

Is there a need for trained nurses in Inflammatory Bowel Disease in Romania? Present conditions, new trends

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ABSTRACT

Recent data reveal changes in the epidemiological and therapeutic trends in Inflammatory Bowel Disease (IBD) in Romania. As both incidence and prevalence increase and new possibilities for diagnosis and treatment emerge, the need for highly skilled nurses in the area of IBD becomes a reality, especially considering the particularities of these patients in the hospital, at the outpatient clinic, at home and in their social environment.

The present system for general training of nurses and their overspecialization in Gastroenterology, Hepatology or Digestive Endoscopy must keep the pace. A protocol for training IBD nurses and for better assessing their role in patient management is needed.

INTRODUCTION

There is a completely new way of thinking about Inflammatory Bowel Disease (IBD) among the medical community as well as the general population in Romania nowadays. This is the consequence of two facts: a significant increase in the overall incidence of IBD –

especially Crohn’s disease (CD) and the wide-spreading of skilled colonoscopists and trained gastroenterologists in Romania in the past years. The higher interest and awareness of IBD has taken an organized form after the founding of the Romanian Crohn’s and Colitis Club (RCCC).

Life care for patients with IBD has several pitfalls and draw-backs derived from the distinctive features of the disease. In the first place,

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the disease may be hard to diagnose especially for mild to moderate forms and particularly for Crohn's disease. Second, they are lifelong diseases. Patients should be directed to referral centers with skilled gastroenterologists and adequate possibilities of diagnosis and treatment. For the hospitalized patients there is a need for special therapeutic measures (i.v. cortisone, cyclosporine, biologic agents). Some situations may be life threatening and there are special emergency decisions that should be made. There is a need for special care for the operated patients (ileal pouch, ileostomy, fistula, perianal disease). Patients should be surveyed both in their social/ home environment in order to support them in their family decisions: having babies, screening for other relatives with IBD etc.

In order to achieve high standards in the quality of care there is a need for multidisciplinary cooperation. This includes General Practitioners, Gastroenterologists or Internists in the outpatient clinics, Gastroenterologists in dedicated Centers, Radiologists/Imagists, Surgeons, Psychologists and last, but not least, experienced nurses in the field of IBD, who are essential members of the team. Unfortunately, the lack of trained nurses specialized in IBD becomes a reality and we expect that in the future it will represent a considerable problem for the quality of life and medical care of these patients.

In western countries where there is a lot of concern about IBD a lot of measures have been taken lately in this direction. The role of the specialist nurse in IBD is rapidly growing in number, stature and credibility. In Romania though, the problem is only at the beginning. □

IBD IN ROMANIA – WHERE ARE WE NOW?

The epidemiologic data point out a constant increase in the number of cases, especially for CD in Western and Northern Europe and for both UC and CD in the Southern and Eastern Europe.

The westernization of the Romanians' lifestyle, a reality over the past decade, had an unpredictable yet obvious impact on the digestive pathology. The incidence of CD is constantly increasing. In certain domains, the improved technical equipment and the higher index of suspicion of the general practitioners and spe-

cialists can be biases in determining the real increase in the epidemiologic trends. A typical example to illustrate this is IBD.

Romania is still situated in a low area of prevalence of IBD. A multicentric study published by the Romanian Society of Digestive Endoscopy in 2003 (1) reported the following figures: incidence for UC 1/100 000 inhabitants and for CD 0.5/100 000 inhabitants and prevalence UC 2.42/100 000 inhabitants and CD 1.51/100 000 inhabitants. The data are similar to other neighboring countries and are consistently lower than in the Western literature. The same study assessed a slight male predominance especially for CD, a first peak of incidence in the fourth decade and a second one in the sixth-seventh decade of life which was less significant compared to the literature.

A study conducted in a tertiary referral centre in Romania (2) showed a high percentage of patients with urban backgrounds (almost 75% of cases), which is consistent with the international data showing IBD tends to affect persons with a high socio-economic standard and education.

For UC the dominant forms were mild and moderate disease (90%) with a recurrent course of symptoms in 90% of patients, which is similar to the data from areas with high incidence of IBD. The extent of the lesions was limited to the rectum and sigmoid colon for the mild forms while extensive colitis and pancolitis were associated with the moderate and severe cases.

