as a guide,^{9,10} a 5-session program was designed and implemented. The WOCNs focused on training Ostomates to become problem solvers, rather than simply giving them a health professional's solution. For example, potential problem areas (skin problems and pouch selections) were identified by the WOCNs, and the survivor group was asked how they would approach solving these problems. Those who experienced the problem shared what actions they took with others in the group, demonstrating problem-solving strategies. Two peer ostomates, 1 male and 1 female, were trained in the intervention, attended each session, and worked with participants between formal sessions. The program curriculum is described in Table 1 and in more detail elsewhere.¹ One intervention session was devoted to family caregivers only to share their challenges and coping strategies among themselves, and the WOCNs could reinforce key coping skills and fill ostomy care knowledge gaps.

3.6 | Perspective of this economic analysis

Our perspective was incremental resources required by an oncologic surgical practice to implement this WOCN/family-based ostomate support program. We did not measure the direct and indirect economic costs incurred by ostomates and their family caregivers to participate in this intervention other than ostomates' HRQOL before, during, and after the intervention.²²

4 | RESULTS

4.1 | Labor inputs

Three classes of labor inputs included cancer surgeon, WOCNs, and an administrative assistant (Table 2; annual salary rates for each class of labor are presented in Appendix A). The cancer surgeon was the medical provider who designed the OSMT rehabilitation program, trained two WOCNs to serve as the primary interventionists, trained the administrative assistant to support the intervention program, and facilitated the regular project team meetings. The WOCNs traded-off leading all 5 intervention sessions, but both served as coleads for the session with spouses/significant others/family caregivers of the ostomy survivors. A part-time administrative assistant served as the communications hub for the intervention team and program participants, arranged for meeting space, ordered ostomy supplies and brochures, prepared meeting materials for each session, recruited patients for each cohort, scheduled patients into intervention groups, scheduled ostomy buddies for each session, oriented participants to the intervention by telephone prior to the first session, consented

TABLE 1 Ostomy Self-Management Training (OSMT) intervention session syllabus^{a,b}

Session	Content
1	Self-management; Ostomates' immediate concerns (eg, definitions and associated disease states); daily care; nutritional needs; impact on feelings, skin care and clothing changes. Interactive teaching methods with hands-on practice with equipment, pouches, and belts. Discussion of potential ostomy complications. Assignment: Monitor ostomy output (frequency and consistency) and problems with pouching system.
2	Discuss completed assignment of personal OSMT goals. Address social well-being, problems of social/interpersonal relationships, public appearances, being prepared for emergencies, intimacy and sexuality, and communication skills within the cultural framework of the individual participant and their family in home and social contexts. Fatigue as a model of long-term effects of cancer.
3	Family caregivers attend a separate session akin to ostomates' session 2, covering the same topics, but specifically tailored to support adjustment of CGs. Additional content as needed to ensure CG has achieved a comfort level with ostomy care. Focus for the CG customized to their cultural framework and home environment. Includes HRQOL assessment of CG and self-evaluation of their participation.
4	Discuss completed assignment. Promoting healthy lifestyles via nutritional management, physical activity, overcoming barriers, improving psychological health, and improving attitudes. Participants encouraged to set new priorities, evaluate friends, and work on changing negative attitudes. Traveling tips included. Discuss potential ostomy complications. Assignment: Review personal goals in regards to ostomy care.
5	Booster intervention content driven by group demands and needs. CGs are invited to this session to help ensure a well-rounded understanding of issues, comfort with ostomy care, and anticipated future dilemmas. Discuss attainment of personal goals for participation in OSMT.

^aGrant M, McCorkle R, Hornbrook MC, Wendel CS, Krouse R. Development of a chronic care ostomy self-management program. *J Cancer Educ* 2013; **28**: 70-78.

