Gastrointestinal Nursing

Describing the socio-demographic characteristics and self-care management knowledge of patients with ostomy

--Manuscript Draft--

Manuscript Number:	
Full Title:	Describing the socio-demographic characteristics and self-care management knowledge of patients with ostomy
Short Title:	Patients' knowledge on stoma care management in Italy
Article Type:	Original research
Section/Category:	Stoma care
Keywords:	ostomy, stoma, stoma knowledge, stoma care, stoma management
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Abstract:	Background: Currently, an increasing number of patients worldwide are living with an ostomy. Among these patients, self-care management skills and stoma self-care abilities are associated with better quality of life. Aims: To identify the socio-demographic and clinical characteristics of Italian ostomy patients and to investigate their knowledge about stoma management. Methods : We implemented a questionnaire to gather the socio-demographic and clinical data of 433 adult patients. Participants responded to a nine-item survey assessing their knowledge of stoma care management. Findings: Respondents reported having received extensive or adequate information in 64.4% of cases, although 35.6% reported receiving little or no information preoperatively. The health care professional who imparted at least adequate information was a stomatherapist in 32.1% of cases, usually during admission (24.0%) or before and during admission (19.6%). Conclusion: Our study demonstrated that most patients received adequate information regarding the ostomy.
Additional Information:	
Question	**Response**
Please enter the word count of your manuscript **excluding references and tables**	2464

23/05/2020

Dear Editor-in-Chief

Gastrointestinal Nursing

Dear Editor

Please find enclosed our manuscript entitled, "Describing the socio-demographic characteristics and self-care management knowledge of patients with ostomy" which we request you to consider for publication as a original research for your Journal Gastrointestinal Nursing.

Nowadays an increasing number of patients worldwide are living with an ostomy. Among these patients, self-care management skills and stoma self-care abilities are associated with a better quality of life. Our study showed the socio-demographic and clinical characteristics of Italian ostomy patients and their knowledge about stoma management.

We believe this article is appropriate for your journal because it provides an opportunity to discuss about chronic patients' knowledge and self-care, at this particular time especially.

This manuscript has not been published elsewhere and is not under consideration by another journal. We have approved the manuscript and agree with submission to *Gastrointestinal Nursing*. There are no conflicts of interest to declare.

We believe that the findings of this study are relevant to the scope of your journal and will be of interest to its readership. The manuscript has been carefully reviewed by an experienced editor whose first language is English and who specializes in editing papers written by scientists whose native language is not English.

We look forward to hearing from you at your earliest convenience.

Sincerely,

Giulia Villa

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TITLE PAGE

Title

Describing the socio-demographic characteristics and self-care management knowledge of patients with ostomy

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ABSTRACT

Background: Currently, an increasing number of patients worldwide are living with an ostomy. Among these patients, self-care management skills and stoma self-care abilities are associated with better quality of life.

Aims: To identify the socio-demographic and clinical characteristics of Italian ostomy patients and to investigate their knowledge about stoma management.

Methods: We implemented a questionnaire to gather the socio-demographic and clinical data of 433 adult patients. Participants responded to a nine-item survey assessing their knowledge of stoma care management.

Findings: Respondents reported having received extensive or adequate information in 64.4% of cases, although 35.6% reported receiving little or no information preoperatively. The health care professional who imparted at least adequate information was a stomatherapist in 32.1% of cases, usually during admission (24.0%) or before and during admission (19.6%).

Conclusion: Our study demonstrated that most patients received adequate information regarding the ostomy.

Keywords: Ostomy, stoma, stoma knowledge, stoma care, stoma management

Acknowledgment

The authors would like to thank all the patients who participated in the study for their invaluable contribution

Conflict of Interest statement for all authors

None. The authors have no affiliation with any organization with a direct or indirect financial interest in the subject matter discussed in the manuscript.

Funding

This study was funded by the Centre of Excellence for Nursing Scholarship (CECRI), Rome, Italy, research Grant No. 2.16.22, and the Lega Italiana Lotta contro I Tumori (LILT), Rome, Italy, Research Grant No. 2016/U0114.