A different Romanian epidemiological study on CD reported a more benign course as compared to the literature, with lower rates of severe, extensive or complicated disease. 50% of the cases were in clinical remission or had a mild course of disease, 37% had moderate disease and only 13% were severe cases. 66% had a peak age of onset under 40 years old.

The extension of the disease was predominantly colonic (53%), ileo-colic and ileal forms were 26% and 18%, which is significantly different from the international data (25% colonic, 40% ileocolic, 30% ileal) (3).

Complications of the disease consist of: toxic megacolon (5%), lower gastrointestinal bleeding (more frequent with UC than CD), intestinal perforation. Characteristic for CD are abscesses and fistulae (enteroenteric, entero-cutaneous, enterovesical, enterovaginal) defining the fistulizing pattern (the most aggressive) as well as stenosis and perianal disease (4).

Patients with extensive forms of IBD (pancolitis, extensive colitis) and long-standing disease (over 8 years) have an increased likelihood of developing colon carcinoma; thus, surveillance programs are designed to detect pre-malignant dysplasia. The approach is colonoscopy every 1-2 years beginning 8-10 years after diagnosis and taking random biopsies every 10 cm of the colon (5). Mild dysplasia requires more frequent surveillance (at three months) and severe dysplasia calls for total colectomy.

A Romanian study from 2007 reports a rate of dysplasia of 9% for CD and 2% form carcinoma. Neither the duration nor the extent of disease correlated significantly with the presence of dysplasia (6).

Regarding management of IBD, the European Crohn's Colitis Organization (ECCO) provided guidelines for the treatment of CD in 2006(7) and UC in 2008 (8).

The general features to consider for treating active disease are: activity site (ileal, ileocolic, colonic, other), pattern (inflammatory, stricturing, fistulizing), course of the disease (frequent/infrequent relapses), response to previous medications, presence of extraintestinal manifestations and patient decision.

Active ileocecal CD disease requires a course of budesonide 9mg/day for three months for the mild forms, budesonide 9mg/day or prednisolone 1mg/kg p.o. for moderate forms.

The severe flares necessitate methylprednisolone 60mg/day or hydrocortisone 400mg i.v. daily for 5-7 days followed by oral corticosteroids and azathioprine (AZA) 2.5 mg/kg/day p.o. or 6-mercaptopurine(6MP) if relapse upon steroid reduction or frequent previous relapses; for relapses or intolerance, the next step is methotrexate (MTX) 25 mg/week i.m.

For steroid refractory course Infliximab 5 mg/kg i.v. weeks 0.2 and 6 is necessary for induction of remission. If the patient is still unresponsive/intolerant surgery is required.

The mild-moderate colonic forms are treated with prednisolone 1mg/kg p.o. or Sulfasalazine 3g p.o. The severe courses of disease follow the same algorithm already mentioned above.

For the maintenance of medically induced remission abstinence from nicotine is needed, and mesalazine is proven inefficient. When dealing with early or frequent relapses AZA 2-2.5 mg/kg p.o is effective for maintenance of

remission. When used for induction, MTX 15mg/week or IFX 5-10mg/kg/8 weeks can be administered chronically for preventing relapses.

Obstructive symptoms refractory to medical treatment are an indication for surgery and endoscopic dilation. Abscess require antibiotics (Metronidazole/Ciprofloxacin) as well as drainage (percutaneous, surgical).

Regarding UC, the current management also depends mainly on the activity of the disease and the site (proctitis, left side colitis, extensive colitis).

For the induction of remission in flares with mild/moderate activity the recommended drug is mesalazine 1-2 g rectally, or combination of topical mesalazine 1-2 g/day with oral mesalazine 3-4 g/day.

If nonresponsive, Prednisolone 1 mg/kg/day po is added.

Severe UC of any extent should be treated in the hospital with i.v. steroids: methylprednisolone 60mg/day or hydrocortisone 400mg daily.

If relapse upon steroid reduction appears AZA 2.5 mg/kg/day should be added.

If the remission is not obtained with i.v. steroids then cyclosporine 2mg/kg/day i.v. or tacrolimus 0.1 mg/kg/day p.o. or IFX 5 mg/kg i.v. must be used.

Surgery (proctocolectomy with ileo-anal pouch) should be considered if the previous therapies show no response.