^bKrouse RS, Grant M, McCorkle R, Wendel CS, Cobb MD, Tallman NJ, Ercolano E, Sun V, Hibbard JH, Hornbrook MC. A chronic care ostomy self-management program for cancer survivors. *Psycho-Oncology*. 2016; **25**: 574-581. PMID:26804708, NIHMS 749541, DOI: 10.1002/pon.4078

intervention participants, conducted follow-back telephone calls with participants who missed any intervention sessions to problem solve the reason(s) for absence and encourage them to attend the next session, entered data from surveys, and produced minutes of intervention team meetings.

The time input of the cancer surgeon included eight 1-hour intervention team meetings per cohort of 4 ostomy patients—2 meetings prior to the first group session to manage recruitment for the new series, 5 intervention team meetings to review each group session, and 1 meeting after the last group session to review the final status of each participant—for a total of 8 hours direct time per 4-patient cohort.

Time input from the lead WOCN included the following: 0.5-hour pre-session preparation time; 1-hour/session face-to-face time with participants and ostomy buddies; 0.5-hour postsession check-in, and 0.5-hour round-trip travel time to/from meeting for a total of 2.5 hours per face-to-face intervention session. With 5 sessions, this equaled 12.5 hours per cohort plus eight 1-hour weekly team meetings for a total of 20.5 hours per intervention cohort. The time input of a second WOCN was 8 hours of intervention team meetings, and 2.5 hours

TABLE 2 Incremental resource costs per Ostomy Self-Management Training (OSMT) intervention cohort

Personnel ^a	Tasks	Quantity and Cost of Resources per OSMT Intervention Cohort ^b	Total Cost per Cohort ^b	Per Patient Cost ^b
Medical director/ cancer surgeon	Provide medical supervision of WOCNs; provide supervision of administrative assistant; conduct eight 1-h intervention team meetings with WOCN and administrative assistant; telephone consultation with WOCN as needed.	8 weekly intervention team meetings (1 h/ meeting × 8 meetings × \$125/h × 155% fringe benefits) ^b	\$1550	
WOCNs	Prepare and set up for ostomate intervention group meetings; lead intervention group sessions; conduct in-person individual counseling of patients immediately before and immediately after group sessions; provide PRN telephone counseling of patients and ostomy buddies between group sessions; maintain record of session attendance; attend regular meetings of intervention team; participate in spouse/ significant other/family caregiver session	WOCN #1: 5 sessions × 2.5 h/session (0.5 h pre-session preparation time + 1 h/session face-to-face time + 0.5 h postsession check-in + 0.5 h round-trip travel time to/from meeting = 2.5 h) = 12.5 h, plus 8 h of team meetings = 20.5 h × \$48/h × 1.55 fringe benefits and overhead costs WOCN #2: 1 session × 2.5 h = 2.5 h, plus 8 h of team meetings = 10.5 h × \$48/h × 1.55 fringe benefits and overhead costs	\$1525 \$781	
Ostomate peer buddies	2 ostomy peer buddies for 4 sessions	0.5 h pre-meeting preparation time + 1 h/ session face-to-face time + 0.5 h postsession check-ins + 0.5 h round-trip travel time to meeting place = 2.5 h/ session × 4 sessions × 2 buddies = 20 h/ cohort × \$24/h × 1.55 fringe benefits ^b	\$744	
Administrative assistant	Recruit patients into intervention; set up session times and places; inform participants and staff of meeting places and times; send out session reminders; order ostomy supplies and brochures; consent patients, contact no-shows to ascertain reason(s) for not attending; attend regular meetings of intervention team.	8 h/week × \$25/h × 8 work weeks × 1.55 fringe benefits ^b	\$2480	
Nonlabor inputs	Description	Quantity and cost of resources per intervention cohort	Total cost per cohort ^b	Per patient cost
Transportation	Auto mileage reimbursement for WOCN (2 WOCNs × 8 intervention staff meetings = 16 trips + 5 trips to group sessions = 21 trips)	WOC nurse mileage to/from meetings = 10 mi RT × 21 trips × \$0.55/mi	\$116	
Photocopying	Purchase and photocopy intervention materials for WOCNs and participants	Intervention brochures = 4 @ \$1 ea. = \$4 + \$30 for stoma equipment brochures = \$34	\$34	
Supplies	Ostomy supplies for teaching and demonstration	Stoma wafers, ostomy bags, skin protectant, water bottles, small duffel bag, disposable wipes, etc—donated by supply companies	Donated	
Postage	Mailings to participants	Postage for mailings	\$16	
Telephone	Telephone service to participants and among staff members	Use surgeon's medical office telephone line + WOCN/buddy personal cell phones	\$0	
Internet	Assume all intervention staff have an internet service provider as part of their household utility expenses	Use household internet service provider	\$0	
E-mail	Assume all intervention staff have a personal internet appliance, e.g., smartphone, tablet, laptop, personal computer, etc.	Use university/hospital/household email service	\$0	
Meeting room	Surgeon's medical office facility and/or free community meeting room space	Donated meeting space	\$0	
Total cost/cohort and average cost/patient:			\$7246	\$1812

