# Sociodemographic characteristics and self-care management knowledge of patients with an ostomy.

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**Abstract:** Background: An increasing number of patients worldwide are living with an ostomy. Among them, self-care management skills and stoma self-care abilities are associated with better quality of life. Aims: To identify the sociodemographic and clinical characteristics of Italian ostomy patients and investigate their knowledge of stoma management. Methods: A questionnaire was used to gather the sociodemographic and clinical data of 433 adult patients. Participants responded to a nine-item survey assessing their knowledge of stoma management. Findings: Respondents reported having received extensive or adequate information in 64.4% of cases, and the remaining 35.6% reported receiving little or no information at any time. The health professional who imparted at least adequate information was a stoma nurse specialist in 32.1% of cases, usually during admission (24.0%) or before and during admission (19.6%). Conclusion: This study demonstrated that most patients received adequate information regarding the ostomy.

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STOMA MANAGEMENT

Keywords: Ostomy; Stoma; Patient knowledge; Patient education; Stoma management

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 USA, one million people are living with an ostomy (Maydick-Youngberg, 2017), while in Europe the number is around 700 000 (Claessens et al, 2015). Colorectal cancer and bladder cancer are among the main causes of temporary or permanent ostomies (Vonk-Klaassen et al, 2016; Merandy

et al, 2017). It has been estimated that 18-35% of colorectal cancer survivors received temporary or permanent intestinal ostomies as part of their cancer treatment (Sun et al, 2013). Colorectal cancer and bladder cancer are common cancers worldwide (Bray et al, 2018) and have a 5-year survival rate of 40-65% (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 colorectal or bladder 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 (Pazar et al, 2015; Näsvall et al, 2017; Villa et al, 2018). Indeed, patients who have undergone difficult treatments for cancer (eg, surgery, chemotherapy, 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 behavioural/environmental changes (Villa et al, 2018; Villa et al, 2019a; Sun et al, 2020). According to previous studies, stoma self-care and management skills were found to be associated with better adjustment (Cheng et al, 2013) and quality of life (Merandy, 2016). In addition, other studies (Villa et al, 2019b; Giordano et al, 2020) looked at the stoma self-care abilities if Italian patients, and identified variables that were significantly associated with high levels of self-care in patients: being female, being able to independently manage the stoma and having a higher level of education.

As length of hospital stays has shortened, many patients are being discharged before they master the knowledge and techniques needed to manage their ostomy (Krouse et al, 2016; Villa et al, 2018; Villa, 2019a). 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 Society (WOCN) has recognised the need for 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 specialist nurse (Colwell et al, 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 et al, 2015), while in others many patients reported having difficulties, especially with ostomy appliances and caring for them (Sun et al, 2020).

## Aims

The aim of this study was to evaluate the extent of knowledge and skills of Italian ostomy patients with a history of cancer. Their sociodemographic 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 pre-testing 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 1 month following cancer surgery, both elective and urgent cases, were enrolled. All patients were adults (≥ 18 years of age), able to speak the Italian language, and willing to provide written informed consent. Patients with severe psychiatric deficits or cognitive impairments were excluded. The tools described below were administered to gather the patients' sociodemographic and clinical characteristics and to analyse the extent of their knowledge of stoma management.

### Sociodemographic and clinical questionnaire

A questionnaire developed by the research team was used to collect sociodemographic characteristics (gender, age, marital status, employment, educational level, whether living alone), and clinical data (type of ostomy, months with ostomy, disease that led to the ostomy, comorbidities, information received during admission, health professional that imparted the information, moment of information, stoma siting 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 stoma nurse specialist after obtaining participants' consent. Patients were able to fill in the survey in 5-10 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 sociodemographic 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 SPSSv20.0.

## Results

The 433 patients enrolled in eight hospitals of Rome and Milan were mainly males (66.7%) and had a mean age of 70 years (standard deviation (SD)=11.14) (Table 1). 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 or enterostomy (62.6%): 38.8% had a colostomy, 23.8% had an ileostomy, and 35.6% had a urostomy. There were 112 patients (25.9%) who underwent a temporary stoma, while 321 patients (74.1%) underwent a permanent stoma. The mean number of months living with their ostomy was 37.1 (SD=59.56). In most cases, the diseases that led to ostomy surgery were colorectal cancer (58.9%) or bladder cancer (35.6%). Almost half 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 (Figure 1). The health professional who imparted adequate or more information was a stoma nurse specialist in 32.1% of cases; 35.6% of patients were not provided with any or with little information at any point (Figure 2 and Figure 3). Just under one quarter of patients said that they had received adequate or more information mostly during admission (24.0%), with 19.6% saying that they had received adequate information both before and during admission (Figure 3).

However, the stoma siting was discussed in only 38.3% of cases (Table 1). In this sample, almost all patients (95.6%) were followed in specialist 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%). Further details on sociodemographic and clinical characteristics of all participants are presented in Table 1.