For maintenance of remission, the first line therapy is mesalazine 1.5g/day p.o. or 1g/day rectally in distal colitis. Azathioprine/6-mercaptopurine are recommended for patients with early/frequent relapse while taking mesalazine at optimal dose.

A study performed in Fundeni Clinical Institute reported a good response to standard therapies: 65% patients obtained clinical remission. 10% of cases had no response or worsened under treatment so Infliximab or surgery were necessary (9).

Infliximab was administered to 24 patients with CD in 2000-2002, 16 with severe inflammatory disease, 7 for fistulizing disease and 1 with fistulizing and inflammatory pattern. 75% of patients with inflammatory pattern and 71% of patients with fistulizing disease responded. Steroid sparing was possible in 71.4% of cases. Adverse reactions to Infliximab were noticed in 16.6% of patients and were severe in 2 cases

(8.3%): death from septic complications and disseminated intravascular coagulation (9).

The same team showed the efficacy of the maintenance treatment with Infliximab 5 mg/kg i.v. administered every 8 weeks: all 9 patients were in clinical remission, 6 of them had no endoscopic lesions and the therapy was well tolerated (10).

Another study elaborated by the same center evaluated the rate of response to standard treatment in patients with UC as 89.23%; steroid refractory or steroid-dependent courses were present in 10.8% (2).

Taking into account the precise measures for identifying and treating IBD in Europe due to those consensuses, we realized that local and national efforts should be made to better characterize and adequately manage our patients according to their particularities.

This is the reason why in 2006 IBDPROSPECT, a multicentric prospective trial, was developed in Fundeni Clinical Institute. Its aim was the evaluation of genotype and phenotype particularities in the Romanian population.

Another important milestone was the foundation of the Romanian Crohn's and Colitis Club, affiliated to ECCO. Its main goals are the creation of the National IBD Registry, the release of local guidelines, elaborating training programs for specialized IBD nurses and the foundation of the IBD patients association.

New protocols for IBD were issued and presented to the Ministry of Health in order to obtain the proper medication free of charge. □

GENERAL NURSE TRAINING IN ROMANIA – FUNDENI NURSING SCHOOL EXPERIENCE

Nursing in Europe is currently facing increasing demands doubled by a shortage of staff as well as differences in education and health care systems.

In Romania, providing high quality training for nurse practitioners has been a constant concern. In 1990, according to EU standards and the recommendations of the WHO Nursing Conference in Wien, the Government issued a resolution establishing a three years education program for young high-school graduates wanting to become general nurse practitioners.

In 1998, by the decision of the National Ministry of Education no 4051/29.06.1998,

training has moved into University settings as the Colleges of Nursing were founded. The University of Medicine and Pharmacy "Carol Davila" Bucharest and other centers with long-standing tradition in the medical field now offer four-years training programs and a graduation diploma.

As a consequence of the Bologna trial, Romania adhered to the system of transferable credits, 180 achieved over a three years period and followed by a license exam.

Presently, based on the current laws (no. 307/30.06.2004 and no. 288/07.07.2004) the education of general nurses can be accomplished either by a three years postgraduate program or by a three/four years university training (180/240 credits).

Founded in 1950, Fundeni Nursing School is one of the most important public Institution for nurse training as well as for the continuous education of the teaching staff in this field. It also paid a major contribution in the elaboration of the national curricula for all basic specialties in nursing: general, laboratory, radiology, pharmacy, balneophysiotherapy and hygiene. After completion of the education program the student nurses have to sustain an exam (written, practical and presenting a personal project) and receive a license that permits them to practice as nurses specialized in the areas already mentioned. □

OVERSPECIALIZING NURSES FOR THE SPECIALTY OF GASTROENTEROLOGY, HEPATOLOGY AND DIGESTIVE ENDOSCOPY – FUNDENI GASTROENTEROLOGY AND HEPATOLOGY CENTER EXPERIENCE

More activities are needed to further enable nursing professionals to meet the demands for health care around the world.

The Gastroenterology and Hepatology Center in Bucharest was for decades the single center for specializing doctors in this field all over the country. The increasing importance of the digestive pathology and the optimized diagnostic and therapeutic techniques in this domain resulted in other University centers as Cluj, Iasi, Timisoara, Targu Mures, Craiova becoming involved.