^aIntervention personnel were employed by the University of Arizona; labor costs included salaries and fringe benefits.

^b2014 dollars.

(work + travel time) for the session with family members/informal caregivers, for a total of 10.5 hours per cohort.

Intervention team meetings reviewed the previous week's intervention group session and the status of each participant and family

caregiver and prepared for the next group session as well as individual feedback to patients and caregivers. Since these activities are participant and session specific, they must be repeated for each session and participant. These labor costs vary with the number of participants and number of sessions. We found that experienced WOCNs required only modest fixed training time before the start of the intervention sessions. Note that Table 1 does not contain any labor costs for pre-program training. Labor costs start with a pre-session staff meeting to discuss each patient cohort.

The administrative assistant worked 25% time for each 4-patient cohort for 8 work weeks performing the tasks identified above.

4.2 | Nonlabor inputs

Nonlabor inputs and costs are described in Table 2. Wound, Ostomy, and Continence Nurses were reimbursed for round-trip mileage to intervention sessions. Patients and gender-matched ostomy buddies arranged for their own transportation to and from group sessions. We produced a color descriptive brochure for the intervention program and printed copies to mail to participants. Postage costs were incurred for recruitment and orientation mailings. Ostomy supplies from various manufacturers were purchased and demonstrated during intervention sessions. Patients were instructed on differences among product brands with respect to price and quality and on how to cut the ostomy wafers to fit their own stomas. Some patients were accustomed to pre-cut wafers. We assumed that the intervention could be replicated by cancer surgeons and WOCNs and, therefore, assumed that incremental costs were more appropriate for this analysis than fully allocated direct and indirect costs of a surgical practice. We assumed that the surgical practice would already have telephone and office support, including a conference room where group sessions could be conducted. We also assumed that free public-use conference rooms were available in the community to reduce lengthy travel times for participants. All intervention staff had university e-mail accounts and personal smart phones.

4.3 | Intervention HRQOL outputs

Previously, we showed that our self-management training program improved and sustained scores on multiple HRQOL outcome measures, including patient activation ($P = .0004$), self-efficacy ($P = .006$), total HRQOL ($P = .01$), physical well-being ($P = .005$), and social well-being ($P = .002$). Survivor anxiety was significantly reduced²² by end of follow-up ($P = .047$).

4.4 | Total costs

The total incremental cost of a complete 4-session program with 4 ostomy patients was \$7246, with a per-patient cost of \$1812 (2014 dollars).

5 | DISCUSSION

Program costs did not vary appreciably by attendance rates because of the largely fixed labor resources required to provide the intervention.

