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# The inflammatory bowel disease care manager: Italian state of the art

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## Abstract

**Background** In the inflammatory bowel disease (IBD) multidisciplinary team, a key figure is the IBD care manager, usually an independent practice nurse, responsible for evidence-based assessment, care planning, treatment evaluation, and provision of practical information, health education, and emotional support to patients. The objective of this study was to evaluate the profile of this figure in Italy.

**Methods** A team of experienced nurses created a questionnaire based on the Second N-ECCO declaration, which was administered to nurses who worked in an IBD unit for a period of at least 3 years. A definition of IBD care manager was provided to every participant. The questionnaire consisted of 3 sections: behavioral, knowledge and managerial skills that an IBD care manager should exhibit. Results were studied in relation to the benefits for the patient, organizational advantages, clinical advantages and Italian state of the art.

**Results** Fifty-five nurses participated in the study, from 28 Italian centers. In the evaluation of behavioral skills of IBD care managers, "management and support of the pregnant patient" was the lowest scored item, while "patient privacy" obtained higher scores. In the evaluation of knowledge, "knowledge of intimacy and sexuality" obtained the lowest scores, while "knowledge of psychophysical and social impact of the disease" obtained a higher score. In managerial skills "management of pain" obtained the lowest scores.

**Conclusion** Our study confirmed that IBD care managers are invaluable nursing figures within the multidisciplinary team that cares for IBD patients, providing benefits to both patients' clinics and management.

**Keywords** Inflammatory bowel disease, care manager, nurse, clinical-therapeutic pathways, multidisciplinary approach

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## Introduction

The complexity of care and the increase in the incidence of inflammatory bowel disease (IBD) introduced the necessity to appoint a multidisciplinary team [1] for these patients' diagnostic/therapeutic path [2,3], able to provide a better level of assistance and to improve quality of life, while also trying to control the costs of health management, which have risen over the years [4].

With the advent of biological therapies, clinics initially run by gastroenterologists and nurses with little knowledge in the field of pathophysiology have increasingly begun to specialize and build a network of specialists around the patient, able to guarantee the holistic treatment approach [5]. Nurses have evolved, and over time developed high levels of competence and knowledge within the IBD field, specializing and providing professional support for the patient, while being able to help the entire team during the care path [6]. These positions

were developed first in America, then in England and finally in the rest of Europe. They are occupied by individuals with both welfare and managerial expertise, who are called "care managers" [7,8].

Care managers can play a very important role in redesigning and improving care delivery, providing direct patient care, coordinating and helping patients navigate the system, improving access and communication across the care team [9]. In Italy, the figure of the care manager has been included within the patient's diagnostic/therapeutic path. Having skills in triage and patient selection, identification of nursing care needs, care design, correct application of therapy and evaluation of outcomes, these individuals can manage the patient with a personalized approach [10].

The care manager is an independent expert nurse, responsible for evidence-based assessment and planning of care, treatment evaluation and providing practical information, health education and emotional support to patients. They offer nursing care with professional competence and responsibility, supported by protocols or guidelines in collaboration with the multidisciplinary team. care managers play a direct role in patient care, providing patient education and training in self-management skills. They coordinate care with other clinicians and settings, connecting patients to community resources and social services [11]. The care managers ensure that all healthcare providers involved are up to date with case information and collaborate with patients' families, friends and caregivers to effectively share information [12]. Thus, the nurse care manager is responsible for planning, organizing and facilitating the entire care path (meeting planning, managing agendas, managing technology-based assessment activities, monitoring outpatient activity) but it is also a figure of support to the path team, from the moment of taking charge of the patient, diagnosis and follow up, ensuring continuity of care throughout the patient's journey. The objective of this study was to evaluate the profile of the care manager in Italy.

## Materials and methods

We enrolled experienced IBD nurses, who had worked in the IBD Unit for a period equal to or longer than 3 years, from 28 II or III level IBD centers throughout Italy. We collected demographic characteristics and information about their professional careers, work experiences and operational skills on IBD-related activities. We sent them an article describing in detail the figure of the care manager and all the behavioral skills that this figure should possess in the field of IBD. Then we asked them to complete a questionnaire assessing the importance they attributed, on the basis of their considerable experience, to the various behavioral skills that the figure of the IBD care manager should guarantee.