ABSTRACT

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BACKGROUND

An ostomy is a surgically created opening in the abdomen that re-routes bodily wastes (faeces and urine) to exit the intestine (Sun et al., 2020) or the urinary tract and is a common outcome worldwide: in the United States, there are a million people with an ostomy (Maydick-Youngberg, 2017), while in Europe around 700,000 people live with an ostomy (Claessens et al., 2015). Colorectal cancer (CRC) and bladder cancer (BC) are among the main causes of temporary or permanent ostomies (Merandy, Morgan, Lee, & Scherr, 2017; Vonk-Klaassen, de Vocht, den Ouden, Eddes, & Schuurmans, 2016). It has been estimated that 18%–35% of CRC survivors received temporary or permanent intestinal ostomies as part of their cancer treatment (Sun et al., 2013). CRC and BC are common cancers

worldwide (Bray et al., 2018) and have a five-year survival rate of 40% to 65% (Liu et al., 2016; Siegel et al., 2017). All the statistics reported above suggest that there is a growing number of individuals living longer with a history of CRC or BC cancer and, consequently, with an ostomy.

Several studies have found that living with an ostomy can lead to multiple physical and psychosocial challenges that impair quality of life (Näsvall et al., 2017; Pazar, Yava, & Başal, 2015; Villa et al., 2018). Indeed, patients who have undergone difficult treatments for cancer (e.g., surgery, chemo-therapy, or radiation therapy) are then confronted with changes in body image, excretory functions, and personal hygiene (Hu et al., 2014; Nam et al., 2019). Patients and their families must cope with new ostomy self-management skills and make substantial behaviour/environmental changes (Sun et al., 2020). According to previous studies, stoma self-care and management skills were found to be associated with better adjustment (Cheng, Meng, Yang, & Zhang, 2013) and quality of life (Merandy, 2016). Recently, as the length of hospital stays has shortened, many patients are discharged before they master the knowledge and techniques needed to manage their ostomy (Krouse et al., 2016; Villa et al., 2018). Therefore, patients and families are often left to trial-and-error methods to adjust to self-management (Krouse et al., 2016). Although they have not yet established a minimum body of postoperative skills and knowledge for ostomy patients, the Wound Ostomy and Continence Nurses (WOCN) Society has recognized some minimal discharge criteria for ostomy patients, including instructions on emptying the pouch, pouch replacement, assessment of stoma and peristomal skin, assessment of stoma output, ostomy supplies and resources, dietary issues, and access to a specialized nurse (Colwell, Kupsick, & McNichol, 2016). Despite these criteria and the positive influence of self-management skills, few studies to date have investigated ostomy knowledge and skills following surgery, and their results are inconsistent. In some studies, patients demonstrated adequate knowledge and skills (Cheng et al., 2013; Pandey, Baral, & Dhungana, 2015), while in others, many patients reported having difficulties, especially with ostomy appliances and caring for them (Sun et al., 2020).

AIM

This study's aim was to evaluate the extent of knowledge and skills of Italian ostomy patients with a history of cancer. Their socio-demographic and clinical characteristics were analysed, and their knowledge about stoma management was investigated using a nine-item survey.

METHODS

A survey, developed after considerable literature review and pretesting with 10 patients, was administered to patients who had undergone ostomy surgery between 2017 and 2018 in eight hospitals in Rome and Milan. A total of 433 ostomy patients who met the inclusion criteria were purposively sampled. Patients who had been using an ostomy device—ileostomy, colostomy, or urostomy—for more than one month following cancer surgery, both elective and urgent cases, were enrolled in the study. All patients were adults (≥ 18 years of age), able to speak the Italian language, and willing to provide their written informed consent. Patients with severe psychiatric deficits or cognitive impairments were excluded. The tools described below were administered to gather the patients' socio-demographic and clinical characteristics and to analyse the extent of their knowledge of stoma care management.

Socio-demographic and clinical questionnaire

A questionnaire developed by the research team was used to collect socio-demographic characteristics (gender, age, marital status, employment, educational level, whether living alone) and clinical data (kind of ostomy, months with ostomy, disease that led to the ostomy, comorbidities, information received during admission, health care professional that imparted the information, moment of information, preoperative design and stoma management, complications, hospital readmission).

