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OSTOMY CARE

The Impact of Specialty Practice Nursing Care on Health-Related Quality of Life in Persons With Ostomies

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■ ABSTRACT

PURPOSE: Ostomy patients suffer significant physiological challenges that can affect psychological variables and health-related quality of life (HRQOL). The purpose of this study was to compare HRQOL in a group of patients cared for in hospitals that employed nurses specializing in ostomy care versus patients who were cared for at hospitals that did not employ nurses specializing in ostomy care.

DESIGN: Multicenter, quasi-experimental, prospective, longitudinal study.

SUBJECTS AND SETTING: This is a national study set in Spain. We collected data from 402 ostomy patients in health centers among 16 Spanish regions from March 2012 to June 2013. The average age of the patients was 61.3 ± 13.71 years (mean ± SD).

METHODS: Questionnaires were administered by the investigators prior to and 3 months after the ostomy surgery. Two groups of patients were compared: patients in group 1 were treated by nurses specializing in ostomies; patients in group 2 were not treated by an ostomy nurse specialist. Two validated scales were used to determine HRQOL: EQ-5 D (Spanish version) and the Montreux questionnaire.

RESULTS: Patients in group 1 adapted better to their ostomies than group 2. They exhibited less concern with appearance; increased comfort with cleaning, changing, and throwing away ostomy bags; and decreased pain and pain frequency. They reported less fearfulness; improvements in sleep, weight concerns, and strength; and better overall health, leading to a greater percentage of patients able to lead a normal life ($P < .05$). Sexual activity was the only variable that worsened in both groups, but it was more satisfactory at postoperation stage in group 1 ($P = .015$).

CONCLUSIONS: Patients who received specialized ostomy care experienced significant improvements in HRQOL compared to patients who were not cared for by specialist nurses. Our findings strongly suggest that patients undergoing ostomy surgery should be provided access to a nurse specialist in ostomy care since our results highlight the potential benefit promoting the HRQOL of patients.

KEY WORDS: continence nursing, health-related quality of life, ostomy, ostomy, specialty practice nursing, well-being, wound

■ Introduction

The creation of an ostomy impacts body image, sexual function, mood, daily functioning, and social activities; its presence affects the person and those around them.[1-4] Persons living with an ostomy require education and training to manage their stoma and to identify and prevent stomal or peristomal complications.[5,6] While creation of an ostomy is associated with an increased lifespan, it exerts variable effects on health-related quality of life (HRQOL).[7-11] The clinical relevance of HRQOL is increasingly recognized in recent decades, partially due to an increase in the number of persons living with 1 or more chronic conditions.[12,13] Since HRQOL is based on subjective assessment, valid and reliable instruments are essential for its assessment in both clinical and research settings.[14]

Persons living with an ostomy require comprehensive and personalized care.[15,16] The first training program devoted to enterostomal therapy was created in the United States over 50 years ago.[17] The professionalism, competence, and ability of stoma therapists have received widespread recognition.[18-22] Nevertheless, Spanish hospitals manage patient care in patients with ostomies in very different ways. Some

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centers employ nursing professionals that specialize in ostomies, while others do not. The purpose of this study was to compare HRQOL in 2 groups of persons with ostomies; subjects in group 1 were cared for by hospitals that employed nurses specializing in ostomy care and group 2 participants were cared for at hospitals that did not employ nurses specializing in ostomy care. We hypothesized that stoma care delivered by specialty practice ostomy nurses will result in better outcomes for persons with stomas. Specific outcomes we evaluated were mobility difficulties, difficulties in personal care and usual activities, pain/discomfort, anxiety/depression, and self-reported health status.

Methods

The target population comprised patients scheduled to undergo ostomy surgery during a 15-month period (March 2012 to May 2013). Inclusion criteria were (1) creation of a new ostomy (colostomy, ileostomy, or urostomy); (2) >18 years of age, and (3) sufficiently literate to complete study forms and provide informed consent for participation. Exclusion criteria were inability to care for their stoma, inability to complete the questionnaire, and voluntary study withdrawal. Research procedures were reviewed and approved by 20 ethics committees enabling us to sample patients from 160 hospitals in Spain. Our informed consent protocol assured confidentiality, the voluntary nature of participation, and anonymity; it conformed to Organic Law 15/1999 for the Protection of Information.

Instruments

Study materials included presurgical intervention data such as demographic information, clinical data related to surgical intervention, and stoma type. Participants also completed 2 instruments designed to measure HRQOL. The EuroQol EQ 5D is a generic HRQOL instrument previously validated for a Spanish population.[23,24] It consists of a questionnaire and a visual analogue scale (EQ-VAS). The EQ-VAS measures self-rated health status using a visual analog scale. The EQ-VAS records the subjects' perceptions of their own current overall health and can be used to monitor changes with time. The self-assessment questionnaire queries the subject's current health in 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Respondents are asked to grade their level of function in each dimension based on a 3-point Likert scale (severe, moderate, or no disability).