The questionnaire was created by a team of expert nurses and gastroenterologists (3 nurses and 3 gastroenterologists), based on the Second N-ECCO consensus statement. The questionnaire consisted of 3 sections: behavioral, knowledge and managerial skills that an IBD care manager should possess. The nurses were asked to answer the questions in each section (Table 1), assigning a score to a "Likert scale 1-5" for each item, in relation to the benefits the skill offered to the patient, the organizational advantages, the clinical advantages and the actual Italian state of the art.

The data were collected from May 1 to July 15, 2022. All nurses received an email with the questionnaire and a letter explaining the study. The data were collected in a database for the calculation of the average scores.

**Table 1** Questionnaire: for each skill set (knowledge, managerial, and behavioral), responders were asked about the relative advantages of 7 items in 3 sections (patient, organizational, and clinical), and in relation to the Italian state of the art

| | | Patient advantages | Organizational advantages | Clinical advantages | Italian state of the art |
|---|---|---|---|---|---|
| Knowledge skills | Knowledge of pathologies, diagnostic and therapeutic path | | | | |
| | Knowledge of psychophysical and social impact of the disease | | | | |
| | Advocacy | | | | |
| | Knowledge of nutritional aspects | | | | |
| | Knowledge of intimacy and sexuality | | | | |
| | Knowledge of aspects related to fatigue | | | | |
| | Knowledge of scientific evidence | | | | |
| Managerial skills | Management and planning of the care path | | | | |
| | Remote management (telenursing) | | | | |
| | Management of endoscopic examination | | | | |
| | Patient education management | | | | |
| | Pain management | | | | |
| | Management of exacerbation of pathology | | | | |
| | Management of biological therapies | | | | |
| Behavioral skills | Interaction and coordination with multidisciplinary teams | | | | |
| | Empathy role in the care path | | | | |
| | Comfort management | | | | |
| | Pregnant patient management and support | | | | |
| | Patient privacy | | | | |
| | Management of pediatric transiction | | | | |
| | Supervision of the patient's clinical path | | | | |

### Statistical analysis

The data was analyzed using descriptive statistical methods with the calculation of absolute frequency and relative percentage. Furthermore, to evaluate any differences between groups, Student's *t*-tests and ANOVA were also performed. As these were ordinal categorical data, the correlation matrix was studied as an analysis method with the calculation of Kendall's Tau B. All tests were considered statistically significant for a P-value less than 0.05. For the correlation study, analyses were performed using Jamovi software.

## Results

Fifty-five nurses were enrolled from different IBD centers scattered throughout the Italian regions (Fig. 1). The main demographic and professional characteristics of the enrolled nurses are listed in Table 2.

### Behavioral skills

In evaluating the behavioral skills of care managers (Fig. 2), the highest score in the "patient advantages" section was for "pregnant patient management and support" (3.9). The lowest was for "supervision of the patient's clinical path" (2.7).

In the "organizational advantages" section, the highest score was again related to "pregnant patient management and support" (3.9), followed by "management of pediatric transition" and "supervision of the patient's clinical path" (both 3.6). The lowest scores were for "empathic role in the care path" and "comfort management" (both 1.7). In the "clinical advantages" section the highest score was again for "pregnant patient management and support" (3.9), while the lowest was for "patient privacy" (1.8). The "Italian state of the art" appeared to gather much lower values than the other sections. The lowest was for "pregnant patient management and support" (0.7), while the highest was for "patient privacy" (3.2).

Comparing the different sections, the items "pregnant patient management and support" and "supervision of the patient's clinical path" showed the biggest gap between the "Italian state of the art" (respectively: 0.7 and 1.1) and the other sections (respectively: 3.8 and 3.6), suggesting the need for more dedicated attention to this issue.

Conversely, the "patient privacy" resulted more relevant according to "Italian state of art" (3,2) and for "organizational advantages" (2,9), compared to "clinical advantages" (1,8) and "patient advantages" (2,5).