Survey on stoma care and management knowledge

The survey, a nine-item instrument to assess patients' knowledge of stoma care management, was developed by the research team. The items consisted of closed-ended or multiple-choice questions to assess the following aspects: knowledge of the meaning of ostomy, cleaning technique, knowledge and skills in case of complications, choice of device, and legislation. The survey was printed on paper and administered to patients by a stomatherapist nurse after obtaining participants' consent. Patients were able to fill in the survey in 5 to 10 minutes, and it was retrieved immediately.

Ethical considerations

Before data collection, the study was approved by an institutional review board of one of the hospitals included in the study. The procedures were performed in compliance with relevant laws and institutional guidelines. All participants provided informed consent and a privacy statement. The anonymity of the respondents and their data was ensured.

Statistical analysis

Descriptive statistics such as frequencies and percentages were used to describe socio-demographic characteristics, clinical data, and patients' knowledge of stoma care management. All variables were coded before being manually loaded into the statistical software. Data were analysed using the Statistical Package for Social Science (SPSS) version 20.0 (IBM Corporation, Armonk, NY).

RESULTS

The 433 patients enrolled in eight hospitals of Rome and Milan were mainly males (66.7%) with a mean age of 70 years (SD = 11.14). Most patients were married (73.2%), retired (72.1%), had middle or high school education (68.8%), and did not live alone (85.2%). Most (90.8%) had one ostomy and enterostomies (62.6%): 38.8% had a colostomy, 23.8% had an ileostomy, and 35.6% had a urostomy. One hundred twelve patients (25.9%) underwent a temporary stoma, while 321 patients (74.1%) underwent a definitive stoma. The mean number of months with their ostomy was 37.1 (SD = 59.56). In most cases, the diseases that led to ostomy surgery were colorectal cancer (58.9%) and bladder cancer (35.6%). Almost half of the ostomy patients (46%) had comorbidities. Patients reported receiving extensive information in 14.1% of cases, adequate information in 50.3%, limited information in 17.1%, and no information in 18.5% of cases. The health care professional who imparted adequate or more information was a stomatherapist in 32.1% of cases; patients received adequate or more information mostly during admission (24.0%) or before and during admission (19.6%). However, the preoperative design was discussed in only 38.3% of cases. In our sample, almost all patients (95.6%) were followed in specialized ostomy outpatient facilities; only 4.4% did not have access to outpatient

facilities. About half of the ostomy patients were autonomous in performing their own stoma care (48.3%), while 154 patients referred to asking for help from a partner (35.6%). Details on the data of all participants are presented in Table 1.

The results derived from the survey show that most patients (88.5%) were aware of the significance of an ostomy. Regarding ostomy care, the majority (89.4%) clean the ostomy with water and neutral soap. Concerning the size of the baseplate hole used, 68.1% use a size equal to the stoma, 27.5% use a larger hole than the stoma, while only 4.2% use a baseplate hole smaller than the stoma. In most cases (73.7%), patients were familiar with accessories for dealing with complications and the different kinds of ostomy devices (69.5%). In case of irritated skin, more than half of the patients (68.1%) applied a protective coating on the skin. In the event of infiltration of liquids below the plaque, our patients mainly used a convex device (26.3%), accessories such as rings or adhesive paste (35.6%), or placed a call to the stomatherapist (36.7%). Finally, 24.9% of the patients had chosen the ostomy device independently, in 61.9% of cases the device was chosen by the stomatherapist, and in only 8.3% was the choice made by the doctor. Only 36% of patients were aware of regional legislation regarding the provision of an ostomy device. The majority (79.4%) did not experience complications during hospitalization; this trend remained stable after discharge and during follow-up. Only 15.9% had complications, and only 14.1% had been re-hospitalized in the three months following. The participants' data are presented in detail in Table 2.