The Montreux instrument is a disease-specific HRQOL instrument previously validated for a Spanish population by Barbero Juárez and colleagues.[7,25] This 40-item questionnaire was based on a Likert scale of 6 values (0-5) and collects information from different dimensions related to the HRQOL and then organized into 3 sections: Section 1 queries self-management related to the hygienic care of the stoma; section 2 queries HRQOL in the following domains—physical well-being, psychological well-being, body image, pain, sexual activity, nutrition, social concerns, and management of devices; and Section 3 queries general issues in relation to the acceptance of the stoma and family relationships. Scores range from 0 to 100. Higher scores indicate greater HRQOL. Both questionnaires can be completed in approximately 15 minutes.

Study Procedures

Two hundred ninety-seven investigators from 160 hospitals collected data from March 2012 through June 2013. Participants completed the instruments prior to and 3 months after ostomy surgery. Questionnaires were administered by the on-site investigator upon admission to hospital and during a follow-up clinic visit. Patients were informed of the purpose of the study and provided written and oral consent. Patients under care from a nurse specializing in ostomy care received a minimal suite of services during the preoperative and postoperative phases. During the postoperative phase, the minimum suite of services included (1) a comprehensive nursing assessment and (2) assessment of HRQOL including body image and sexual activity. In the protocol, we did not include stoma site marking since data collectors assessed both urgent and scheduled operations and were not consistently able to provide this service. The minimum suite of services offered during the postoperative phase (1) education regarding evaluation, care, and hygiene of the stoma and peristomal skin; (2) education and skill training focusing on pouching system care and changes; (3) dietary and nutritional advice; (4) instruction on how to prevent and recognize complications; and (5) discharge with support (by telephone or appointment), including emotional support, support to promote adherence to pharmacological treatment, and evaluation and monitoring.

Data Analysis

Data were collected and analyzed using the Statistical Package for the Social Sciences software, version 15 (SPSS, Chicago, Illinois). We used the Student *t* test to evaluate between-group differences for means of quantitative variables with normal distribution. When the requirements are not met for using parametric tests, we chose the chi-square test (χ^2) to analyze frequencies within categorical variables and the Fisher exact test for dichotomous analysis of frequency tables. The Mann-Whitney *U* and Kolmogorov-Smirnov (K-S) tests for 2 independent samples were also used to compare group differences. Finally, the Wilcoxon rank test and the Signs test for 2 related samples were used to test questions in the same group at 2 different time points (before and after 3 months of the operation). P values $< .05$ were deemed statistically significant.

Results

Two thousand two hundred questionnaires were sent to participants. Nine hundred were returned, but 506 were

eliminated because they were incomplete, the individual did not require ostomy surgery, or the person died. Four hundred two responses were deemed suitable for analysis (313 in group 1 and 89 in group 2), reflecting a response rate of 18.3%.

Two hundred eighty-nine (72%) participants were male. Respondents' mean age was 61.3 ± 13.7 years (mean ± SD). More than three quarters of participants (78%) were married, and slightly more than half (50.8%) were retired. Table 1 summarizes sociodemographic characteristics of the study sample.

Ostomy Characteristics

The most common disease leading to ostomy creation was cancer, occurring in 80.3% of participants. Colostomy was the most prevalent form of stoma, occurring in 51.6% of participants, followed by ileostomies in 28.7% and urostomies in 16.5%. Surgical procedures requiring creation of 2 to 3 types of ostomies occurred in 3.0% of respondents. More than half of participants had a permanent ostomy: 47.2% of group 1 participants and 52.8% of group 2 participants. Temporary ostomies were performed in 41.8% of operations, including 61.7% of operations in group 1 and 38.3% in group 2.

More than three quarters (81.1%) of the surgical procedures leading to ostomy creation were scheduled, but 18.9% of participants had emergency operations. Scheduled interventions were more common in group 1; nearly two-thirds of emergency procedures were performed on group 2 participants (P = .004). Patients in group 1 were more likely to undergo preoperative stoma site marking than were group 2 participants (80.4% vs

TABLE 1.