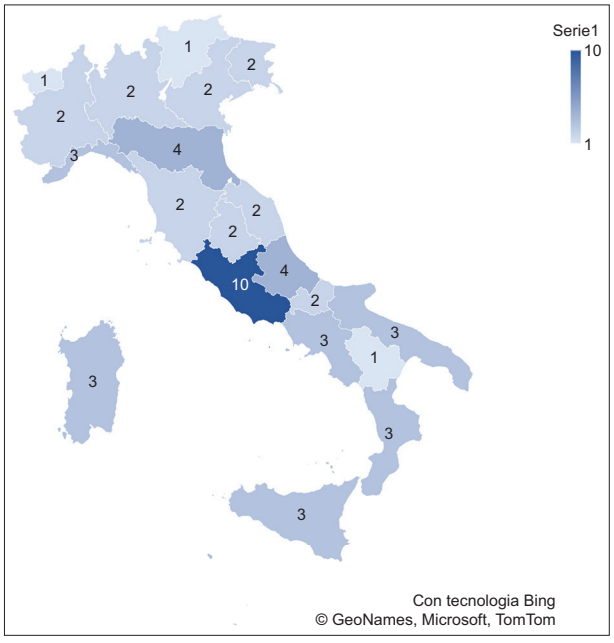


**Figure 1** Distribution of nurses in the Italian territory

**Table 2** Demographic and professional characteristics of enrolled nurses

| Characteristic | Value |
|---|---|
| Age, years (mean±SD) | 46.7±6.3 |
| Male/Female | 12/43 |
| Geographical distribution (north/central/south) | 17/26/22 |
| Educational Level: Diploma/Degree/Master | 1/48/6 |
| Part time/Full time | 1/54 |
| Level of participation in the multidisciplinary team (Likert Scale 1-5) | 3.2 |
| Level of participation in IBD congresses (Likert Scale 1-5) | 3.4 |
| Level of participation in scientific studies in the field of IBD (Mean Likert Scale 1-5) | 2.1 |
| Level of participation in endoscopic activity (Mean Likert Scale 1-5) | 1,8 |
| Level of participation in the activity of the enterostomist (Mean Likert Scale 1-5) | 1.2 |
| Level of participation in the Italian IBD network of nurses (Mean Likert Scale 1-5) | 3.9 |
| Years of nursing (mean±SD) | 27.1±6.8 |
| Years of working in a Gastroenterology Unit | 6.9±3.5 |
| Years of working in a IBD unit | 5.1±2.6 |
| Working center type: General hospital/Academic hospital | 22/33 |
| Number of IBD patients on biologics followed <25/<50/<100/≥100 | 19/21/9/6 |

*SD, standard deviation; IBD, inflammatory bowel disease*

### Knowledge skills

In evaluating the knowledge skills of care managers (Fig. 3), the highest score in the "patient advantages" section was for "knowledge of psychophysical and social impact of the disease" (4.0) and "advocacy" (4.0). The lowest was for "knowledge of scientific evidence" (1.6). In the "organizational advantages" section, the highest score was related to "knowledge of pathologies, diagnostic and therapeutic path" (3.0). The lowest scores were for "advocacy" and "knowledge of intimacy and sexuality" (both 1.4). In the "clinical advantages" section, the highest score was again for "knowledge of pathologies, diagnostic and therapeutic path" (4.0). The lowest was for "advocacy" (1.7). The "Italian state of the art" appeared to gather much lower values than the other sections. The lowest score was for "knowledge of intimacy and sexuality" (0.7), while the highest was for "knowledge of pathologies, diagnostic and therapeutic path" (1.9).

Comparing the different sections, the item "knowledge of pathologies, diagnostic and therapeutic path" showed the