DISCUSSION

The aims of this study were to identify the socio-demographic and clinical characteristics of Italian ostomy patients and to investigate their knowledge about stoma management. Regarding socio-demographic and clinical characteristics, patients enrolled in this study were mainly males (63.9%) with a mean age of 70 years. These characteristics were similar to other studies conducted among colorectal and bladder cancer patients with ostomies (Cheng et al., 2013; Merandy, 2016; Pandey et al., 2015). It is known that CRC and BC have higher incidences in the fifth and sixth decades of life and in male patients. The prevalence of married and cohabiting patients (70%) and retired patients (67.5%), and the

patients' middle to high education levels are common findings in previous studies conducted with cancer patients with ostomies (Cheng et al., 2013; Merandy, 2016). Most patients enrolled in this study (58.9%) had a history of CRC, and their ostomies were mainly definitive (74.1%). These results are not surprising as CRC is among the most frequent cancers in males (Bray et al., 2018) and considering that both CRC and BC often lead to definitive ostomies (Sun et al., 2013; Villa et al., 2019). In line with other studies underscoring the importance of education preoperatively and at follow-up performed by a specialized nurse (Faury, Koleck, Foucaud, M'Bailara, & Quintard, 2017; Seo, 2019; Wen et al., 2019), we found that most patients received extensive or adequate information during admission (64.4%), usually from a stomatherapist or nurse (44.1%). Notably, we found that only 38.3% of patients received preoperative design information, even though this procedure is strongly recommended in the literature (Maydick, 2016). Finally, in our sample, about half the patients (51.8%) were supported by caregivers in stoma management. This is consistent with results of other studies conducted on ostomy patients who reported having a caregiver (Cheng et al., 2013; Merandy, 2016). Regarding knowledge of stoma management, we found that patients had a good level of knowledge regarding their ostomy management. Specifically, patients showed an awareness of the ostomy's meaning, an effective and appropriate technique for washing the stoma (i.e., with water and neutral soap) and knowledge of the different kinds of ostomy devices. These findings are consistent with a study by Pandey et al. (2015), in which patients reported an adequate level of knowledge on normal stoma and good daily care practices (i.e., cleaning the stoma) but contrast with other studies (Cheng et al., 2013; Sun et al., 2020) in which patients reported only moderate levels of knowledge and having challenges with their ostomy appliances. Our study's results may be due to the participants' access to outpatient services where they were periodically attended by stoma therapists who advised them on the necessary self-management skills.

Regarding knowledge and management of stoma-related complications, we found that patients were aware of the various accessories that are useful for managing complications. Moreover, in case of irritated skin or infiltrations, they reported using protective skin coatings and accessories such as rings or adhesive paste. As mentioned, these results are consistent with the descriptive study by Pandey et al. (2015), but contrast with other findings in which patients reported challenges and less knowledge of

complication management (Cheng et al., 2013; Sun et al., 2020). The good level of patient stoma-related knowledge and management is confirmed also by the low prevalence of complications (15.9%) and re-hospitalizations (14.1%) among our enrolled patients. A possible explanation for this could be that our participants were regularly seen by ostomy nurses who advised them how to recognize and manage stoma-related complications. Indeed, according to the literature, when patients are followed regularly by a specialized ostomy nurse, they experience a lower prevalence of peristomal skin problems (Carlsson, Fingren, Hallén, Petersén, & Lindholm, 2016). These data are pertinent because they suggest that further exploration is warranted of the level of stoma-related knowledge in patients who do not have access to regular follow-up attention.

CONCLUSION

This study demonstrated that in our Italian sample, many patients received adequate information regarding ostomy characteristics, and in most cases, there was a good level of ostomy care, whereas less frequently had patients been adequately informed about the preoperative design. In our series, the acceptable level of patient stoma-related knowledge and management is borne out by the low incidence of complications. Instructing patients more diligently is beneficial to promote further improvement in ostomy management and to reduce the physical, psychological, and social stresses that patients often experience after surgery.

KEY POINTS

Few studies have investigated ostomy knowledge and skills among patients following cancer surgery.

This study investigates the socio-demographic and clinical characteristics of Italian ostomy patients and their knowledge about stoma management.

Patients surveyed had received extensive or adequate information in 64.4% of cases, although 35.6% of patients had received little or no information preoperatively. Only 38.3% of the patients were informed of the preoperative design.

Many patients received adequate information regarding ostomy characteristics, and in many cases there was a good level of ostomy care, whereas less frequently had the patients been adequately informed about the preoperative design.