Sociodemographic Characteristics by Group and Total Sample

	Group 1 (With SOC)	Group 2 (Without SOC)	*P*	Total
Mean age (S.T.)	62.7 years old (S. T = 13.1)	59.3 years old (S.T = 14.2)	0.13[a]	61.8 years old (13.7)
Marital status			.88[b]	
Married	80.8%	74.5%		77.9%
Single	10.3%	13.8%		11.9%
Widow	6.1%	4.3%		5.2%
Other	2.8%	7.4%		5.0%
Living situation			.88[b]	
Partner and children	48.8%	48.4%		48.6%
Partner without children	33.0%	31.4%		32.3%
Alone	8.8%	7.4%		8.2%
With parents	6.0%	3.7%		5.0%
With friends	0.6%	2.7%		1.5%
Other	2.8%	6.4%		4.5%
Education level			.88[b]	
Elementary	48.6%	58.3%		52.8%
High school	29.0%	23.9%		26.8%
University level studies	12.9%	16.6%		14.5%
Other	9.5%	1.2%		5.9%
Work situation			.88[b]	
Pensioner	54.5%	47.0%		50.8%
Employed	27.6%	38.7%		33.1%
Unemployed	6.5%	3.9%		5.3%
Retired (disabled)	3.3%	2.8%		3.0%
Student	0.9%	2.2%		1.5%
Other	7.0%	5.5%		6.3%

Abbreviation: SOC, specialized ostomy care.

[a]Student *t* test.

[b]Chi-square test.

TABLE 2.

Descriptions of Perceived HRQOL, VAS EQ-5D in Accordance to Group and Evaluation Time, Before and After (3 Months) the Ostomy

	Group 1 (With SOC)			Group 2 (Without SOC)		
Descriptions	Preoperative	3 Months Following Ostomy Surgery	*P*	Preoperative	3 Months Following Ostomy Surgery	*P*
Median (typical deviation)	70.0 (21.6)	80.0 (14.8)	<.001[a]	50.0 (24.4)	60.0 (21.1)	.100[b]
			<.001[a]			1.00[b]

Abbreviations: HRQOL, health-related quality of life; SOC, specialized ostomy care; VAS, visual analogue scale.

[a]Statistically significant difference Wilcoxon and Signs tests in preoperative and after 3-month ostomy VAS EQ-5D.

[b]No statistically significant difference Wilcoxon and Signs tests in group 2.

27.0%; $P > .001$). We compared sociodemographic characteristics of the 2 groups, using the Mann-Whitney and Kolmogorov-Smirnov tests (P values have been provided in Table 1). We found no statistically significant difference between groups 1 and 2, based on these variables.

HRQOL in Patients With and Without Care From an Ostomy Nurse Specialist

Mean HRQOL improved in both groups, but these differences were statistically significant only in group 1 ($P < .001$ for the Wilcoxon and Sign Test). Descriptions of Perceived HRQOL assessed using a visual analogue scale (VAS) EQ-5D in accordance to group and evaluation time, prior to and following ostomy surgery, are summarized in Table 2. Global score from index EQ-5D (5 dimensions) is described in Table 3 (the digits for 5 dimensions can be combined in a 5-digit number describing the respondent's health state global score). Table 4 summarizes HRQOL Montreux index scores in accordance with group and study time. We found significant differences in terms of physical well-being at 3-month follow-up following ostomy surgery (group 1: 71.51 ± 16.64 vs group 2: 65.49 ± 18.01; K-S = 1.458, $P = .029$; Mann-Whitney $U = 18{,}261.5$, $P = .003$). After 3 months, all patients reported less discomfort/pain, but the magnitude of improvement was significantly greater in group 1 ($\chi^2 = 18{,}825$; $P < .001$) (Figure 1).

Group 1 participants reported more strength 3 months after the operation (87.5%, group 1; 77.5%, group 2; K-S = 1.458, $P = .029$; Mann-Whitney $U = 18{,}409.5$, $P = .002$). Approximately one-third of participants (31.8%) reported that they were easily tired at 3 months after ostomy surgery, 25.3% reported getting a little tired, 32.0% got very little tired, and 10.9% stated that they felt no tiredness. Participants in group 2 reported being more tired at 3 months than did patients in group 1 (K-S = 1.867, $P = .002$; Mann-Whitney U: 16,089.5, $P < .001$).

When queried prior to stoma surgery, 76.4% of participants felt that despite the ostomy, they would be able to lead a normal life. Three months following surgery, the percentage of participants who felt they could carry on a normal life increased to 83.5%; significantly more subjects in group 1 reported that they would be able to lead a normal life than participants in group 2 (87.9% vs 78.5%; K-S = 1.9865, $P < .001$; Mann-Whitney $U = 17{,}942$, $P < .001$). Patients from group 1 were also more likely to report enjoying leisure time and social life (K-S = 1.9865, $P < .001$; Mann-Whitney U: 17,942, $P < .001$).