Increasing the number of participants per session over 4 would likely weaken the power of the intervention; the WOCNs felt that 4 was the maximum number of dyads that could be effectively and equitably handled in a 1-hour group session. In large cities, larger class sizes could be tested—up to 5 or 6 participants—but at the risk of reducing OSMT effect sizes. Medley conducted an incremental budget analysis under local reimbursement rules and demonstrated the cost-effectiveness of adding a WOCN to a joint inpatient-outpatient service in one hospital.²³

5.1 | Clinical implications

Cancers and treatment aftereffects may cause functional and emotional losses that could benefit from outpatient rehabilitation, distinct from routine physician-delivered primary care.² Ostomy Self-Management Training should be prescribed by cancer surgeons as a component of postostomy rehabilitation.^{1,2,5-7,9,10,14-16,18,22,24,25} Participation should be based on patient needs, not recency of the ostomy procedure. Local OSMT programs should be linked to national and local cancer support programs, such as the American Cancer Society national program office and local American Cancer Society chapters.

5.2 | Research implications

Program costs were approached from a short-term provider perspective. Future research is needed on induced decreases and/or increases in medical care utilization and expenses caused by the intervention over time, such as fewer postoperative complications, lower incidence and severity of postoperative depression for patients and their family caregivers, higher levels of postoperative physical and social activities for both patients and family caregivers, fewer postoperative skin infections, reduced emergency room and outpatient visits for postsurgical complications, better management of postoperative diet and bowel function, and lower rates of hospital readmissions for postsurgical complications. Data needs include health insurance claims and payments, coinsurance and deductible payments by families, and uncovered out-of-pocket health care and long-term care expenses for intervention and observation-only comparison groups. Research is also needed to evaluate extending health insurance coverage for this WOCN-based intervention and the effects of out-of-pocket medical care outlays on families' economic assets.

A telehealth version of OSMT may improve inclusiveness and cost-effectiveness. A newly funded project by the Patient-Centered Outcomes Research Institute, entitled "Ostomy Telehealth for Cancer Survivors" (PCOR grant #1507-31690, PI: Robert S. Krouse MD), is a multisite randomized trial of a telehealth version of OSMT to test the feasibility and acceptability of a Web-based health intervention for ostomy survivors. Future research should examine innovative models of care and support for ostomates and their family caregivers, including an integrated face-to-face small-group plus telehealth model. Variations on intervention team composition and intervention intensity are also needed to better understand program cost and outcome trade-offs.

5.3 | Study limitations

Our participant numbers were small; we could not explore economies of scale or learnings from experience with greater numbers and variety of patients. Travel distance to meeting facility, lack of familiarity with our program, and concerns about coping with unfamiliar environments were oft-cited reasons for not accepting our recruitment invitations. The oncologic surgeon leading this study strongly valued this WOCN-based intervention program, which limits replicability to similarly motivated surgeons. Cost-effectiveness or cost-utility analyses are required to determine OSMT's actual value for money.

6 | CONCLUSIONS

Our demonstration sets the stage for larger studies in different types of communities using innovative implementation methods responsive to wishes and needs of cancer survivors with ostomies. Because the OSMT intervention has been shown to benefit cancer survivors with ostomies,²² and had reasonable program costs (\$1812 per patient), we recommend consideration for coverage by health insurers. Based on qualitative input from informal caregivers of our study participants, future studies should focus on improving our understanding of caregivers' responsibilities, stressors, and unmet resource needs for their OSMT support role.

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CONFLICT OF INTEREST

The authors do not have any conflicts of interest.

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APPENDIX A

ANNUAL SALARY RATES FOR OSMT INTERVENTION PERSONNEL

Annual Salary Rates for Intervention Personnel Based on the University of Arizona Salary and Wage Structure	Annual Salary ^a	Fringe Benefits @ 55% ^a	Total Annual Labor Cost ^a
Specialist MD annual salary + fringe benefits	\$260 000	\$130 000	\$390 000
WOCN annual salary + fringe benefits	\$83 200	\$41 600	\$124 800
Administrative assistant annual salary + fringe benefits	\$52 000	\$26 000	\$78 000

Source: University of Arizona College of Medicine, Tucson, Arizona

^a2014 dollars.