Overspecializing a Nurse in Digestive Diseases includes several subspecialties:

- a) Gastroenterology and Hepatology;
- b) General surgery;
- c) Radiology (Imagistics);
- d) Diabetes and Nutrition;
- e) Pediatrics;
- f) Intensive Care.

Gastroenterology and Hepatology nurses face two distinct problems: the specialized training itself and obtaining special rights from the Ministry of Public Health: risk support for infectious disease (viral hepatitis B and C, HIV, Helicobacter Pylori), for radiation exposure (ERCP, Barium enemas etc), for contact with chemotherapeutical drugs.

Specialized training for Gastroenterology and Hepatology nurses includes several steps:

- a) training in Gastroenterology;
- b) training in Hepatology;
- c) training in Digestive Endoscopy;
- d) training in chemotherapy and other special therapies.

In Romania, training in Gastroenterology and Hepatology takes place in the same period. The overspecialization program is structured in two phases. First, one year training by a complex team consisting of Gastroenterology university doctors and by a trained Nurse in the Gastroenterology and Hepatology Center in Fundeni, under the survey of the National Specialization Nurse Center From The Ministry of Public Health. After completion of the course they receive a diploma and they may practice in Gastroenterology departments in hospitals all over the country.

Second, the training will continue with periodical intensive courses of up-dating their knowledge in the Fundeni Nursing School or in Bucharest Gastroenterology and Hepatology Center.

Training in Digestive Endoscopy includes a course in Fundeni Gastroenterology and Hepatology Center for 3 weeks with lectures by doctors, by nurses, practice in the Endoscopy department and a final examination after which they are entitled to practice in their own Department of Digestive Endoscopy, in a Private Practice or in an Outpatient Clinic.

Their training will be continuously improved by periodical courses and update lectures in special designed conferences at the yearly National Congresses and Symposia.

Over the past seven years all the Gastroenterology nurses in Fundeni Gastroenterology and Hepatology Center and the Gastroenterology

and Hepatology of ELIAS Hospital Department underwent the 3 weeks course of Digestive Endoscopy got their license to practice there. This was considered an essential need for those departments in order for every nurse working in a Gastroenterology department to be acquainted with the special problems in preparing a patient for the different endoscopic procedures and also for having the possibility of access to the endoscopes in the ward round 24 hours a day seven days a week for emergencies (see FIGURE 1).

Since then, several other Departments of Digestive Endoscopy asked for training of their nurses and the number of nurses trained in Fundeni Gastroenterology and Hepatology Center increased from year to year (see FIGURE 2). □

IBD OVERSPECIALIZED NURSES IN ROMANIA IN THE NEXT YEARS

The chronic nature of IBD requires frequent contacts between patients and the Health Care system in regards to lifelong medication, follow-up in out-patient clinics and psychological support and (11). So far, the general drawbacks in health care for IBD in Europe are the general lack of IBD specialists, the lack of interdisciplinary collaborations and the lack of clarity in the role of the barely installed IBD-nurse (12,14).

Through information and education the working group consisted of doctors, nurses and patient organizations can help the patients understand their disease and cope with their therapy, increasing quality of life (QoL) and reducing their psychological discomfort (see FIGURE 3).

For all these reasons, we can definitely state that there is a need of overspecialized nurses in IBD in Romania in the next years. There are some issues regarding this problem that we can foresee.

Trained nurses in IBD will be assigned for the next 5 years only in **Centers designed by the Ministry of Public Health via the National Committee for Gastroenterology and Hepatology**. These centers must be affiliated with Universities of Medicine and Pharmacy and have dedicated and well-equipped Departments of Gastroenterology.

For obvious reasons they are also designated for the application of biological treatments.