REFLECTIVE QUESTIONS

What are the reasons for the low level of information given to patients regarding the projected preoperative design of the ostomy?

Are there effective measures to be implemented to ensure improvement in the level of knowledge and management of an ostomy?

What specific measures can be taken to improve patients' knowledge of self-care of colostomy, ileostomy, and urostomy pouches?

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TABLES

Table 1. Socio-demographic and clinical characteristics of ostomy patients (n=433)	**n (%)**
Age *mean (SD)*	70 (11.14)
Gender	
Female	144 (33.3)
Male	289 (66.7)
Marital Status	
Married	317 (73.2)
Divorced	30 (6.9)
Widow	61 (14.1)
Single	25 (5.8)
Employment	
Worker	69 (15.9)
Retired	312 (72.1)
Other	52 (12)
Educational level	
Elementary school	92 (21.2)
Middle school	135 (31.2)
High school	163 (37.6)
Graduation	43 (9.9)
Live alone	
Yes	64 (14.8)
No	369 (85.2)
Numbers of ostomy	
One	393 (90.8)
Two	40 (9.2)
Kind of ostomy	
Colostomy	168 (38.8)
Ilestomy	103 (23.8)
Urostomy	154 (35.6)
Colostomy and urostomy	2 (0.5)
Ileostomy and urostomy	2 (0.5)
Kind of ostomy.2	
Temporary	112 (25.9%)
Definitive	321 (74.1%)
Months with ostomy *mean (SD)*	37.1 (59.56)
Disease that lead to a stoma formation	
Colorectal cancer	255 (58.9)
Bladder cancer	154 (35.6)
Other cancers	10 (2.3)
Missing data	14 (3.2)
Comorbidities	
Yes	199 (46)
No	234 (54)
Information received during admission	
Many	61 (14.1)
Enough	218 (50.3)
Few	74 (17.1)
None	80 (18.5)
Health care professional that informed the patient (at least enough)	
Nurse	52 (12)
Stomatherapist	139 (32.1)
Physician	85 (19.6)
Others	2 (0.5)
Nurse and Stomatherapist	1 (0.2)
Moment of information (at least enough)	
Before admission	8 (1.8)
During admission	104 (24)
Before and during admission	85 (19.6)
Only at discharge	74 (17.1)
In several moments of admission	8 (1.8)
Pre-operative design	
Yes	166 (38.3)
No	267 (61.7)

Stoma management	
Autonomous	209 (48.3)
Supported by partner	154 (35.6)
Supported by others	70 (16.2)

Table 2. Knowledge on stoma care management (n=433)	**n (%)**
He knows what a stoma is	
Yes	383 (88.5)
No	50 (11.5)
How to clean ostomy	
Water and neutral soap	387 (89.4)
Special detergents	29 (6.7)
Saline solution	15 (3.5)
Water and neutral soap and saline solution	1 (0.2)
Baseplate hole size	
Equal to the stoma	295 (68.1)
Larger than the stoma	119 (27.5)
Smaller than the stoma	18 (4.2)
Knowledge about accessories for complications	
No	111 (25.6)
Yes	319 (73.7)
He knows different kind of ostomy device	
Yes	301 (69.5)
No	132 (30.5)
Solution if irritated skin	
Cut the plaque correctly	38 (8.8)
Apply a skin protective	295 (68.1)
Call the stomatherapist	96 (22.2)
Apply protective skin and call the stomatherapist	1 (0.2)
Solution in case of infiltration	
Convex Device	114 (26.3)
Accessories (rings or adhesive paste)	154 (35.6)
Call the stomatherapist	159 (36.7)
Accessories and call the stomaterapist	2 (0.5)
Who had chosen the device	
Independently	108 (24.9)
Stomatherapist	268 (61.9)
Nurse	19 (4.4)
Physician	36 (8.3)
Knowledge of the local laws on ostomy device provision	
Yes	156 (36)
No	276 (63.7)
Missing data	1 (0.2)
Complications during admission	
Yes	88 (20.3)
No	344 (79.4)
Missing data	1 (0.2)
Complications in the last three months	
Yes	69 (15.9)
No	364 (84.1)
Re-hospitalization in the last three months	
Yes	61 (14.1)
No	372 (85.9)