Sexual activity decreased in both groups following ostomy creation. Before surgery, 66.9% of participants reported that their sexual activity was completely sufficient for their needs (71.5% group 1, 61.7% group 2). However, subjects in group 1 were more likely to report

TABLE 3.

Descriptions of HRQOL EQ-5D Index, in Accordance With Group and Study Time

	Group 1 (With SOC)			Group 2 (Without SOC)		
Descriptions	Preoperative	3 Months Following Ostomy Surgery	*P*	Preoperative	3 Months Following Ostomy Surgery	*P*
Median (typical deviation)	0.7902 (0.2307)	1.0000 (0.2178)	<.001[a]	0.7486 (0.2749)	0.7406 (0.2221)	.625[b]
			<.001[a]			.406[b]

Abbreviations: HRQOL, health-related quality of life; SOC, specialized ostomy care.

[a]Statistically significant difference Wilcoxon and Signs tests in preoperative and after 3-month ostomy EQ-5D index.

[b]No statistically significant difference Wilcoxon and Signs tests in group 2.

TABLE 4.

Descriptions of HRQOL Montreux Index in Accordance With Group and Study Time

Descriptions	Group 1 (With SOC)			Group 2 (Without SOC)		
	Preoperative	3 Months Following Ostomy Surgery	*P*	Preoperative	3 Months Following Ostomy Surgery	*P*
Median (typical deviation)	68.7 (14.2)	74.8 (12.8)	<.001[a]	67.9 (15.1)	69.6 (14.8)	.383[b]
			<.001[a]			.885[b]

Abbreviations: HRQOL, health-related quality of life; SOC, specialized ostomy care.

[a]Statistically significant difference Wilcoxon and Signs tests in preoperative and after 3-month ostomy EQ-5D index.

[b]No statistically significant difference Wilcoxon and Signs test in group 2.

sexual activity rated as sufficient than were subjects in group 2 (K-S = 1.420, P = .035; Mann-Whitney U = 19,926, P = .015). Concerns about the effect of the stoma on body image were also more likely to decrease in group 1 patients (K-S = 1.996, P < .001; Mann-Whitney U = 16,728, P < .001).

Psychological well-being in groups 1 and 2 differed 3 months postostomy. Group 1 reported higher levels of happiness (K-S = 1.527, P = .019; and K-S = 1.543, P = .017), while group 2 experienced a decline in happiness and satisfaction with life (Mann-Whitney U: 18,159, P < .001; Mann-Whitney U = 18,862, P = .008). More than half of participants (56.3%) reported fear of odors or leakage from the stoma preoperatively; only 32.6% retained that fear 3 months postoperation. The highest levels of fear of odor and leakage were reported in group 2 (K-S = 1.441, P = .031; Mann-Whitney U: 36,604.5, P < .001). Thirty-four percent of patients reported anxiety related to looking at their ostomy prior to surgery; no significant differences were found when groups were compared. By month 3 following surgery, the proportion of patents who experienced difficulty looking at their ostomy decreased to 15.9%. Patients in group 1 were less likely to report difficulty looking at their stomas (K-S = 1.420, P = .035; Mann-Whitney U: 19,926, P = .015).