The results derived from the survey show that most patients (88.5%) understood what an ostomy was in terms of the surgery and the consequences of living with one (Table 2). Regarding ostomy care, the majority (89.4%) reported cleaning the ostomy with water and neutral soap. Concerning the size of the baseplate hole used, 68.1% said they used a size equal to the stoma, 27.5% used a larger hole than the stoma, with only 4.2% using a baseplate hole smaller than the stoma. In most cases (73.7%), patients were familiar with accessories for dealing with complications and the different types of ostomy devices (69.5%). In case of irritated skin, more than half the patients (68.1%) applied a protective coating on the skin. In the event of infiltration of liquids below the baseplate, the patients mainly used a convex device (26.3%), accessories such as rings or adhesive paste (35.6%), or placed a call to the stoma nurse specialist (36.7%).

The choice of ostomy device had been made independently by 24.9% of patients, in 61.9% of cases it was chosen by the stoma nurse specialist, and in only 8.3% it was made by the doctor (Table 2). Only 36% of patients were aware of regional legislation regarding the provision of an ostomy device (Figure 4). The majority (79.4%) did not experience complications during hospitalisation (Figure 5); this trend remained stable after discharge and during follow-up. The percentage of those who experienced complications was just 15.9% and only 14.1% had been re-hospitalised in the 3 months following formation of the ostomy.

## Discussion

The aims of this study were to identify the sociodemographic and clinical characteristics of Italian ostomy patients and to investigate their knowledge about stoma management. In terms of sociodemographic and clinical characteristics, the patients enrolled in this study were mainly males (63.9%) with a mean age of 70 years. These characteristics were similar to those found in other studies conducted among colorectal and bladder cancer patients with ostomies (Cheng et al, 2013; Pandey et al, 2015; Merandy, 2016). It is known that there is a higher incidence of colorectal cancers (CRC) and bowel cancers (BC) in male patients, and also in the fifth and sixth decades of life. The prevalence of married and cohabiting patients (70%), retired patients (67.5%), and that the education level of patients was middle to high were common findings in earlier studies conducted with cancer patients with ostomies (Cheng et al, 2013; Merandy, 2016).

Most of the patients enrolled in this study (58.9%) had a history of CRC, and their ostomies were mainly permanent (74.1%) (Table 1). These results are not surprising because CRC is among the most frequent cancers in males (Bray et al, 2018) and in view of the fact that both CRC and BC often lead to permanent ostomies (Sun et al, 2013; Villa et al, 2019a). In line with other studies underscoring the importance of education preoperatively and at follow-up performed by a specialist nurse (Faury et al, 2017; Seo, 2019; Wen et al, 2019), the authors found that most patients received extensive or adequate information during admission (64.4% (Figure 2), usually from a stoma nurse specialist or non-specialist nurse (44.1%). Notably, the authors found that only 38.3% of patients received stoma siting information (Table 1), even though this is strongly recommended in the literature (Maydick, 2016).

Finally, in our sample, about half the patients (51.8%) were supported by caregivers in managing their stoma (Table 1). 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, the authors found that patients had a good level of knowledge about their ostomy management. Specifically, patients showed an awareness of what an ostomy was in terms of the surgery and the consequences of living with one, used an effective and appropriate technique for washing the stoma (ie with water and neutral soap) and had knowledge of the different types of ostomy device. These findings are consistent with a study by Pandey et al (2015), in which patients were found to have an adequate level of knowledge about normal stomas and good daily care practices (ie cleaning the device), but they contrast with the findings of other studies (Cheng et al, 2013; Sun et al, 2020) in which patients were found to have only moderate knowledge about their stomas and found it challenging to manage their ostomy appliances. The findings of the study reported--that most patients were knowledgeable about their stomas and were aware of how to manage their device may be due to the fact that participants had access to outpatient services, where they were periodically attended by stoma nurse specialists who advised them on the necessary self-management skills.

Regarding knowledge and management of stoma-related complications, the authors 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 the findings of other studies, in which patients reported challenges and being less knowledge about how to manage complications (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-hospitalisations (14.1%) among patients (Figure 5). A possible explanation for this could be that participants in this study were regularly seen by ostomy nurses who advised them how to recognise and manage stoma-related complications. Indeed, according to the literature, when patients are regularly followed up by a specialist ostomy nurse, they experience a lower prevalence of peristomal skin problems (Carlsson et al, 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.

Limitations and strengths

This study had several limitations. First, it was cross-sectional in nature and patients were purposively sampled. Second, even though this was a multicentre study, the sample was enrolled in a single European country and, consequently, there may be sociocultural issues unique to this population. Moreover, the study enrolled participants attending specialist centres which employ ostomy nurses, who were able to follow up patients regularly and educate them on stoma management. Therefore, it is likely that ostomy patients in general are likely to be less knowledgeable and skilled in managing their appliances than those who took part in this study--not all stoma patients have the benefits of being followed by specialist ostomy nurses (Sun et al, 2018).