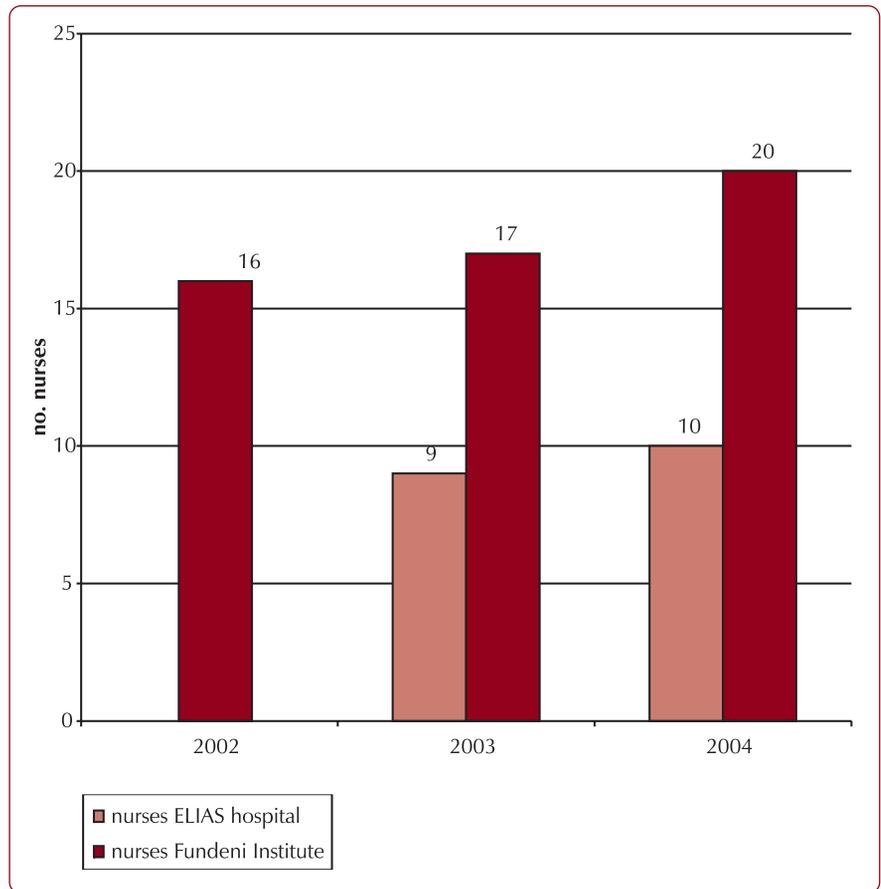


FIGURE 1. Nurses trained in Endoscopy between 2002-2004

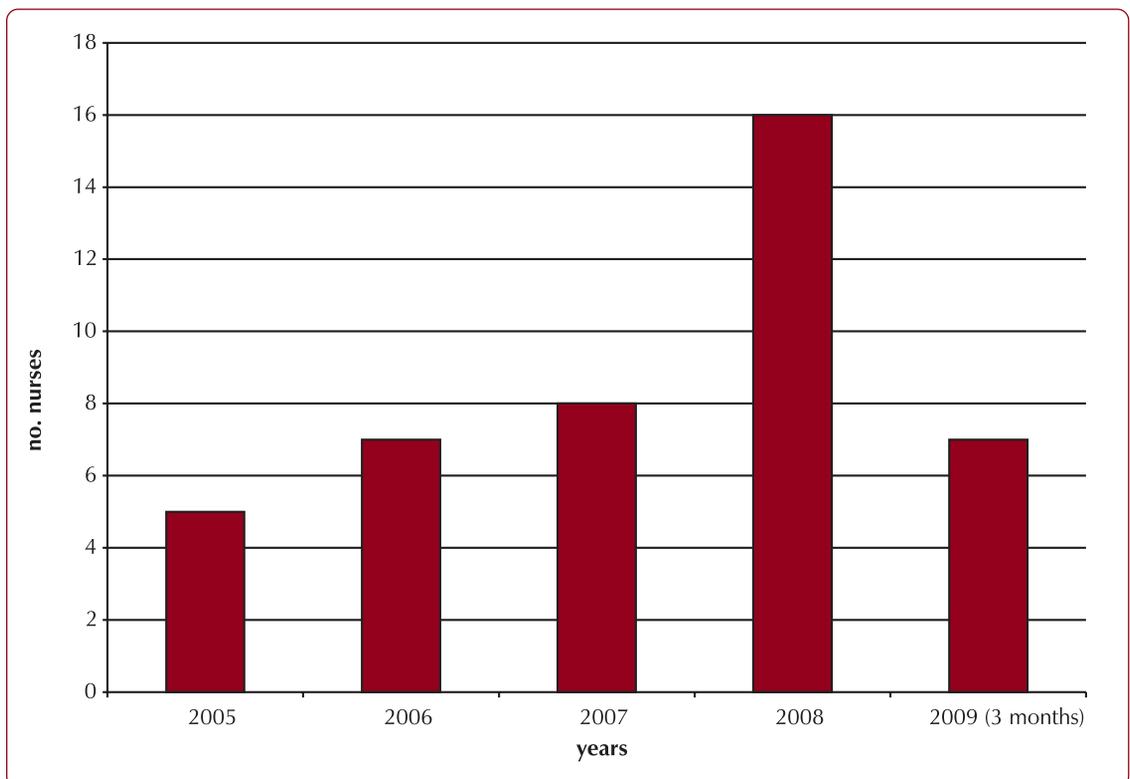


FIGURE 2. Nurses trained for endoscopy between 2005-2009.

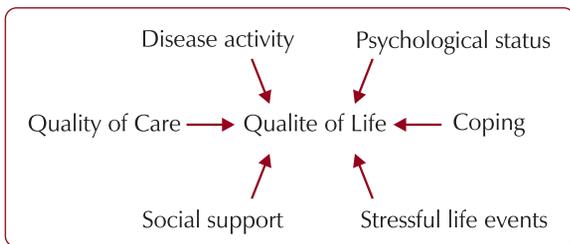


FIGURE 3. The influence and interaction between Quality of Care and Quality of Life and other events in the IBD patients life (12)

Maybe in late future the need for specialized care will extended all over the country, but for the foreseeable future it should be directed to these special Centers.

The IBD training should be aimed at experienced nurse practitioners with the overspecialization in Gastroenterology and Hepatology and who also graduated the Course of Digestive Endoscopy.

The **curricula** for IBD must include the following topics:

1. *General information about IBD diagnostic and treatment.*

It was recently stated (15) that the quality of Health Care depends on level of disease information available to the patient with IBD. This is why the nurse specialist's role in individual education of IBD patients can significantly increase their insight and knowledge in IBD and rationale for medical therapy, thus enhancing compliance, patients' satisfaction and reducing outpatient visits.

The IBD nurse may also help in developing and leading of patient education programs, providing and interpreting complex information about the disease and providing resources such as helplines, rapid access and follow up in the future.

2. *Courses for preparation special diagnostic tools for IBD patients (rectoscopy and colonoscopy in UC active /remission, ileoscopy in CD, small bowel/colon wireless capsule /colon, etc)*

3. *Courses about administration of special agents (corticosteroids, cyclosporine, infliximab, etc). The role of the IBD nurse in assessment of patients who receive biological agents is crucial: tuberculosis screening, testing for Hep B, Hep C, HIV, verify vaccinations. Premedication, drug preparation and administration of treatment following the infusion protocol, patient monitoring and management of drug reactions are also mandatory.*

4. *Courses about nutrition and diet in IBD*