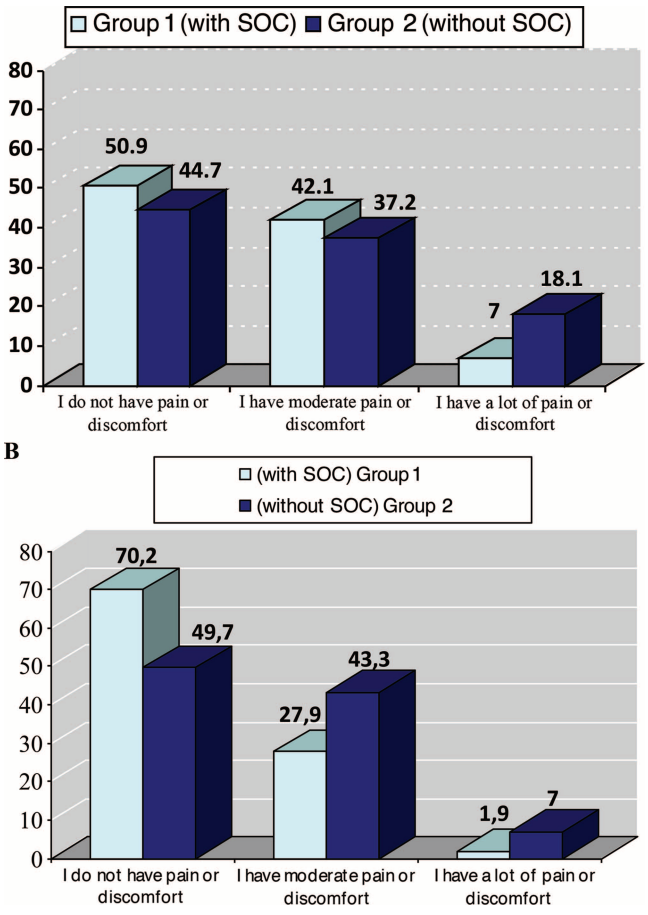

FIGURE 1. Percentage of persons with ostomies with pain/discomfort (A) pre- and (B) 3 months postsurgery, stratified according to whether participants received specialized ostomy care (SOC) (P = .027) (χ^2 = 18,825; 2 l.g; P < .001).

Self-management of the ostomy also differed based on availability of an ostomy nurse specialist. Participants in group 1 reported feeling more secure in cleansing their stoma than those in group 2 (92.1% vs 75.0%; K-S = 1.834, P = .002; Mann-Whitney U = 21,457.5, P = .005). They also reported feeling more changing the ostomy (94.8% in group 1 vs 80.0% in group 2; K-S = 2.644, P < .001; Mann-Whitney U: 20,987, P < .001). Group 1 subjects reported greater security in their ability to obtain ostomy supplies than group 2 patients (94.8% vs 80%; K-S = 2.677, P < .001; Mann-Whitney U: 19,071, P < .001). Group 1 subjects also reported greater confidence in access to someone who could provide expert advice about problems with their ostomies than group 2 participants (97.2% vs 77.3%; K-S = 3.571, P < .001; Mann-Whitney U: 17,435.5, P < .001).

When queried about adaptation to their ostomy, 56.7% of participants felt that they would sometimes, often, or always be able to completely forget about their stoma. More patients in group 2 reported optimism prior to surgery when compared to group 1 subjects (63.1% vs 50.7%). These proportions changed following surgery; group 1 subjects experienced a rise in the proportion who reported the ability to forget about their stoma at times (50.7% vs 65.5%), while group 2 participants experienced a slight decline in this component of adaptation to their

ostomy (63.1% vs 52.8%); differences in adaptation to the stoma at 3 months was statistically significant (K-S = 1.856, $P = .002$; Mann-Whitney U: 19,776.5, $P = .011$). When queried about negative adaptation to an ostomy before surgery, 45.9% of participants agreed, very much agreed, or completely agreed with the statement "…it would be impossible to accept having an ostomy" (52.0% group 1, 39.2% group 2). This proportion declined to 35.8% following surgery, and subjects in group 1 were less likely to report difficulty accepting having an ostomy than were subjects in group 2 (32.2% vs 41.8%; K-S = 2.185, $P < .001$; Mann-Whitney U: 36,387, $P = .008$).

Discussion

Participants who received specialized ostomy care experienced higher HRQOL than those who did not receive care from an ostomy specialist ($P < .05$), as measured by the EQ-50 and Montreux questionnaires. Our findings are similar to those reported in other studies of specialized care.[26-29] Our results were also consistent with those of Sharpe and colleagues,[30] who reported statistically significant improvements in the HRQOL when patients received care from an ostomy nurse specialist 3 months after stoma surgery. Our findings are also consistent with other studies that reported more positive adaptation to a stoma after hospital discharge when patients receive care from an ostomy nurse specialist.[21,31,32]

We identified several aspects of HRQOL that improved in group 1 but deteriorated in group 2 (continuation of presurgical activities, finding a support person). We also found that other aspects of HRQOL improved in both groups (self-management of the ostomy, concerns related to appearance, hygiene, and changing and throwing away ostomy bags) but the magnitude of change was greater in group 1. When evaluated 3 months following surgery, more group 1 participants reported being able to lead a normal life than subjects who did not receive care from an ostomy specialist. These findings have also been reported in prior studies.[30,33]

Consistent with results of 2 prior studies,[34,35] we found that sexual activity declined in both groups. This finding suggests that a preventative psychosexual intervention may be appropriate for ostomy patients.[36,37]

Limitations

Subject dropout due to incomplete forms may limit generalizability of our findings. We were also not able to randomly allocate group assignment that may have limited the generalizability of between-group comparisons.

Conclusions

The findings of this study are consistent with prior research on the benefits of specialized ostomy care.[34] Our findings suggest that patients undergoing ostomy surgery should be provided access to an ostomy nurse specialist. We further recommend a cost-benefit analysis to provide further knowledge of the impact of receiving care from an ostomy nurse specialist following creation of a stoma.

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