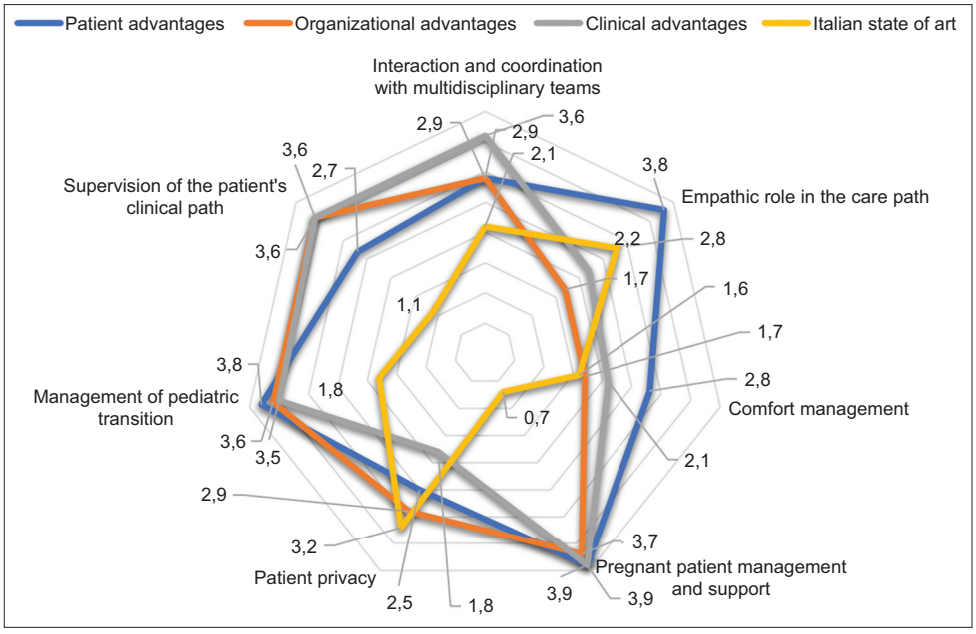


**Figure 2** Inflammatory bowel disease care manager behavioral skills

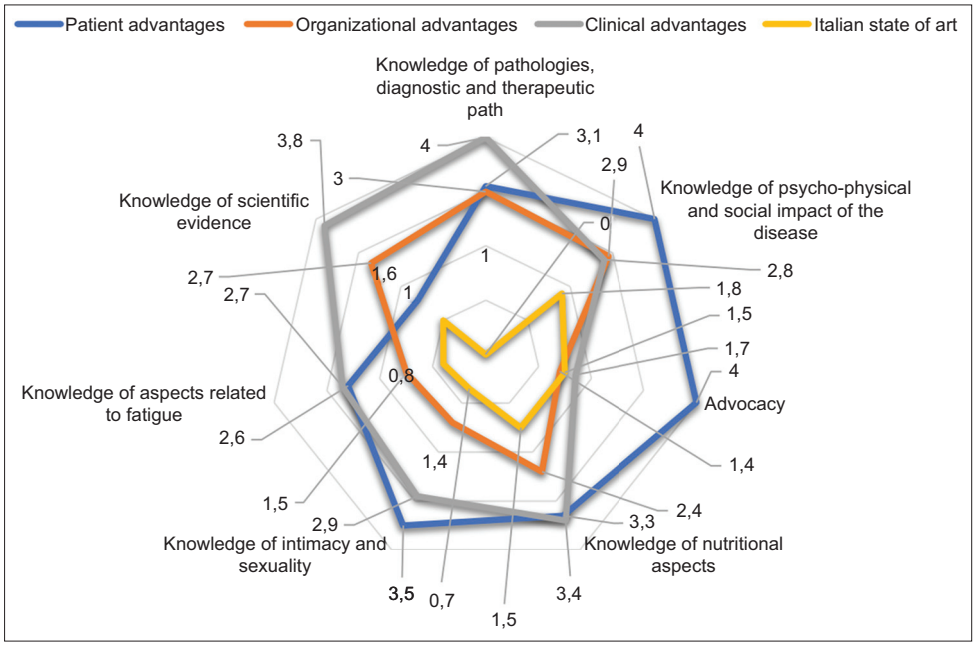


**Figure 3** Inflammatory bowel disease care manager knowledge skills

biggest gap between the "Italian state of the art" (0) and the other sections (4 in "patient advantages", 3 in "organizational advantages", and 3.1 in "clinical advantages").

## Managerial skills

In evaluating the managerial skills of care managers (Fig. 4) the highest score in the "patient advantages" section was for "management of exacerbation of pathology" (3.8). The lowest was for "patient education management" (2.2). In the "organizational advantages" section, the highest score related to "remote management (telenursing)" (3.7). The lowest score was for "patient education management" (2.3). In the "clinical advantages" section the highest score was for "management of biological therapies" (4.0). The lowest was for "management and planning of the care path" (3.2). The "Italian state of the art" appeared to gather much lower values than the other sections. The lowest is for "pain management" (0.8), while the highest was for "management of exacerbation of pathology" (2.6).

Comparing the different sections, "pain management" showed the biggest gap between the "Italian state of the art" (0.8) and the other sections (3.4 in "patient and clinical advantages", 2.4 in "organizational advantages"). "Management and planning of the care path" also showed a big distance between the "Italian state of the art" (1.1) and the other sections (3.2), while "patient education management" showed the smallest difference between "Italian state of the art" (2.3) and the other sections (3.4 in "clinical advantages", 2.3 in "organizational advantages", and 2.2 in "patient advantages").