The strengths of this study include the large sample size and the fact that it was collected in multiple centres both in the north and south of Italy.

## Conclusion

The findings of the study demonstrated that in this Italian sample many patients considered that they had received adequate information regarding ostomy characteristics and, in most cases, they demonstrated a good level of ostomy care, although they were less frequently adequately informed about the stoma siting. The conclusion that patients had an acceptable level of stoma-related knowledge and management is borne out by the low incidence of complications. It is important that nurses provide patients with timely and comprehensive information and guidance on how to manage their devices in order to further improve patients' ostomy management and reduce the physical, psychological, and social stresses patients often experience following surgery.

Declaration of interest: none

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## KEY POINTS

* Few studies have investigated patients' knowledge of their ostomy and their skills in managing their devices following cancer surgery

* This study investigated the sociodemographic and clinical characteristics of Italian ostomy patients and their knowledge of 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 at any time. Only 38.3% of the patients were informed of the stoma siting

* Many patients received adequate information regarding ostomy characteristics, and in many cases there was a good level of ostomy care; however, patients were adequately informed about their stoma siting less frequently

## CPD reflective questions

* What are the reasons for the low level of information given to patients regarding the projected stoma siting of their ostomy?

* Are there effective measures that could be implemented to ensure improvement in the levels of patient 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?

## Table 1. Sociodemographic and clinical characteristics of ostomy patients (n=433)

| Characteristic | 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) |
| Number of ostomies | |
| One | 393 (90.8) |
| Two | 40 (9.2) |
| Type of ostomy | |
| Colostomy | 168 (38.8) |
| Ileostomy | 103 (23.8) |
| Urostomy | 154 (35.6) |
| Colostomy and urostomy | 2 (0.5) |
| Ileostomy and urostomy | 2 (0.5) |
| Nature of ostomy | |
| Temporary | 112 (25.9%) |
| Permanent | 321 (74.1%) |
| Months with ostomy | |
| Mean (SD) | 37.1 (59.56) |
| Disease that lead to 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) |

| | |
|---|---|
| Stoma siting discussed | |
| 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)**

| Aspect of management | n (%) |
|---|---|
| How to clean stoma | |
| 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) |
| Solution if irritated skin | |
| Cut the flange correctly | 38 (8.8) |
| Apply a skin protective cream or other coating | 295 (68.1) |
| Call the stoma nurse specialist | 96 (22.2) |
| Apply a skin protective cream or other coating and call the stoma nurse specialist | 1 (0.2) |
| Solution in case of infiltration | |
| Convex device | 114 (26.3) |
| Accessories (rings or adhesive paste) | 154 (35.6) |
| Call the stoma nurse specialist | 159 (36.7) |

| | |
|---|---|
| Accessories and call the stoma nurse specialist | 2 (0.5) |
| Who had chosen the device | |
| Independently | 108 (24.9) |
| Stoma nurse specialist | 268 (61.9) |
| Non-specialist nurse | 19 (4.4) |
| Physician | 36 (8.3) |

==

**Figure 1. Patient perception of amount of information received on stoma management (n=433)**

| | |
|---|---|
| Extensive | 50.3% |
| Adequate | 14.1% |
| Limited | 17.1% |
| None | 18.5% |

**Figure 2. Health professional who informed the patient (at least adequate)**

| | |
|---|---|
| Stoma nurse specialist/other nurse | 0.2% |
| Others | 0.5% |
| Physician | 19.6% |
| Stoma nurse specialist | 32.1% |
| Non-specialist nurse | 12.0% |

NB Of the total of 433 patients, 154 (35.6%) received limited or no information from any health professional

**Figure 3. Timing of information (at least adequate) (n=433)**

| | |
|---|---|
| Little/no information at any time | 35.6% |

| | |
|---|---|
| At several points during admission | 1.8% |
| At discharge only | 17.2% |
| Both before and during admission | 19.6% |
| During admission only | 24.0% |
| Before admission only | 1.8% |

**Figure 4. Knowledge about stoma, accessories, ostomy device and local laws on ostomy device (n=433)**

| | Yes | No |
|---|---|---|
| Knowledge about what a stoma is | 88.5% | 11.5% |
| Knowledge about accessories for complications | 73.7% | 25.6% |
| Knowledge about different kinds of ostomy device | 69.5% | 30.5% |
| Knowledge of the local laws on ostomy device provision | 36.0% | 63.7% |

**Figure 5. Complications during admission or in the preceding 3 months and rehospitalisation in the preceding 3 months (n=433)**

| | Yes | No |
|---|---|---|
| Complications during admission | 20.3% | 79.4% |
| Complications in the preceding 3 months | 15.9% | 84.1% |
| Rehospitalisation in the preceding 3 months | 14.1% | 85.9% |

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