These are of extreme importance especially with children and adolescents who need special attention to increase Quality of Life (16). The disease has often a more aggressive course, with related risk of lifelong consequences to growth, reproductive health, education, future employment and psychological well being (17). The dietician should be always be consulted in these cases.

5. *Courses about counseling in IBD*

Psychological distress, depression and anxiety are some triggers for relapse of IBD (18). Support and advice for patients and families in coping with IBD might have a favorable impact on psychological distress and efficacy of medical treatment (19,20). Studies suggest that patients perceive support, advice, caring, empathy and disease management to be of particular importance to their care. The traditional nursing values and qualities such as empathy, support, continuity, closeness of contact, communication, and time favor the position of the specialist IBD nurse as a supportive link between patients and doctors, at the heart of the therapeutic relationship.

6. *Courses about nursing a patient with ileal stoma, ileal pouch, peri-anal disease and fistulas.*

7. *Courses about IBD and pregnancy.*

The **final examination** (theoretical and practical), concluded with a **diploma**, allows them to work both in Hospital Gastroenterology Departments, in Outpatient clinics and in Private Care Units.

Periodical up-dates through 1-3 days courses and / or attendance to the special topic courses at the National Congresses or Symposia will fully complete the education as specialized IBD nurse practitioners. □

CONCLUSION

The possibilities of improving health care for IBD patients in Romania will improve shortly. Nursing in this domain must keep up with the rest of the medical system. We must now create a new system for the formation and continuous education of these nurses. The system must include perfecting our basic training for nurses in the Gastroenterology and Hepatology Departments and elaborating a special curricula for them.

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