The possible correlations between items ion the same category ("knowledge skills", "managerial skills", and "behavioral skills") in each of the sections ("patient advantages", "organizational advantages", "clinical advantages", and "Italian state of the art") were analyzed.

### *In the "patient advantages" section*

Among the knowledge skills there was a high correlation between "knowledge of nutritional aspects" and "knowledge of pathologies, diagnostic and therapeutic path" (Kendall 0.423, P<0.001).

Among the managerial skills there was a very good correlation between "patient education management" and "management and planning of the care path" (Kendall 0.362, P<0.001).

Among the behavioral skills there was a high correlation between "comfort management" and "interaction and coordination with multidisciplinary teams" (Kendall 0.836, P<0.001); a high correlation between "pregnant patient management and support" and "empath role in the care path" (Kendall 0.671, P<0.001); a good correlation between "patient privacy" and "comfort management" (Kendall 0.370, P<0.001); and a good correlation between "management of pediatric transition" and "pregnant patient management and support" (Kendall 0.382, P<0.001).

### *In the "organizational advantages" section*

Among the managerial skills there was a good correlation between "management of endoscopic examination" and "management and planning of the care path" (Kendall 0.408, P<0.001) and a good correlation between "management of exacerbation of pathology" and "patient education management" (Kendall 0.389, P<0.001).

Among the behavioral skills we found a high correlation between "supervision of the patient's clinical path" and "interaction and coordination with multidisciplinary teams" (Kendall 0.420, P<0.001).

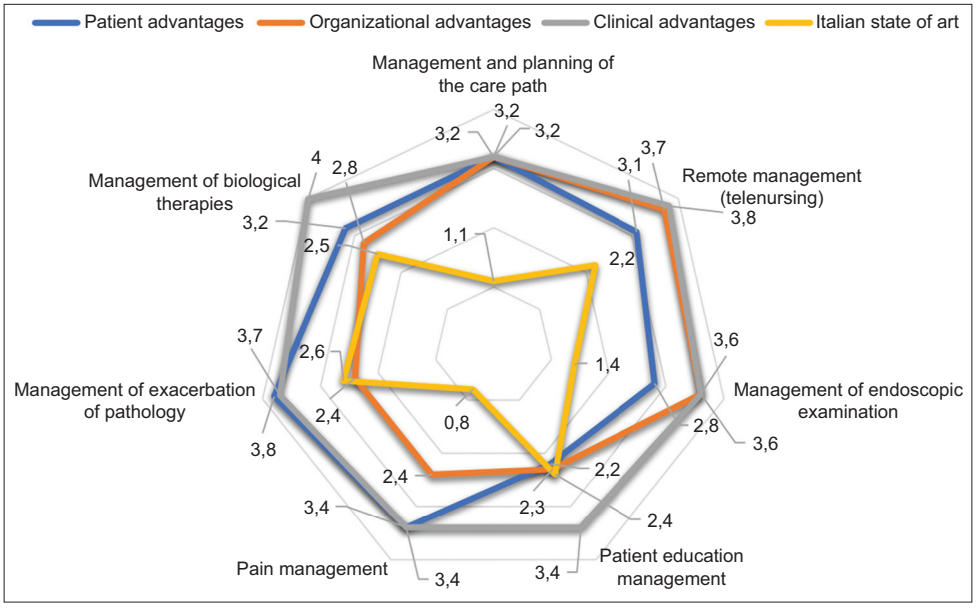


**Figure 4** Inflammatory bowel disease care manager managerial skills

***In the "clinical advantages" section***

Among the knowledge skills there was a good correlation between "knowledge of aspects related to fatigue" and "advocacy" (Kendall 0.383, P<0.001).

Among the managerial skills we found a good correlation between "pain management" and both "management and planning of the care path" (Kendall 0.427, P<0.001) and "telenursing" (Kendall 0.408, P<0.001). We also found a good correlation between "management of exacerbation of pathology" and both "telenursing" (Kendall 0.380, P<0.001) and "patient education management" (Kendall 0.441, P<0.001).

Among the behavioral skills we found a high correlation between "comfort management" and "empathy role in the care path" (Kendall 0.554, P<0.001).

***In the "Italian state of the art" section***

Among knowledge skills we found a high correlation between "knowledge of aspects related to fatigue" and "knowledge of intimacy and sexuality" (Kendall 0.781, P<0.001). Among managerial skills we found a good correlation between "patient education management" and "pain management" (Kendall 0.408, P<0.001). In behavioral skills we found a high correlation between "supervision of the patient's clinical path" and "patient privacy" (Kendall 0.459, P<0.001).

## Discussion

Patients who suffer from IBD are complex patients who require a multidisciplinary approach. In this scenario, the IBD care manager, as the person responsible for complex clinical/therapeutic pathways, may be the ideal professional figure to create a link between physicians and patients.

More specifically, IBD care managers work as part of the IBD multidisciplinary team, practicing within their own professional competency and accountability, enhancing patient care and experience, and providing efficient, holistic and accessible care with the support of guidelines and of the entire path team. Their goal is to monitor treatments, organize clinical appointments, provide education and arrange appropriate investigations with other departments, as required, through regular face-to-face or remote patient reviews. The IBD care managers' role is often described as a "gatekeeper" role, available under the same roof (a "one-stop shop") in some hospitals [13]. In more than 90 randomized controlled studies in both primary care and specialty settings, the care manager has been shown to improve patient outcomes, reduce depression and anxiety, improve quality of life, increase both patient and provider satisfaction, and reduce health care costs [14-16].

In this pilot study, we indirectly evaluated, with the help of expert IBD nurses, the Italian state of the art regarding the actual application of the IBD care manager model. The aim of the study was to examine the value and importance that advanced IBD nurses ascribe to the skill profile that the IBD care manager should provide, and to evaluate how this is applied in Italy at present. We divided the entire skill set that this figure should guarantee into 3 sections: behavioral, knowledge, and managerial skills, each examined with a corresponding questionnaire.

In respect of the behavioral skills of Italian IBD care managers, we found the highest scores overall were for "pregnant patient management and support" and "management of pediatric transition", while "Italian state of the art" received much lower scores for these skills.

Several studies suggest the presence of a significant deficit in pregnancy-related knowledge in women with IBD [17]. They often present with doubts about potential heredity, the use of drugs during pregnancy and lactation, or the best mode of delivery. In this setting, the IBD care manager's position within the team, with the support of obstetricians and gynecologists, facilitates the approach to pregnancy in IBD patients, making the care manager the person who is able to support and educate patients on family planning steps, including contraception, birthing and postpartum modes, and breastfeeding, as well as alleviate concerns about issues such as heredity [18]. Moreover, IBD nurses with the necessary skills can assist patients in making informed decisions about the use of a particular drug in pregnancy, based on the risk-benefit profile of their specific case, in consultation with the doctor. Finally, the IBD nurse works with the patient during pregnancy to reduce the risk of relapse and ensure that any changes in therapy are made at the appropriate time [19].

Transition is defined as the purposeful and planned movement of care for adolescent and young people with IBD, from a pediatric to an adult-orientated healthcare service, aiming at empowering young adults to take responsibility for and manage their own health [20,21]. This objective can be achieved by equipping them with the required knowledge and skills, underpinned by appropriate healthcare support. In this context, the IBD care manager plays a pivotal role, liaising with the adult and pediatric multidisciplinary team to ensure a flexible and individualized transition process with the patient at the center.

In respect of the knowledge skills of care managers, the highest scores were "knowledge of psychophysical and social impact of the disease" and "advocacy", looking out for the patient's advantage. Nursing involves advocacy for all patients, and this is one of the most important skills for IBD patients, given the complex, uncertain and chronic nature of their condition [22]. Advocacy requires the nurse to understand the patient's concerns, needs and preferences, and to assist them in meeting those needs or in overcoming concerns in order to ensure appropriate access to the best healthcare available.

The lowest scores were observed for "knowledge of scientific evidence" and "knowledge of intimacy and sexuality", mostly in relation to the "Italian state of the art". Issues relating to sexuality may cause anxiety, depression and concern for patients with IBD. High levels of sexual impairment have been identified among male and female patients with IBD [23], and sexual difficulties need to be identified and treated [24]. In this scenario, IBD nurses could identify problems in sexual function and sexuality through the IBD nurse-patient relationship and should be able to support the patient. Moreover, through liaison with the IBD care manager, they can refer them to specialist services as appropriate. Our questionnaire showed care managers do not have adequate awareness about patients' intimacy, and they need to promote more tactful prompting and more open discussion with patients, in order to build confidence that sexual concerns may be raised and faced.

In evaluating managerial skills, we found the highest scores for "remote management (telenursing)". A study by Chauhan *et al* evaluated the utilization of telephone and e-mail services by Canadian IBD nurses, demonstrating that nurse-managed IBD advice lines are proactive services that can address most of the patient's disease-related concerns [25]. Moreover, a recent meta-analysis highlighted that telephone interventions, compared to face-to-face collaborative care, led to similar improvements in depressive symptoms; therefore, strictly virtual delivery of care may be effective, but only in situations where the tools to screen patients and deliver care are well developed for virtual use [26].

The introduction of initially the IBD nurse, and then the more qualified IBD care manager to the team allowed the optimization of the patients' clinical path through the creation of direct contact with patients via dedicated e-mails and phone line. This also serves to connect to the flow of multidisciplinary management and to avoid emergency room visits as far as possible.

The highest scores in the "patient advantages" section were observed for "management of exacerbation of pathology", while in the "clinical advantages" section the highest scores were for "management of biological therapies". "Italian state of the art" showed lower scores for both items. A careful selection of patients undergoing biological therapies and close follow up may decrease the side-effects associated with these therapies [27]. The IBD care managers involved in the management and delivery of biologic therapies must ensure that appropriate screening and identification of any contraindications to therapy have been undertaken and recorded. On the other hand, IBD nurses are skilled and competent at administering infusions, are aware of treatment side-effects, and know how to manage infusion reactions. Nursing practice should be underpinned by evidence-based protocols for protecting the patient [28,29]. The IBD care manager can facilitate patients' education and ensure information is conveyed in an uncomplicated manner. Moreover, patients need to be educated about self-administration of subcutaneous biologics [30]; here, assessment of the patient's competence and a training plan are essential.

Although in most parts of the world the role of the IBD care manager is not yet officially recognized, the experience gained in the management of these patients is recognized within the care team and the manager is involved in patients' diagnostic/therapeutic path through participation in multidisciplinary meetings.

Our study showed that nurses dealing with IBD demonstrate competence and experience in the management of IBD patients. Nevertheless, despite the need for professionalism, IBD care managers only have access to academically provided training programs, such as the Crohn's & Colitis Foundation's Advanced Practice Provider Preceptor program [31] and the European Crohn's and Colitis Organisation IBD Nurse Education Program [32], which specifies the competences that an IBD nurse must acquire, distinguishing the characteristics required for basic and those required for advanced training [6]. However, to date, there is no official or national certification and/or licensing of IBD care managers [13]. The correlation study highlights how knowledge of pathologies improves the entire care process, including patient education. A good level of interaction and coordination of the multi-professional team has positive effects on patient education management and comfort management. In general, the positive effect is present in all areas, benefiting the patient, clinicians and the organization. Naturally, good management also has positive effects on the management of patient privacy.

In conclusion, our study confirmed that IBD care managers are invaluable nursing figures within the multidisciplinary team that cares for patients with IBD, providing invaluable advantages to patients, clinicians and management. However, the "Italian state of the art" evaluation shows that this role is still at the beginning of its development and has not yet been implemented in all those settings where the manager could provide the greatest benefits. Indeed, IBD care managers are crucial both from the clinical assistance point of view, and for providing information to patients as part of their therapeutic education, thus ensuring an improvement in patient health and quality of care, while reducing the waiting times for admission. Furthermore, they perform a fundamental organizational function for the team and for the bureaucratic machine of the IBD center, managing patients' follow-up appointments, acting as a "filter" between doctor and patient, and saving time for the doctor that can be used for more outpatient visits. Hence, it is crucial for this emerging professional role to be formalized and made standard in all IBD centers.

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### Summary Box

**What is already known:**

- The prevalence of these inflammatory bowel disease (IBD) is increasing
- The diagnostic/therapeutic management of these patients is complex
- The figure of the IBD care manager is an emerging role

**What the new findings are:**

- Italian IBD centers consider the role of the IBD care manager to be fundamental
- This role has not yet established itself in IBD centers
- Is crucial for this emerging professional role to be formalized and made standard in all IBD centers

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